# THE ECONOMIC IMPACT OF HIV/AIDS ON URBAN HOUSEHOLDS

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# DECLARATION

I declare that the following thesis is my own work, except where noted, and it has not been submitted for a degree at any other university[1].

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# DEDICATION

This study is dedicated to the people of Soweto, to all those infected and affected. We hope in some small way we have touched your lives as you have ours. Thank you for opening our world by sharing your world with us.

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# ABSTRACT

The overall objectives of the study are to analyse the economic impact of HIV/AIDS on income-earning urban households and in so doing to develop a methodology for HIV/AIDS household surveys. The study started with 125 households in the first wave. Of these, 113 households were followed over 4 waves[2], over a 12-month period, and across two cohorts referred to as affected[3] and non-affected[4] households. Data on the household were collected from the financial head[5] using the diary method. The methodology for this study was done after a review of 33 HIV/AIDS economic studies conducted around the world. The study obtained buy-in and support from various stakeholders in government, non-government organisations, community, academic and funding institutions as from people living with HIV/AIDS. Due to the comprehensive design of the research instrument, the study is able to draw relationships between the various facets of the household and the possible influence that HIV/AIDS has on them.

Methodologically, the study found that there are "hidden" costs of morbidity and mortality that needs to be quantified. The costs of health care and funerals are higher in the affected cohort, as expected, due to the frequency of illness or death and not necessarily because there are cost differences as a result of whether a household member has HIV/AIDS or not.

The key finding is that affected households re-organise themselves in terms of household size, composition and structure as well as through transfers in, income from grants and other non-market sources, especially to pay for funeral costs. Surviving members are affected not only socially and economically but also psychologically and the needs of this group should not be ignored.

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[2] Each visit is referred to as a wave

[3] Affected household is a household where at least one person is HIV positive

[4] Non-Affected household is a household where the index case is HIV negative and no other members presented with an HIV/AIDS-related symptom

[5] The person responsible for the finances in the household

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# CHAPTER ONE
# INTRODUCTION

## 1.1 Introduction

A study of the impact of HIV/AIDS at household level is crucial to an understanding of the impact of HIV/AIDS at the macro economic level. Individuals that are part of households carry the cost of HIV/AIDS that is not borne by the government, business or other non-government organisations. Households either survive this extra burden or dissolve depending on their economic behaviour.

An urban study is of particular interest since very few HIV/AIDS socio-economic studies have been conducted in urban areas although by October 1999, 53.9% of the population of South Africa and 96.5% of the population of Gauteng lived in urban areas (Shisana and Simbayi, 2002:16). There are reasons to expect that urban and rural households will respond differently to one of its members being diagnosed with HIV/AIDS. Urban households are organised differently to rural households because of the manner in which income is earned and spent. In a South African survey of households which contained an AIDS-symptomatic person, food shortages were more acute in rural areas where more than half the households (55%) reported food shortages compared to 42% in urban households (Steinberg et al., 2002:20), due to the manner in which income is earned. In South Africa, urban households have more formal infra-structure and therefore face higher expenses for services such as rates and taxes, electricity, water, and refuse removal (Naidu et al., 2004:21-22). Urban households are closer to health care facilities and this coupled with good access to transport, promotes health-care seeking behaviour. The composition and structure of urban households are different to that of rural households and therefore the survival strategies employed by urban households are expected to be different. Steinberg et al., (2002:14) found that on average rural households are larger (seven people) than urban households (five people).

Households become vulnerable if one or more of the primary income-earners become infected. Will this lead to reorganisation of the household? Households

usually have either one or more primary income-earners. Some 78% of households in Soweto in 2002 were income-earning (Naidu et al., 2004:32). Sickness or death of income-earners leads to changes in household income as well as changes in household expenditure patterns. Sickness of non-income earners do not cause changes in income because income from disability grants do not cease as a result of illness, although they do cease upon death. However, changes in expenditure priorities due to illness can be expected, as found in the Free State pilot study (Booysen et al., 2001). This study focuses on how the economic impact of HIV/AIDS affects the entire household when one member, whether or not they are an income-earner, is HIV positive.

South Africa has one of the highest incidences of HIV transmission in the world (UNAIDS, 2002:14). According to the *Nelson Mandela/HSRC 2002 Household Survey*[1], the national prevalence of HIV amongst persons two years and older was estimated at 11.4%. Of these, 9.5% were males and 12.8% were females.. Regionally, the Free State led and Gauteng followed with a prevalence rate of 14.7%. In terms of urbanisation, those living in urban informal settlements (21.3%) were more likely to be HIV positive than those living in rural areas (7.9%). In terms of age categories, children two to fourteen years had a prevalence rate of 5.6%, youth fifteen to twenty four, 9.3% and adults twenty-five plus 15.5%. (Shisana and Simbayi, 2002:45-52). These prevalence rates illustrate the importance of understanding the economic impact of HIV/AIDS on urban households.

By 2015, total deaths in South Africa (AIDS related and non-AIDS related) are expected to exceed total births, thereby reducing the total population (ASSA 2000 Model, assa.org.za). According to the Bureau of Economic Research, both the Actuarial Society of South Africa (ASSA) and Abt Associates/Metropolitan projections estimate that the total growth in the South African population could amount to 1.5 million people between 2000 and 2015 (cited in Smit, 2001:1). The total population is expected to be 10 million less due to AIDS than it would have been in the no-AIDS scenario by 2015 (Smit, 2001:1).

[1] There has been much debate about the prevalence rates presented in the Nelson Mandela/HSRC report because of the refusals to participate in the study as well as refusals to undertake the HIV test. Approximately 73% of selected individuals agreed to be interviewed and 15% of those who agreed refused to give an oral fluid specimen.

The impact of 10 million less in total population will affect overall country expenditure. In a Thai study, even households with few or no resources reduced overall household consumption following the death of a household member (Pitayanon et al., 1997:18). However, the impact on the household sector is not straight forward and needs to be examined at the micro level. The household sector is likely to experience shifts in expenditure, as found in the Kagera study of rural households in Tanzania (World Bank, 1999:212), which reported changes in the distribution of income due to morbidity and mortality as well as withdrawal of savings and conversion of assets to pay for essential services (Bharat, 1995:177-194, Pitayanon et al., 1997:11).

The impact of HIV/AIDS from the household sector has broader implications for firms whose customer base may be vulnerable to the epidemic. The JP Morgan study suggested that retailers who target the lower income and emerging market consumers will be the highest risk category (Adler et al., 2001:22). This is because market segments such as food retailers are dependent on population growth. Before a micro analysis of a firm's impact is conducted, it is important to first understand what expenditure categories of the household are affected if any by morbidity and mortality. Thereafter focus can be on consumption of a firm's products and or services. This study focuses on the broad expenditure categories that highlight industries that will most likely be impacted. To study the effects on households and on firms is too big a task for a single study to undertake and therefore this study focuses on the impact at household level.

## 1.2 Definitions of Concepts

### 1.2.1 Household

A household for the purpose of this study is defined as, "a person or a group of persons who live together at least four nights a week at the same address, eat together and share resources." This definition includes members who are temporary absent, for example, due to hospitalisation and heads of households that are migrant workers. These types of household heads are included because of their influence on household spending patterns.

The different types of households for the purpose of this study are defined in terms of other HIV/AIDS household surveys conducted in South Africa so as not to confuse readers. Two types of households are investigated in this study, AIDS-affected households and non-affected households. In an **AIDS-affected household,** the impact of the epidemic is direct. The household contains at least one adult member who is HIV positive with a CD4 cell count of 200 or below. The **non-affected household** is described as one in which no death or illness has taken place in the household.

### 1.2.2 Unit of Analysis

The unit of analysis is the household, because the impact from HIV/AIDS is felt at household level. Whilst illness or death occurs in individuals, the costs are not borne by individuals but by members of the household. Decisions about health care utilisation, the allocation of resources as well as finances, consumption cut-backs, reduction or substitution as well as how the household survives are made on a household level. The sickness of one member has the potential to affect other household members in terms of the use of their time and financial resources.

### 1.2.3 Employment

The labour market definition of employment is "someone that had worked in the last seven days for pay, profit or family gain" (Statistics South Africa, 2000, PO317). The definition used in this study is someone that has been involved in the production of goods or services in the last seven days but not necessarily earning profit or pay in consequence. The definition used in this study is encompassing of those who consider themselves employed and therefore may not be seeking alternative employment. This definition includes individuals who were:

- Volunteers at home-based care or other non-governmental organisations who were occasionally paid an allowance.
- Engaged in home-production but made a loss or did not work the month prior to the interview.

- On maternity leave and did not receive any income.
- Self employed without having any contractual work the month before or did not get paid for work completed the month prior to the interview.
- Part-time or casual contractors who had no work or did not get paid the month prior to the interview.
- Not working for the last seven days because they were temporarily off sick.
- Engaged in wage/salaried employment.

### 1.2.4 Income-Earners

Income-earners are individuals who earn an income either from being self employed or from salary or wages.

### 1.2.5 Economically-Active and Not Economically-Active

The working age population includes all those aged between 15 and 65 years. The economically active population consists of both those who are employed and those who are unemployed. Those who are not economically active are those who are not available for work.

### 1.2.6 Formal and Informal Sector Employment

The formal sector includes all businesses that are registered for tax purposes. The informal sector consists of those businesses not registered (Statistics South Africa, 2000, PO317).

### 1.2.7 Dependency Ratio

Dependants are usually regarded as individuals 15 years and younger and 65 years and older. The dependency ratio is calculated by taking the ratio of dependants to the working age (16 to 64 years of age), and multiplying by 100 to give a percentage. This definition of the dependency ratio assumes that everyone over the age of 16 is working or in a position to seek work and those retired are not

producers of income (Bannock, et al., 2003:93-94). Given the high rate of unemployment in South Africa and the fact that many households rely on grant income, alternative measures of dependency ratios are calculated.

### 1.2.8 Surviving Household Members

Surviving household members refer to household members whose HIV status is unknown.

### 1.2.9 Index Case

The index case refers to the person who was screened at the health care facility for HIV infection and who was used to select the sample households.

### 1.2.10 Household Debt

Household debt represents amounts that were outstanding for 30 days or more.

## 1.3 Problem Definition and the Need for the Study

One of the criticisms levelled at household research in the HIV/AIDS field is that the surveys are not comprehensive, they do not build on previous research or that they are not action-oriented (Teljeur as cited in Kelly et al., 2002:67). If household impacts are measurable or predictable, then surveys of these impacts become an important tool for advocacy (Barnett and Whiteside, 2000:11). This study is comprehensive, policy-oriented and focuses on problem solving. This study provides an understanding of how households organise themselves during times of economic hardships and highlights issues that have implications for policy.

The study attempts to establish how adult AIDS morbidity and mortality alters income and expenditure at household level, and how this impacts on other surviving household members. Very few studies have documented the impact of HIV/AIDS on income and expenditure patterns in AIDS affected households versus a cohort of non-affected households. Some 33 studies in Appendix 5 such are reviewed in

chapter four and are examined from a methodological perspective. Some are extensive in nature such as the Kagera study (Tanzania) and the Chiang Mai study in Thailand (World Bank, 1999). In terms of explanation, these studies are limited to rural communities which, as we have noted, may be expected to cope differently from urban communities. There are other household studies including some conducted in Southern Africa such as the Zimbabwe study (Mutangadura, 2000) and the Zambian study (Nampanya-Serpell, 2000) that are urban in nature but which, although classified as "economic studies", do not cover all aspects of income and expenditure. In short, there have been various HIV/AIDS economic studies of rural households and very few studies of urban households conducted elsewhere in the world.

Little is known about how households cope with debt and finance HIV/AIDS costs. The disposable income of households and their changing consumption patterns have implications for policy-makers. Changes in income may push certain households further into poverty and make them more dependent on the state and other agencies for health services. Households lose income due to morbidity and mortality. It is not known to what extent households make up this shortfall or how they reorganise themselves to cope with reduced income.

No urban study has yet been conducted in South Africa on the impact of HIV/AIDS on income-earning households. Income-earning households are of particular interest because of the households' participation in the economy. The only other comprehensive study is the pilot study conducted in the Free State, South Africa (Booysen et al., 2001) that investigates the direct and indirect impact of morbidity and mortality on rural and urban households. In terms of identifying cost of morbidity and mortality to households, many previous studies published the impact of morbidity or the impact of mortality. No HIV/AIDS household study has estimated the combined cost of morbidity and mortality on households.

No HIV/AIDS household studies have focused on the impact of HIV/AIDS on surviving family members. Some studies such as the Kagera study focused on the impact of HIV/AIDS on household size and composition in terms of the net migration of children and adults between households. Little has been documented

about how children in an urban setting survive or who would take care of them should their caregivers die. It is assumed that the greatest burden facing households are the cost of education and food for children. None of the HIV/AIDS household studies investigated inter-household obligations of care in an urban setting.

A central argument of this study is that in order to understand the relationship between adult morbidity and mortality on urban households, it is necessary to analyse income, expenditure, the combined costs of HIV/AIDS morbidity and mortality to the household, the impact on surviving members and how households survive the burden of the additional costs. To understand the dynamics of income and expenditure, one has to understand the role of the extended family, the inter-relationship of household members and their role in the household, how they contribute either income or services, what happens to surviving household members when income-earners become too sick to work and eventually die. For a broad understanding of the economic organisation of the household, the relationship between AIDS morbidity and mortality and the economic activities of the household has to be explored in depth and breadth.

For many countries, including South Africa, household surveys retain an important role in providing information that will inform policy and decision-makers. These surveys will be discussed in chapter two. The sensitive nature of the disease, it must be noted, does not allow for mass surveys and the general household studies investigating income and expenditure make no differentiation between AIDS-affected households and non-affected households.

### 1.4 Overall Objectives and Specific Research Questions

The overall objectives of the study are to analyse the economic impact of HIV/AIDS on income-earning households in one South African urban area, Soweto, and in so doing to develop a methodology for HIV/AIDS household surveys.

The specific research questions are:

1. What is the cost of morbidity and mortality to urban households?

2. What are the income shifts (amount and type of income) for income-earning households where at least one member is infected with HIV/AIDS?
3. How does household expenditure change and how are basic economic needs (food, clothing, and housing) sacrificed to accommodate increased HIV/AIDS related costs?
4. What are the social and economic consequences of morbidity and mortality on surviving family members?
5. What is the role of inter-household obligations in the care of AIDS survivors (infected member and surviving family members)?
6. How do HIV/AIDS affected households survive the extra burden of HIV/AIDS costs?

### 1.5 Organisation of the Thesis

The first chapter covers the background to the problem as well as the overall objectives and specific research questions.

Chapter two contains a review of previous HIV/AIDS economic impact studies conducted elsewhere in the world and in South Africa. In particular, it explores theoretical frameworks in which relationships between morbidity and mortality on the one hand, and changes in income and expenditure on the other, have been studied and explained.

Chapter three discusses the economic context of the study area. It presents information on the economic organisation of families and the household in Soweto.

Chapter four discusses methodologies of previous household studies conducted elsewhere in the world, particularly in sub-Saharan Africa. It also discusses methodological bias and the method used in this study to investigate the impact of HIV/AIDS on urban households.

Chapter five examines the impacts from HIV/AIDS morbidity and mortality on household size, composition and structure and highlights the various types of households that emerge from this study.

Chapter six examines the cost of HIV/AIDS morbidity and mortality to households.

Chapter seven investigates income changes due to sickness and death in AIDS-affected households.

Chapter eight measures shifts in spending on various expenditure categories especially food, clothing and housing in AIDS-affected households versus non-affected households. It further explores the essential expenditure categories that are sacrificed as a result of increased spending in HIV/AIDS care.

Chapter nine investigates the impact on surviving family members as a result of sickness and death. It further describes changes to the economic organisation of the household in terms of re-allocation of labour resources.

Chapter ten investigates the incidence of inter-household obligations of care in urban settings.

Chapter eleven investigates how households survive the extra burden of increased HIV/AIDS costs by investing aspects such as assets, savings, borrowings, debt and access to safety networks.

Chapter twelve draws conclusions, identifies gaps for future research and highlights issues that have implications for policy.

**1.6 Summary**

South Africa has one of the highest prevalence of HIV/AIDS in the world particularly amongst prime-age adults. AIDS morbidity and mortality has the potential to cause changes to household income and expenditure patterns. This may result in the economic reorganisation of the household as a result of HIV/AIDS.
This study focuses on the impact caused to AIDS-affected income-earning households. It investigates the pattern of resource use and activities pursued by households. It further investigates changes in income, savings and debt, consumption and the cost of HIV/AIDS at household level. Changes in size,

structure and composition of the household are investigated to assess its influence on income and expenditure.

Besides the Free State study, there are no other known comprehensive urban studies on this topic. This study adds to the existing body of knowledge as well as developing a methodology that can be replicated in other household surveys that investigate the economic impact of HIV/AIDS.

# CHAPTER TWO

# THE IMPACT OF HIV/AIDS MORBIDITY AND MORTALITY ON HOUSEHOLDS – A REVIEW OF PREVIOUS STUDIES

## 2.1 Introduction

A literature search was conducted in mid-2002 using EBSCOnet, Social Science Index, Academic Search Humanities Index, EconLit and Aidssearch databases for 1990 to 2002 using the key words HIV, AIDS, in combination with each of the terms: costs, cost-effectiveness, cost-benefit analysis, economic, household, culture, family, children, HIV/AIDS, HIV, AIDS, income and expenditure, income, expenditure, remittance, savings, debt, economic impact, social, social economic and Africa. Furthermore, recent studies, some of which were in the process of being published, were obtained directly from the researchers. Not all the studies contained full details of the methods used or a full description of the study results. In the absence of the method of data collection and analysis it is often difficult to compare the results of other studies. Hence caution is exercised in the criticism of other studies. The intention is not to supply a critical review of the methods or findings of other studies, but to cite what other authors have found so that research gaps can be identified.

There are only four comprehensive studies conducted on the economic impact of HIV/AIDS morbidity and mortality on households, two of which were conducted in South Africa. The four comprehensive studies are the Kagera study (rural Tanzania), the Thai study (rural), the Limpopo study (rural) and the Free State study (urban and rural). Although these studies are context specific, they report important findings and indicators that can be measured in household surveys conducted elsewhere in the world. Households are not homogeneous and household surveys need to be replicated in all parts of South Africa. Comprehensive surveys are important because they offer extensive data that may be used to explain the impacts and the responses.

This chapter reviews the findings of other economic impact studies of HIV/AIDS morbidity and mortality on household size, composition and structure, cost of HIV/AIDS to households, income, expenditure, impact on surviving household members, and household survival strategies. Besides inter-household re-allocation of resources, there are also intra-household transfers of financial or time resources to assist households during times of sickness or death. A household's ability to survive in the long-term depends on the strategies it employs.

To study the effects of HIV/AIDS four important issues need to be raised. These include the HIV/AIDS epidemic in South Africa, the nature of HIV/AIDS regarding prime age adults, the progression of the disease from HIV to AIDS (period of morbidity) and the fatality of the disease (period of mortality). These factors impact on household income and expenditure, on surviving household members and on the strategies that households employ in order to survive.

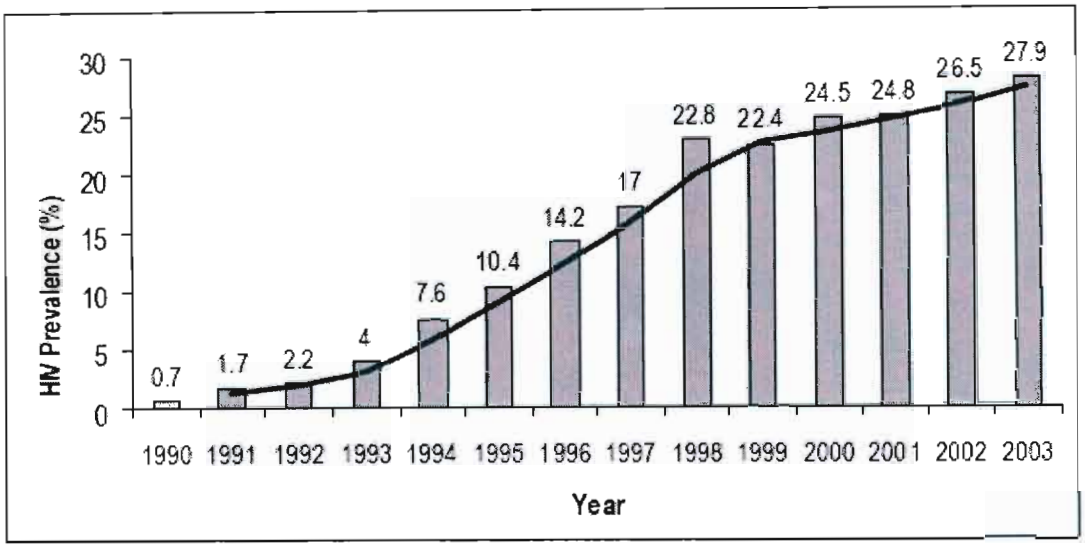
### 2.1.1 The HIV/AIDS Epidemic in South Africa

South Africa appears to be at the mature phase of the epidemic because the rise in HIV prevalence for 2003 was not significantly higher than that of 2002 in women who attended public antenatal clinics. The overall HIV prevalence rate for women attending public antenatal clinics in South Africa in 2003 was 27.9% (see Figure 2.1). Gauteng, the province in which Soweto is located has the third highest prevalence of 29.6%. The Department of Health using an extrapolation model[1] estimates that 5.6 million people (men, women and children) were infected with HIV by the end of 2003 (Makubalo, et al., 2004:10).

The majority of women who participated in the 2003 *National HIV and Syphilis Antenatal Sero-Prevalence Survey in South Africa* were women between the ages of 20 and 39 (77.2%) (Makubalo, 2004:5).

[1] One of the key assumptions used in the model is that the prevalence rate of HIV infection in all pregnant women in South Africa is the same as the prevalence rate in women attending public antenatal clinics.

**Figure 2.1: HIV Prevalence in South Africa (Percentage)**




Source: 2003 National HIV and Syphilis Antenatal Sero-Prevalence Survey in South Africa.

### 2.1.2 Nature of the Disease in Adults

HIV/AIDS affects those that are potentially the greatest contributors to economic activity. Surviving family members experience loss in terms of income and labour that prime age income earning individuals provide. It is not known what the economic or social consequence of such a death or sickness is on surviving household members.

In 2002, approximately 25.5% of the population of Soweto was under 15 years of age and 47% under the age of 25 (Naidu et al., 2004:25). It was estimated that over 60% of all new infections occurred in those between 15 and 25 years of age with women generally being infected earlier than men (Lovelife, 2000:21). Households depend on youth for the generation of future income. Children in many African communities have been regarded as a form of security for future income. Without this security, households could dissolve over time.

If one member of the family is infected, the likelihood of the spouse and newborn babies becoming infected is high (Loewenson and Whiteside, 1998:21). This is due to the low rate of disclosure for fear of rejection, ostracism and partner abuse. In a study conducted with 170 pregnant women at Chris Hani Baragwanath Hospital

voluntary counselling and testing (VCT) sites, 84% of women were concerned that their community might treat them differently, 57% were concerned that their primary partner might leave them and 48,8% were concerned their primary partner might abuse them (unpublished report, Peri-natal HIV Research unit, 2001). Despite this fear, 50% of women reported disclosing their HIV status to a significant other.

### 2.1.3 The Progression of the Disease from HIV to AIDS (Period of Morbidity)

The progression of HIV infection to AIDS follows a series of stages as listed in Table 2.1.

**Table 2.1: Stages of Infection**

| | |
|---|---|
| Stage 1 – HIV Infection | Initial infection with HIV. |
| Stage 2 – Window Period | HIV infection with no signs or symptoms of disease and no detectable antibodies. |
| Stage 3 – Sero-conversion | The development of antibodies. |
| Stage 4 – HIV/AIDS related illness. | Antibody tests are positive, but no sign or symptoms of illness. |
| Stage 5 – HIV/AIDS related illnesses | Signs and symptoms of diseases increase because HIV is damaging the immune system. |
| Stage 6 – AIDS | Life threatening infections occur because the immune system is severely weakened. Life expectancy depends on the conditions that develop and the treatments available. |

(Source: Department of Health, 2000:15)

During stages 1 to 4, individuals lead a normal healthy life without showing or even feeling any signs or symptoms. Individuals have a range of responses to immune deficiency, with some becoming symptomatic earlier than others. As the immune system becomes progressively more deficient, the body becomes increasingly more vulnerable to opportunistic diseases. Earlier immune deficiency (stage 5) usually results in the reactivation of dormant infections such as tuberculosis, herpes and candidacies. Later with progression of immunodeficiency (stage 6), the body becomes susceptible to severe infections such as fungi, rare viral and bacterial

conditions, lymphoma and kaposi sarcoma, dementia and severe muscle wasting (Mpuntsha, 2000:12).

Progression from HIV to AIDS may take anytime from eight to ten years to occur (Whiteside and Sunter, 2000:3). As individuals move through the stages of HIV and AIDS, the economic organisation of the household is expected to change. Sick individuals are expected to be less productive, to stay away from work more often and to earn less.

### 2.1.4 The Fatality of the Disease (Period of Mortality)

In phase 6, life threatening opportunistic illnesses occurs which eventually leads to death. A deceased individual creates reduction in monthly household income however it may result in "other income" entering the household by means of group life, funeral and other life insurance benefits. Funeral assistance from friends and family in the form of lump sum contributions affect changes to household income.

With little disposable income in the lower income categories, the probability of inheritance may be low. The surviving household members taking time off to attend funerals may lose income, which further increases indirect funeral costs.

## 2.2 Household Size, Composition and Structure

There are noted differences in household size between affected and non-affected households depending on the stage of the disease at the point of research. The study in the Free State for example found affected households larger in size (Booysen et al., 2003:42) while the study in Limpopo found affected households smaller in size due to fewer births and more deaths (Oni et al., 2002:1181). The reasons cited for changes in household size have been:

- New births (Oni et al., 2002:1181)
- The migration effect (members leave and join the household) (Booysen et al., 2003:47-72)

- The morbidity effect (sick members or children sent elsewhere to be taken care of) (Booysen et al., 2003:46).
- The mortality effect (household members die) (Janjaroen, 1997:3, Yamano and Jayne, 2002:1, World Bank, 1999:215).

The Kagera study found that the household size dropped from 6.0 members to 5.7 members following death. Household size was calculated (net effect) by taking into account those members that left through death or other reasons, members joined and members born (World Bank, 1999:215-216). No reasons were given for why members left or joined the household or whether or not they were sick. Studies have found migration patterns changing as a result of HIV/AIDS, for example, people migrating to seek treatment or care (Berk, et al., 2003:1091). The same study found that about 40% of households that suffered an adult death experienced migration of household members compared with 20% of households that did not experience an adult death (World Bank, 1999:216).

Knowledge of such migration and the impact of HIV/AIDS morbidity and mortality on migration patterns are necessary to inform planning with regard to the delivery of health and other services. HIV positive women were found to have significantly more negative pregnancy outcomes, such as spontaneous abortions and still-births, than HIV negative women (De Cock et al., 1994, Temmerman, Chomba and Piot 1994 as quoted in Ntozi and Zirimenya, 1999:195).

Studies have found that affected households were able to adjust household size and composition in ways that made them similar to households that did not suffer an AIDS death (World Bank, 1999:216). Some did this by attracting household members of the productive age group to join the household (Janjaroen, 1997:2).

The Thai study, by contrast, found the dependency ratio almost doubling because there was no replacement of household members (World Bank, 1999:216) especially through the death of economically active, leaving children and the elderly (Berkley et al., 1990 as quoted in (Ntozi and Zirimenya, 1999:195; Barnett and Blaikie, 1992 as quoted in Bharat, 1995:185). Studies in the Free State and

Thailand found that affected households had more dependants (non-economically active members) and fewer members of working age (Booysen et al., 2003:42, Janjaroen, 1997:2). Hence, some studies have found the dependency ratios increasing rather than declining such as that found in the Kagera study and the study in the Rakai district, Uganda (World Bank, 1999:215).

What happens to the dependency ratio therefore depends on factors such as the net effects of mortality and changes in household composition as well as the fertility rate since HIV-related damage is caused to the reproductive capacity of infected men and women (Setel, 1995 as quoted in Ntozi and Zirimenya, 1999:195).

HIV/AIDS brings about new household structures such as households headed by widows, women never married, children under the age of 18 years and orphans (Mukiza-Gapere and Ntozi 1995, as quoted in (Ntozi and Zirimenya, 1999:195). It is not known how many types of household structures exist in Soweto as a result of HIV/AIDS. The range of household structures identified in the literature (Ntozi and Zirimenya, 1999:199, Seeley et al., 1995:81, Crewe, 2000:19) are as follows:

- Monogamous with children (husband, wife and children with or without other relatives)
- Monogamous without children (husband, wife without children and possibly with other relatives)
- Polygamous with children (household heads with two or more spouses with children)
- Polygamous without children (household heads with two or more spouses without children)
- Polygamous extended (household head with two or more spouses with members other than their children.
- Extended 3 generations (grandparent, child and a grandchild)
- Extended skipped generation (grandparent, grandchild with or without other relatives)
- Single male (one person household)
- Single female (one person household)

- Male-headed (according to gender of household head)
- Female-headed (according to gender of household head)
- Remnant male (man and children or other relatives but no wife)
- Remnant female (woman and children or other relatives but no husband)
- Single parent households (man or women with children)
- Grandparent headed households (household headed by a grand-parent)
- Child headed households (household headed by a child)

While the extended family concept has been the norm, with modernisation, there has been a tendency towards a nuclear family system (Ntozi and Zirimenya, 1999:193). It is not known whether the nuclear family system is the norm in urban societies. Furthermore, it is not known whether family breakdown has been less or more severe during times of morbidity and mortality.

### 2.3 Cost of HIV/AIDS Morbidity and Mortality to Households

HIV/AIDS affects expenditure patterns as well as the ability of households to survive. It is therefore appropriate to include a discussion of HIV/AIDS costs to households prior to a discussion of household expenditure patterns and survival strategies. When HIV/AIDS costs are spoken of, this implies the costs associated with the disease irrespective of who bears the cost. In general it refers to the cost of illness of one individual person. Of the total HIV/AIDS costs, some costs are borne by individuals, households, the government or non-governmental organizations. When HIV/AIDS costs to the household are spoken of, this implies the cost to the household or the out-of-pocket expenses incurred by individuals within the household.

This section focus on what constitutes HIV/AIDS costs to the household. HIV/AIDS costs are costs related to morbidity (illness) and mortality (death). These are costs incurred by households as individuals move through the stages of HIV infection, AIDS-related illnesses and ultimately death. The economic impact

of HIV/AIDS morbidity and mortality on households are most commonly analysed in terms of direct and indirect costs (Bollinger and Stover, 1999:1).

Some studies report actual cost of morbidity and mortality to households. This type of information has relevance to the year of study and to the study site area. It is more relevant to report on costs in proportion to income or expenditure so that comparisons between studies can be made.

### 2.3.1 Direct Costs

Direct costs to households represent the out-of-pocket costs to the household, that is, actual expenditure on goods and services purchased (UNAIDS, 2000:37). In HIV/AIDS studies, direct costs represent the direct costs associated with treatment (Booysen et al., 2002:109, Danziger, 1994:906, Bowie, 1996:51) and in the case of mortality direct costs, include the cost of the funeral (Pitayanon et al., 1995:8, Booysen et al., 2002:109).

The Thai study found that families spent on average US$1 000 per patient during the last year of an AIDS patient's life, the equivalent of an average annual income (UNAIDS, 2000:27). In New Zealand, direct costs of HIV/AIDS per person ranged from NZ$200 per month for those who were symptomatic without AIDS and NZ$400 per month for those symptomatic with AIDS (Bowie, 1996:53). In the New Zealand study, transport accounted for a third of the direct costs. Most participants in the same study received about NZ$1 000 per month to live on. In Cote d'Ivoire, households with an HIV/AIDS patient spent twice as much on medical expenses as other households (Bollinger and Stover, 1999:2). The average health care expenditure on an HIV infected adult equals almost four times the average monthly household income (Hassig et al., 1990, as quoted in Guinness and Alban, 2000). The South African study conducted by Steinberg et al., found that on average households spent about a third of their household monthly income on HIV/AIDS related medical expenses for AIDS-symptomatic patients (2002:18).

In the Kagera study households spent more on funerals (60% of total cost of medical and funeral expenses) than they did on medical care (Kagera study, World

Bank, 1999:209). In that study, the total cost of medical care and funerals in households in the preceding 12 months of an adult death was found to be 8% of total household expenditure compared to 0.8% in households without adult death (Bollinger and Stover, 1999:2). Families also contributed to expenses associated with the death of relatives who lived outside the household (Over and Mujinja, 1993, quoted in Cohen and Trussel 1996:214). In Ethiopia, a study on 24 AIDS-affected rural families found that the costs of morbidity and mortality amounted to several times the average household income (Bollinger and Stover, 1999:2). In South Africa, households without funeral and other insurances, consumed as much as 3.4 times (Booysen et al., 2001:2) or 4 times (Steinberg et al., 2002:21) average monthly household income. The cost of one funeral could be as high as R40 000 (Steinberg et al., 2002:21).

As the number of funerals increase in a community, one wonders whether changes to funeral practices will occur. Many African funerals are conducted in a traditional way by slaughtering at least one cow to ensure that all funeral attendees are fed as well as ensuring that close relatives have money to pay for the transport to attend the funeral, in some instances worsening the already threatened food security of the bereaved family (Ayieko, 1997:16). In a village in Uganda, Barnett and Blaikie (1992) found that the mourning period reduced from one week to one-and-a-half days due to the increasing number of funerals while in the Free State, funerals have become the responsibility of the community through street collections (Booysen et al., 2003:103).

These studies emphasise the large proportion of health care and funeral expenditure to total household income costs which are reduced to the households depending on the availability of health care insurance or public health care services.

### 2.3.2 Indirect Costs

In HIV/AIDS studies, indirect costs are most commonly associated with loss of earnings for the sick person and the caregiver (Booysen et al., 2002:109). In the case of mortality, it is the loss of income to the household as a result of the deceased person or loss of earning for the caregiver prior to death (Booysen et al., 2002:109).

Sickness and death in individuals in a household has an impact on the income of income earners whether they themselves are sick or whether they are taking care of someone who is sick (Cohen and Trussell, 1996:212). A sick individual loses income in two ways, reduced productivity (Cornia and Zagonari, 2002:4) and loss of income (Oni, et al., 2002:1182) or loss of employment due to illness or death (Oni, et al., 2002:1183; Mutangadura, 2000:4). During the AIDS-symptomatic phase the worker may not be capable of working (Cornia and Zagonari, 2002:4). Pallangyo and Laing (cited in Rugalema, 1999:6) observed that an adult Tanzanian suffered an average of 17 episodes of AIDS-related illnesses which lasted between one and two years before the individual died. This period of morbidity required about 280 days of both hospital and home care for the AIDS-symptomatic individual. This means that in the last year of the individual's life, the individual would spend three quarters of the year in bed.

A bus company in Zimbabwe found that AIDS-related absenteeism accounted for 54% of all absenteeism, with 35% being absenteeism due to HIV-related symptomatic illness (Whiteside and Sunter, 2000:100). The indirect costs in all studies were found to be higher than the direct costs. In Tanzania and Zaire, indirect costs accounted for 97% and 94% of the total economic costs respectively (as quoted in McMurchy, 1997:12). In the Lesotho study, indirect costs accounted for 80% of the total economic costs (McMurchy, 1997:11).

The Thai study found that the largest part of the economic costs of an HIV/AIDS-related death was the foregone income of the deceased. The study calculated foregone earnings to include all future earnings until retirement age of 60 years (Pitayanon et al., 1995:11). Studies of this nature that calculate the foregone earnings assume a situation of full employment and that the deceased would have been employed for the duration of life only to retire at age 60 or 65 years of age. Furthermore calculating foregone life's earnings will estimate high-income households to be greater impacted than low-income households. If the person is young, foregone earnings will be higher than for an older person earning the same income. A study on 7 enterprises in Tanzania showed that the average age of death

among workers was between 31 and 37 years (ILO 1995, as quoted in Cornia and Zagonari, 2002: 4).

### 2.3.3 Systemic Costs

Whiteside and Sunter's business model for calculating costs include systemic costs, that is, costs related to reduced workforce morale or reduced productivity of co-workers (2000:112). Bowie further added intangible costs such as the impact of the illness on social and sexual relationships, elements of stigma and discrimination and quality of life considerations (1996:51). Most studies ignore the intangible /systemic costs because they are more difficult to measure in monetary terms.

Systemic costs are determined by calculating the opportunity cost of illness such as the cost of activities lost as a result of caring for the sick person or the loss of activity for the sick person. These represent the foregone value of the time diverted. This is consistent with Becker's (1965) argument that households produce commodities by combining inputs of goods and time with "full income" being the sum of money income and that foregone by the use of time.

## 2.4 Income

Various studies point to the effects of HIV/AIDS morbidity and mortality on household income. In Botswana, per capita household income for the poorest quarter of households was predicted to fall by 13% while income-earners in this category were expected to care for an additional four dependants as a result of HIV/AIDS (Botswana Institute for Development and Policy Analysis, 2000:1). In a rural study in the Kafue District, Zambia, households affected by chronic illness including HIV/AIDS reported annual income levels 46% lower than those households not affected by chronic illness (Mutangadura and Webb, 1999 as quoted in Topouzis, 2000:18). In a rural study in the Limpopo Province of South Africa, Oni et al., found that the annual average income was approximately 35% lower in households affected by HIV/AIDS compared to non-affected households (2002:1182).

In a study conducted in Zambia on HIV/AIDS-affected families, monthly disposable income dropped by more than 80% for more than two thirds of the families (Nampanya-Serpell, 2000:8). In the Zambian sample 70% of the deaths were paternal the majority of whom were breadwinners. In rural Thailand, Kongsin et al., (2000) found household income dropped by 70.7% and per capita income dropped by 68.4% following an adult death. AIDS mortality reduces the household's potential to earn future income unless reorganization of labour within the household takes place.

In the Free State study on urban and rural households measuring the effects of morbidity and mortality in South Africa, Booysen et al., reported average adult equivalent income in affected households on average representing 62% of the levels of total household income in non-affected households (2003:74).

Having seen the broad extent of the effects of HIV/AIDS on household income, it is crucial to recognise that there are various ways in which a household earns income, depending on their productive activities (Redclift and Mingione, 1985:20).

1. Formal – this is formal employment either by working for an individual or a firm whose business is registered or from being self-employed in a registered business.
2. Informal – Employment without contract, or informal self-employed where the business is not registered.
3. Mixed formal and informal – formal work producing income and in part informal through holding of second jobs.
4. Illegal – criminal sectors, employment of minors or illegal immigrants.
5. Work not exchanged for income – reciprocal work and activities such as taking care of sick members of other households, etc.
6. Home production for self-consumption – cultivating vegetable gardens for self-consumption, home production of clothing, do-it-yourself activities.

Formal work contributes to the state fiscal system and can be easily measured through the inspection of pay-slips. Informal work is a little more difficult to measure unless income is received or details of income and expenditure are kept.

Attempts will be made to capture net profit from home-produced goods and services. Illegal work is difficult to detect, quantify and measure in terms of who practices it. Reciprocal and supportive activities that one household conducts in favour of the survival of another household occurs from time to time. These activities could be measured by using the labour cost of the activity or by the opportunity cost of labour of the providers. The present study will not quantify reciprocal activities but will mention the types of support received by and given to other households.

In addition to the above ways in which a household earns income, households generate income through various "non-earned" means such as remittances (transfers), special events such as marriage (bride price lobola), once-off donations and income from grants. In poorer households, non-earned income may form a significant portion of household income (Lundberg et al., 2000:6).

Remittances into the household may come from migrant workers or from members of other households. Since there have been fewer urban studies it is unknown whether urban households are more likely to transfer money out than receive money. Milanovic (2001:25) argues that the propensity to remit will depend on factors such as the number of family members left at home, the duration of stay abroad, and so on) and not on the income group of the household while other authors argue that the income group of the household has significant effects of the value of remittances received especially from migrant workers (Posel, 2001, Stack and Lucas, 1998). It can be argued that poorer households facing sickness and death would require the help of migrant family members especially if no-one else in the household is employed. Transfers into the household may also come from relatives and non-relatives for various reasons such as altruism and may be selective towards certain kin in particular (Posel, 2001:178) or as a form of insurance for help given today may be reciprocated sometime in the future (Lundberg et al., 2000:6).

Another form of income to the household is in the form of state grants. South Africa has a well developed system of social security compared to other developing countries (Seekings, 2002). Given that individuals lose employment as a result of sickness, one can expect that non-market household income, particularly in the form

of disability grants to increase. The Free State study conducted in South Africa, found that not only a large number of affected households qualified for the grant, they also became more dependent on income from social grants (Booysen, 2004).

Previous studies did not state whether reported income refers to gross or net household income or whether total household income includes non-earned income. The Zambian study made reference to disposable income (Nampanya-Serpel, 2000:8). It is obvious from the literature that earned income will be affected as individuals become sick and exit the labour market. However, the role of transfers (remittances from relatives and non-relatives) and government grants in households experiencing sickness versus households not experiencing sickness should not be ignored.

In reporting household income, besides the Free State study, the Limpopo study and the South African study conducted by Steinberg et al., (2002) none of the other studies distinguish between the various forms of earned and non-earned income.

The present study focuses on all types of earned income and non-earned income that enters the household on a regular or irregular basis (see Appendix 1).

**2.5 Expenditure**

The ultimate aim of economic activity is to satisfy human wants. The income that is generated is used to pay for goods and services and individuals within households consume goods and services, which are referred to as consumption or household expenditure.

A large proportion of expenditure in the average South African household goes towards buying essential items such as food and housing (Orkin, 1997:29). In South Africa, the poorer households spend a greater proportion of their income on food (50%) leaving little money for other expenditure (Hendricks, 2001:11). As income increases, a smaller proportion of income is spent on food. The percentage of income spent on food can be a proxy for economic status of the household. In an HIV/AIDS infected household a higher proportion of the expenditure budget is

expected to be spent on health care, funerals and other essentials and less on non-essential categories.

Increased health care or funeral costs at household level due to morbidity and mortality may cause expenditure patterns to change. The Kagera study (Lundberg and Over, 2000:4) found that households with a death allocated a larger share of total expenditure to medical care and funerals and a smaller share to purchased food and "other" food items including clothing. The same study found that households with a death had higher total expenses as well as higher expenditures on all components of consumption than households in which no death occurred. In the Kagera study, total household expenditure included the cost of medical care and funerals.

Few studies have documented changes in consumption as a result of morbidity while most studies reported on the changes in consumption as a result of mortality, with the exception of the Free State study. The Free State study reported that average adult equivalent expenditure was relatively lower in the affected group of households than in the non-affected group especially if the affected group had experienced morbidity or mortality more frequently (Booysen et al., 2003:78). Furthermore the study found that affected households that had experienced morbidity and mortality in two or more periods allocated more of their resources to food, health care and rent and less to education, transport, clothing, and personal items when compared to non-affected households (Booysen et al., 2003:79). The study conducted by Steinberg et al., in South Africa found that 21% of households reduced expenditure on clothing, 16% on electricity and 9% on other services (2002:17).

Bechu (1997, in Cornia and Zagonari, 2002:10) found a 28% decline in per capita consumption of basic needs, in households in the urban areas of Cote d'Ivoire when a person died of AIDS. The same study showed a recovery in consumption the year after death. These findings were also confirmed in the Thai study (Janjaroen, 1997). The rural Kagera study found that in the poorer half of households in the sample, food expenditure fell dramatically following a death and then recovered almost fully as households minimized spending on other categories (World Bank,

1999:214). For the non-poor half, food expenditure actually rose following a death (Lundberg and Over, 2000:5).

In rural Thailand, the per capita expenditure in households affected by an adult death dropped by 43.5% with the decrease being worse when the deceased was an adult woman (Kongsin et al., 2000). Moreover, the study found that more of the poorer households were adversely affected by consumption due to illness and death of the working member than non-poor households (Pitayanon et al., 1997).

Lower expenditures on food may have broader implications for the nutritional status of members of the household. An Eastern Cape study in South Africa, found food consumption lower in rural households experiencing chronic illness (Samson, 2002:1157). The Free State study found the average adult equivalent expenditure on food represented 78% of that in non-affected households (Booysen et al., 2003:78).

Some studies have found children in AIDS-affected households being withdrawn from school, with long-term impacts on human capital (Booysen et al., 2003:115, Bonnel, 2000:6).

Some studies that reported a reduction in total household consumption did not take into account household size. Most household survey data have indicated that household expenditure was positively associated with household size (Laurie and Sullivan, 1991:122). However, as household size increases, total outlay rises less than in proportion resulting in per capita household expenditure being negatively correlated with household size (Lanjouw and Ravallion, 1995:1415). Change in household size comes about as a result of sickness and death as members exit the household and change in composition arises when one or more members leave the household or new members enter the household. The household suffers loss of income or labour as a result of the departed member especially when non-income generating members replace income-generating members. These factors should be taken into account for consumption to be understood and predicted. Since households vary in size and composition, it is appropriate to measure consumption per capita and/or per adult equivalent. Households with the same level of expenditure do not necessarily enjoy the same level of welfare. At similar levels of

household expenditure, the larger the household, the lower the level of welfare. Measures of adult equivalent expenditure are employed to allow for these differences in standard of living related to household characteristics (Lipton and Ravallion, 1995: 2574; Burkhauser et al., 1997: 154-161).

Besides the Kagera (rural), Thailand (rural), Free State (urban and rural) and Limpopo (rural) household surveys, no other studies focused on detailed expenditure pattern changes as a result of increased health care and funeral expenses.

## 2.6 Impact on Surviving Family Members

Besides the possibility of cross-infection at household level, the loss of income and changes in spending priorities surviving members may experience other disruptions in household activities. The surviving spouse may be forced to seek employment to supplement income or to stay home from work to care for the sick. There may be re-allocation of time spent on household economic activities. New members may be forced to enter the household to care for the sick or sick members and children may leave the household to be cared for by extended family members outside of the household.

In the Thai study, 15% of children were taken out of school and over half the elderly were left to take care of themselves (UNAIDS, 2000:27). When family members in urban areas fall ill, they often return to their villages to be cared for by family members (UNAIDS, 2000:27). This could result in a non-affected household to become affected. In the Zambian study, two-thirds of the children aged 6 to 15 were currently enrolled at school in both the urban and rural samples, with the proportion of boys (70-71%) being slightly higher than that of girls (67-88%). The study further reported that 21% of females and 17% of males in the urban sample and 8% of girls and 6% of boys in the rural sample dropped out of school after parental death (Nampanya-Serpell, 2000:9). This showed that girls were more likely to drop out of school.

In the Zambian study on HIV/AIDS-affected families, families were displaced if the breadwinner who died was a tenant on the employers' premises. Of those who didn't move, half of them rented out rooms in their dwelling to earn some income. This resulted in over-crowding with as many as five children into one room (Nampanya-Serpell, 2000:8).

The disruptions of family life are felt on the psychological level (Ankrah, 1993:15). Long periods of care are needed by people living with AIDS. The care-giving function not only tires out caregivers but is difficult for surviving family members to see the infected person in poor health. Following death, the mourning period often involves family members not working for 3 days after the death (Ankrah, 1993:15).

Children become orphans or are fostered. Many parents do not make alternative living arrangements for their children before they die. In the Uganda study on orphans, only 3.7% of families stated that sick parents had made prior arrangements with friends and relatives to help take care of their children. Approximately 59% of caregivers were identified by virtue of being the closest relative. This brought about resentment because many caregivers were not necessarily willing to care for orphans (Ayieko:1997:11)

No HIV/AIDS economic impact studies in South Africa or elsewhere, besides the study conducted by Rugalema in Bukoba, investigated the time allocation of labour in households affected by HIV/AIDS (see Appendix 5). The present study explores these gaps in the literature in detail, including the psychological impact that illness has on surviving members. Furthermore, this study captures kinship linkages which link the child to the parent and parents to each other. This type of information is helpful in establishing the means test for child support and old age pension grants.

### 2.7 Intra and Inter-Household Obligations of Care and Support

The concept of pooling refers to the contribution of individual members to joint household income. A portion of the literature rejects the "income pooling"

phenomenon of individuals within households (Haddad and Hoddinott, 1993, Blumberg, 1988, Hoddinott and Haddad, 1995, Browning et al., 1994, Bourguignon et al. 1993, Fortin and Lacroix, 1993) while others suggest that this phenomenon cannot be rejected all together (Phipps et al., 1998, Hanan et al., 1998).

Household members may pool their income for some categories of household expenditure, but not for all since not all, individuals in the household would have similar utility functions (Phipps, 1998). The receipt of transfers into a household complicates the decision-making powers in the household (Attanasio and Lechene, 2002). In poor households, especially in cases of high unemployment where there may only be one income-earner there might be little choice about whether or not to pool income to pay for household expenditure, since most of the household budget is spent on a few essential expenditure categories. The present study did not examine pooling of expenditure from one income-earner.

The present study accepts that all individuals in all households may not pool all of their income (Doss, 1996) but most of their income which is used to pay for essential household expenditure categories is pooled. Households also depend on safety nets especially help from other households (inter-households) to compensate for income shortfalls.

Care and support may be provided by family members within households by caregivers (intra-household) but also by members outside the household such as that provided by the government, non-governmental organizations and other households (inter-household).

The nature and extent of treatment and care needs differ at different stages of illness and therefore requires different approaches. An individual with full-blown AIDS requires outpatient care for opportunistic infections compared to those in the final stages of the disease who require access to hospice care and continuing pain control (Cohen and Trussell, 1996:210). As an alternative to hospitalisation, the Gauteng provincial department introduced various home-based care programmes. There are also non-governmental organisations such as Hope Worldwide that offer home based care in Soweto. They operate with volunteers providing assistance with the

patient's personal hygiene, administering medication as well as assisting with domestic chores (personal communication, Eddie Phillips, 2003). In Rwanda, a training program was designed to teach families how to care for people with AIDS at home and a volunteer programme was designed to provide family members with emotional support (Cohen and Trussell, 1996:210). Besides the care provided by the medical team and other home-based care organizations, what type and quality of care is being provided by relatives, neighbours and friends in an urban community? Not much information exists in the literature about this type of home-based care that is provided by members of other households.

A study on home-based care in Zimbabwe found that households lacked counselling and the quality of care was varied (Loewenson and Whiteside, 1997:36). In a study, conducted in the United States on unmet needs for persons living with AIDS, almost three-quarters of respondents stated that they had unmet needs. The unmet needs identified in this study were help required with domestic chores and transportation (Smith and Rapkin, 1995:353).

Alubo et al., (2002), Cobb and De Chambert (2002), and Herek (2002) argue that HIV/AIDS programmes will not be effective until such time as there is greater acceptance of people living with AIDS. In addition, disclosure allows HIV-positive persons to become AIDS educators and AIDS activists, resulting in reduced stigma and greater community involvement (Fitzgerald and Simon, 2001, Paxton, 2002), which further reduces stigmatisation within communities.

Households receiving care and support from the community face the consequence of stigma and discrimination. Families face having to deal with stigma associated with disclosing the diagnosis. They also have to face discussing issues surrounding lifestyle and behaviour of the sick individual (Bor et al., 1993:191). King (1990 quoted in Bor et al., 1993:191) also notes that there is increasing discrimination against people with HIV infection and that there may be secrets within family units where children and some members of the family may not be told of the sick person's HIV status (Bor et al., 1993:191).

## 2.8 Household Survival Strategies

The extent to which the impact is felt at household level is dependent on the use of survival strategies. Rugalema (2000:537-543) argues that households are "surviving" rather than "coping" because "coping" means that they are dealing successfully with the situation and this was not the case for many households affected by HIV/AIDS. Households survive by employing a variety of short-term strategies. A household's ability to survive means ensuring the welfare of the household not only in the short-term but also in the long-term.

According to Mutangadura et al., a household's ability to cope depends on their access to resources, household size and composition, access to resources of extended families and the ability of the community to provide support (1999:18). Mutangadura et al., identified poor small households as being most vulnerable in their ability to cope (1999:19).

Sauerborn, Adams and Hien (1996:293-297) established a hierarchy of household strategies, using household savings as a first choice to cover the financial costs of HIV/AIDS. This was followed by the sale of assets, borrowing, re-allocation of household labour then followed by the reliance on community assistance to finally doing nothing.

**Table 2.2: Household Survival Strategies**

| Strategies aimed at alleviating the loss of income | Strategies aimed at surviving the financial cost | Strategies aimed at alleviating the loss of labour | Strategies aimed at utilizing safety networks |
|---|---|---|---|
| • New members who are employed join the household<br>• Diversity of income | • Utilize savings<br>• Dispose of assets<br>• Borrow<br>• Children drop out of school<br>• Reduce | • Reallocate household labour<br>• Encourage non-economic active members to join | • Inter-household care and psycho-social support<br>• Inter-household financial |

| Strategies aimed at alleviating the loss of income | Strategies aimed at surviving the financial cost | Strategies aimed at alleviating the loss of labour | Strategies aimed at utilizing safety networks |
|---|---|---|---|
| • Remain at work until the person can no longer work<br>• Dissolve the household<br>• Do nothing | consumption on certain items<br>• Beg<br>• Adjust household size and composition<br>• Apply for State assistance | the labour market<br>• Withdraw children from school to help with household chores<br>• Work extra hours | support<br>Fostering of children<br>• Transfers from relatives and non-relatives<br>• Coping with discrimination |

(Adapted from Mutangadura et al., 1999:17)

### 2.8.1 Household Survival Strategies Aimed at Alleviating the Loss of Income

Sauerborn et al., (1996:291) in rural Burkina Faso found that due to illness intra-household labour substitution was the main strategy to compensate for labour losses. The same study also found that individuals from poor households were able to generate additional revenue by engaging in a variety of income-generating activities such as brewing millet beer, fetching firewood, weaving straw mats and tailoring to supplement income (Sauerborn et al., 1996:294). Diversifying household income may also take the form of one or more members participating in micro enterprises (Donahue, 1998:5).

The study conducted in Zimbabwe, (Mutangadura, 2000:11) found that 65% of the households where the deceased adult female used to live before her death was no longer in existence in both rural and urban areas. In a Ugandan study on orphans, it was found that a significant number of women returned to their maternal homes when their husbands died where they found emotional security amongst maternal kin. In some cases where both parents die, households dissolve and children are sent to live with extended families having to adjust to unfamiliar relatives in foreign places (Ayieko, 1997:10).

Some households may not have the opportunity to diversify income, or have new members to join the household and therefore find they can do nothing to alleviate the loss of income.

### 2.8.2 Household Survival Strategies Aimed at Surviving the Financial Cost

Households survive the extra burden of the financial costs of HIV/AIDS through one or a combination of short-term strategies.

In the Thai study almost 60% of households that experienced an HIV/AIDS–related death utilised savings to finance 88% of their increased costs (Pitayanon et al., 1995:16). This means that future household investment will be negatively impacted including the loss of interest from the investment. The Thai survey, as well as a survey in Zimbabwe, found households that experienced an HIV/AIDS-related death were more likely to sell assets and borrow more money as well as experience a change in food consumption (Pitayanon et al., 1995:17, Mutangdura, 2000:17-20). In South Africa, the Free State study found that affected households saved 40% less and a slightly larger percentage of affected households (30%) borrowed money in the past twelve months compared to non-affected households (23.5%). The majority borrowed money to cover expenses incurred by sickness and death (Booysen, et al., 2001:58-60). Paying off debt is a form of savings. The biggest debt for most South African households is the home loan (Moodie and Fram, 2001:11). A study commissioned by the Micro Finance Regulatory Council (MFRC), showed that poorer households had outstanding debt of around 10% compared to the international norm of debt not exceeding 25% of gross salary. This could be because low-income households in South Africa rarely have sufficient income to cover expenses. Furthermore, they have limited access to loans from the formal sector (Hendricks, 2001:11).

The longer-term impacts will be felt when assets and savings are not replaced, when children drop out of school during parental sickness to take care of the sick and after parental death due to a lack of funds. In a study conducted in Botswana on orphans in 1998, it was found that 30% of the children had dropped out of school

particularly because caregivers could not afford to provide uniforms, school shoes or school feeding (Smart, 2001:25). Children who drop out of school create a disinvestment in human capital and thereby jeopardise the family's ability to secure future income. Selling off assets such as land, motor vehicles or livestock (Sauerborn et al., 1996:294) result in a negative long-term impact.

Households also rely on financial help from governmental and non-governmental organizations especially during times of crisis.

HIV/AIDS also impacts on the supply of labour. In cases where individuals are too sick to go to work, they become unemployed and therefore form part of the economically inactive population. On the other hand, they may not have been working prior to the illness and after being classified as disabled, they may be eligible to collect disability in which case although they may be unemployed and not economically active, they are generating grant income.

Households that wish to self-insure take out burial insurance during times of illness or through preserving extended family ties as an insurance mechanism since such ties allow households to share risk and gain access to additional resources (Donahue, 1998:5).

### 2.8.3 Household Survival Strategies Aimed at Alleviating the Loss of Labour

Adult death may reduce the labour force and the mean age of labour (Loewenson and Whiteside, 1998:13). In Tanzania the labour force was expected to shrink by 20% by 2010 and the average age of workers to fall from 32 to 28 (Loewenson and Whiteside, 1998:13). The lowering of age means that younger people including children are forced to enter the labour force. The question is, are there jobs available, especially in view of younger people's inexperience in the labour market?

Family members may reorganize their time to minimise the income loss particularly by withdrawing children from school which lowers their future earning capacity (Pitayanon et al., 1995:8). The elderly may be forced to go back to work or children may be withdrawn from school to start working or to conduct household chores.

The Thai study found that the labour supply affected 52% of households leading to about a 47% loss of income even though other family members had to reallocate their time and take on more work time (Pitayanon et al., 1995:12).

### 2.8.4 Household Survival Strategies Aimed at Utilising Safety Networks

Some studies have found the poor having less access to social support networks as well as the burdens on social networks in poor communities growing as the burden of disease increases due to reciprocity (Kawachi, Kennedy, Lochner and Porthrow-Stith, 1997, Kawachi, Kennedy and Glass, 1999, Kunitz, 2001).

Safety networks play a role in household survival strategies. Children are sent to live with extended family (Ryder, Kamenga, Nkusu, Batter and Heyward, 1994:678, UNAIDS, 2000:27). Households access help in cash or in-kind from relatives, non-relatives, neighbours as well as institutions who are a source of strength during illness/death (Bharat, 1995:87, Sauerborn et al., 1996:291). In a study conducted on people living with AIDS in California, 93% of the sample utilised at least one emotional or practical support service since becoming HIV symptomatic (Wight et al., 1995:5). In India, the family is characterised by strong emotional ties that fosters mutual dependence maintaining links with the extended family and the wider kinship network (Ramu, 1988 as quoted in Bharat, 1995:182). Although there is a growing individuation, the family continues to be a source of strength and support for most people especially during sickness and death (Sinha, 1988 as quoted in Bharat, 1995:182). In African countries, the situation is similar with HIV/AIDS being a family burden and the extended family becoming involved and providing assistance (Bharat, 1995:183; Barnett and Blaikie 1992, World Bank, 1999:218). Families are known to support sick members even when impoverished and the amount and type of care depends on the availability of financial resources (Bharat, 1995:184). Orphaned children may be fostered by extended families (Pitayanon, 1995:8). Private transfers from other households play a large role especially following death (Lundberg et al., 2000:5). In the Kagera study, the median amount received during the half-year of the death was twice that received during the year

before the death as well as twice that received by households that did not suffer a death (World Bank, 1999:219).

Households presenting with HIV/AIDS-related illnesses face discrimination and are forced to cope on their own. The Thai study found discriminatory practices to include pressure to leave a job, former customers no longer ordering goods from the family business, no new customers and employees quitting the family business (Pitayanon, 1995:15).

There has been much written about household survival strategies and in one study even the sequence of household survival strategies. Most surveys have been conducted in rural settings where the survival strategies employed are very different from those employed in urban settings. For example, in an urban setting there is not much that can be done to increase home-grown production. A variety of studies revealed different survival strategies. The present study examines all strategies outlined in Table 2.1 and investigates the frequency of use as a proxy for their priority.

Households' ability to survive may depend on their asset portfolio prior to sickness and death. No studies assessing the impact have conducted an inventory of the household assets prior to illness and after death. This study also focuses on the role played by social grants and applies the means test to establish eligibility and take-up rates on grants.

**2.9 Summary**

HIV/AIDS has been found to be mostly prevalent in prime-age adults with more than one member of the family being infected. Prime-age is of significance because it is at this age that people are most productive with the potential to earn income. Declines in household income are expected not only because of the sick member not being able to work but also because of caregivers' giving up employment.

As individuals move from the HIV phase to being AIDS-symptomatic the direct and indirect cost of illness to the household increases and the impact on surviving

family members begin. The direct and indirect HIV/AIDS costs to households further increase as a result of death. The combined cost of morbidity and mortality to a household is therefore high. Income changes combined with high morbidity and mortality costs result in changes to expenditure patterns and reductions in the consumption of certain essential commodities. Since households vary in size and composition, income and expenditure is measured in adult equivalent terms.

Not only do these changes affect surviving household members, they are further impacted in various other psycho-social ways such as disruption to family life and being exposed to discrimination. Household size, composition and structure are expected to change as a result of HIV/AIDS.

Care and support may be provided by non-relatives and relatives within the household and between households. Care needs differ depending on the stage of illness. Home-based care provides an important support system and as such needs to be evaluated in terms of quality and unmet needs in the presence of stigma and discrimination.

Households employ various survival strategies to alleviate loss of labour and income, survive the financial cost and optimise the use of safety networks.

Various lessons have been learnt from the previous studies which the present study will explore further. Some of the lessons are recording all types of income and expenditure including applying the means test to calculate take-up rates of child-support and old age pension grants, reporting the combined costs of morbidity and mortality, the psycho-social and economic impact on surviving members, and various household survival strategies.

No HIV/AIDS economic impact studies focused on inter-household obligations of care and support prevalent in urban settings. No HIV/AIDS economic impact studies have documented the type of care provided and received by urban households and who the caregivers have been. It is further unknown how stigma and discrimination is being handled if neighbours and relatives were to find out about the true nature of illness and whether or not families are disclosing members'

HIV status and were in fact receiving the type of support required. All of these issues are investigated in the present study. The present study is comprehensive and attempts to uncover the wide range of impacts on and responses by HIV/AIDS affected households.

# CHAPTER THREE
# SOWETO

## 3.1 Introduction

This chapter gives a brief overview of the study area and its history to present day (2002). The data on Soweto for 2002 has been obtained from research commissioned by the Perinatal HIV Research Unit (PHRU). The sample design was a stratified, two-stage cluster sample of 4912 households in 226 enumerator areas (EA's) covering all households across all districts.

Soweto, an acronym for South Western Township is by definition an urban area, being characterised by "dense population, concentrated living space, social networks, and a variety of economic activities and lifestyles" (Andranovich and Riposa, 1993:3). The development of African urban areas in Johannesburg dates back to the discovery of gold in 1886 (Mohlamme, 1993:4). Historically, many Africans arrived in the city of Johannesburg to work on the mines and were housed in single-sex hostels. Later, people migrated to the city to work as domestic workers and lived on the premises of their employers. During industrialisation, many more Africans came to the urban areas to work in the factories (Mohlamme, 1993:6, Sorodnov, 1988:65) and Soweto is now inhabited by all strata of society from the elite in private sector houses, to the middle class professionals and the poor hostel dwellers (Sorodov, 1988:65).

## 3.2 History

In an attempt to find alternative accommodation for the homeless in and around Johannesburg, the first suburb Pimville then known as Klipspruit was established, 15 kilometres south west of Johannesburg after the outbreak of the bubonic plague in 1904 (Mohlamme, 1993:4, Carr, 1990:11, Magubane, 1983:17). Soweto was referred to as a "township" that had been reserved as a residential area for Africans under apartheid (Sorodnov, 1988:59, Carr, 1990:29). Temporary corrugated iron shelters were constructed then (Mohlamme, 1993:4) for the migrant mine workers,

however as the industries in Johannesburg developed, the need for permanent homes became necessary. By 1935, 31 years later, 3000 dwellings were built in Orlando East to house about 18 000 people. The two-roomed houses of 397 square feet cost about R230 in Orlando East in 1935 (Lewis, 1966:9). In 1990, there were 90 000 houses in Soweto with an average household size of between seven or eight. Soweto is populated by all ethnic (Hellmann, 1971:4) and racial groups (Statistics South Africa, Census 2001). The different townships in Soweto were separated on the basis of language groups, for example, Naledi was a Sotho speaking district, and Zola a Zulu speaking district (Boner and Segal, 1998:44). Since migration out of Soweto has been low, these divisions remain largely unchanged.

Soweto was the centre of political campaigns aimed at the overthrow of the apartheid state. Many of the most eminent anti-apartheid leaders, including Nelson Mandela and Walter Sisulu, spent all or much of their formative years in Soweto (Morris et al., 1999). It was in Soweto where the student uprising of June 16, 1976 started and spread throughout the country embracing all ethic groups (Magubane, 1990:28) characterised by boycotts and protests. It began with children protesting against Afrikaans being used as a joint medium of instruction with English in African schools. A 13-year-old student, Hector Peterson was killed, his photograph symbolising the tragedy of that day, and each year June 16 is remembered with a holiday called Youth Day (Hopkins and Grange, 2001:2).

### 3.3 Family Life

According to Hellmann (1971:14-15), only married men qualified to live in Johannesburg were entitled to obtain houses in Soweto, thus being permitted to have their wives with them. This requirement might have induced many men to marry in order to qualify for a house. Average household size in mid 1969 was 5.85 (Hellmann, 1971:12). Hellman argues that the household size did not reveal the number of families which were in fact multi-generational or the extent of marital instability. Early studies conducted in East London in 1963, showed a tendency for children to lose their father at an early stage (Pauw, 1963:149 as quoted in Hellman, 1971). In 1966 in Soweto, only 15% of the respondents were born in Johannesburg (Hellman, 1971:10). According to Hellman (1971:11-12) a survey in Soweto

conducted in 1962 revealed that "on average 6% persons were not members of the conjugal family", suggesting that most families were nuclear, that is, mother, father and children.

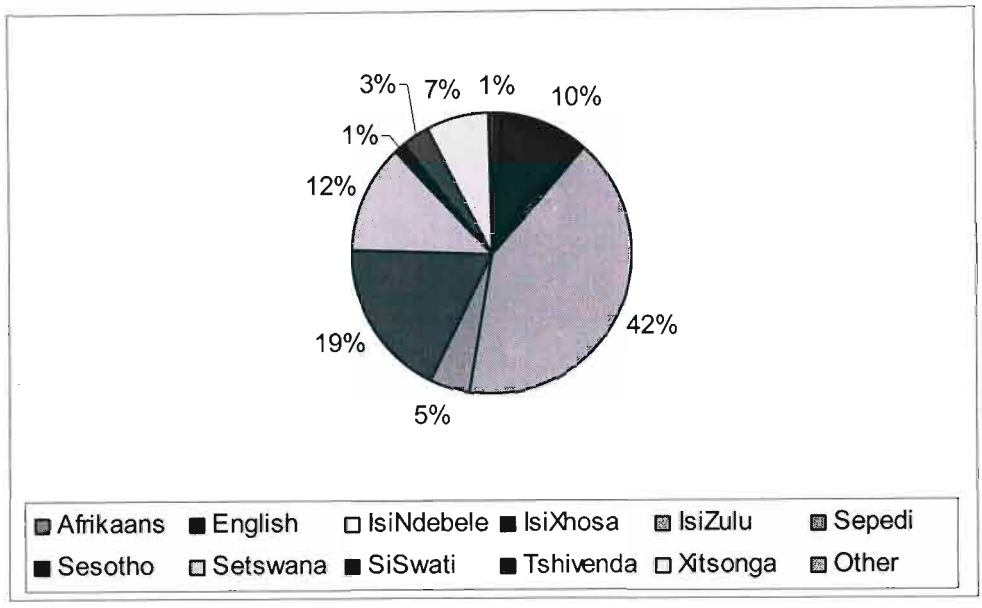
In 2002, the PHRU study, found only a third of the households nuclear. Approximately 19% of household members had partners living elsewhere, the main reason being for work. Approximately 42% of mothers and 50% of fathers, who were alive, did not live in the same household as the child while 12% had siblings under the age of 16 living elsewhere.

As in other parts of Africa the extended family in Soweto constitutes a hierarchy of relationships, the grandparents sometimes even great-grandparents, the father, the mother and the children. The grandparent's role would predominately centre on the upbringing of children. Traditionally, the father would be the head of the household and the primary bread-winner. In most African societies, it would be unusual to find households headed by married women (Ntozi and Zirimenya, 1999:197). A household headed by a married woman may be possible in the case of the husband working elsewhere or in the case of widows. The mother would be responsible for the care and support of the children, the husband and other members of the family. Mothers would be tasked not only with care-giving and nurturing activities for the young but also responsible for homemaking and engaging in formal/informal production of market and non-market goods (Bharat, 1995:185, De Bruyn, 1992:255). Children have been greatly desired for continuance of the family lineage. Children would help their families with household chores (Ntozi and Zirimenya, 1999:193).

### 3.4 Spoken Languages

Census 2001 data revealed that the most common languages spoken in Soweto is IsiZulu followed by Sesotho and Setswana (see Figure 3.1).

**Figure 3.1: Most Common Languages Spoken by Sowetans**




Source: Statistics South Africa, Census 2001

### 3.5 Provision and Utilisation of Health Care

The Chris Hani Baragwanath Hospital was officially opened in September 1942 with 1544 beds to provide medical care for the African population of the Witwatersrand (van den Heever, 2002:1). The hospital had grown in stature. In 2001 it had 2 964 beds with a staff of about 5000 in 429 buildings with a total floor space of 233 785 square metres and known as the largest acute hospital in the world (www.chrishanibaragwanathhospital.co.za) (van den Heever, 2002:14). In 2001, approximately 80% of patients paid between R13 and R39 per outpatient visit and between R129 and R194 per admission. Maternity cases and all children under the age of 6 years were treated free of charge. Approximately 20% of patients were classified as "private patients", which included patients with medical aid and foreign patients (www.chrishanibaragwanathhospital.co.za).

The PHRU (2002) study found that 78% of all sick adults accessed health care services. Of those who accessed health care services 75% utilised a public health service for their first visit while 25% utilised a private service. Approximately, 13% of sick individuals had access to private health care insurance. Of those who did not utilise a health service, the majority (80%) was because they chose to self-

treat while only 5% did not think treatment would help. A small percentage (0.2%) accessed traditional methods of healing for their first visit. This could be because public health care facilities are easily accessible and efficient in Soweto. The majority of Sowetans travelled for less than 30 minutes and waited less than an hour for treatment in the public health care facility.

In many parts of Africa, herbs and other natural ingredients have been used for healing purposes. Illnesses were thought to have been brought about by evil spirits. Hence, two types of traditional groups of healers exist, herbalists and diviners. Herbalists help people with every day medical problems and diviners help people with divine intervention performed by a supernaturally-ordained person (Ankrah, 1993:11). Traditional methods of treatment have been known to be sought by people living with HIV/AIDS.

### 3.6 Transport Costs

In the 1930s transport between Soweto and Johannesburg was inadequate and expensive. The journey on public transport would cost 2 shillings and 6 pence whilst average earnings were only 21 shillings a month (Bonner and Segel, 1998:18). In 1997, nearly half of all employed Sowetans used the taxi as their main mode of transport, only one in six used trains and one in ten used buses (Morris, et al., 1999:12). In 2002, a return taxi trip within Soweto would cost between R7.00 to R8.00 and a trip between Chris Hani Baragwanath hospital and the city of Johannesburg R8.00. The transport cost to attend the clinic or hospital would be half the cost of public health care. Despite the high proportion of travel cost to total heath care cost, the PHRU study found only 1.8% of sick individuals not accessing a health care facility because they could not afford the transport fee.

### 3.7 Burial Societies

Burial Societies, better known in Soweto as "makgotlas" in Sotho and "masingcwabisane" in Zulu, provide members with financial assistance when a death occurs in the family. The role of burial societies was to guard against financial ruin after death of a household member and they emerged in response to

the need of families to provide a dignified burial (Kuper and Kaplan, 1944 as quoted in Thomson and Posel, 2002:4). Many started as informal savings schemes particularly by women (Thomson and Posel, 2002:2) and grew to more sophisticated operations. Although there is an increase in deaths due to HIV/AIDS, this is not widely discussed within the communities experiencing death or within the burial societies themselves (Thomson and Posel, 2002).

Bonner and Segel (1998) describe funerals as large scale events with lengthy and costly rituals such as slaughtering an ox or a goat to feed the mourners after the burial. In African communities, a funeral has tremendous traditional and spiritual significance (Black Enterprise, 1989:54 as quoted in Verhoef, 2002:4). In 2003, the total cost of funerals (pre and post funeral costs) cost families about R30 000 (Philp, 2003:6).

Stokvels, better known as "mohodisano" in Sotho and "umholiswano" in Zulu are another form of informal savings scheme or credit unions that raised money. Stokvels are voluntary organisations utilised to facilitate social interaction (social network), saving and access to a lump sum of cash (Verhoef, 2002:3). In his case studies undertaken in Gauteng and Mpumalanga Verhoef uncovered the main reasons why people belong to that particular stokvel:

- "8.7% belonged to be with trusted friends
- 41.6% belonged specifically for savings purposes
- 19.5% belonged to survive economically
- 31.7% belonged to gain access to a social support network." (2002:20)

Verhoef (2002) highlighted three major forms of stokvels besides the burial society: savings clubs, investment and credit groups and high-budget stokvels. The earliest stokvels were general savings clubs which rotated pooled funds to members on a mutually agreed time. Each member of the stokvel would have an opportunity to host a party with the food and drinks also being sold to raise funds (Bonner and Segel, 1998:47). Membership ranges from five to eighty people (Verhoef, 2002:4). The investment stokvel emerged in response to a growing need to invest in business.

Participation in such stokvels provided members with the opportunity to obtain "seed capital" to finance small business (Verhoef, 2002:5). Furthermore, these types of stokvels offered non-members loans at an interest rate similar to that of micro-lenders (Personal Communication, Daphne Moloi, stokvel chairperson, December 1, 2003). High budget stokvels consisted of large membership with contributions varying between R200 and R2 000 per month and payouts between R7 000 and R15 000 per month; members might wait up to five years for a payout (Verhoef, 2002:6).

### 3.8 Population of Soweto

In July 2002, Soweto had 29 districts in a 78 $km^2$ radius with a total population of 1 140 347 (see Table 3.1) with 46.6% being males and 53.4% females (PHRU, 2002). Infants (0 to 1 year olds) made up 3.3% of the total population, a quarter (25.5%) of the population were under the age of 15 and almost half (46.9%) were under the age of 25.

Of the female population, 8.3% of females were of pensionable age (60+) and of the male population 4% were over the age of 65. There were more males than females in the younger age groups 0 to 19 and more females in the older age groups 20 to 49. The age group 65+ was dominated by females.

**Table 3.1: Population of Soweto by Housing Type**

| Type of Dwelling | Number of Units | Distribution of Dwelling Type Percentage | Estimated number of Residents | House hold Size | Popula-tion across dwelling type Percent-age | Average House hold Income (Rand) | Median House hold Income (Rand) |
|---|---|---|---|---|---|---|---|
| Hostels | 13 167 | 4.5 | 43 798 | 2.8 | 3.9 | 1197 | 101 |
| Council houses | 106 853 | 36.1 | 533 236 | 4.9 | 46.7 | 2216 | 1251 |
| Informal settlement | 27 742 | 9.4 | 114 153 | 4.1 | 10.0 | 1283 | 751 |
| Backyard dwellings | 120 744 | 40.9 | 339 319 | 2.8 | 29.8 | 1580 | 751 |
| Private sector houses | 27 019 | 9.1 | 109 841 | 4.1 | 9.6 | 4296 | 3001 |
| Total | 295 525 | 100.0 | 1 140 348 | 3.8 | 100.0 | 2007 | 852 |

Source: PHRU 2002

### 3.9 Education

For some individuals schooling commenced from the age of six. According to Ricky Smith, Department of Education (telephone communication, department of education, 10 December 2003), in 2002 schooling commenced for children aged six turning seven by 12 June. It was required by law that children had to be at school up to the age of 15. In the 2002 PHRU survey, 60% of all those aged six were already at school, 97% of those aged seven and 99% of those aged eight and older.

The PHRU survey found of all adults (20 years and over) 28% had matriculated and 6% had tertiary education. Only 5% had no education which was lower than in the rest of the country (8%) according to the 2001 Census (Statistics South Africa, Census, 2001).

### 3.10 Employment and Unemployment (16 to 65 year olds)

The PHRU survey reports that in 2002, of the total population of 1 140 347, there was an estimated 778 350 (68%) individuals aged 16 to 65, referred to as the working age population. Of the working age population (256 722) 33% were working, (521 628) 66% were not working and 1% had unknown employment status.

Of those not working:

- 21.6% (111 580) were going to school/ college/ university
- 2.5% (13 124) were full-time homemakers
- 6% (30 806) were pensioners
- 61.6% (317 710) were not working, but looking for work
- 5.2% (26 644) were not working and not looking for work
- 2.9% (14 695) were permanently unable to work but wanting work

Of the total population, 601 076 were economically active, that is, were either employed or unemployed according to the expanded definition. The employment rate in Soweto was 43% (256 722). The majority of those employed were in the 26 to 50 age group with the average age for all those employed being 38 years.

In 2002, the unemployment rate in Soweto was 57% (344 354) including those unemployed and not looking for work (expanded definition). Of those unemployed and looking for work (job searchers), 59% were female. The majority of job seekers were in the age group 20 to 34. The majority (74%) of the youth both males and females in the 16 to 20 age category who had left school were unemployed and actively searching for work. Some 32% of job seekers were matriculated and a further 4% had tertiary education suggesting that lack of skills (education) was not the only reason for being unemployed.

In 2002, the dependency ratio, calculated as the number of dependants (children below 15 years and adults aged 65 and older) over the productive age (16 to 64), was estimated at 0.55.

### 3.10.1 Where Do Sowetans Work?

The three major employment sectors investigated in the PHRU survey were formal, informal and domestic work. The majority of Sowetans worked in the formal sector (72.5%) versus (24%) in the informal sector followed by 3.5% in domestic employment.

Of those employed in the formal and informal sectors, the majority appears to be from the younger age group 26 to 50 while those employed in the domestic sector appears to be females 36 to 60 year olds.

## 3.11 Income Profile

In 2001, approximately 22.5% of employed Sowetans earned less than R800 per month and 85% earned less than R3200 per month (Statistics South Africa, Census 2001). At a household level, the Census 2001 data revealed that 22% of households in Soweto generated no income and 61% of households earned annual incomes of less than R19 200 or R1 600 per month. The 2002 PHRU survey found 23% of households did not report any income (earned or from non-market sources). The 2002 survey reported the average total household income in Soweto as R2 007 (per capita R694 and per adult equivalent R1 014).

## 3.12 Physical Living Conditions

In 1999, a household survey was conducted in Soweto by the University of Witwatersrand's Department of Sociology and in 2002 the Perinatal HIV Research Unit conducted a similar survey. Some of the data in this section obtained in the 2002 PHRU survey is compared to the 1999 survey.

Access to services had improved since 1999. Approximately 73% of dwellings in Soweto were brick houses, 90% had access to electricity (previously 86%), 93.6% (previously 87.5%) had access to piped water within the yard and 92% (previously 87%) had flush toilets. Furthermore, the 1999 survey found that in case of informal settlement residents, 87% were dependent on communal taps while only 2% had a

tap within the yard (Morris et al., 1999). In 2002, 54% of informal settlement residents were dependent on communal taps while 36% had access to a tap in the yard.

The majority (72.7%) of the dwellings in Soweto are made from bricks. In the informal settlements houses were mainly built from corrugated iron (74.3%) as well as 57.7% of the backyard dwellings (see Table 3.2).

**Table 3.2: Building Materials of the Walls of the House (% of Households)**

| | Hostels | Council Houses | Informal Settlement | Backyard Dwellings | Private Sector | Total |
|---|---|---|---|---|---|---|
| Brick | 97.8 | 92.7 | 21.0 | 57.7 | 99.7 | 72.7 |
| Mud | 0.0 | 0.0 | 0.4 | 0.1 | 0.0 | 0.1 |
| Concrete | 2.0 | 2.1 | 0.7 | 0.6 | 0.1 | 1.2 |
| Temporary material | 0.0 | 0.3 | 3.3 | 1.9 | 0.0 | 1.2 |
| Corrugated iron (Zinc) | 0.2 | 4.8 | 74.3 | 39.6 | 0.1 | 24.7 |
| Other | 0.0 | 0.1 | 0.3 | 0.1 | 0.0 | 0.1 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Source: PHRU, 2002

In terms of other socio-economic indicators, the study found that 36% of dwellings were one room units and just under half had more than four rooms. The majority of backyard dwellings or informal settlements were single roomed units and those in hostels were one or two roomed units. The majority of council houses or private sector dwellings comprised four or more roomed units. Overcrowding was considerable in the informal settlements and the backyard dwellings where the average household size was 4.1 and 2.8 respectively and where it was most common to only have one room in the dwelling.

Table 3.3 shows the percentage of households by domain that had marketable assets in working condition. Most households in Soweto owned a radio, television, and a refrigerator. Cars were more likely to be owned by those who lived in private sector

or council houses. There was a higher percentage of households in the private sector or council houses that had marketable assets in working condition. The reliance of a cellular phone in hostels was high.

**Table 3.3: Assets in Working Condition (Percentage of Households by Domain)**

| | Hostels | Council Houses | Informal Settlement | Backyard Dwellings | Private Sector | Total |
|---|---|---|---|---|---|---|
| Television | 48.9 | 83.0 | 42.5 | 58.4 | 91.6 | 68.3 |
| Radio | 63.9 | 75.4 | 61.1 | 70.7 | 86.7 | 72.6 |
| Computer | 0.2 | 6.1 | 1.0 | 1.5 | 11.1 | 3.9 |
| Cellular Telephone | 40.9 | 37.1 | 23.7 | 35.1 | 59.5 | 37.3 |
| Bicycle | 1.1 | 7.4 | 5.3 | 2.6 | 15.0 | 5.6 |
| Car | 10.5 | 17.5 | 5.9 | 6.7 | 37.0 | 13.5 |
| Refrigerator | 32.3 | 84.9 | 27.3 | 49.8 | 91.4 | 63.2 |

Source: PHRU, 2002

### 3.13 HIV/AIDS, Stigma and Discrimination

HIV/AIDS has been a major health concern in Soweto. In 1997, almost 40% of those who lived in the informal settlement or hostels did not know what AIDS was or how it was spread, (Morris et al., 1999:38-39) and in 2002, over 90% of caregivers living in these dwellings indicated that they would care for someone who was sick with HIV/AIDS and 91% indicated that they would allow their children to play with other children who had HIV/AIDS. This suggests that HIV/AIDS is widely heard of in Soweto.

Of those respondents who admitted to having someone HIV positive in the house, approximately 30% of households experienced some form of discrimination. This highlighted the fact that although HIV/AIDS was widely known of in Soweto, when someone was sick, they did experience some discrimination. Although there is knowledge of HIV/AIDS, there is not wide acceptance.

### 3.14 Summary

Only a third of households in Soweto were nuclear. The majority of Sowetans have access to electricity, water and health care services. The township is serviced by the world's largest hospital, the Chris Hani Baragwanath hospital. Traditional medicine still plays a small role. Informal savings schemes and burial societies play a larger role than formal investment schemes.

In present day Soweto, most children of school-going age attend school. The unemployment rate in Soweto is high (57.3%). The majority of those who are employed work in the formal sector. One fifth of households in Soweto do not generate any income and almost two-thirds earned monthly incomes less than R1500 per month.

In 1997 a high percentage of those who lived in informal settlements or hostels stated that they did not know what HIV/AIDS was but by 2002, over 90% of those living in these dwelling types indicated they would care for someone who was sick with HIV/AIDS.

# CHAPTER FOUR
# RESEARCH METHOD

## 4.1 Introduction

The objective of this chapter is to propose a research method investigating the impact of HIV/AIDS on urban households. To do this, lessons from methodologies of 33 rural and urban HIV/AIDS studies have been drawn upon. Since this study is interested in the methodologies used by other studies, primary research that entailed research design, data collection, sampling, sampling stratification, and fieldwork procedures at individual and household level is compiled in the Table in Appendix 5[1]. This summary table was initially developed by Booysen et al., (2001) and was adapted and updated with more recent HIV/AIDS household economic impact studies.

It was difficult to obtain full details on methodologies since not all journal articles or conference presentation papers report such details and this lack of data made it difficult to critically review methodologies. The discussion entails the methods used in the various studies since 1990 and the implications for the methods adopted in the present study.

Due to the sensitive nature of conducting HIV/AIDS studies, all study approaches introduce bias. This chapter discusses bias in the study approach as well as sampling bias in the present study and makes recommendations in the final chapter for how sampling bias can be overcome in future studies using this approach.

There are also general income and expenditure household surveys conducted in South Africa and as a starting point it is instructive to describe these surveys.

[1] Each study in Appendix 5 is numbered 1 to 33. The studies are generally referenced by the author or if the location of the study is referred to the number in the table is referenced.

## 4.2 South African Income and Expenditure Surveys

Even as early as the 18th and 19th century, household studies were designed to inform policy makers about how income was produced/earned and spent at household level by region, occupation, income and by family composition (Deaton and Case, 1988:3). Such data show the distribution of the household budget and highlight the living conditions of the poor in contrast to the rich.

For many countries, including South Africa, household surveys retain an important role in providing information to inform policy and decision-makers. Some of the major household surveys conducted in South Africa are the *Project for Statistics on Living Standards and Development* (PSLSD) conducted nationally once in 1993, *South African Demographic and Health Survey* conducted once in 1998 and repeated in 2003/2004, *Census* conducted every five years; the *October Household Survey* (in the past was conducted every year and now replaced by the *Labour Force Survey*, *Income and Expenditure Survey* conducted every five years); the Bureau of Market Research I*ncome and Expenditure Pattern Survey* conducted on an ad hoc basis and *AMPS* (All Media and Products Survey) conducted every six months.

In 1993, the South African Labour Department Research Unit from the University of Cape Town conducted a household survey in all provinces covering 9000 randomly selected households. The main purpose of the survey was to collect data of the conditions in which South Africans live. The national survey was conducted once off, however, households in KZN were followed up again in 1998 and in 2004 as is known as the KIDS dataset.

The 1998 South African Demographic and Health Survey (SADHS) was the first health survey carried out in South Africa after the 1994 elections with another cross-sectional survey in 2003/2004 with the purpose of providing indicators for child health as well for the medical care of mothers. This study did not collect data on income and expenditure.

The 2001 *Census* was conducted over two nights in October 2001. The data represent a snapshot of the country at that specific point in time. The *Census* focused on population demographics, income distribution, employment and unemployment, access to education and other infrastructure and household living conditions. It does not include amounts spent on various expenditure categories.

The *October Household Survey*, conducted annually by Statistics South Africa since 1993 to 2002, investigated changes (what and how) in the life circumstances of South Africans. In 1999, it sampled 30 000 households across the country. The sample size varied each year depending on funding (Lehohla, 2001:7-8) which made comparisons difficult.

The main purpose of the *Income and Expenditure Survey* (IES), last conducted in 2000, was to collect base-line information on household income and expenditure patters for re-weighting the Consumer Price Index (CPI) (Orkin, 1997:2). It considers all sources of household income as well as overall expenditure of the household on all goods and services during a specified time period. To obtain annual expenditure the monthly expenditure was multiplied by 12; hence no adjustment has been made for seasonality. This study classifies income as regular income and other income. Regular income is defined as salaries and wages, profit from own business, pension and interest. Other income included sale of assets, trade-ins, fringe benefits, lump sums from insurance policies and gifts received. Expenditure is defined as purchases during the survey period.

The Bureau of Market Research *Income and Expenditure Pattern Survey* has been carried out since 1960 on an ad hoc basis (BMR, 1992:1). A random probability sample of 500 households have been chosen for the 2000 income and expenditure survey conducted in Gauteng. Respondents were questioned about their income from all sources and their expenditure on approximately 550 items of expenditure (BMR, 2000:3). The study dealt with income patterns of various race groups, as well as the distribution of the market for specific products by race group. Since this study is not conducted on a regular basis or regular time period, comparisons can not be made over time.

The *AMPS* have been conducted by the South African Advertising Research Foundation (SAARF) since 1975 and were last conducted at the end of 2001. It sampled 17 000 people over a six-month period (Haupt, 1999:12). The study investigated expenditure and media patterns of adults 16 years and older. The main purpose of this study is to monitor media usage at household level; in addition, expenditure on 155 product categories and services are documented and one specific point in time.

The above household studies conducted in South Africa have been largely cross-sectional surveys, samples of which have been randomly chosen and the results of which can be generalised to the entire population. However, none of these studies focus on the impact from HIV/AIDS. Studies to collect data on the impacts from HIV/AIDS require a specific methodology with specific questions that generate appropriate answers without breaking client confidentiality. To understand the impact of HIV/AIDS on households, it is more appropriate to conduct surveys on households in which a member's HIV status is known so that information can be shared in a trusting environment. Since the surveys discussed above pertain to the population in general, their methodologies were not considered in the design of the method for this study. However, the instruments used in those studies have been used to inform the development of the instrument for the present study.

### 4.3 Research Design

There have been two primary approaches to research design. First, the randomised trial (experiment) approach, used mostly in clinical settings, would give a more accurate answer to the question of causation. However, it was deemed unsuitable because of the large number of dependent variables in this type of socio-economic study. The second is the cohort (non-experiment) approach, that identifies two groups (or cohorts) and track events that occur in each cohort forward in time (Sackett et al., 1991:287). The cohort approach has been used in this study to compare the experience of households with at least one infected member (referred to as affected households) with those with no members presenting an HIV/AIDS-related illness (referred to as non-affected households). The cohort approach was used in most of the socio-economic impact surveys tabled in Appendix 5. Sackett et

al., argue that cohort studies are weaker than randomised trials in establishing causation (1991:288) because the inclusion and exclusion criteria used in sample selection create bias.

Bias arises from the selection of only women who attend public health care facilities. The spending pattern of households with women who attended public health care facilities such as antenatal or HIV clinics might differ from those who did not. However, cohort studies would be useful in investigating multiple outcomes that might arise. A second type of non-experimental study is the case-control study (Sackett et al., 1985:289). In a case control study, the researcher gathers "cases" of patients who already had suffered some adverse event and "controls" that had not. The direction of enquiry would be backwards in time. For example, the researcher would use infection as an outcome and determine the factors most likely to have caused infection by going back in time.

Very few studies have documented the impact of HIV/AIDS on income and expenditure patterns in HIV/AIDS affected households versus a cohort group of HIV/AIDS non-affected households. Since the impact can be better understood using a cohort group of non-affected households, the present study opted for this option.

### 4.3.1 Research Pre-planning

One of the most important aspects of conducting HIV/AIDS research is the time spent on pre-planning. The pre-planning phase informs the research design and all other aspects of research methods. In this study nine months was spent in Soweto before the commencement of field work for a number of reasons.

Firstly, studies of this nature needs to be approved by provincial and local political structures if it is going to make any impact on policy. Permission and buy-in was obtained from the following types of institutions:

- Gauteng and local government structures

- Community leaders and community structures
- Non-governmental organisations
- People living with HIV/AIDS
- Hospital and health care authorities at the hospital and primary-health care clinics

In order to obtain permission and buy-in from these institutions, various meetings and presentations were held and these institutions contributed to the development of the final instrument to ensure that the data collected was relevant and useful to inform policy. Various visits were made to the recruitment centres to establish a relationship with the medical staff that assisted with sample screening and selection. A focus group was held with people living with HIV/AIDS who were heads of households to help the researcher understand how to maintain issues of confidentiality, how to approach the households, how to find the households and what activities are generally done on week-days and on week-ends to better capture time allocation of labour. The results of this meeting can be found in Appendix 4.

Secondly, a study of this nature and magnitude requires many partners to help share the burden of the costs and to provide useful services. The Perinatal HIV Research Unit (PHRU) was approached to assist with sample screening and sample selection. Most studies ignore the impact that this type of research will have on the psyche of the fieldworkers. It is important that fieldworkers do not carry the burden of the suffering into their own homes on the one hand and do not project their own suffering or burdens on the respondents on the other hand. The University of Vista was approached to provide the field team with psychotherapy. Unilever South Africa was approached to provide the respondents with a hamper of groceries to thank them for their time. Various funding organizations were approached to fund the field work. The HIVSA services unit of the PHRU was approached to provide households with support services such as support groups and help with income-generation activities including the preparation of food gardens.

Thirdly, the study was required to be approved by ethics committees of two universities. This was because the researcher was studying at one university and the

institution that assisted with the sample selection and screening was associated with a university in another region.

Planning also involved mapping out suburbs in Soweto in order to become familiar with landmarks and services such as hospitals and clinics, police station, and so on.

### 4.4 Longitudinal Versus Cross-Sectional

The HIV/AIDS focused studies itemised in Appendix 5 are mostly cross-sectional surveys. Cross-sectional surveys are usually once-off and collect data at a specific point in time. Collecting data once-off will mean that more data can be collected in a shorter period of time by employing more fieldworkers, thereby saving time and money. The results can be available sooner and HIV interventions can be implemented sooner rather than later.

In longitudinal surveys, the same household is followed over a period of time. The analysis showed only eight (Kagera (1) Zambia (4), Zaire (10), Burkina Faso (11), Uganda (12), Ivory Coast (13), Haiti (14) and Free State (17)) of the thirty-three studies included in Appendix 5 were longitudinal in nature, of which seven were conducted in African countries. The main strength of longitudinal surveys is its ability to study change and development (Saunders et al., 1997:77). As there is a slow progression from HIV to AIDS, the impact occurs slowly over time. The Kagera study showed that the effects of an adult death were seen up to 18 months before and 30 months after the death (UNAIDS, 1995).

There are other advantages to longitudinal surveys. It gives the fieldworker time to build trust with the household and the researchers an opportunity to check and verify data as well as to improve the instrument before the next scheduled visit. Longitudinal studies are usually hampered by time and cost constraints. Longitudinal surveys in general are more expensive because fieldworkers have to be employed for the period of the study as opposed to the period of data collection. It is important that the same fieldworker goes to the household for every visit to maintain trust and rapport with the respondent.

Since this study was designed to investigate changes in income and expenditure in HIV/AIDS affected household during times of sickness and/or death, it was designed as a longitudinal study. The study found three households dissolved and surviving family members moved out of Soweto, three sick members left the household to be taken care of by other households and one household head/respondent died; such events complicate longitudinal studies. It was especially difficult to follow the movement of orphans as they moved between districts and regions. The study tried to follow all households that split or moved away but due to time and distance this was not always possible. The study did manage to follow one household that split. One part of the household remained in Soweto while the other moved to the surrounding informal settlement.

The same fieldworker returning to the household every three months over a year meant that there was constant contact between the researchers and the respondents. Contact was also maintained between interviews to remind respondents to complete the diary and the activity sheets. A week prior to the next appointment, as well as the day of the appointment, calls were made to respondents giving them the opportunity to postpone the interview should it be necessary, particularly as a result of sickness and death. The constant contact with the respondents was one of the reasons for the low drop-out rate of 5.6% (seven out of the 125 households interviewed in wave 1, dropped out because of the nature of the study, four moved out of the study area). Other reasons attributed to the low drop-out was the trust that was built between the researchers and the respondents by constant contact, the research team's participation in household events (especially funeral attendance) as and when invited or requested and the willingness of the researchers to assist households especially with regard to information. Households mainly required information pertaining to the access of grants, psycho-social support services and the release of school reports when school fees were not paid.

A realistic period for longitudinal studies proposed by many researchers is between three and four years with households revisited every six months (for example, Kongsin et al., (2000), Booysen et al., (2001:6), and Seeley et al., (1995). This study was restricted by time and cost and the household was therefore visited every three months over a period of 12 months to keep the recall period to a minimum.

### 4.5 Sampling and Selection Criteria

The basic idea of sampling is that by selecting some elements of a population, conclusions can be drawn for the entire population. Sampling can be divided into two major categories, probability sampling and non-probability sampling. In probability samples, the probability of each case being selected from the population is known and is usually equal for all cases (Saunders et al., 1997:126). This means that all income-earning households had an equal chance or probability of being selected for this study.

Since HIV/AIDS has not been a notifiable disease and because stigma and discrimination exists, there was no way of identifying all HIV infected income-earning households. These households could therefore not be chosen at random, unless the households were randomly selected and all adults in the household tested for HIV.

Studies that chose households at random were the Kagera study, the Thai study and the Uganda studies conducted in the districts of Mbarara, Kabale, Masaka, Iganga, Mbale and Hoima (See Appendix 5). The Kagera and the Thai study that chose households at random did a quick "health check" of all households in the study area, using a series of questions that were asked of all members of the household to detect signs of sickness or death. Once this was established, they separated the households into "sick" households and households which had experienced "death". From these households, random selection took place. There was no guarantee that the households had or were experiencing an AIDS-related illness since illness and death was self-reported. The Ugandan study requested people to state the illness that made them sick or the illness that caused death (Ntozi and Nakayiwa, 1999). This method of sampling was possible because people spoke more openly about HIV/AIDS.

The Nelson Mandela/HSRC study of HIV/AIDS conducted in 2002 selected households randomly. This study identified 7 249 households and 14 450 individuals. Only 13 518 individuals were contacted of 8 428 agreed to give an oral fluid specimen to be tested for HIV, a response rate of 62% (Shisana and Simbayi,

2002:36). Whilst this response rate might be considered good (Babbie, 1990, as quoted in Shisana and Simbayi, 2002:36), the characteristics of individuals who agreed to be tested and those who refused to be tested were unknown. The point is that in randomly selected households, the researcher depends on the respondent to supply accurate information about all household members' health status. As can be seen in the HSRC study, knowledge of the status of all household members is unlikely, admitting to being HIV positive to a fieldworker in a cross-sectional survey without building trust is also unlikely (PHRU, 2002), and refusing to supply the information (PHRU, 2002), as may be giving incorrect information. Such issues complicate the ideal of randomly-selected households for surveys to investigate the impact of HIV/AIDS.

In non-probability sampling, the selection of a population element to be part of the sample is based partly on the judgement of the researcher. There are a number of different sampling procedures that fall into the category of non-probability methods, namely, convenience sampling, judgement or purposive sampling and quota sampling. Convenience sampling involves selecting those cases that are easiest to obtain. The sample selection process continues until the required sample size has been reached (Saunders et al., 1997:147). Judgement or purposive sampling is selected on the basis of what the researcher thought sample members would contribute to answering the research questions (Saunders et al., 1997:145). According to Cooper and Schindler, the researcher selects sample members to conform to some criterion (1998:245). Quota sampling would require knowledge of the distribution of HIV/AIDS in the population.

The non-probability sampling technique was used in most HIV/AIDS household studies under review. The design was either convenience or purposive. Since HIV/AIDS has not been openly discussed at household level, researchers have to weigh up the relative advantage of a non-random selection of households which have at least one person that is HIV infected who may or may not have had members who have died from an AIDS-related illness vis-à-vis randomly choosing the households but never being sure whether or not these households were sick from other causes. Since it is difficult to obtain population estimates of sickness and

death due to AIDS at local and district level, the quota sampling technique was not used in most HIV/AIDS household studies.

Three major sampling selection approaches have been identified in the literature. The sampling approaches used depended on the research question. The first approach used is the recruitment of sample members from health care facilities. The advantage is that the household can be categorised according to the presence or absence of HIV/AIDS. The disadvantage is that only those who go for voluntary counselling and testing and or treatment for opportunistic illnesses have an equal chance of being selected. Often studies ignore this method of sampling because of a lack of co-operation from health care workers. Sampling at health care facilities requires extensive and lengthy approvals and buy-in at all levels.

In the Zaire study, pregnant women were selected on the basis of their sero-status. Approximately 8108 pregnant women were screened for HIV-1 antibodies during a one- year period at two Kinshasa hospitals (Ryder et al., 1994:674). At the same time, age and parity-matched sero-negative women were selected to form the control group. The advantage of this is that the sero-status is known for certain over the three-year period since serology in initially sero-negative women was determined annually during each year of the study. The disadvantage is that only those who sought medical help were recruited. Purposive sampling technique was used in this case since the objective of the study was to determine the number of children born to a large cohort of HIV sero-positive mothers in Kinshasa who would be orphaned by the death of their mothers during the three-year period after delivery of their most recently born child.

The second approach taken was by selecting a geographical area, either by subjecting individuals to HIV-testing or by checking for the presence of illness or death in the households. The Uganda study by Seeley et al., chose three villages and subjected the people to HIV/AIDS tests (1995:81). The Zaire study used the modified version of the clinical case definition for paediatric AIDS to diagnose AIDS in children of HIV positive mothers (Ryder et al., 1994:675). The disadvantage of using the latter approach is that other opportunistic illnesses could

be confused with normal illnesses. Conducting voluntary counselling and testing in a geographical area is costly and time-consuming.

The third approach used was in collaboration with non-governmental organisations (NGO's) and community based organisations (CBO's). In some instances, these organisations provided the researchers with a list of HIV positive households from which a random sample was selected (Booysen et al., 2001, Steinberg et al., 2002). In other instances, the organisations assisted the research teams to screen and select the households as well as to obtain verbal consent. This approach allowed the researcher discreet access to HIV positive households without necessarily jeopardising HIV positive individuals. This approach is appropriate when small samples are required since these organisations have a limited list of HIV positive people to whom they provide services. The advantage of this approach is that there is a guarantee of the sample member's HIV status. The disadvantage is that it is limited to those HIV positive people that seek help and financial assistance.

From the analysis of studies in Appendix 5, thirteen employed the health care facility approach, five employed a population-based approach, eight collaborated with NGO's and CBO's while three did so in conjunction with health care facilities. Each of these approaches is exposed to bias which is discussed in section 4.6.

This study focuses on income-earning households in Soweto that have at least one member who is HIV positive with a CD4 cell count of 200 and below. To identify such households in Soweto, the researcher found a way of entry to the household via women who attended public antenatal and HIV clinics in Soweto. The sample members have been purposively chosen on the basis on their HIV and CD4 cell count status. Household member's HIV status and CD4 cell count was assured since index cases volunteered for HIV testing at these facilities. HIV negative households have been chosen on the basis that the index case tested HIV negative and the remaining members of the household suffered no illness or death in the past 18 months.

The researcher planned to interview at least 25% more respondents than was required to account for refusals before the first interview and drop-outs during the

course of the study. This was also done to avoid replacing households during the course of the study, thereby limiting the potential to introduce bias. Furthermore, households joining after wave 1 would not have the opportunity to complete all 4 waves.

Women who received antenatal care services from nine sites in Soweto and both the HIV clinics in Soweto during the period July to December 2002 and who had a CD4 cell count below 200 were given an opportunity to participate in the survey. Approximately 203 individuals were selected to participate. Three wished not to participate for fear of possible disclosure. The 198 individuals (from different households) who agreed to participate supplied contact details of their household heads. Of the 198 household heads, 73 were not interviewed with only 22 from the infected category. The reason 73 household heads were not interviewed were:

- 26 refused to be interviewed;
- 15 gave a wrong address;
- 14 moved without a forwarding address; and
- 18 households could not be contacted within three visits due to the absence of household members.

This study recruited at least 50% more sample members than was required to take into account incorrect addresses, households collapsing or moving away before the first interview. Recruitment was a slow process because only individuals with a CD4 cell count of 200 or below were recruited in the affected cohort. Hence, the recruitment process took five months to complete. This was typical of studies of this nature, as evidenced by the Thai study (Kongsin et al., 2000).

The refusal rate between sample selection and recruitment was 13% (26/198) and the drop-out rate between first and last interviews was 5.6%[2]. The Kagera study found 6% of households dropped out prior to the first interview and less than 10%

[2] Further analysis of refusals and drop outs revealed that two thirds of the non-affected cohort refused participation at the beginning of the study as well as two thirds of households from the non-affected cohort dropped out during the course of the study.

dropped out from wave one to the end of the survey (Ainsworth and Semali, 1995 as quoted in Lundberg et al., 2000:4).

The fieldworkers were often not able to complete an interview because of grief or extreme illness. The present study found that in 23% of the interviews, fieldworkers had to go back one or more times. In the Thai study, fieldworkers had to go back in 30% of the time (Kongsin et al., 2000:1). The lower than expected repeat visits was due to the fact that there was constant contact between the respondent and the fieldworkers. In cases of death, the fieldworkers would make the appointment for a month later to give the family time to grieve. The 23% did not include appointments that were postponed but only households that were physically revisited more than once.

### 4.6 Bias in Sampling Design

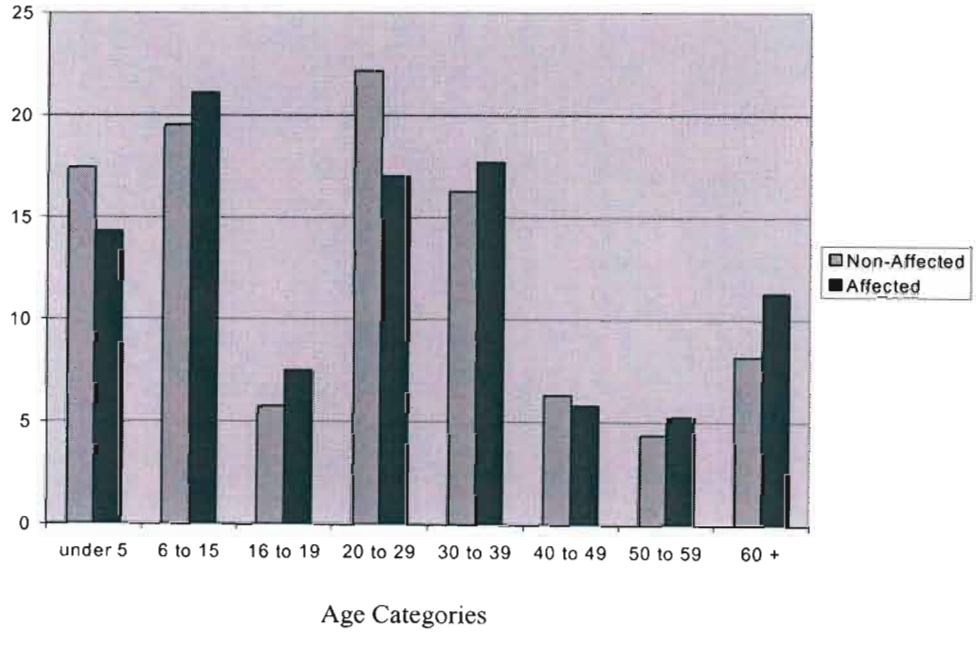
According to Leedy (1997:219), bias can be defined as "Any influence or condition that distorts the data from what may have been obtained under the conditions of pure chance including any influence that may have disturbed the randomness by which the choice of a sample population has been selected." Each of the four sampling approaches would be exposed to bias.

The first approach relies heavily on the fact that all people would go for testing and/or treatment and therefore could be selected from the health care system. Generally, it was found that people did not go for testing unless they started experiencing HIV symptoms and were either asked to go for testing or requested testing themselves (Nandakumar et al., 2000). The women who attended antenatal clinics in South Africa, for example, are not representative of all pregnant women. Some have private heath care insurance and therefore go to private facilities. Of all those who were sick and attended health care facilities in the PHRU Soweto 2002 survey, 75% accessed public health care facilities and 25% accessed private health care facilities (see Section 3.5). For this reason, most of the studies on household impact has been context specific and to draw conclusions for the entire population would pose statistical challenges.

The second approach might be biased in the sense that those who suspect that they were safe may go for testing and those who suspected that they were high-risk might avoid testing. Bias in the third approach would occur because of the lists supplied by NGO's and CBO's would include only those who knew their HIV status and who sought help from these organisations.

Due to the nature of recruiting sample households via antenatal and HIV facilities, the study was interested in establishing sampling bias that might have crept in. Accordingly, a number of comparisons were made between affected and non-affected households. The first "test" conducted was on the age distribution of household members.

**Figure 4.1: Age Distribution Across Cohorts**




The average age of all individuals and of all adults in the households was significantly different between the groups (see Table 4.1). The affected cohort contained individuals who were on average two years older. There were no significant differences in the average age of individuals 50 years and older or the average age of income-earners. Individuals in older age groups enjoy the positive effect of experience on earnings.

**Table 4.1: Average Age of Individuals Across Cohorts**[3]

| | Non-Affected | Affected | T-stat | p-value |
|---|---|---|---|---|
| All individuals | 23 | 25 | -2.95 | 0.0000* |
| All adults | 34 | 36 | -3.23 | 0.0000* |
| Adults 50+ | 61 | 63 | -1.12 | 0.2624 |
| Income earners | 36 | 38 | -1.84 | 0.0659 |

Table 4.2 indicates that the average age of the household head in the affected cohort was significantly higher. One reason may be that sick adult children returned to their family home to be taken care of. Furthermore, upon death of their husbands, wives often return to their family home.

**Table 4.2: Average Age of Household Head Across Cohorts**

| | Non-Affected | Affected | T-stat | p-value |
|---|---|---|---|---|
| All heads | 45 | 52 | -4.46 | 0.0000* |
| Male heads | 42 | 53 | -4.18 | 0.0000* |
| Female heads | 51 | 52 | -0.50 | 0.6167 |

Table 4.3 shows that the affected cohort was dominated by female heads, by female income-earners and by female adults. This is due to the fact that there were more heads never married in the affected cohort coupled with the fact that sick adult children who were never married rejoin the household. The majority of sick adults were never married (see Section 6.2).

**Table 4.3: Gender – All Waves (Percentage)**

| | Non-Affected | Affected |
|---|---|---|
| All adult males | 42 | 39 |
| All adult females | 58 | 61 |
| Income earner males | 44 | 32 |
| Income earner females | 56 | 68 |
| Household head males | 61 | 27 |
| Household head females | 39 | 73 |

[3] * shows significance at the 5% level

In terms of marital status (all adults 16+), in the non-affected cohort 29% were married legal or traditional and a further 11% were cohabiting. In the affected cohort, only 14% were married and a further 5% were cohabiting.

Other bias has been introduced in the way the non-affected cohort was selected. The index cases were chosen from antenatal clinics which will result in household size increasing as a result of new births while some of the non-affected group was selected from HIV clinics where they go for treatment. The HIV clinics are a natural progression from the antenatal clinics. Once sickness occurs, individuals are referred to the HIV clinics. Furthermore, if the non-affected group was chosen on the basis of household members having any sickness, the cost of morbidity in the non-affected group may have been higher.

### 4.7 Sample Stratification

Analysis of previous household surveys showed that there was a high correlation of stratification in cases where a control group was used. Sample members were generally stratified according to the presence or absence of HIV/AIDS or whether they were from a rural or urban setting which allowed comparisons to be drawn on the impacts. One study was stratified according to homosexual and heterosexual persons living with HIV/AIDS (Smith, 1995) and another according to stage of the disease (Bowie et al., 1996). This last study recruited 25 sample members who were categorised according to their health status, symptomatic without AIDS and symptomatic with AIDS. This type of stratification is possible if recruitment is via health care facilities and in collaboration with health officials and patient consent.

In the present study households were stratified in two groups, affected and non-affected. For a household to be classified as affected, there had to be at least one person (index case) who tested HIV positive with a CD4 cell count of 200 or below. For a household to be classified negative the index case tested HIV negative and reported no known episode of illness among all household members. Any illness besides flu (in which the household member recovered within seven days) was considered as sickness. In most household surveys considering impact, this was the chosen method of sampling households where there was at least one person infected

versus households without anyone being ill. This type of sampling rules out other chronic illnesses which individuals in the household may have experienced. The reason for doing this was to ensure that the non-affected cohort was not erroneously selected with any HIV/AIDS-related illnesses.

It was evident from the study (see Table 4.4) that the index case did not know the health status of all members of the household. Also evident was the fact that household members on chronic medication were not considered ill because they were not physically ill. To keep the study totally clean of all illnesses, a question about medication should have been asked of all household members during the screening process. The alternative, to include members, in both cohorts who were sick for reasons other than HIV/AIDS or HIV/AIDS-related was considered. However, by doing this, it would have been difficult to assess the impact from HIV/AIDS alone. The study would then have to include the impact from HIV/AIDS and other illnesses in the household.

It should also be acknowledged that it is not possible to ensure that all individuals in the non-affected cohort will not suffer any illness during the period of a longitudinal study.

**Table 4.4: Number and Percentage of Households Experiencing Illness during Each Wave Across Cohorts**

| | Unit | Wave 1 | Wave 2 | Wave 3 | Wave 4 |
|---|---|---|---|---|---|
| **Non-Affected – Number of households sick in each wave** | Number | 14 | 8 | 7 | 8 |
| | Percentage | 27 | 15 | 13 | 15 |
| **Affected - Number of households sick in each wave** | Number | 47 | 34 | 18 | 21 |
| | Percentage | 77 | 56 | 30 | 34 |

Of the 14 sick individuals from 14 non-affected households in wave 1, two were sick with flu, one from hypertension, two from arthritis, one from a brain tumour, one tried to commit suicide, one from a nervous disorder and five didn't know the

diagnosis. Of the five who didn't know the diagnosis, two infants experienced a skin rash, two adults experienced abdominal pains and one infant experienced loss of appetite.

### 4.8 Sample Size

The sample size of the studies listed in Appendix 5 range from 24 households in the Indian study (Bharat, 1995/1996) to 1797 households in the Ugandan study (Ntozi and Zerimenya, 1999). The sample size of the studies depended on the research questions, the funding available and the time constraints in having the research completed. Many of the small studies focussed on in-depth analysis using case study techniques. Only in eleven studies did the sample size exceed 500 respondents with seven studies interviewing more than 1000 respondents (Uganda (5), Uganda (6), Zaire (10), Kenya (18), Kenya (19), Soweto (29), and South Africa (32)). While small in-depth studies provide rich qualitative data, large studies are necessary to make inferences for the total population. Small-scale in-depth studies answer questions about why, what and how. These questions need to be asked in qualitative assessments and can make significant contributions to program design (UNAIDS, 1999). The fact that this is a comprehensive in-depth study means that a relatively small sample is chosen. A later step will be to conduct large-scale household impact studies in South Africa.

The researcher proposed a sample of 50 households in the AIDS-affected cohort and 50 households in the non-affected cohort. Table 4.5 shows the number of households that were interviewed in each wave.

**Table 4.5: Sample Interviewed**[4]

| | Total (All Waves) | Non-Affected Households | Affected Households |
|---|---|---|---|
| Wave 1 (September 2002 to December 2002) | 125 | 59 | 66 |
| Wave 2 (December 2002 to February 2003) | 117 | 53 | 64 |
| Wave 3 (February 2003 to May 2003) | 115[1] | 52 | 63[1] |
| Wave 4 (May 2003 to August 2003) | 115[1] | 52 | 63[1] |

## 4.9 Methods of Data Collection

The method of data collection will depend on the research question, the availability of previous research as well as financial and time constraints. The analysis also revealed that extensive studies used more than one data collection approach while studies that were more intensive in nature used one method only.

Most of the household surveys in Appendix 5 collected data via structured or semi-structured questionnaires. The Uganda study (Seeley et al., 1995) used participative observation. The Thai study (Kongsin and Watt, 2000) and the Free State study (Booysen et al., 2001) complemented the structured questionnaire with in-depth case studies.

The study done in the Bukoba district by Rugalema in 1996 (1999:19) used a checklist to collect the bulk of the data, which was used to develop intensive case studies. The case study strategy is a good strategy to gain a rich understanding of the context of the research and it is better able to answer the "why" questions. The case study method includes techniques such as interviews, observation, documentary analysis and questionnaires (Saunders et al., 1997:77).

This study used the focus group approach to gather information that informed the questionnaire development about how to approach households in Soweto as well as understand cultural nuances. Focus groups were held with household heads, people

[4] One household split in wave 3 and both households were followed

living with HIV/AIDS, non-governmental organisations, community based organisations, local and provincial government officials in the HIV/AIDS strategic planning department.

In the present study, the survey method using a structured and semi-structured questionnaire is considered the best approach for data collection as it involves the collection of problem-specific data from selected individuals by way of direct and indirect questioning. Respondents were asked a variety of questions about household size and composition, time allocation of household labour, impact on surviving family members, income, expenditure, savings, investment, borrowings and debt.

The present study used the survey method which allowed for the collection of large amounts of data in a cost effective way. It was based mainly on a questionnaire as the data collection instrument and data was standardised to other surveys for easy comparison. Stories supporting the quantitative data was captured and documented for each household thereby creating a bank of qualitative data. Since the household head is generally nominated by the name of the person who owns the house (see Appendix 4), this study drew kinship diagrams which showed the relationships between spouses and between parents and children. Techniques used in surveys besides questionnaires are structured interviews where standardised questions are asked of all interviewees as well as structured observation (Saunders et al., 1997:76). The survey method has several advantages (Malhotra, 1993:189). It is simple to administer; the responses are limited to a few alternatives, which makes coding, data analysis and interpretation of data relatively simple. A disadvantage is that respondents might be unable or unwilling to provide the desired information.

The three most common approaches for data collection using the survey method are personal interviews, telephone interviews and self-administered surveys. In personal interviews, the advantages are that probing could be done. Since the subject of income and expenditure is considered sensitive, the personal interviewing technique was used. The disadvantage of this method is that it is expensive and time-consuming. A telephone survey would not be appropriate in this study due to

the sensitive nature of the topic. A self-administered survey as used in the United States (Le Blanc and Wight, 1995) was not considered.

Respondents were interviewed and informed how to complete the diary and activity sheets. This was an enormous task because respondents had to be reminded at the beginning of the month to start recording items of expenditure in their diary. The time sheets required that each individual over the age of seven complete a sheet for one day during the week and for the following Saturday and Sunday. These sheets were completed for waves 2, 3 and 4. In wave 1, respondents were informed how to complete the time sheets and were given pens, time sheets and a folder in which to store the time sheets. Due to the fact that activities differ between week-days and week-ends even between a Saturday and a Sunday, three time sheets were prepared. One time sheet was to be completed for any day of the week, the other for the following Saturday and Sunday. In order to promote compliance, anyone who refused in wave one was not requested to complete the time sheets from wave 2 onwards. Those who completed the time sheets in wave one were encouraged to complete it in the subsequent waves. Frequent telephone calls were made to household members to encourage them to complete the time sheets and have them ready for the fieldworkers. The same individuals who completed the time sheets for a week-day completed it for a Saturday and a Sunday.

Approximately, 15% of respondents refused to keep the diary and were assisted by the fieldworker. A further 15% of respondents did not know how to accurately record items of expenditure and they were revisited and informed.

Data was collected at the respondents' place of residence to maintain trust and to build a relationship (see Appendix 4). Interviews with respondents were conducted during the day in cases where the financial head was not employed. In cases where the income earner was also the financial head or where the income-earner was required to supply data on income, interviews took place during the evenings and on week-ends. Despite warnings about not entering Soweto after dark, this could not be avoided because some respondents were only available during the evenings or on week-ends. Data collection commenced in September 2002 once the sampling process had been completed.

### 4.9.1 Non-Response Errors

Non-response errors generally occur when the sample members cannot be located or when they lack the enthusiasm to complete the questionnaire (Cooper and Schindler, 1998:297). During the course of the study, households were telephoned regularly to encourage participation and completion. A full-time research assistant was employed to be in continuous contact with the households on a daily, weekly and monthly basis. Households which did not understand how to complete the diary the first time were revisited or assistance was provided via the telephone.

If the respondent was not at home, a later appointment was made as soon as possible. When sickness and death occurred, the researchers were sensitive to these events and made an appointment to collect data at an appropriate time.

### 4.9.2 Response Errors

Response errors occurs when the respondent fails to complete some of the questions or misunderstand the questions (Cooper and Schindler, 1998:298). Respondents were given the right to skip questions they did not wish to answer. These were recorded as "refused to answer". Completed questionnaires were checked for completeness, internal validity, inconsistencies or missing data by two people, the researcher and the data capturer. Respondents were contacted within a week for verification. This verification process also contributed to the respondents knowing that their answers were being taken seriously and in some cases they volunteered information to be corrected on other data or would phone in to advise of any other changes to household composition or household events. Fieldworkers were requested to sign next to any unusually high amounts and the amount was double checked with the respondent.

## 4.10 Interviewers/Fieldworkers

Employing the right type of people and offering training is crucial to research of this nature. The same researcher should go to the household for the duration of the study to maintain trust. Research papers generally did not report details about

fieldworkers and only five of the thirty-three studies that explicitly stated that interviewers had received training. A few studies reported that fieldworkers were local persons specifically trained for the purpose of interviewing people living with HIV/AIDS. For the present study, two fieldworkers were recruited from Soweto and worked in the same households for the duration of the study. Various reasons why local people made better fieldworkers were highlighted. They would be trusted once a rapport had been built either because they worked for an NGO supplying a service to that household or the community. They would understand the local languages better and would be able to pick up on non-verbal communication and subtle nuances. They would also be more familiar with the dynamics and structures of households. Involving local people in research would mean that there would be a greater understanding of the purpose for the research and the research could be made relevant to local communities (Seeley et al., 1995:82).

Involving local people in research meant that local skills could be developed. This study went further by offering the project team an opportunity to develop skills in all aspects of research from concept to writing of stories. This ensured a high level of commitment from the field team. This project team were all able to secure jobs as a result of this research and the training that they received. Some feedback from the project team:

Fieldworker 1: "This project helped me in developing my counselling and listening skills. It gave me an opportunity to deal with people who are HIV positive and to understand their world and family life. My research knowledge and skills has been enhanced to such an extent that I can conduct my own research project with confidence."

Fieldworker 2: "I am what I am today because of you, if it wasn't for you, I would be nothing. I thought you should know that I really appreciate what you did for me. I have learnt so much about how families survive and how to conduct research."

Data Capturer: "This project has exposed me to facets of the HIV/AIDS epidemic that I would not have experienced otherwise – poverty, pain, suffering (physical and emotional) and hopelessness through the researchers and their questionnaires. It has turned me into a better listener and improved my understanding of people affected

and infected with the virus. I was exposed to database design and management, project management, problem-solving, basic data analysis using Stata. Being involved as part of the team, I interacted with all levels of staff. With the training and development I received, I am now in a better position to perform data management functions in the research environment."

In this study, interviews were conducted in any of the main languages spoken in Soweto and recorded in English. Fieldworkers were expected to document stories about the household, including the mood of the respondent, in a field journal.

Due to the sensitive nature of the research, it was important to train fieldworkers on aspects of confidentiality and ethics as well as on HIV/AIDS. In the literature it was unclear whether fieldworkers were trained in data collection and interviewing techniques in the presence of illness and death or training in HIV/AIDS related issues.

In this study the field team attended a week's training held in September, 2002. Training included objectives of the study, definition of concepts, identification of respondents, obtaining consent, data collection as well as all aspects of confidentiality and ethics and empathy in dealing with families who might have experienced death or were experiencing severe illness. The field team was trained to interview, collect and edit data. A 42 page training manual was devised which was frequently referred to during field work (see Appendix 6).

However, training interviewers was an ongoing task. On-the-job training was also provided by the researcher while working with each of the fieldworkers. Two fieldworkers/interviewers with nursing/psychological/counselling backgrounds from Soweto were employed. Interviewers were given books in which to document their unique, individual experiences. They also used this book to document events of the household that was used as "ice breaking" tools for the next interview and conversation pieces in between appointments. This contributed towards the development of the relationship with the respondent.

Respondents also took it upon themselves to phone in if someone was ill at home or to advise of a death in the family. Respondents felt comfortable with the interviewers to tell them about the hardships experienced by the family and to seek comfort. Respondents used the interviews as a counselling session. Often, fieldworkers were kept longer at a household than was necessary. These conversations while contributing useful information to the research sometimes were emotionally draining to the field team.

This study acknowledged the difficulties that the field team would face in the presence of sickness and death and approached the University of Vista's School of Psychotherapy in Soweto to provide the research field team with psychotherapy. The initial plan was to assess the interviewers' baseline levels of functioning by means of a pre-testing procedure (assessing in particular the stress levels, emotional stability as well as levels of control. However, due to attrition only one interviewers' baseline functioning was assessed at the beginning of the period. The second phase of the intervention encapsulated the therapeutic process. Fieldworkers visited the psychotherapists every two to four weeks depending on fieldworkers need and availability. Due to the fact that the initial tests were not completed at the beginning of the study, it was difficult to measure the effectiveness of the therapy at the end of the study.

However, here are some comments on what the fieldworkers had to say about the psychotherapy:

- "Psychotherapy helped me to separate my work from my personal life, thereby keeping my core self and identity intact."
- "Debriefing was a good idea since it allowed me to discuss the emotional issues and problems encountered during the interviews. At times, I was very touched by the scenarios and challenges and felt the need to speak to someone about it. It helped me cope with my job."

- "Psychotherapy helped me deal with some of my own issues that surfaced while listening to the problems of other people. I realised how small my problems were in comparison with the hardships faced by families."

### 4.11 Unit of Analysis

Either the individual or a household was the unit of analysis in most of the HIV/AIDS impact studies. Studies in the developed countries focussed on the individual patient or infected household member (see Appendix 5). In developing countries, since the role of the extended family is prominent, these studies focussed on infected as well as non-infected household members.

The unit of analysis in this study is an income-earning household. This means that at least one person in the household has to earn an income through employment or from being self-employed. Individuals who are HIV positive in most cases do not disclose their status to surviving household members but their status does affect household income and expenditure patterns. Using the household as the unit of analysis assumes that most income from all individuals is pooled. This study found only three households where income from all members was not pooled because the individual income-earner did not wish to contribute to the joint household[5]. Their income was not counted as household income although these individuals did impact on household expenditure. This study found an average of 1.2 members employed per household which might explain why individuals have little choice in whether their income should be pooled or not.

### 4.12 Respondent

Depending on the research question, household surveys use either the head of household (Ainsworth et al., 1992:7) or the most knowledgeable person on the topic (Ainsworth et al., 1992:7) or other family members (foster parents, caregivers or patients) as the respondent (Ryder et al., 1994, Bharat, 1995, Le Blanc and Wight, 1995, Naidu et al., 2004). In the present study interviews were conducted with

[5] There were two households from the non-affected cohort and one household from the affected cohort.

financial heads of households for information on expenditure and the income-earner for information on income. This avoided situations where the financial head may not know the income of all income-earners in the household. Financial heads were considered the most appropriate person because they were most knowledgeable about income and expenditure (Booysen et al., 2001). Often interviews with the income-earner took place during week-ends or during the evenings.

### 4.13 Compensation for Participation

Only in four studies, the authors indicated that respondents were rewarded for participating. In the Zaire study, transport costs for clinic visits were paid to the respondents. Two of the US studies participants were paid US$25 and US$15 respectively to compensate them for their time and travel expenses. In South Africa, other household surveys have indicated that respondents required some form of compensation. The Soweto survey conducted by the Perinatal HIV Research Unit (Naidu et al., 2004) gave each respondent a Telkom voucher to the value of R20 after the interview and the Nelson Mandela/HSRC HIV prevalence survey gave R50 to the respondent (Shisana and Simbayi, 2002:25). The Free State study paid R100 per visit, which was paid only after the second wave of interviews (Booysen et al., 2001). Some studies recorded that respondents asked what was in it for them and what they could expect to receive in terms of payment. During the Free State study (Booysen et al., 2001), the Uganda study (Seeley et al., 1995:84) as well as in the present study, members from non-sampled households offered to be interviewed. Their motivation for self-selection was because they wanted their voices heard. In the Kagera study, it was found that households despite their grief were willing to be interviewed (Ainsworth et al., 1992:5). Since in some studies, HIV/AIDS counsellors from known agencies were used, interviewers were therefore known and trusted by the interviewee and this could have helped the process of information sharing. It could also be that the respondents found it therapeutic to talk to someone given that fieldworkers are adequately trained to deal with HIV/AIDS issues in a professional way (Booysen et al., 2001). Help and support given to sample households should be recorded so as not to jeopardise the results of the study.

The study did not offer any monetary incentive. A hamper of groceries sponsored by Unilever, South Africa, was given to each household after the final wave to compensate respondents for their time. Sample households were not recruited on the basis of the incentive. They were told about the incentive during the first interview only if they asked. The informed consent did not mention any incentive. This was done deliberately so as not to allow the incentive to encourage households to participate. During a focus group session with 10 household heads held during the planning phase of the project, only one household head insisted on an incentive - of R100 for every visit. Help was offered in terms of referrals for support services. Households were informed how to complete the expenditure diary. In this way, households were exposed to budgeting if they were not already. This information made them more aware of their spending patterns and their budgets. Some households that generated income from home production became aware of the profits or losses that were incurred as a result of maintaining a record of income and expenditure.

### 4.14 Ethical Considerations

Due to the stigma and discrimination that surrounds the issues of HIV/AIDS careful consideration was taken not to focus on HIV/AIDS, the disease, behaviour surrounding the disease, or education at household level. Since disclosure to the spouse and remaining family members occur in a smaller proportion of families, it was assumed that there was non-disclosure at household level. The selection process was kept separate from the fieldwork.

The attending physician together with the patient completed the sample selection form gave consent to contact the household head as well as contact details of the household head and the person in charge of the daily organisation of the household if not one and the same person. A separate nurse independent of the fieldwork was appointed to seek consent from the household head as well as to make the appointment for the first visit. The fieldworkers then visited the household head to obtain signed consent and to interview the financial head. At any time, respondents were allowed to discontinue with the study should they chose to do so and another household was recruited in its place. Should the respondent not wish to answer any

question, they were allowed to do so. See Appendix 2 for the way in which the study was explained to the respondents.

The fieldworkers were not told which sample group the household belonged to and the same instrument was used irrespective of which group the household belonged. The fieldworkers were trained on all aspects of research confidentiality.

Participation in the study was voluntary and research protocols of the University of Cape Town and the University of the Witwatersrand were followed in order to safeguard the rights of the participants and to ensure ethical standards of research. Participation was voluntary and respondents were allowed to drop out of the study for any reason at any time or refuse to answer any question they felt uncomfortable with. Only seven financial heads of households felt the need to drop out of the study because the study raised personal issues they felt not ready to deal with. Respondents were most reluctant to talk about savings in their bank accounts and who they borrowed a loan from.

A challenge identified by Booysen et al., (2001), was the terminology used in the introduction of studies of this nature. Respondents were reluctant to participate when the words "HIV/AIDS" were used. Booysen et al., (2001) cited participation rates lower in studies that had disclosed the HIV status of a household member. The openness of the research project might lead to households becoming stigmatised as a result of the study. There were other ways of introducing the study as a "communicable disease" study or a study of "morbidity and mortality" as used in the Free State Study. This survey was introduced as a study of the effects of sickness and death on income, expenditure, savings and debt. This ensured that the researchers did not become known in the local community as people researching the impact of HIV/AIDS. During fieldwork the researchers were approached by neighbours enquiring why their households were not being surveyed and that they too want to share their income and expenditure status with policy-makers. They felt that by not being researched their voices would not be heard.

Although HIV/AIDS was not openly discussed among all household members, respondents felt at ease discussing their circumstance with the fieldworkers and did

in fact disclose members' HIV status. This indicates the establishment of trust over time. There was an expectation by respondents for fieldworkers to get involved in household events by sharing in their joy and grief. Households in need were given contact details of relevant support organisations in Soweto. Six households requested letters to be written for them requesting social grants or to school principals requesting children's school reports to be released in the absence of paying school fees.

Although most studies in Appendix 5 did not explain what ethical procedures were followed, studies that interviewed the infected member did so at the health care facility rather than the individual's home. Perhaps this was done so as not to compromise the HIV infected member. Individuals who might be HIV positive, in most cases do not disclose their status to remaining household members yet impact on the household income and expenditure patterns. This might be a reason why many studies interview the infected individual outside the household while other studies collaborate with NGOs, CBOs and health care facilities to assist with recruitment since these families either have a member that has disclosed or has a member that is seeking help due to sickness.

During training, the fieldworkers insisted on having written consent from the households because they felt that the agreement would then be more binding. The consent form was adapted to include signatures of the fieldworker and the respondent.

**4.15 Recall Period**

The recall period for the longitudinal studies ranged from monthly (Uganda, Seeley et al., 1995 and Burkina Faso, Sauerborn et al 1996) to six monthly (Kagera study, Ainsworth et al., 1992:2). To keep the recall period to a minimum so as not to rely heavily on the memory of the respondents, the present study visited the households once every three months referred to as a "wave". Four waves were carried out during a 12-month period.

Since most studies visited the household every six months and one study visited the household each month for six months, it was decided to visit the households every third month to keep recall to a minimum and to give the fieldworkers a chance to build rapport with the respondents.

### 4.16 Reliability and Validity

Reliability means consistency. If another researcher carried out the same survey with the same people at the same time, the results should be consistent. Saunders et al., (1997:82) poses two important questions to measure reliability. The first question relates to whether the same measure will yield the same results on different occasions and the second question whether similar observations will be made by different researchers on different occasions.

Researching issues surrounding HIV/AIDS brings about certain threats to reliability. The first threat would lie in the research sample not being comfortable with the research subject and the interviewer/observer. During recruitment, the majority of index cases requested that their identity remain anonymous since other household members were not aware of their HIV status. To overcome this, some interviews took place in another room, in private, at the request of the respondent. Once trust was established between the interviewer and the respondent, the study found that respondents were able to discuss issues surrounding HIV but only, in the absence of some household members.

Most people are also not comfortable with topics such as income and expenditure (Deaton, 1997:29). In the Uganda study, sample members were reluctant to answer questions on landholdings and income for fear of taxation (Seeley et al., 1995:81). They may either raise their income or raise expenditure in certain categories. To overcome this, respondents in the present study were requested to supply pay-slips which helped alleviate some of the sensitivities about the topic. Furthermore, electricity, water and telephone bills were requested.

The second major threat lies in the accurate interpretation or complete recording by the interviewer/observer. In the Uganda study, different interviewers produced data

of different quality from their household visits (Seeley et al., 1995:85). To overcome this in the Uganda study, research assistants joined the less thorough interviewers on a few home visits and wrote a separate account of their observations. The present study used a structured instrument reducing the threat to reliability. The researcher worked with the interviewers to reduce interpretation errors thereby lessening the threat to reliability.

Validity refers to the extent to which the research measures what it is supposed to have measured (Cooper and Schindler, 1998:166). It deals with the soundness and the effectiveness of the measuring instrument. Respondents were trained concerning the purpose of the study and the informed consent was signed by the respondent as an agreement to offer accurate data. The recall period was kept to a minimum as explained in the previous section. Furthermore, the use of the diary method also validated the data.

A threat to validity was the dissolution of households due to sickness or death of one or two income-earners. One household that split was followed while the other left no forwarding address.

The comprehensive nature of the instrument contained various checks that were used as an additional measure to ensure reliability and validity. Respondents were asked to clarify answers that were not consistent.

### 4.17 Development of the Instrument

The questionnaire was developed to collect qualitative and quantitative data. It consisted of open, closed and multiple-choice questions. Key stakeholders consisting of a multi-disciplinary team including policy-makers, non-governmental organisations, community based organisations and people living with HIV/AIDS were consulted in the development of the questionnaire. Various household questionnaires were referenced such as the Kagera study, the Free State study, the Abt Associates study, the PHRU study, labour market survey, October Household survey and the income and expenditure survey conducted by Statistics South Africa. The questionnaire was divided into various sections (see Appendix 7). The

annotated questionnaire in Appendix 1 and the instrument in Appendix 7 will give the reader a sense of the comprehensive nature of the instrument.

The instrument was available in English and translated in a Soweto dialect of isiZulu and seSotho. This was done so that the subtle language differences of the region were taken into account so as not to change the meaning of the word. These two languages were chosen because during the screening process the index cases were asked in which language(s), the financial head would prefer to be interviewed in. In wave one the instrument was 47 pages in length. It was field tested with ten household heads in the study area. The lessons from the field test were incorporated in the final instrument. It mainly pertained to the use of words not familiar in the local setting. The instrument took one and a half to two hours to complete during wave 1 and thereafter between 45 minutes to 1 hour to complete in subsequent waves. Table 4.6 adapted from the Kagera study (Ainsworth et al., 1992) reports:

**Table 4.6: Sections of the Instrument**

| Number | Section | Respondent | Wave |
|---|---|---|---|
| 1 | Instructions | Interviewer | All Waves |
| 2 | Identification | Interviewer | All Waves |
| 3 | Interviewer Visits | Interviewer | All Waves |
| 4 | Editing and Coding | Interviewer | All Waves |
| 5 | Demographic Profile of the Household (name, age, gender, education level, health status) | Respondent | All Waves |
| 6 | Migration | Respondent | Wave 1 |
| 7 | Main Activities of the Household (Time Allocation) | Members over 7 years | All Waves |
| 8 | Migrant Workers | Respondent | All Waves |
| 9 | Remittances In | Respondent | All Waves |
| 10 | Income from market and non-market activities | All income-earners | All Waves |
| 12 | Household Assets | Respondent | All Waves |
| 11 | Expenditure (including Education and Transfers Out) | Respondent | All Waves |
| 13 | Savings, Borrowings and Debt | Respondent | All Waves |
| 14 | Morbidity – reallocation of duties, reallocation of expenditure, income shifts, reallocation of household members | Respondent | All Waves |

| Number | Section | Respondent | Wave |
|---|---|---|---|
| 15 | Mortality – reallocation of duties, reallocation of household members, income and expenditure shifts, economic impact on remaining household members. | Respondent | All Waves |
| 16 | Home Production and Consumption | Respondent | All Waves |
| 17 | Anthropometry | Children under 5 | All Waves |

### 4.18 Strengths and Limits of the Design

The advantage of a focussed localised sample such as this study was the opportunity to address intensively and extensively the issues that would be critical to accurate modelling of the socio-economic impact of HIV/AIDS at the household level. However, like other studies of this nature, the findings cannot be generalised to the entire population.

The longitudinal nature of the study presented the opportunity to build trust with the respondents and to draw kinship diagrams to identify the relationship of children to their parents and not just to the household head.

Since HIV/AIDS has been known to be a long-term illness, it needs to be monitored and measured on a long-term basis. This study was limited to a period of one year due to the fact that the funders required a methodology to be developed for future household surveys that will be conducted on a larger scale, ideally three to five years.

Like most surveys a limitation would be reliance on the honesty and integrity of the respondent to report truthfully on very personal and sensitive topics. This study had gone to great lengths to build trust. Since much time was spent on obtaining buy-in and permission from various stakeholders, this also contributed to building of trust in the community.

Like most household surveys the study relied on one the responses of one individual. Although the financial head of the household was chosen as the respondent supplying information on household expenditure, not all expenditure of

all household members were captured, only household expenditure that was spent from the household budget.

This study took the time to obtain buy-in and permission from various political and local community structures thereby ensuring that the results would be used to inform policy. Various presentations were held with various authorities in the development of the instrument and in the release of interim results.

The study is limited to women who attended public antenatal or HIV clinics in Soweto. It would have been useful to include men, but their utilisation of such health care services to seek voluntary testing or treatment for HIV/AIDS is limited. Sampling bias has been introduced in the way the non-affected group has been selected.

**4.19 Summary**

Lessons from other HIV/AIDS socio-economic surveys were used to develop a methodology for this study. The various South African general household surveys were used to inform the development of the instrument for this survey.

This research used the cohort approach and followed two cohorts of HIV affected households and non-affected households visiting each household every three months for a 12-month period. Sample households were chosen via women from income-earning households who attended public health care facilities or HIV clinics in Soweto.

Research capacity was built in Soweto by utilising local people and training them on all aspects of research. Fieldworkers received psychotherapy to help them cope with a very difficult task of facing illness and death on a daily basis. Interviews were conducted at the home of the respondent using a structured instrument. Fieldworkers were trained to document stories to support the quantitative data.

A comprehensive instrument was designed collecting information on a broad range of issues. The instrument was informed by different previous household surveys, by

political and community structures and by people living with HIV/AIDS. It was field tested.

A period of nine months was spent in the field getting to know the right authorities, establishing relationships and building trust with the local community before commencing the first interview with sampled households. The diary method combined with the respondent's memory was used as a method for data collection. Response errors were clarified within a week and captured using Microsoft Access. The drop-out rate was low because of the constant contact that was maintained with the respondents on a monthly, weekly and daily basis.

Households were compensated for their time with a hamper of groceries at the end of the study. The study was approved by the ethics committee of two universities.

Good relationships were built with the respondents and the fieldworkers including the researcher such that if changes were experienced at household level the respondents would call the office. This type of relationship building is essential for longitudinal studies. This also validates the data and ensures reliability.

No study is without limitations and this study has introduced sampling bias as well as the results cannot be generalised to the entire population of Soweto.

# CHAPTER FIVE
# PROFILE OF THE SAMPLE HOUSEHOLDS

## 5.1 Introduction

This chapter reports on the profile of the sampled households particularly the characteristics that distinguish the affected households from non-affected households. It also discusses the impacts from HIV/AIDS morbidity and mortality on household size, composition and structure and highlights the various types of households that emerge as a consequence of HIV/AIDS.

The analysis investigates the impact of new births, morbidity, mortality or migration effects on household size, composition and structure particularly on households affected by HIV/AIDS. Some studies (see Section 2.2) have found that the number of dependants increase as a result of grandparents and children being left behind, while others (see Section 2.2) have found that the number of dependants decline as a result of HIV/AIDS, or affected households adjust their household sizes in similar ways to that of non-affected households via:

- Fewer births
- Economically-active members joining the household
- Children leaving the household
- The mortality effect

Given the high rate of unemployment in Soweto (see Section 3.10), this study investigates alternative ways of calculating the dependency ratio.

## 5.2 Characteristics of Affected and Non-Affected Households

Individuals not married or not in one-partner relationships may increase their vulnerability to HIV/AIDS due to multiple sexual partners or a lack of condom use. One of the distinguishing characteristics of affected households in this study is that they have half as many adults married or living together compared to non-affected households. Over time, adult deaths should create more widows/widowers (Ntozi et

al., 1999:211) but because of the low rate of married individuals in affected households, this has not been the case in the households of the present study.

Collecting retrospective data on widows would have revealed the cause of death of the spouse and provided some explanation as to whether widows were created long before the start of the study. Due to sampling bias of recruiting women with CD4 cell counts of 200 and below, and the fact that the majority of them were single (see Section 6.2), they migrated back home to be taken care of by their parents who also happened to be in many cases household heads that were single.

In Soweto, having children out of wedlock is an accepted norm. Despite the fact that the non-affected cohort had twice as many individuals married, approximately 40% of children across both cohorts were raised by a single parent. When questioned about the reasons for having children out of marriage, many females stated that not finding a suitable life-partner did not deter them from not having children. Children not only bring joy but also form a safety network for the mother in her old-age. Some mothers looked for immediate economic relief from the father of their illegitimate children. One HIV infected mother stated that she wanted to leave something of herself behind although she was aware of the risk of losing the child. She has appointed her adult sibling to care for the child when she dies. The implication of HIV-positive mothers having children is that children eventually become orphans and are left to be raised in the care of someone else frequently retired persons (see Case Study 5.1 and Table 9.5).

Another distinguishing characteristic of affected households is headship. In this study, headship was self-reported. Despite the fact that the self-reported heads may simply be the oldest person in the household, approximately 73% of households from the affected cohort were headed by older females compared to 39% from the non-affected cohort (see Appendix Table 8 and 9). The affected cohort not only had more single household heads but also more single household members compared to the non-affected cohort (See Appendix Table 8 and 9).

Households in Soweto are patriarchal in that 84% of households with married or living together heads are men versus only 4% of households with female heads.

Half of the female-household heads from the affected cohort were never married while half of the female-heads from the non-affected cohort were widowed.

### 5.3 Household Size, Dependency Ratio and Household Composition

The average household size was six members for all households. Affected households had slightly more household members (6.5) at the beginning of the study (t stat = 1.60, p-value 0.1115) decreasing slightly to 5.9 over the year (see Table 5.1). As noted, these decreases are gradual over time with more noticeable changes expected over a longer-period of time or when more than one household member dies, as noted in case study 5.1.

The study found the household size reducing in the affected cohort gradually as a result of:

- Fewer births
- More deaths
- Children being sent to live elsewhere either for economic reasons or because their parents died

It is interesting to note that even after one year, the affected cohort still had more household members than the non-affected cohort. At the beginning of the study the affected cohort had 16% more household members; a year later they had only 3.5% more household members.

**Table 5.1: Household Size**

| | Wave 1 | Wave 2 | Wave 3 | Wave 4 | All Waves |
|---|---|---|---|---|---|
| **All Households** | 6.1 | 6.1 | 5.9 | 5.8 | 6.0 |
| **Non-Affected** | 5.6 | 5.8 | 5.8 | 5.7 | 5.7 |
| **Affected** | 6.5 | 6.3 | 6.0 | 5.9 | 6.2 |

While household size is an indication of the number of people in a household, it does not inform us about household composition, particularly about the number of dependants. Assessing the number of dependants is important because households

with higher numbers of dependants have more members to take care of and therefore in the long-term may become vulnerable.

The dependency status of individuals can change over the four waves. An employed individual in wave 1 could exit the labour force and become a dependant in the next wave or vice versa. On the other hand, an unemployed ill person could become an income-generator through the receipt of grant income.

There were two categories of dependants considered in this study. The first category being age specific which relates to individuals less than 15 and 65 years and over as being the non-productive category of the population and the remaining 16-64 years of age as being the productive category of the population. Due to high levels of unemployment in Soweto and the fact that non-economically active members join the labour market coupled with the fact that grant income make up 41% of total monthly household income for the affected cohort (see Table 7.11), it is realistic to consider a second category of dependants. The second category of dependants was based on income-generation irrespective of age.

In the first category, there were more dependants[1] in the affected households for each wave and 30% more across all waves. The percentage of dependants over time for the affected cohort increased from 39% in wave 1 to 44% in wave 4.

Using the second category of dependants, the affected cohort still had more dependants across each wave and 22% more across all waves. The percentage of dependants across time for the affected cohort in the second category of dependants decreased from 71% to 65%.

In wave 2 there was a sharp increase in the number of dependant household members across both cohorts for different reasons. For the non-affected cohort, almost all the increase in membership was due to births (due to sampling bias), while for the affected cohort, it was mainly due to children moving back for schooling or to be taken care of (see Figure 5.4).

[1] Children under 15 and adults over 65 years of age

**Table 5.2: Number of Dependants Across Cohorts and Across Waves**

| | Non-Affected Households | | | | Total | Affected Households | | | | Total |
|---|---|---|---|---|---|---|---|---|---|---|
| | W 1 | W 2 | W 3 | W 4 | All Waves | W 1 | W 2 | W 3 | W 4 | All Waves |
| Dependants (<15 & ≥65) | 117 | 142 | 141 | 132 | 532 | 165 | 192 | 172 | 162 | 691 |
| Dependants (non-income generation) | 228 | 245 | 234 | 218 | 925 | 305 | 311 | 265 | 245 | 1126 |
| Total (all individuals) | 331 | 329 | 320 | 305 | 1285 | 429 | 437 | 395 | 379 | 1640 |

The number of dependants in a household is influenced by net migration which is derived from the difference between those who left and those who joined the household. The data shows net positive in-migration for the non-affected cohort resulting in an increase in household size over the four waves (see Table 5.1). There is a net negative in-migration for the affected cohort (see Appendix Table 10) across all waves.

### 5.3.1 Dependency Ratio

The dependency ratio is used as a proxy measure of the economic burden which the productive population is expected to bear (Lehutso-Phooko, 2004:8).

Four methods of calculating the dependency ratio have been considered in this study (see Table 7.2). The first method - age dependency ratio - represents the numeric relationship between the number of persons per 100 working age persons (using the number of dependants over the number of individuals in the productive age group 15 to 64), and results in the dependency ratio of 0.72 for all households (compared to 0.55 in the PHRU 2002 survey). The limitation with this definition is that it assumes that all those under 15 and over 64 are non-workers and all those between 15 and 64 have the potential to work. Using this method, affected households have a 3% higher dependency ratio across all waves. This is because there are 28% more individuals and 30% more dependants in affected households. Over time, the dependency ratio in the affected cohort increased in wave 2 and then started to decrease from wave 3 due to fewer dependants (fewer children born and more

deaths). On the other hand due to more births and migration of household members, the dependency ratio increased in the non-affected cohort over time.

Given an unemployment rate in Soweto of 57% (See Section 3.10), two further methods of calculating the dependency ratios have been considered. The second method calculates the proportion of the not economically active to the economically active population. Using this formula, the dependency ratio is higher in the affected cohort (1.73 versus 1.12). Almost two thirds (63.4%) of individuals in affected households are not economically active. This method considers adults who are not working and not looking for a job. Over time, the dependency ratio increases for both cohorts as a result of high unemployment, individuals resign themselves to not finding employment. The limitation with this indicator is that non-economically active members generate income while economically active members may be out of work for lengthy periods of time.

The third alternative method considers the proportion of dependants to the employed. Using this formula result in a dependency ratio of 2.22 for affected households compared to 1.77 in non-affected households. The limitation with this indicator is that it excludes those who receive grant income.

There are also individuals who receive grants that contribute to joint household while some households rely solely on income from grants. The fourth method includes those receiving any form of income including grant income. Using this method, the affected cohort has a lower dependency ratio than the non-affected cohort (2.19 versus 2.57). This is because grant income plays a large role in the survival of households affected by HIV/AIDS.

The first three methods of calculating the dependency ratio resulted in the affected cohort having a high dependency ratio to non-affected households. While the fourth method taking grant income into account lowers the dependency ratio in affected households, the role of grants and how it is utilised at household level requires further research.

### 5.3.2 Household Composition

In all households for all waves 64% were adults and 36% children. There were no differences noted across cohorts. However, over the year, the proportion of children under 7 increased in the non-affected cohort due to more births and reduced in the affected cohort because of fewer births[2] (see Table 5.3). The non-affected cohort had 40% male adults compared with 36% in the affected cohort for all waves.

**Table 5.3: Proportion of Adults and Children Across Waves 1 and 4**

| | W1 | | W4 | |
|---|---|---|---|---|
| | Non-Affected | Affected | Non-Affected | Affected |
| Children under 7 | 15.1 | 18.4 | 22.3 | 17.9 |
| Children 7 to 15 years | 19.0 | 17.5 | 17.7 | 19.0 |
| Adults | 65.9 | 64.1 | 60.0 | 63.1 |

HIV/AIDS morbidity and mortality is one of the main causes of mobility among household members. For all waves, there were 142% more individuals from the affected cohort compared to the non-affected cohort that left the household as a result of sickness or death and 44% more members from the affected cohort that left the household for any reason (see Appendix Table 10). The main reasons for members of the affected cohort leaving the household were as follows:

- Morbidity and mortality (26% of individuals that left died and 6% left to be taken care of by members of other households (see Figure 5.2) either because they themselves were sick or because of sickness in the household).
- Financial reasons (47% left because the household could no longer afford to keep the individual. It can be argued that HIV/AIDS makes households poorer and therefore households may respond by sending household members to live with relatives. This was also found to be high amongst the reasons for individuals from non-affected households leaving the household see Figure 5.1).

[2] This is due to sampling bias

- Schooling elsewhere is related to the fact that the household could not afford schooling in Soweto nor care for the child after school. Only 2% of individuals who left the non-affected cohort left for schooling elsewhere because there were no caregivers to care for them after school.
- Only 5% of individuals that left (see Figure 5.2) affected households did so either to look for work or moved because they found their own accommodation. This compared to 52% in the non-affected cohort.

The average age of all individuals who left were 25 years of age (ranging from 2 months to 83 years).

**Figure 5.1: Reasons why Individual Members Left the Household (Non-Affected Cohort, n=43 from 19 households – All Waves)**

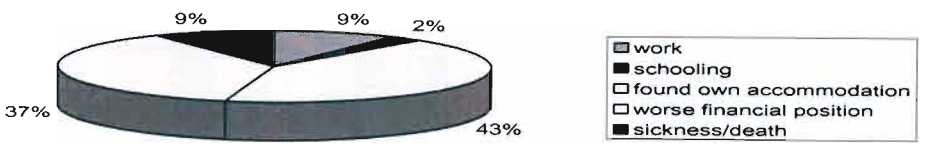
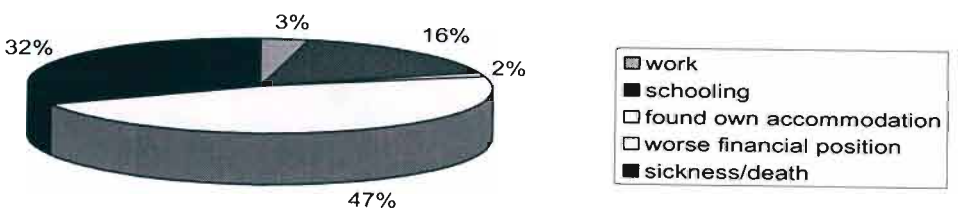



**Figure 5.2: Reasons why Individual Members Left the Household (Affected Cohort, n=62 from 35 households – All Waves)**



Fewer individuals joined the affected households compared to the non-affected households. This could be attributed to:

- There were fewer births in the affected cohort (of those who joined 59% were new-born babies - see Figure 5.3 in the non-affected cohort versus 16% in the affected cohort – see Figure 5.4).
- Because of their financial position fewer affected households attracted new members.

The main reasons for the affected cohort attracting members were (see Figure 5.4):

- Sickness and Death: 24% of individuals that joined the affected cohort were because of sickness or death (see Figure 5.4) versus 4% in the non-affected cohort. Children joined the affected household because their parents had died. Adults joined to take care of someone sick or because they themselves were sick.
- Children: 13% of those who joined were children involuntarily inherited (see Figure 5.4) by the affected household because the child's own family could no longer take care of them either because one spouse was sick or had recently died.
- Improved financial position: 16% (see Figure 5.4) of those who joined the affected cohort and 25% (see Figure 5.3) of those who joined the non-affected cohort were attracted to the household because of improved financial position.
- Work related: 15% of those who joined the affected cohort joined for work related reasons compared to 12% in non-affected households.
- Joining for schooling: 16% joined affected households to attend school, yet none joined the non-affected cohort to attend school.

**Figure 5.3: Reasons why Individual Members Joined the Household (Non-Affected Cohort n=51 joined 37 households – All Waves)**

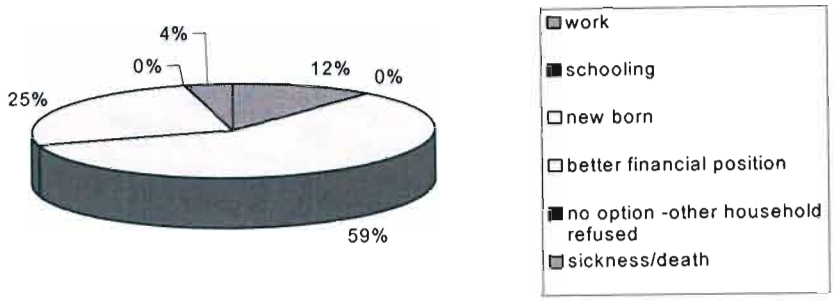
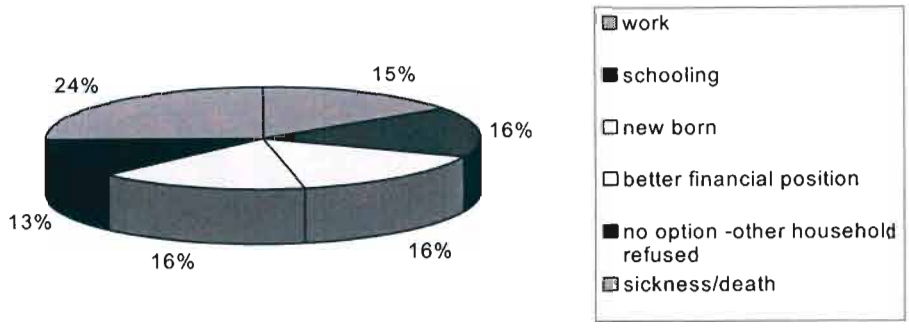



**Figure 5.4: Reasons why Individual Members Joined the Household (Affected Cohort n=32 joined 21 households – All Waves)**




The average age of those who joined all households to look for work or return home because they could not find work was 28 (range from 20 to 47 years). Approximately 80% of those who came to look for work in the affected cohort were men. Only six employed members joined the households, three in the non-affected cohort and three in the affected cohort.

A possible response to HIV/AIDS by affected households is to attract economically active members to join the household (see Section 11.5.1). They are faced with

additional responsibility for children of relatives who can no longer care for them. This is mainly undertaken by grandparents (see Case Study 9.1). The implication of this is that individuals in their retirement are called upon to perform care-giving functions and to raise children, which is physically tiring as well as draining on financial resources. Not only are affected households burdened with sickness and death, but they also attract new members due to sickness and death in other households.

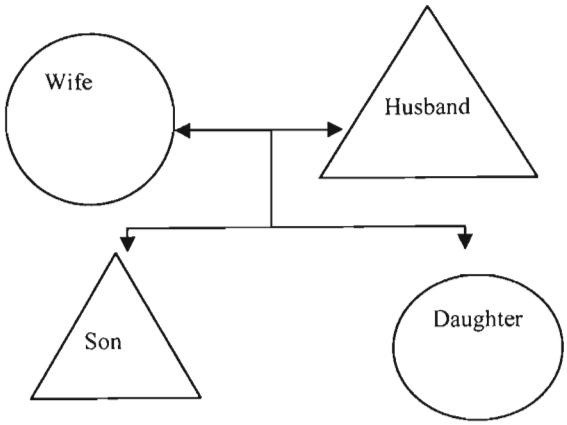
Non-affected households attract members because they are viewed as being better resourced. The study found non-affected households attracting members (see Figure 5.4) as well as two households which hosted funerals for individuals who died of HIV/AIDS.

### 5.4 Household Structure

To better understand the structure of the household, kinship diagrams were drawn for each household in wave 1 and updated in subsequent waves. There are various household structures in Soweto with the extended family structure being the norm (see Table 5.4). The extended family typically includes grandparents, adult children, their children and sometimes great-grandchildren. Approximately 42% of households contained three or more generations of inhabitants and almost 5% of households contained non-related members or members who were not immediate family such as uncles and aunts.

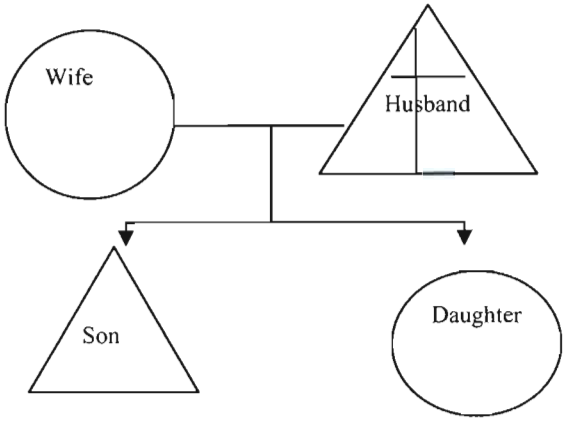
Typically, a nuclear family is made up of husband, wife and children as illustrated in Figure 5.5.

**Figure 5.5: Nuclear Family**




When the husband dies, this becomes a household with a single female with children.

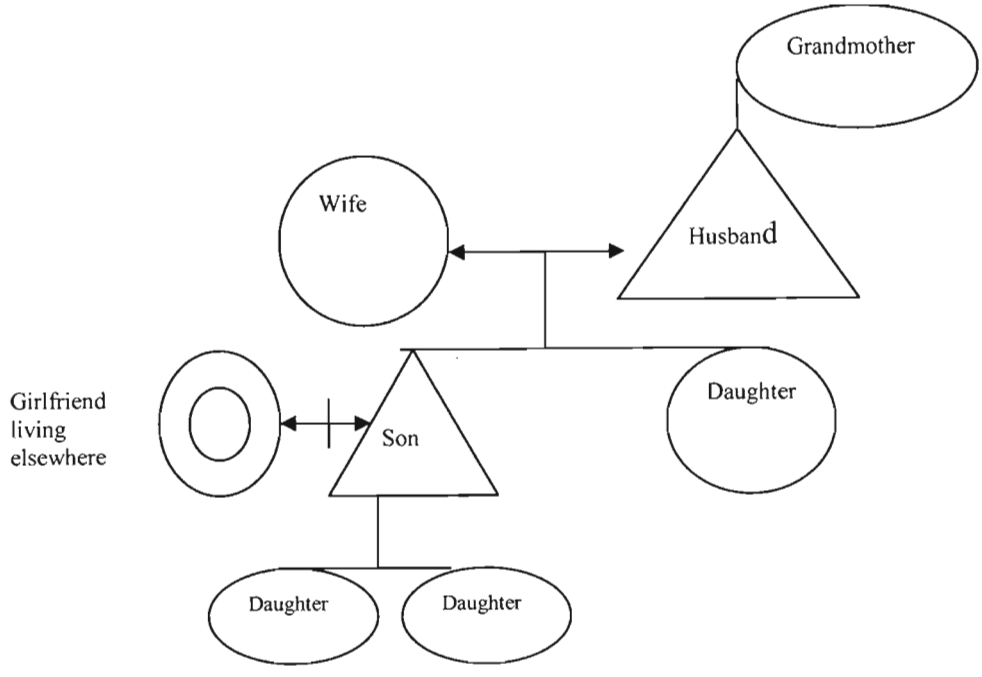
**Figure 5.6: Single Person with Children**




If both the children are sent elsewhere to live after the husband dies, then this household changes to a single person household. If the wife brings another partner to live with her, this household is classified as a cohabiting household.

The same household easily changes to an extended household structure, as when a grandmother moves in to take care of the children and an adult son brings his two children to live in the household while his partner lives elsewhere.

**Figure 5.7: Extended Family Structure (4 generations)**




Affected households were characterised by:

- A low percentage of nuclear families (see Table 5.4). The number of households classified as nuclear did not change dramatically over time. In wave 2, two of the three nuclear households dropped out of the study. The movement of household members were such that it created nuclear families in the future waves.
- An increase in single households with children across time due to death of spouse or partner. For privacy and to maintain confidentiality of HIV status, some individuals prefer to live on their own.
- The majority of households were extended family structures (see Table 5.4).

HIV/AIDS has the potential to change the structure of the household over time. In the affected cohort, nuclear families, single households and extended families decreased over time while single females and single males with children and cohabiting household structures increased (see Table 5.4). When a male and female live together as husband and wife without being married in the traditional or legal

way with or without their biological children, these structures are referred to as cohabiting.

**Table 5.4: Household Structure Changes Across Waves (Number of Households)**

| All Households | Wave 1 | Wave 2 | Wave 3 | Wave 4 | All Waves |
|---|---|---|---|---|---|
| Nuclear | 15 | 12 | 15 | 14 | 56 |
| Single | 7 | 9 | 6 | 8 | 30 |
| Extended family | 89 | 83 | 81 | 77 | 330 |
| Co-habit | 9 | 7 | 5 | 6 | 27 |
| Single female + children | 5 | 6 | 8 | 9 | 28 |
| Single male + children | 0 | 0 | 0 | 1 | 1 |
| Total | 125 | 117 | 115 | 115 | 472 |
| | | | | | |
| **Non-Affected** | **Wave 1** | **Wave 2** | **Wave 3** | **Wave 4** | **All Waves** |
| Nuclear | 12 | 12 | 13 | 12 | 49 |
| Single | 2 | 4 | 2 | 4 | 12 |
| Extended family | 36 | 32 | 33 | 30 | 131 |
| Co-habit | 7 | 5 | 3 | 4 | 19 |
| Single female + children | 2 | 0 | 1 | 2 | 5 |
| Single male + children | 0 | 0 | 0 | 0 | 0 |
| Total | 59 | 53 | 52 | 52 | 216 |
| | | | | | |
| **Affected** | **Wave 1** | **Wave 2** | **Wave 3** | **Wave 4** | **All Waves** |
| Nuclear | 3 | 0 | 2 | 2 | 7 |
| Single | 5 | 5 | 4 | 4 | 18 |
| Extended family | 53 | 51 | 48 | 47 | 199 |
| Co-habit | 2 | 2 | 2 | 2 | 8 |
| Single female + children | 3 | 6 | 7 | 7 | 23 |
| Single male + children | 0 | 0 | 0 | 1 | 1 |
| Total | 66 | 64 | 63 | 63 | 256 |

Case study 5.1 demonstrates how household size, composition and structure changes when households are impacted by HIV/AIDS.

**Case Study 5.1: Changing Household Size, Composition and Structure**

Maria is the household head and the only breadwinner (60 years of age, a divorcee who has never attended school). She has three adult children, all of whom are HIV positive. Her eldest son left the household in wave 2 to find work and died, leaving her to raise a pair of twins. She cannot claim foster care grant because the children's mother is living elsewhere and Maria is unaware of her whereabouts.

In wave 2, her youngest son also left the household to take care of someone sick and died in wave 4 from HIV/AIDS.

Maria's daughter Thando is in the AIDS-symptomatic phase and is cared for by a nurse. Thando and her two children also live with Maria. Thando receives the state disability grant. Prior to her illness she worked as a casual in an up-market furniture store in the city. The loss of income has caused the family some stress. They supplemented their income by growing crops in their back-garden for home-consumption. Thando has disclosed her HIV status to the church so the members can pray for her but not to the community as she is afraid of stigma. Maria is very religious and believes that the prayers and support from church members give her hope.

Maria is sad that the research highlights how much money is spent on health care. Before she decided to participate in the study, she used to pretend that HIV did not exist in her house.

The household incurred debt mainly because of expenditure on health care, special-dietary food for Thando and the purchase of a washing machine because Maria feared the risk of infection through hand washing. Members of Maria's household do not feel safe in Soweto and borrowed money from a micro-lender to build a wall and install a gate. Their debt also increased because they stopped paying their services bill. Maria does try to pay some money towards the electricity bill as she believes she would be cheating if she didn't. She is grateful to Eskom for not disconnecting the electricity despite her high bill. She is reluctant to convert to the

electricity card system for fear of not having electricity in the months that she cannot afford the card.

Maria will eventually lose all three of her adult children and will be left to take care of her grandchildren. One of her grandchildren of 17 years went to live elsewhere. She currently takes care of four of the five grandchildren age ranging from 4.5 months to 20 years. In the event of Maria and Thando's death, this household will become a child-headed household without any means of income.

There were 23 types of households that were identified in the present study as a result of HIV/AIDS (see Table 5.5). The analysis was conducted over 4 waves on 126 households, that is, on the unbalanced data set. These household types are not mutually exclusive. However, for the purpose of illustration, these households were put into one or other type. The data reveals the following types of households. Each of these types of households may respond very differently to the economic impact of HIV/AIDS. In this study the main types of households that emerge were grandmother headed, single female, three generation, households with recent adult death and households with multiple HIV/AIDS-related illnesses.

**Table 5.5: Household Types**

| **Household Type** | **Number n=126[3]** | **Percentage = 100.0** |
|---|---|---|
| Household with multiple AIDS sickness | 53 | 42.1 |
| Female headed household where at least one adult member is infected | 48 | 38.1 |
| Three generation household | 46 | 36.5 |
| Grandmother headed household | 41 | 33.5 |
| Household with recent adult death | 39 | 30.9 |
| Household with adult death in the recent past (6 months prior to interview) | 39 | 30.9 |
| Single female headed household | 28 | 22.2 |
| Infected member – AIDS sick unemployed | 20 | 15.9 |

[3] This counts the split household as two

| Household Type | Number n=126[3] | Percentage = 100.0 |
|---|---|---|
| Household that were mainly reliant on government grants | 19 | 15.1 |
| Male headed household where at least one adult member is infected | 18 | 14.3 |
| Nuclear household | 18 | 14.3 |
| Single male headed household | 18 | 14.3 |
| Infected member – AIDS sick employed | 14 | 11.1 |
| Household large in size – 10 to 18 members | 17 | 13.5 |
| Household with multiple AIDS deaths | 8 | 6.3 |
| Household with an infected member that is the breadwinner | 7 | 5.5 |
| Four generation household | 7 | 5.5 |
| Household with single mothers – intergeneration | 5 | 4.0 |
| Grandfather headed household | 5 | 4.0 |
| Household with recent child death | 3 | 2.4 |
| Households that have split. | 3 | 2.4 |
| Households with female-head infected and employed | 3 | 2.4 |
| Household with male-head infected and employed | 1 | 0.8 |

### 5.5 Methodological Lessons

One of the contributions of this study is drawing of kinship diagrams at the beginning of the study to establish the relationship of household members between each other not just to the household head. In this way, informal relationships were avoided and biological relationships documented. The kinship diagrams served as a useful tool in obtaining information for the means test which was used to establish eligibility for state grants.

## 5.6 Summary

Affected households had more single adults and were headed mainly by slightly older females. Having children out of wedlock appeared to be the norm with one in four children being raised by one parent.

The study confirmed that household size was impacted by new births, deaths, sickness, or for financial reasons. In terms of new births, the study confirmed the findings of other authors that the rate of fertility was lower in the affected cohort (De Cock et al., 1994, Temmerman, Chomba and Piot, 1994 as quoted in Ntoza and Zirimenya, 1999:195). Moreover, this study found that household size was impacted by the financial situation. When households prosper, individuals leave the family home because they are able to cope on their own and new members join to be taken care of. Conversely, when the household cannot cope financially, children are sent to be schooled elsewhere, or adults sent to live elsewhere.

The study also found affected households had no option but to care for children abandoned by parents because of sickness or death thereby creating an additional financial burden to already strained resources. This confirms the view of kinship obligations during times of need (Ankrah, 1993:7).

In the affected cohort, household size gradually declined over time. This confirms the findings from the Kagera study (World Bank, 1999:215). There was a higher dependency ratio in the affected cohort, using three different methods of calculating dependency due to affected households having more dependants. This was confirmed in the Thai and the Free State studies (Janjaroen, 1997:2, Booysen et al., 2003:42). This study found that the dependency ratio increased initially but by the end of the study, affected households were able to adjust household size and composition to make them similar to households not affected by HIV/AIDS. A similar result was found in the Kagera study (World Bank, 1999:216).

The study confirms the findings of other authors that the number of dependants in the affected cohort is higher whether dependants are measured as individuals under 15 and over 65 years of age (Booysen et al., 2003:42, Janjaroen, 1997:2) or non-

income generation members. The study found net in-migration negative for the affected cohort indicating that in the longer-term household size may drop to the levels of non-affected households or even lower.

The study confirms that HIV/AIDS morbidity and mortality is one of the main causes of mobility of household members. The financial reasons why household members left the household were greater than HIV/AIDS morbidity and mortality. Migration of household members for other reasons was low.

The study found that non-affected households over time are affected by HIV/AIDS in the sense of taking care of members of other households and subsidising the cost of funerals. Over time, there will be very few households not affected directly or indirectly by HIV/AIDS.

The extended family structure still appears to be the norm in Soweto, with nuclear households in the affected cohort. The study establishes that HIV/AIDS increases the number of households headed by single parents. Extended family structures provide families with additional security of income therefore they are able to survive during financial crises.

# CHAPTER SIX

# THE COST IMPACT OF HIV/AIDS ON HOUSEHOLDS

## 6.1 Introduction

To fully appreciate the total cost of the epidemic to the household, costs should be recorded from the day of diagnosis of HIV to full-blown AIDS and finally through to death. To do this, sample members should be followed over a period of 8 to 10 years or even longer. However, due to constraints in research budgets, most surveys only capture costs from a baseline through the period of the study. Thus, when interpreting costs, it is important to understand the context in which such costs were measured.

In the present study, the cost of morbidity and mortality was determined by establishing the total values for each household experiencing sickness and/or death for the eight month period and then averaged for all relevant households. Actual costs were collected for the two months preceding each interview (4 interviews altogether). For comparative purposes, this study reports the cost of morbidity for sick persons who are still alive, the cost of mortality for deceased members including the cost of illness prior to death, and on the combined cost of morbidity and mortality. In this way, the true cost impact to the household can be assessed since households either experience sickness and or death.

The average cost for each cost item is calculated for all households, including those who did not pay for treatment. This is because it is not unusual in Soweto for households not to pay for treatment. Some households do not lose income because either the sick member or the caregiver is unemployed. The average cost impact on households using this method of analysis therefore represents a more realistic picture. Only 10 out of 96 households did not incur any financial cost of sickness for reasons explained above.

The magnitude of these costs is determined by expressing the combined cost of morbidity and mortality as a percentage of annual income, as the number of months

of savings and the number of months to clear debt at the current rate of savings and repayment of debt.

Most studies report on direct and indirect costs and some studies report systemic costs as part of indirect costs. This study will clearly distinguish between direct, indirect and systemic costs and will indicate when these are combined for comparative purposes.

Data on direct costs includes expenditure for consultation, medicines, transport to and from the health care facility, food at the hospital, hospitalisation, physiotherapy, laboratory and other costs directly related to HIV/AIDS. It also includes the cost of medicines/vitamins incurred by the household. These direct costs are out-of-pocket health care expenses incurred as a result of illness. In the case of death, funeral costs are accounted for as a direct cost (see Table 6.1). The median for many of the cost items under direct costs are zero (see Appendix 12), this is due to the fact that most individuals access public health care services where the hospital entrance fee is R13 and this covers all of the ancillary services offered such as medicines, cost for physiotherapy, and so on.

Indirect costs (see Table 6.1) include lost income of the sick member and the caregiver(s). Some sick members and caregivers had already lost employment, prior to the observed period as a result of HIV/AIDS, which was not recorded since retrospective data was not collected. Only loss of employment or loss of earnings for the sick member and the caregiver for the two months prior to the first interview was captured. In the case of death, these costs were captured for the deceased member and the caregiver. The income loss to the sick member and the caregiver was recorded by asking respondents how much net income was lost during the observed period as a result of taking time off to care for the sick person, to visit them or accompany them to health care facilities.

A differentiation is drawn between financial and economic cost. Direct plus indirect costs represent the financial cost to the household. Thus, financial costs represents those costs actually incurred or lost to the household. Economic costs, on the other hand, are estimated values given for the use of time. The value given

is equivalent to the activity given up and not the activity itself. For example, if individuals gave up doing domestic tasks to take care of sick household members, the value of time for conducting domestic tasks was taken as the economic cost involved.

Systemic costs involve imputing values for the time given to care for a sick member, as well as for the time "lost" by the unemployed sick member. In this study, the opportunity cost is calculated at the cost of domestic work (see Section 6.4) since the opportunity to conduct domestic work was foregone. The minimum wage for domestic work was R4.10 per hour or R36.90 per day (Anon, 2003, www.safrica.info/public_services/citizens/your_rihts/domesticrights.htm).

These were calculated for the unemployed caregiver by multiplying the number of days sick with the number of hours spent caring multiplied by the minimum hourly rate of a domestic worker (R4.61). Systemic costs were calculated for the unemployed sick member by multiplying the number of days sick by the minimum daily wage of a domestic worker (R36.90).

This minimum wage was used because most of the time taken up with care-giving activities was a result of time given up doing domestic tasks (see Table 6.4). It can be argued that caregivers might have been employed had it not been for this event. One way of establishing this would be to have asked caregivers if they would have sought employment had it not been for their care-giving activities. The study asked caregivers what activities were given up as a result of care-giving.

This study acknowledges that income also enters the household as a result of death in the form of funeral insurance, lump sum receipts from life insurance and donations from relatives and non-relatives to cover the cost of the funeral. Therefore, it takes into account funds received as a direct result of death in calculating the net impact of morbidity and mortality on households (see Table 6.1).

**Table 6.1: Breakdown of Morbidity and Mortality Costs of HIV/AIDS to a Household**

| |
|---|
| **DIRECT COSTS** |
| Consultation |
| Medicine/drugs |
| Hospitalisation |
| Transport/Food |
| Physiotherapy |
| Laboratory |
| Other direct costs |
| **Total Direct Costs** |
| Funeral Cost |
| **Total Direct Cost including Funerals** |
| **INDIRECT COSTS** |
| Loss of earnings sick member or loss of employment - deceased member |
| Loss of earnings - caregiver |
| **Total Indirect Costs** |
| **Total Financial Cost (Direct plus Indirect Costs)** |
| **SYSTEMIC COSTS** |
| Foregone cost of earnings - caregivers |
| Foregone cost of earnings - sick member |
| **Total Systemic Costs** |
| **Total Costs of Morbidity and Mortality** |
| **INCOMING FUNDS AS A RESULT OF DEATH** |
| Cash |
| Goods |
| Total cash and Goods |
| Lump Sum receipts |
| **Total Incoming Funds** |
| **NET EFFECT OF MORBIDITY AND MORTALITY (TOTAL ECONOMIC COSTS)** |

A brief discussion of the characteristics of ill and deceased individuals as well as caregivers precedes the discussion on costs.

## 6.2 Characteristics of Ill Individuals

Over the four visits, there were 25 households from the non-affected cohort and 61 from the affected cohort, altogether having 129 individual members that were sick at least once.

In the non-affected cohort there were 44 episodes of illness in 36 individuals. An episode of illness represents one count of illness. Of the 36 individuals, 58% were female (n=21) with an average age of 37. Ill females were older than ill males who averaged 20 years. Approximately half (50%) of all ill males and females were single (never married). Of all ill individuals, 94% were adults over the age of 15 years. Of all adult males that were ill, 47% were economically active and 33% were employed. Of all adult females that were ill, 52% were economically active and 24% were employed.

In the affected cohort there were 139 episodes of illness in 93 individuals of which 69% were females with an average age of 33 years compared to males with an average age of 27 years. Approximately 72% of all ill males and 61% of all ill females were never married. This means that the rate of HIV cross-infection intra-household, from one spouse to another, (see Section 2.6) is expected to be low. Of all adult males that were ill, 31% were economically active and 14% were employed compared to adult females that were ill, 45% were economically active and 19% were employed.

For both cohorts, ill females were older than ill males and the majority of all those ill were adults who had never married. The likelihood of being employed as a sick female was lower than that for sick males. Employment is low for all sick individuals however sick adults from the affected cohort appear worse off.

Out of the 26 ill adults that were employed, 10 received sick leave or workman's compensation, 7 received pension benefits and 4 received death and disability benefits. Only two of the 129 ill individuals were on medical aid.

Approximately 88% of ill individuals sought treatment (see Table 6.2) compared to 78% in the PHRU (2002) household survey (see Section 3.5).

**Table 6.2: Health Seeking Behaviour of Sick Individuals**

| | Number of Individuals Sick | Sought Treatment | Didn't seek Treatment |
|---|---|---|---|
| Wave 1 | 56 | 50 | 6 |
| Wave 2 | 31 | 24 | 7 |
| Wave 3 | 14 | 13 | 1 |
| Wave 4 | 28 | 26 | 2 |
| Total all Waves | 129 | 113 | 16 |

Due to the nature of the disease, individuals get ill and then recover, depending on the treatment received for opportunistic illnesses. Therefore, it can be expected that households experience lower health care costs during periods of no illness or no death. The study also found 8 sick individuals being sent to live elsewhere. This means that the cost of morbidity is transferred to another household in which case cost to the study household is reduced. During the AIDS-symptomatic phase of the disease, individuals can be ill continuously and in some cases do not recover. In this study, 16 ill individuals died between the start and the end of the study representing 12% of all ill individuals. Across all waves, in 51% of the episodes of illness individuals were sick once only, in 49% of the episodes individuals were ill more than once and in 28% of the episodes individuals were sick continuously. Approximately 50% of individuals were sick once during the year, 27% twice, 16% three times and 7% in all four waves.

The nature of HIV/AIDS is such that when individuals are in the AIDS-symptomatic phase, they are confined to bed. Approximately 75% of ill individuals were too sick to get out of bed and 25% were sick but could still perform usual tasks. This meant that the majority of those ill required home-based care.

## 6.3 Characteristics of Deceased Individuals

In total there were 51 deaths, 7 from non-affected households and 44 from affected households. Of the 44 deaths from affected households, 32 were HIV/AIDS related and the average age of individuals who died from HIV/AIDS-related illnesses was 33 years. There were two individuals who died of HIV/AIDS from the non-affected cohort. The deceased individuals were not part of the non-affected household prior to death but the funeral took place from these homes and the cost of the funeral was borne by these households. Over 80% of deceased individuals were ill before death and 63% were ill for 4 weeks or more. In terms of health care utilisation, 23% died even before seeking treatment, 67% either sought treatment at the government clinic or hospital, 6% went to a traditional healer and 4% to a private health care facility.

Households lose income as a result of death either because the deceased was employed or was collecting a state grant (see Table 6.3).

**Table 6.3: Previous Employment Status of Deceased Individuals**

| | Non-Affected Households | Affected Households |
|---|---|---|
| Employed | 1 | 12 |
| Collecting Disability | 1 | 9 |
| Unemployed | 5 | 23 |
| Total | 7 | 44 |

## 6.4 Characteristics of Caregivers

Approximately, 9% of the ill individuals (n=12) cared for themselves. Depending on the length of illness, some ill individuals (almost 40%) had multiple caregivers. For the 129 ill individuals there were 163 caregivers in total, of whom 139 lost some form of activity as a result of the caring. There were multiple activities lost by a one caregiver. Almost 90% of the activities lost were as a result of time given up doing housework, gardening or leisure (see Table 6.4). This was because most of the caregivers were unemployed adult members of the household; two-thirds

were females mean age=30) and a third males (mean age=24.5). Only 16% of caregivers were employed.

**Table 6.4: Caregiver Activity Lost (Individual Caregivers)**

| Type of activity lost | Frequency of activity lost | Average hours lost in a day |
|---|---|---|
| School or schoolwork | 8 | 6.3 |
| Income-generation activity | 9 | 6.7 |
| Housework or Gardening | 130 | 6.8 |
| Leisure activities | 105 | 4.04 |

## 6.5 The Cost of Morbidity and Mortality

This section reviews the cost of morbidity, the cost of mortality and the combined cost of morbidity and mortality to non-affected and affected households. There were 86 households that experienced morbidity, 61 from the affected cohort and 25 from the non-affected cohort. All households from the affected cohort except one had at least one episode of illness during the observed period of the study. This was to be expected because the index cases were chosen with CD4 cell counts of 200 and below. There was one individual from the affected cohort who admitted to being HIV positive but refused to talk about the illness. No health care costs were recorded for this household because the individual did not miss a days' work or lose income and purchased a house on mortgage during the period of the study.

There were 43 households in total that experienced at least one death, 36 households from the affected cohort and 7 households from the non-affected cohort. An individual infected with HIV progresses from HIV infection to being AIDS symptomatic and finally to death.

There were 96 households in total that experienced either sickness and or death; 30 households in the non-affected cohort and 66 households in the affected cohort. The process of combining the costs of mortality and morbidity was also used to verify that costs were not duplicated.

Table 6.5 is a summary table of the cost of morbidity, the cost of mortality and the combined cost of morbidity and mortality. For a detailed breakdown of the costs in each category, please see Appendix Tables 11, 12, 13 and 14.

**Table 6.5: Cost of Morbidity, Mortality and Combined Cost of Morbidity and Mortality to Households (8 months cost averaged over relevant households)**

| | Cost of Morbidity (Rand) | | Cost of Mortality (Rand) | | Combined Cost of Morbidity and Mortality (Rand) | |
|---|---|---|---|---|---|---|
| | Non-Affected n=25 | Affected n=61 | Non-Affected n=7 | Affected n=36 | Non-Affected n=30 | Affected n=66 |
| Direct Cost | 164 | 381 | 21 | 324* | 142 | 529* |
| Direct Cost including Funerals | n/a | n/a | 7 434 | 10 211 | 1 872 | 5 922* |
| Indirect Cost | 288 | 1 022* | 2 286 | 8 337* | 773 | 5 492* |
| Systemic Cost | 2 196 | 3 581* | 9 778 | 23 464* | 3 492 | 14 857* |
| Incoming Funds | 0 | 0 | 2 788 | 8180 | 650 | 4 461 |
| Net Total Cost | 2 648 | 4 984* | 16 712 | 33 832* | 5 486 | 21 810* |

### 6.5.1 Direct Costs

The results indicate that the direct cost of morbidity more than double when someone has HIV/AIDS in the household (R381 versus R164 respectively – see Table 6.5). The higher cost in the affected cohort is due to more frequent visits to health care facilities as well as the purchase of medicines and vitamins[1] . The average cost for consultation in Soweto including medicines is R13 per public

[1] see Appendix Table 11, medical-self-treated costs

health care visit (see Section 3.5). Consultation fees (33%), medicines (48%) and transport/food incurred in connection with visits to health care facilities (15%) make up 96% of direct costs (see Appendix Table 11).

The actual cost of morbidity for deceased members (see Table 6.5) is slightly lower (R324) than the actual cost of morbidity for sick members (R381). This is because at the late stage of illness, the sick member is often hospitalised reducing consultation fees and medicine costs to the household. The cost of funeral is not related to the cause of death hence the average funeral cost was slightly but not significantly higher in the affected cohort (see Appendix Table 13). In the combined cost model, due to fewer funerals in the non-affected cohort, the average funeral cost was significantly higher (see Appendix Table 14). Households affected by HIV/AIDS spent almost 30.5 times more on funerals (cost of mortality, see Appendix Table 13) or 10 times more (combined cost of morbidity and mortality, see Appendix Table 14) than on direct health care expenses. This is because the major part of the health care costs is covered by the state. Studies in Thailand and Tanzania reported spending up to 50% more on funerals than on medical care (World Bank, 1999:209).

### 6.5.2 Indirect Costs

The indirect costs of morbidity for affected households were three and a half times greater than non-affected households. The indirect costs of morbidity for the affected cohort were almost three times greater than the direct cost of morbidity (see Table 6.5). This is because 20 out of 26 affects households lost income temporarily and nine households lost income permanently through loss of employment compared with one household in the non-affected cohort. The indirect costs would have been higher if the employment rate in Soweto was higher and if the study collected retrospective data of sick members and caregivers from date of illness.

Almost half of the deceased from the affected cohort lost employment and/or income from grants thereby losing income as a result of the death. The loss of caregiver income was only experienced by the affected cohort because members were ill for a lengthy period before death compared to members from the non-

affected cohort who was ill for less than a week prior to death. The proportion of direct costs of mortality in affected households is higher than the proportion of indirect costs due to the costs of funerals. This means that average funeral costs to households far surpass the loss of earnings as seen in Table 6.5 in the cost of mortality and the combined cost of morbidity and mortality columns.

In the combined cost model, approximately 70% of the indirect cost incurred by the affected cohort is due to permanent loss of income to the household either through sickness or through death of the ill member (see Appendix Table 14). This study shows that the financial burden from death is far greater than the financial burden of illness. The financial burden of mortality (direct plus indirect costs) for the affected cohort is almost 12.5 times greater than the financial burden of morbidity (see Appendix Tables 12 and 13).

### 6.5.3 Systemic Costs

An important finding is that the foregone earnings of the caregivers exceeded the foregone earnings of the sick person because in many cases the caregivers stated that they spent 24 hours per day on care-giving functions while the sick members cost was calculated on a working day cost. It can be argued that 24 hours per day care-giving is not possible since caregivers need to sleep and perform other daily functions. A revised set of estimates based on caregivers working an eight hour day (R36.10) (see Appendix Table 12) was carried out so as not to over-estimate systemic costs.

Adjusting the systemic costs, this arguably a more realistic time spent caring reduced the systemic costs (see Table 6.6) and thus the total costs of morbidity (see Appendix Tables 11 and 12). This adjustment resulted in the foregone loss of earnings for the sick member slightly exceeding the foregone loss of earnings for the caregiver (see Appendix Table 12).

**Table 6.6: Systemic Costs – Actual Hours of Caring Compared to Reduced Hours of Caring (see Appendix Tables 11 and 12) (8 months cost averaged over households)**

| | Non-Affected Households Mean (Rand) | Affected Households Mean (Rand) |
|---|---|---|
| Total Systemic Costs – actual hours of caring as stated by Respondents | 3259.79 | 5295.92 |
| Total Systemic Costs – reduced to per working day cost where hours of caring was stated as 24 | 2196.00 | 3580.89 |

Systemic costs for the affected cohort were three and a half times greater than indirect costs for morbidity and almost 3 times greater than indirect mortality costs and combined morbidity and mortality costs due to high unemployment (see Table 6.5).

The study found the indirect costs (including systemic costs) of morbidity to be almost 12 times more (see Table 6.5) than the direct costs for affected households compared to 20 times more as found in the Sri Lankan study (Jayasinghe, in UNAIDS, 1995).

Foregone earnings of caregivers during times of morbidity are almost one and a half times higher than the foregone earnings of caregivers during times of mortality (see Appendix Tables 12 and 13). This is because caregivers spend more time care-giving during periods of illness, while closer to death most sick members were hospitalised. Foregone earnings for the sick member were higher for mortality than for morbidity because of the length of time of sickness coupled with the income loss being permanent, that is, the loss incurred in wave one is carried into subsequent waves (see Appendix Tables 12 and 13).

Indirect costs for the affected cohort including systemic costs of morbidity represent 92% of the total economic cost (see Table 6.7) similar to that found in other studies such as that found in Tanzania (97%) and Zaire (94%), as quoted in McMurchy (1997). The proportion of indirect costs including systemic costs accounts for 76%

of the total economic costs of AIDS mortality for the affected cohort (see Table 6.7). The proportion of indirect and systemic costs in the combined cost model is equally high. Since indirect costs including systemic costs are higher than direct costs, this will have long-term negative impacts on consumption, investment, debt, borrowings and savings patterns for income-earning households affected by HIV/AIDS.

The proportion of direct costs of mortality in affected households is higher than the proportion of direct costs of morbidity due to the cost of funerals (see Table 6.7). The proportion of indirect cost to total mortality in the affected cohort is twice the proportion of the non-affected cohort because of the permanent loss of income experienced in the former (see Table 6.7).

**Table 6.7: Composition of Net Total Household Cost (Percentage)**

| | **Cost of Morbidity Rand** | | **Cost of Mortality Rand** | | **Combined Cost of Morbidity and Mortality Rand** | |
|---|---|---|---|---|---|---|
| | **Non-Affected n=25** | **Affected n=61** | **Non-Affected n=7** | **Affected n=36** | **Non-Affected n=30** | **Affected n=66** |
| Direct Cost including Funerals | 6.2 | 7.7 | 38.1 | 24.3 | 30.5 | 22.5 |
| Indirect Cost | 10.9 | 20.5 | 11.8 | 19.8 | 12.6 | 20.9 |
| Systemic Cost | 82.9 | 71.8 | 50.1 | 55.9 | 56.9 | 56.6 |
| Net Total Cost | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

### 6.5.4 Incoming Funds

To cover the cost of funerals, households rely on donations and on income from burial societies and insurances to cover funeral costs. Therefore, it is important to calculate the net effect of mortality on households. The affected cohort received almost three times more funds as a result of death than the non-affected cohort (see Table 6.5, cost of mortality). Incoming funds represent 20% of the total costs of mortality and 83% of the total cost of funerals in the affected cohort (see Appendix Table 13).

### 6.5.5 Net Total Cost

The net total cost of morbidity, mortality and the combined cost of morbidity and mortality for an eight-month period is significantly higher in the affected cohort (see Table 6.5). The total cost of mortality being 6.8 times the total net cost of morbidity. The total net cost of morbidity and the total net cost of mortality were almost double in households affected by HIV/AIDS and the combined cost of morbidity and mortality was more than four times that of non-affected households (see Table 6.5).

## 6.6 Funeral Costs

Figure 6.1 shows how households finance funeral costs. There are four major ways in which funeral costs are financed by affected households:

- Household income and savings (8%);
- Relatives and friends (27%);
- Non-governmental organisations (25%); or
- Burial societies (32%).

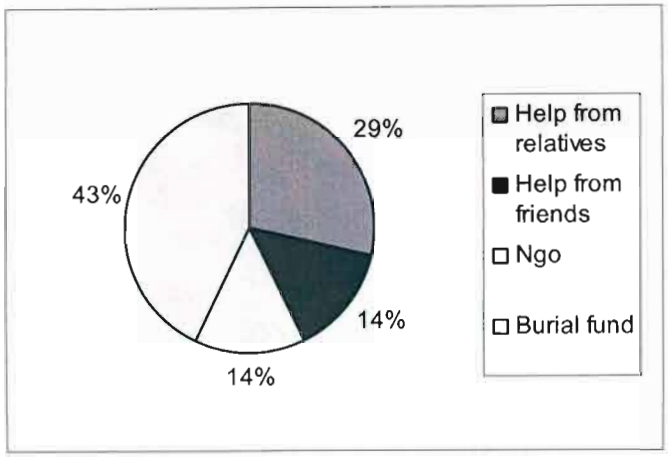
In the affected cohort, 46% of the cost of funerals is covered by burial societies, income, savings, and employers or from borrowings. The rest of the costs are covered by funds from relatives and non-relatives as well as institutions, mainly

from non-governmental organisations. In the non-affected cohort, 43% of the cost of funerals was covered by burial funds and the rest from relatives and non-relatives as well as non-governmental organisations.

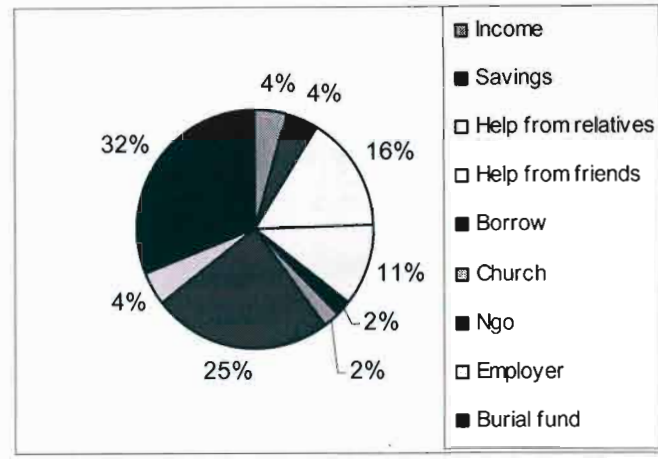
Approximately 46% of households in the affected cohort and 40% of households in the non-affected cohort contribute to a burial society. The average monthly investment in a burial society was R94 in the affected cohort and R82 in the non-affected cohort.

**Figure 6.1: Main Sources of Financing for Funeral Costs by Non-Affected Households and Affected Households**

**6.1a: Non-Affected Households**




**6.1b: Affected Households**




All households suffer the financial burden of the high cost of funerals. Both cohorts reported not having enough money to pay for basic services because of funeral costs. The average cost of a funeral was not different across cohorts. However, the cost of a funeral to a household in the affected cohort was just under R10 000 versus just under R7 500 in the non-affected cohort because some households in the affected cohort experienced more than one funeral. The cost of a funeral ranged from R700 to R22 000. When respondents were asked about the cost of funeral, most respondents supplied the cost of the funeral day itself and omitted the costs incurred prior to the funeral and post funeral. To fully understand the cost of funerals, it is important to understand the funeral process.

### 6.6.1 The Funeral Process

A person either dies at the hospital or outside a hospital. If the person dies at the hospital, the hospital stores the body in the government mortuary until the funeral day and issues a death certificate at no cost to the family. When a person dies outside a hospital, the funeral parlour stores the body and issues a death certificate, costs of which are borne by the family indirectly via the funeral parlour.

There are pre-funeral expenses such as visits to the funeral parlour to make arrangements for the funeral. There are costs associated with contacting relatives and non-relatives to advise them of the funeral. For the week leading up to the funeral, many relatives and non-relatives visit the family. In many cases, there are family members living in other provinces who arrive up to a week prior. There are transport and living costs associated with these visits. Often clothing is purchased for immediate family members who attend the funeral including clothing for the deceased.

For the day of the funeral there are costs such as the hire of the funeral parlour, hearse, coffin, buses, family car, funeral programmes, toilets, marquee, tables and chairs. There are also costs associated with preparation of the graveside. Food and sometimes alcohol is catered for approximately 500 to 1000 people on the day of the funeral.

Post-funeral costs entail cleansing ceremonies that have to be performed. The first cleansing ceremony entails a haircut for family members. This is followed by a bathing ceremony and a cleansing ceremony for children. This ceremony is usually performed by a traditional healer. The cost of the tombstone and food is required for the unveiling ceremony where guests are invited to attend. Finally, there is a one year ceremony that is performed.

So what does a funeral actually cost? Table 6.8 itemises a typical cost of the process described above with average costs applied for a total of 500 people attending the funeral of a person who died at home. These costs were obtained from

in-depth interviews with two households that had experienced a recent death and from three funeral parlours/burial society.

**Table 6.8: Breakdown of Funeral Cost to a Household (Case Study)**

| Item | Absolute value (Rand) | Sub Total (Rand) | Proportion (%) |
|---|---|---|---|
| **Pre Funeral:** | | | |
| Storage of body at mortuary - 1 week at R50 per day, including issue of death certificate | 350 | | |
| Informing relatives and non-relatives of funeral (50 calls @R4.00) | 200 | | |
| Visits to the funeral parlour to finalise arrangements (transport costs) | 90 | | |
| Cost of 7 days tea and snacks for visitors to the family (average no of visitors 300 x R5 ) | 1 500 | | |
| Purchase of outfit for the deceased | 400 | | |
| Purchase of outfits for relatives and children (immediate family) | 800 | | |
| Cost of meals - close family who travelled from afar 14 days - 3 meals a day | 500 | | |
| Cost of night vigil – night before (meal cost) | 500 | | |
| Newspaper Announcement | 300 | **4 640** | **14.4** |
| **Day of the funeral:** | | | |
| Wreath (3 X R150) | 450 | | |
| Hired toilet | 150 | | |
| Hired tables, chairs, tent | 700 | | |
| Coffin (range from R750 to R6500) | 750 | | |
| Buses | 1 000 | | |
| Hearse and family car | 1 500 | | |
| Food for approx 500 people | 5 000 | | |
| Funeral programs | 500 | | |
| Preparation of the graveside | 500 | | |
| Transport cost to bring immediate family to the funeral | 1 000 | **11 550** | **35.8** |
| **Post Funeral:** | | | |
| First cleansing ceremony - haircut for family members –hair shaved at home | 0 | | |
| Bathing ceremony (4-6 months later approx 100 people) | 500 | | |
| Cleansing ceremony for children (6-8 months later herb cost and food for approx 100 people) | 1 500 | | |
| Tombstone cost ranging from R2500 to R8000 | 4 000 | | |
| Tombstone unveiling ceremony (including food approx 500 people) | 5 000 | | |
| One year ceremony (how many invited to this function - approx 500 people including food) | 5 000 | **16 000** | **49.7** |
| **Total Cost** | **31 690** | **31 690** | **100.0** |

The pre-funeral costs represent 14% of the total cost of the funeral, while the actual funeral costs for the day of the funeral represented 36%, with post-funeral costs representing the majority of the total funeral costs. Most studies that asked for funeral costs would miss out on the total funeral cost unless costs are broken down. In this study, only 36% of the cost of funerals was recorded as funeral costs.

The cost breakdown in Table 6.8 represents direct costs of funerals to a household. Indirect costs of funerals includes loss of time and loss of income in some cases for attending the funerals and travel costs for guests. These are not considered in this study.

Case study 6.1 documents the progression of HIV to AIDS describing the period of morbidity and mortality and the funeral process.

**Case Study 6.1: Two Sisters Lost to the HIV/AIDS Epidemic**

Mavis and Letty Ndlovu were the daughters of the late Maria Ndlovu. Letty was the younger sister, aged 30 and Mavis the older sister aged 35. The younger sister did not know that she was HIV positive. She started to show signs of AIDS when she lost weight, coughed badly and had a bad appetite. She went to the Orlando clinic for the HIV test which came back positive. By that time it was full-blown AIDS. She was weak and scared but she went for the treatment. However, there was no change because it was already too late. She was terminally sick and told me that she was diagnosed with AIDS. By that time you could see that she was suffering. She did not know from whom or when she might have contacted the disease.

The next day I heard that the older sister Mavis was admitted to Helen Joseph Hospital and that she was terminally ill, suffering from the same disease. The following day, the younger sister was also admitted at the same hospital and they were in the same ward. I went to visit them. The younger sister felt better and was released from hospital on Friday 13 June 2003. The next day which was Saturday 14 June, the younger sister passed away in the early hours of the morning at home and Kago Funeral Undertakers stored the body at their mortuary. The family started

making funeral arrangements and on Monday 16 June, the family went to tell the older sister that her younger sister had passed away.

That same evening, the hospital called to notify the family that the older sister had passed away. The family was poor and it was bad enough having to plan for one funeral. The community and the church donated funds for the burials. Luckily, the money was enough and the two sisters were buried the next Saturday, 21 June 2003.

On the Friday afternoon prior to the funeral, Kago Funeral Undertakers brought the corpses home for the family and the community to pay their last respects. They did not slaughter anything because the money was not enough for a cow and two sheep, and because they were members of the Zulu Congregation Church (ZCC). We were informed that there would be a night vigil around 10pm. I went to the night vigil and it was a cold evening. Two tents were hired and we gathered inside. The priest started with the prayer and opened with a verse from the Bible. He started to preach the word of the Gospel and warned people about this AIDS epidemic. Other people stepped forward and spoke about how they enjoyed the company of these two sisters and they said they were intelligent at school and cared about other people. It was a sad evening. People were crying, others were standing outside, drinking liquor, making noise and gossiping. They were saying that Mavis's behaviour was bad, she was a prostitute and she would do anything for money because she was poor. You could see that some of guests treat funerals as a meeting place because some young girls and boys were fooling around with each other while we were still singing.

We sang the whole night till the early hours of the morning. The funeral was held at the church the next day. I went to the church and we sang. More people delivered their speeches. The priest kept on preaching the words of the gospel, warning the youth about this AIDS epidemic, telling them to abstain. There was a reading of Rites and the cortege left for the cemetery. At the cemetery, the priest was in charge. He prayed and asked for the coffins to be released down into the holes, and because the sisters were Zulu by tradition, nothing was slaughtered for them. Their coffins had to be covered with blankets. For Zulus, that is the way to show respect. The members of the family were asked to pour the soul inside the graves. Men

helped to seal the graves. One member of the family delivered a vote of thanks to the people and asked the people to return to the family home to partake in the meal that was provided. The priest closed with a prayer and we headed to the buses which took us to the funeral home where we ate and drank.

Unedited story submitted by fieldworker (names have been changed).

### 6.6.2 Changes in Funeral Practices

Approximately 60% of households that experienced death felt that funeral practices have changed for the worse in the sense that funerals have become more extravagant following the Catholic practice of hosting a "wake", a celebration to send off the deceased. For this ceremony, alcohol and food is purchased at high cost. Respondents felt that funerals have become another celebration, an excuse for a party. "People dress up as though they are attending a wedding; new clothes are purchased for the event and women dress their hair in fancy styles". Music is played at the graveyard and at the "wake".

Respondents stated that funerals in the past were attended by family and friends. Today funerals are attended even by those that are unknown to the family. Funerals tend to reflect the wealth of the family and the more they earn the more is spent on the funeral. Some households use the funeral service organisations to act as events organisers.

Households that experienced recent death stated that they felt mourners expected a three course meal whereas previously they brought food to the funeral. In the past mourners would assist with the cooking at the deceased's home but today they expect to be catered for.

## 6.7 Net Impact of the Cost of HIV/AIDS Morbidity and Mortality on Households

Approximately 17% of the total cost of morbidity and mortality is covered by incoming funds in the affected cohort compared to 11% in the non-affected cohort (see Appendix Table 14).

The total net cost of morbidity and mortality for eight months (R21 810 for the affected cohort and R5 486 for the non-affected cohort, see Table 6.5) represents 62% of the annual income of affected households compared to 16% in non-affected households (for annual income[2], see Table 6.9). If household income is not replaced, this has serious long-term implications for the survival of the household. Over time households replace income either by sending members out to work, getting new members to join the household, diversifying income, or by doing nothing. The household survival mechanisms are discussed in detail in chapter 11.

The short-term impact on the household arises from the direct cost (out-of-pocket expenses) of morbidity and mortality. Affected households receive 75% (see Appendix Table 14 or Table 6.5) of the direct costs of morbidity and mortality in incoming funds as a result of death which results in the net direct cost being only slightly higher than the non-affected cohort. For the affected cohort the direct cost of morbidity and mortality is 16.8% of annual income reducing to 14.8% after income from death is taken into account (see Table 6.9). If the affected cohort relied on savings alone, it would take 25.3 months to clear the direct cost of morbidity and mortality. However, with the help from social networks, this is reduced to 6.2 months (see Table 6.9).

Almost all households were in debt for their services (electricity and water). When average monthly debt is added to the eight month direct morbidity and mortality cost, and the average monthly savings is added to the average repayment of debt, then the affected cohort would take 43 months to clear their total debt including

[2] Annual household income excluding income as a result of death was used to calculate the percentage of morbidity and mortality cost to annual income.

direct morbidity and mortality costs or 33 months to clear debt plus net direct morbidity and mortality cost (see Table 6.9).

**Table 6.9: Cost Impact of Direct Costs of Morbidity and Mortality on Households**

| | Non-Affected Households | Affected Households |
|---|---|---|
| Direct Cost of morbidity and mortality (8-month period – see Table 6.5) | R1 872 | R5 922 |
| Net Direct cost of morbidity and mortality (incoming funds accounted for – see Table 6.5) | R1 222 | R1 461 |
| Annual household income including income as a result of death (see Table 7.13) | R34 202 | R39 934 |
| Annual household income excluding income as a result of death (see Table 7.13) | R33 827 | R35 247 |
| Direct cost as a percentage of annual income including income as a result of death | 5.5% | 14.8% |
| Direct cost as a percentage of annual income excluding income as a result of death | 5.5% | 16.8% |
| Number of months savings[3] to clear direct cost of morbidity and mortality | 10.6 | 25.3 |
| Number of months savings to clear net direct cost of morbidity and mortality | 5.9 | 6.2 |
| Outstanding debt[4] plus direct cost of morbidity and mortality | R10 409 | R19 664 |
| Number of months required to clear outstanding debt plus direct costs of morbidity and mortality taking into account savings and repayment of debt (see Tables 11.2 and 11.5) | 25.9 | 43 |
| Number of months required to clear debt plus net direct costs of morbidity and mortality | 24.3 | 33.2 |

[3] Savings = (non-affected household R177.09 per month, affected household R233.90 per month)
[4] see Table 11.4 for value of outstanding debt

## 6.8 Methodological Issues Relating to the Cost Models

Following a similar process of documenting the cost of funerals, two in-depth interviews were held with households that had experienced illness. These case studies revealed that costs of telephone, food, travel and clothing related to the sick individual were not fully captured during the study-interviews because they have been incurred by household members outside of the household budget as well as by non-household members. The true cost of morbidity should include the costs incurred by other household members although they were not from the pooled household budget; that cost would have been incurred had it not been for the non-members' contribution. If the cost would have been incurred, then the cost should be reflected as a transfer in to offset expenditure. It is therefore important to collect all costs relating to morbidity and then to establish who paid for what cost.

In the first case study (see Table 6.10), only 20% of total direct costs were captured, 64% of these were incurred by other household members and were not captured and 16% of the costs were incurred by members outside the household and were not captured.

**Table 6.10: Case Study 1- Direct Household Cost of Morbidity (8 months actual cost)**

| Cost Category | Captured | Not Captured Incurred by Household Members | Not Captured Incurred by Non-household Members | |
|---|---|---|---|---|
| | **Actual (Rand)** | **Actual (Rand)** | **Actual (Rand)** | **Total (Rand)** |
| Consultation | 26 | 0 | 0 | 26 |
| Medicine/drugs | 300 | 300 | 0 | 600 |
| Hospitalisation | 26 | 0 | 0 | 26 |
| Transport/Food | 62 | 1039 | 346 | 1 447 |
| Telephone | | 15 | | 15 |
| Total Direct Costs | 414 | 1 354 | 346 | 2 114 |
| | | | | |
| Proportion of Actual Costs (Percentage) | 20 | 64 | 16 | 100 |

In case study 2 (see Table 6.11), only 18% of the direct costs were captured; 69% of total costs were incurred by other household members not recorded in the diary because it was for items such as food taken to hospital, travel cost of other household members who visited the sick person in hospital and incurred telephone and clothing costs that directly related to the illness. Approximately 13% of the costs were incurred by close family members who lived elsewhere and this should have been recorded as a remittance in.

**Table 6.11: Case Study 2- Direct Household Cost of Morbidity (8 months actual cost)**

| Cost Category | Captured | Not Captured Incurred by Household Members | Not Captured Incurred by Non-household Members | |
|---|---|---|---|---|
| | Actual (Rand) | Actual (Rand) | Actual (Rand) | Total (Rand) |
| Consultation | 0 | 0 | 0 | 0 |
| Medicine/drugs | 0 | 0 | 376 | 376 |
| Disposable nappies | 450 | 0 | 0 | 450 |
| Transport/Food | 50 | 958 | 0 | 1 008 |
| Telephone | 0 | 480 | 0 | 480 |
| Clothing | 0 | 539 | 0 | 539 |
| Total Direct Costs | 500 | 1 977 | 376 | 2 853 |
| | | | | |
| Proportion of Actual Costs (Percentage) | 18 | 69 | 13 | 100 |

If case study 1 and 2 (see Table 6.10 and 6.11) reflects the situation in all households, then direct costs may be under-estimated by five times. This would mean that direct costs would comprise 28%, indirect costs 20% and systemic costs 52% of total costs.

Non-affected households share the burden of funeral costs for members of other households. Therefore, questions regarding funerals should be asked of all households whether or not someone died from the household. Typically, when a male spouse dies, the female spouse moves back to her family home. This study did not capture the cost of mortality of the previous household of the surviving spouse

that incurred the cost because that household was not part of the sampled household, yet the impact from the death was felt in the survey household. Retrospective data is therefore necessary. When a spouse died or when both spouses died, children were sent to live elsewhere. It was difficult to follow both households as in many cases one part of the household moved into another region or city. Depending on the research funds available, studies of this nature should follow all households that split all of the time.

It was important to collect the same information for sick individuals who are still living as well as for individuals who have died. Having two separate sections in the survey instrument for morbidity and mortality confused the fieldworkers because if the person was deceased they tended to complete the mortality section only and therefore some data on the illness itself was omitted.

For funeral costs, only the cost of the actual funeral day was submitted and this does not cover all the costs associated with the funeral. For morbidity costs, it was found that costs incurred by other household members from outside the pooled budget were omitted as well as costs paid by non-household members. Therefore the full cost of morbidity and mortality is under-estimated.

The direct, indirect and systemic costs for the deceased member and the caregiver were only calculated for two months prior to death. An HIV/AIDS infected person can be chronically sick for up to 12 months prior to death (Steinberg et al., 2002). Usually, income was lost by the sick member or the caregiver much before the first interview which was not captured because retrospective data was not collected. The full cost of morbidity and mortality is therefore under-estimated.

### 6.9 Summary

This study focused on documenting the economic cost of HIV/AIDS to households. The nature of the disease is such that individuals get ill and then recover depending on the nature of opportunistic illness, the phase of the disease and the treatment received. Half of all ill individuals in the AIDS-symptomatic phase got ill at least once during the observed period. When individuals are in the AIDS-symptomatic

phase, they are confined to bed and require home-based care for up to 16 hours per day. Caregivers were mainly unemployed females who gave up their leisure time or domestic chores to care for ill individuals. The indirect costs are expected to be lower when caregivers are unemployed.

The total economic cost of morbidity for affected households is almost double the cost for non-affected households similar to the findings in the Cote d'Ivoire study (Bollinger and Stover, 1999:2). The direct costs are significantly higher in affected households and comprise mainly medicines and consultations. The New Zealand study found that transport costs accounted for a third of the direct costs. In this study, it accounted for 15% of the direct cost because the cost of medicines is high and the distance to health care facilities low. The Free State study found that non-affected households spent 77% of the levels of direct costs of affected households while this study found that non-affected households spent 43% of the levels of affected households. This is because a relatively large number of individuals in the Free State study were not able to report the cost of medical care or transport fee to seek treatment (Booysen et al., 2002:110). Indirect and systemic costs of morbidity for the affected cohort accounted for 92% of the total net economic costs which was similar to that found in Tanzania, Zaire and Lesotho (McMurchy, 1997:11-12). Even when adjusting the hours spent caring to a per day cost, indirect costs including systemic costs were 12 times higher than the direct costs of morbidity in affected households.

The total economic cost of mortality for affected households was also double the cost for non-affected households. The study found that households spent 30 times more on funerals than on health care. Studies in Thailand and Tanzania also found the cost of funerals to be significantly higher than health care costs. In terms of indirect costs, only the affected cohort experienced loss of caregiver income since members were sick for a longer period prior to death. Indirect costs of mortality were significantly higher in households affected by HIV/AIDS due to the permanent loss of income as found in other studies. This study took into account foregone earnings of the sick member and the caregiver and found systemic costs to comprise the majority of total costs.

This study confirms the findings of other studies that households spend more on funerals than on health care. Comparing the cost of mortality to the cost of morbidity for the affected cohort, the study found that the net total cost of mortality was 6.8 times the net total cost of morbidity. The direct cost of mortality far exceeds the direct cost of morbidity because of the cost of funerals. Without the cost of funerals, the direct cost of health care for deceased members were similar to the direct cost of health care for members sick only.

In households affected by mortality, the affected cohort received three times more funds to cover the cost of funerals than the non-affected cohort. Most of the funds received were from burial societies, non-governmental organisations and from relatives and friends. Affected households were still worse off although 80% of the cost of funerals were covered by incoming funds.

Methodologically, the study found it is better to document the process of illness and the process of funerals to determine the full composition of costs and then to determine who pays for what cost so the full impact of funerals and illness can be established. Most studies that ask for the cost of funeral are given the cost that relate to the actual day of the funeral and not the pre-funeral and post-funeral costs. In terms of direct health care costs, respondents often forget funds not spent from the joint household budget and by members of other households. It is also important to request some data, especially that on income loss, retrospectively to assess the true impact.

Households found funeral practices changing for the worse in that mourners are expected to be catered for as opposed to bringing food and gifts in the past. Other studies conducted elsewhere in Africa have found the mourning period reducing (Rugalema, 1999). This study found that most funerals were held during week-ends, thus reducing the time taken off work.

This study investigated the combined cost of morbidity and mortality and found the direct, indirect, systemic, total costs as well as net impact costs to be significantly higher in the affected cohort. The combined net cost of morbidity and mortality was more than four times higher than the combined net cost incurred in non-

affected households compared to less than two times higher if the cost of morbidity alone was considered.

The combined cost of morbidity and mortality represents a high proportion of annual income in the affected cohort and if household income is not replaced, these households will face dissolution in the short-term. The affected cohort could never rely on household income or household savings to cover the costs of morbidity and mortality. They rely on the help from their social networks. However, this help brings short-term financial relief. If income is not replaced, coupled with high debt that already exists, these households will find it very difficult to return to a positive financial position.

# CHAPTER SEVEN
# CHANGING PATTERNS OF INCOME FOR HIV/AIDS AFFECTED HOUSEHOLDS

## 7.1 Introduction

Not all income-earners contributed to joint household income (see Section 4.11). Only income contributed by members to form the joint household budget - is considered in this study since household expenses were paid from this pool of household income.

There are two types of household income considered in this study, regular and irregular income. Regular income enters the household on a routinely or monthly basis and is analysed as monthly income. Regular income is the income that the household budget is based on. Irregular income is unplanned and occurs on a once-off, ad-hoc, irregular basis. Examples of irregular incomes are those associated with death such as payments from insurance/burial societies or donations from relatives and non-relatives.

Annual income is calculated by multiplying the monthly average income of the four waves by 12, plus the irregular income. In this study net monthly household income and net annual household income is analysed, where net income represents gross income less deductions from employer for pay-as-you-earn (PAYE), trade union, medical aid, pension and unemployment insurance fund (UIF).

All income data has been adjusted for inflation using the latest average CPI (consumer price index) estimates for each quarter of data collection. All values have been adjusted to wave 1 values (data were collected in the last quarter of 2002). Per capita calculations are based on household size. Estimates of household income have been adjusted for differences in household size by dividing total monthly income by $n^{\alpha}$, where n represents the number of household members and $\alpha$ an adjustment for household economies of scale (Filmer and Pritchett, 1998: 13).

According to Lanjouw and Ravallion (1995), a $\alpha$ coefficient of 0.6 represents an adequately robust and reliable adjustment for household economies of scale.

Household income depends on the supply of labour in terms of quantity and quality. Quantity refers to the number of individuals employed and quality refers to the skill level of the jobs that individuals occupy. A discussion of the supply of household labour will therefore precede the discussion on household income.

This chapter investigates whether affected households earn less across cohorts and whether or not they continue to earn less over time. Furthermore, the study investigates the role of government grants in bridging the gap between earned income and total household income and investigates whether household income is affected by the dynamics of household size and composition.

Since not all households have individuals that are sick or experience death in each wave, the study investigates income changes over time for households affected by sickness and death in wave one to understand the impact of sickness and death over time.

### 7.2 Supply of Labour

To define whether an individual is employed or not is not always straightforward. Some individuals generated income but did not necessarily define themselves as employed (for example, individuals that were retired, disabled or housewives). On the other hand there were 28 individuals (12 from the affected cohort and 16 from the non-affected cohort) who did not generate income the month prior but defined themselves as employed. These individuals were not looking for employment because, as far as they were concerned, they were engaged in productive activities which would result in income at some point.

To determine whether an individual was employed or not it was necessary to first establish the primary occupation of all individuals. The following options were given:

- too young to attend school,
- at school,
- worked for wages or profit,
- unemployed but looking for a job,
- unemployed but not looking for a job,
- retired, disabled, housewife or did not need to work.

The second step was to establish all individuals who were engaged in income-generation activities. This offered the researcher the opportunity to collect income data including income for those activities that did not generate an income in the data collection period but who were otherwise engaged in that occupation. It was therefore necessary to redefine employment in this study (see Section 1.2.3).

The data revealed 12 individuals who classified themselves either as disabled (5) or retired (7) but were engaged in income-generation activities to supplement household income. All but one of these individuals (11) came from the affected cohort. Those who classified themselves "disabled" worked in unskilled jobs such as cleaners, volunteer counsellors, merchandisers or car guards. Those who classified themselves retired were selling items from home, hawking, performing domestic work or traditional healing. With the exception of one male, all were female.

### 7.2.1 Labour Participation of the Employed by Skills Level

The data reveals that on average across all waves, the affected cohort have more members participating in semi-and unskilled occupations and less in professional or skilled occupations compared to the non-affected cohort (see Table 7.2).

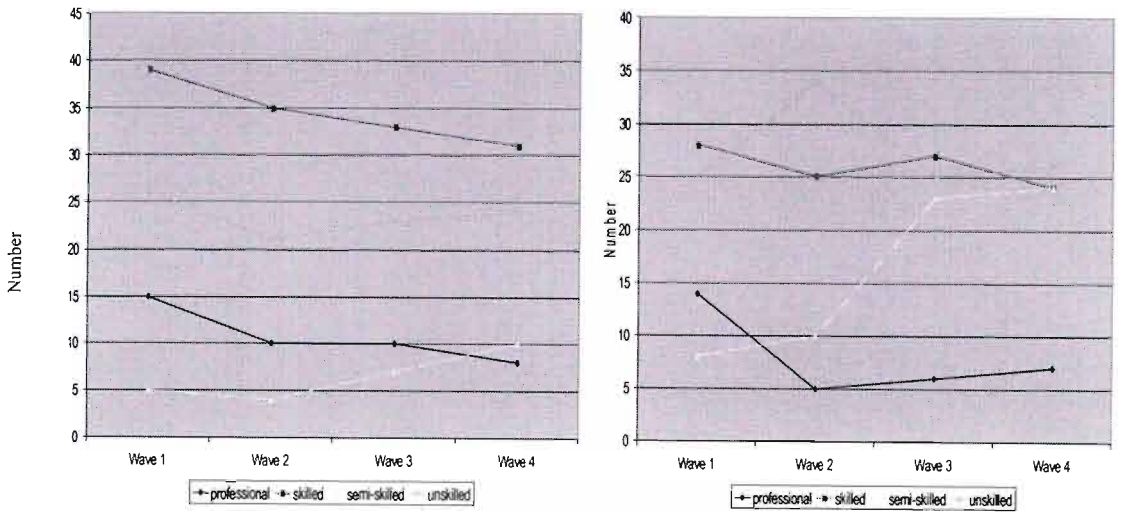
The evidence shows a steady decline in the number of individuals employed in skilled or professional jobs during the study. Whilst the labour market contributes to this decline (see Figure 7.1 – non-affected cohort), HIV/AIDS also plays a role. There were more people sick in wave one than any other wave and this contributed to a decline in professional and skilled jobs over time and an increase in individuals

taking up semi-skilled and unskilled positions. For example, the study found those in professional positions such as nursing or teaching taking up positions such as merchandising, security guards, or hawking after illness.

Whilst there was a greater supply of labour in the semi- and unskilled categories, there was also a greater demand for labour in these skilled categories. It was therefore easier for individuals to be placed as merchandisers or in domestic work than in professional work. In some instances, the study found young professionals at home unemployed while the grandmother or other members went to work as domestic workers.

**Figure 7.1: Skill Level of the Individuals Employed Over Time**

**Non-Affected Cohort** **Affected Cohort**




### 7.2.2 Type of Employment

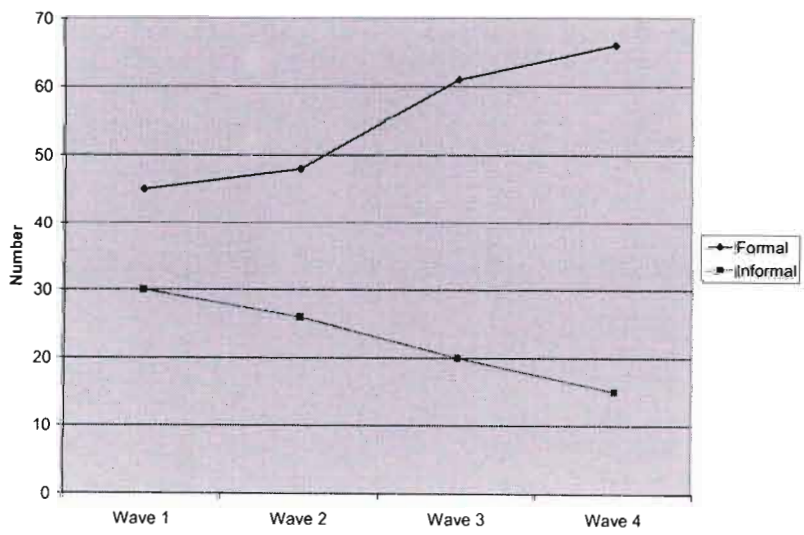
Approximately 60% of employed individuals from the affected cohort held full-time jobs, with a lesser proportion holding part-time or casual work (see Table 7.1). Due to the frequency of illness, infected individuals find it difficult to keep their full-time jobs and opt for part-time or casual work. Over time, as other non-ill individuals in the household took up employment, the proportion of individuals working full-time increased by 14% in the affected cohort.

**Table 7.1: Type of Employment (All Waves) (Percentage)**

| | All Households | Non-Affected Households | Affected Households |
|---|---|---|---|
| Full-time | 66.0 | 72.4 | 59.8 |
| Part-time | 24.5 | 21.3 | 27.7 |
| Casual | 9.5 | 6.3 | 12.5 |
| Total | 100.0 | 100.0 | 100.0 |

It was interesting to note that some of the part-time positions held by individuals were in the formal sector, especially those from the affected cohort. The majority of all employed individuals were in the formal sector (73% from the non-affected cohort and 71% from the affected cohort). While it was expected that the number of people employed in the formal sector in the affected cohort would decline (Barnett et al., 2000:1395), this study found the opposite. There are two possible explanations for this. First, other members of the household may have joined the labour force. Second, the "formalisation" of domestic work may have resulted in an increase in formal sector employment.

**Figure 7.2: Formal versus Informal Sector Employment Over Time – Individuals from the Affected Cohort**



### 7.2.3 Employment and Unemployment

There were fewer individuals employed in the non-affected cohort over time. In wave 1, there were 85 individuals employed but by wave 2, the number had fallen to 73 (see Table 7.2). By wave 4 there were only 14% fewer individuals employed, in part due to three income-earning individuals joining the households (see Table 7.2).

Despite labour market conditions, some non-economically active members (that is retired and "disabled" members) joined the labour force resulting in an 8% increase in the number of individuals employed from baseline in the affected cohort.

The average age of the employed was higher in the affected cohort due to retired members joining the labour force (38 years versus 36 years in the non-affected cohort p=0.0659). It was easier for older members to enter the labour force due to their years of experience. However, if this study were to be followed over a longer period of time, it might find that younger individuals are forced to enter the labour force. The average years of education for the employed were similar across cohorts for the employed as well as the unemployed (10 years [standard eight] for the employed and 9.6 years for the unemployed). It is interesting to note that the average years of education was not a major factor in determining whether or not individuals were employed.

## Table 7.2: Labour Supply[1]

| | | Non-Affected Households | | | | Total | Affected Households | | | | Total | % Differerence |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Unit | Wave 1 | Wave 2 | Wave 3 | Wave 4 | All Waves | Wave 1 | Wave 2 | Wave 3 | Wave 4 | All Waves | Between Means |
| Total All Individuals | number | 331 | 329 | 320 | 305 | 1285 | 429 | 437 | 395 | 379 | 1640 | 21.6 |
| Economically Active[1] | number | 167 | 150 | 146 | 142 | 605 | 170 | 152 | 140 | 139 | 601 | -0.7 |
| Not Economically Active | number | 164 | 179 | 174 | 163 | 680 | 259 | 285 | 255 | 240 | 1039 | 34.6 |
| Dependants (<15 & >65) | number | 117 | 142 | 141 | 132 | 532 | 165 | 192 | 172 | 162 | 691 | 23.0 |
| Dependency Ratio[2] | | 0.55 | 0.76 | 0.79 | 0.76 | 0.71 | 0.63 | 0.78 | 0.77 | 0.75 | 0.73 | 3.0 |
| Dependency Ratio[3] | | 0.98 | 1.19 | 1.19 | 1.15 | 1.12 | 1.52 | 1.88 | 1.82 | 1.73 | 1.73 | 35.0 |
| Dependency Ratio[4] | | 1.38 | 2.03 | 1.93 | 1.81 | 1.77 | 2.20 | 2.59 | 2.12 | 2.00 | 2.22 | 20.5 |
| Employed[5] | number | 85 | 70 | 73 | 73 | 301 | 75 | 74 | 81 | 81 | 311 | 3.2 |
| Unemployed[6] | number | 82 | 80 | 73 | 69 | 304 | 95 | 78 | 60 | 58 | 291 | -4.5 |
| % Employed | % | 0.51 | 0.47 | 0.50 | 0.51 | 0.50 | 0.44 | 0.49 | 0.58 | 0.58 | 0.52 | 3.9 |
| % Unemployed | % | 0.49 | 0.53 | 0.50 | 0.49 | 0.50 | 0.56 | 0.51 | 0.43 | 0.42 | 0.48 | -3.8 |
| Income generation individuals | | 101 | 84 | 86 | 87 | 358 | 124 | 126 | 129 | 134 | 513 | 30.2 |
| Dependency Ratio (income generation) | | 2.28 | 2.92 | 2.72 | 2.51 | 2.59 | 2.46 | 2.47 | 2.06 | 1.83 | 2.20 | -17.9 |
| | | | | | | | | | | | | |
| Proportion of Females employed | % | 55.0 | 56.0 | 53.0 | 60.0 | 56.0 | 64.0 | 70.0 | 67.0 | 63.0 | 66.0 | 15.2 |
| Proportion of Males employed | % | 45.0 | 44.0 | 47.0 | 40.0 | 44.0 | 36.0 | 30.0 | 32.0 | 37.0 | 34.0 | -29.4 |
| Average years of learning employed | number | 9.73 | 9.64 | 9.64 | 9.45 | 9.62 | 9.60 | 9.05 | 9.28 | 9.53 | 9.37 | -2.7 |
| Average years of learning unemployed | number | 10.13 | 9.68 | 10.36 | 10.22 | 10.09 | 9.29 | 9.71 | 9.48 | 9.43 | 9.47 | -6.5 |
| Skill Category of the employed: | | | | | | | | | | | | |
| professional | number | 15 | 10 | 10 | 8 | 43 | 14 | 5 | 6 | 7 | 32 | -34.4 |
| skilled | number | 39 | 35 | 33 | 31 | 138 | 28 | 25 | 27 | 24 | 104 | -32.7 |
| semi-skilled | number | 5 | 4 | 7 | 10 | 26 | 8 | 10 | 23 | 24 | 65 | 60.0 |
| unskilled | number | 26 | 21 | 23 | 24 | 94 | 25 | 34 | 25 | 26 | 110 | 14.5 |
| Total | number | 85 | 70 | 73 | 73 | 301 | 75 | 74 | 81 | 81 | 311 | 3.2 |
| | | | | | | | | | | | | |
| % Skill Category of the employed: | | | | | | | | | | | | |
| professional | % | 17.6 | 14.3 | 13.7 | 11.0 | 14.3 | 18.7 | 6.8 | 7.4 | 8.6 | 10.3 | -38.8 |
| skilled | % | 45.9 | 50.0 | 45.2 | 42.5 | 45.8 | 37.3 | 33.8 | 33.3 | 29.6 | 33.4 | -37.1 |
| semi-skilled | % | 5.9 | 5.7 | 9.6 | 13.7 | 8.6 | 10.7 | 13.5 | 28.4 | 29.6 | 20.9 | 58.7 |
| unskilled | % | 30.6 | 30.0 | 31.5 | 32.9 | 31.2 | 33.3 | 45.9 | 30.9 | 32.1 | 35.4 | 11.7 |
| Total | % | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | |

Unemployment occurs at all skill levels but there were more skilled and unskilled jobs lost by wave 4 (see Table 7.3).

**Table 7.3: Employed in Wave 1 but Unemployed in Wave 4 (aged 15 to 65 All Households)**

| | Number | Percent |
|---|---|---|
| Professional | 1 | 5.9 |
| Skilled | 4 | 23.5 |
| Semi-skilled | 1 | 5.9 |
| Unskilled | 11 | 64.7 |
| Total | 17 | 100.0 |

On the other hand, jobs were found at all skill levels (see Table 7.4) replacing lost jobs (see Table 7.3) with even more members entering the labour market by wave 4.

[1] Persons employed or unemployed. [2] The number of dependants over the productive age group. [3] Proportion of non-economically active over the economically active. [4] Proportion of dependants over the employed. [5] Employed are those aged 15 plus not at school and who have worked in the last 7 days. [6] Unemployed are those 15 plus not at school, who classified themselves as unemployed and looking or not looking for work.

**Table 7.4: Unemployed in Wave 1 but Employed in Wave 4 (aged 15 to 65 All Households)**

| | Number | Percent |
|---|---|---|
| Professional | 2 | 5.6 |
| Skilled | 10 | 27.8 |
| Semi-skilled | 13 | 36.1 |
| Unskilled | 11 | 30.5 |
| Total | 36 | 100.0 |

### 7.3 HIV/AIDS and the Labour Market

The presence of illness forces individuals to leave the labour market and become classified as "disabled" or "unemployed". Individuals classify themselves as disabled when they receive the state disability grant or can no longer work. They classify themselves as unemployed when they are still looking for work. HIV/AIDS forces individuals to accept jobs at semi-and unskilled levels even when they were previously employed in skilled positions, thereby causing job mobility at skill level.

The progressive nature of the illness from HIV to AIDS forces individuals into disability. The number of individuals in affected households that became "disabled" progressively increased, being reduced by the number of deaths.

**Table 7.5: Number of Individuals who classified themselves as Disabled by Wave**

| | Wave 1 | Wave 2 | Wave 3 | Wave 4 | Total |
|---|---|---|---|---|---|
| All Households | 38 | 45 | 42 | 43 | 168 |
| Non-Affected Households | 7 | 7 | 6 | 6 | 26 |
| Affected Households | 31 | 38 | 36 | 37 | 142 |

Of those who were disabled from the affected cohort in wave 1 (n=31), 29% were employed prior to wave 1. The majority worked in a variety of formal industries.

Although this study did not focus on collecting data retrospectively, during the second visit individuals were asked in which industries and in what occupations they were previously employed. The data shows that the majority (77%) of individuals previously employed (n=31) became unemployed in the past three years, the majority (84%) being from the affected cohort. Just over a third of all individuals previously employed were skilled or professional workers (see Table 7.6). Of those individuals from the affected cohort who were previously employed (26), 35% were already collecting the state disability. The fact that affected households lose employment income prior to baseline indicates that collecting retrospective data in HIV/AIDS household surveys is important.

**Table 7.6: Skill Level of Previously Employed Individuals Prior to Wave 1**

| | Number of Individuals | Percent |
|---|---|---|
| Professional | 2 | 6.4 |
| Skilled | 9 | 29.0 |
| Semi-skilled | 7 | 22.6 |
| Unskilled | 13 | 42.0 |
| Total | 31 | 100.0 |

### 7.3.1 Job Mobility

During the one year period of the study, two-thirds (65.6%) of all adult individuals remained employed for the entire period in the same skill category. The study found individuals from both cohorts downgrading their occupations see Table 7.7), which could be the result of labour demand or supply factors; the latter would include infected individuals who were struggling to maintain some type of employment. The study also found some upward mobility of members from being unskilled in wave 1 to holding semi- or skilled jobs after wave 1 or moving from unskilled to skilled jobs or from semi-skilled to skilled jobs (see Table 7.8). Some individuals who were HIV-positive, moved from unskilled to skilled positions by taking on jobs that included HIV education and training or voluntary counselling.

**Table 7.7: Movement of Individuals previously Employed in Professional Occupations in Wave 1 to Skilled, Semi-Skilled or Unskilled Categories in Subsequent Waves**

| Number of Individuals | Skilled | Semi-Skilled | Unskilled | Total |
|---|---|---|---|---|
| Non-Affected Households | 4 | 1 | 0 | 5 |
| Affected Households | 6 | 0 | 3 | 9 |
| Total | 10 | 1 | 3 | 14 |

**Table 7.8: Upward Mobility of Skills in Individuals from Wave 1**

| Number of Individuals | From Unskilled to Semi-Skilled Categories | From Unskilled to Skilled Categories | From Semi-Skilled to Skilled Categories | Total |
|---|---|---|---|---|
| Non-Affected Households | 5 | 1 | 0 | 6 |
| Affected Households | 4 | 5 | 2 | 11 |
| Total | 9 | 6 | 2 | 17 |

Some sick individuals who were unemployed in wave 1 across both cohorts, accepted work in the informal sector as voluntary counsellors, packers, merchandisers, domestic workers or hawkers (see Table 7.9). There were also individuals (two) from the affected cohort who were not looking for employment in wave 1 but were employed in wave 4. The evidence suggests that people, whether retired, disabled (see Section 7.2) and unemployed (see Section 7.3.1), will work if they find employment.

**Table 7.9: Labour Movement of Sick Individuals previously Unemployed in Wave 1**

| Number of Individuals | Hawking | Domestic Work | Merchandisers | Trade Worker | Voluntary Counsellors | Total |
|---|---|---|---|---|---|---|
| Non-Affected Households | 0 | 0 | 1 | 2 | 0 | 3 |
| Affected Households | 2 | 1 | 2 | 0 | 3 | 8 |
| Total | 2 | 1 | 3 | 2 | 3 | 11 |

### 7.4 Income

The study distinguishes between various types of regular and irregular income (see Appendix 7, Section 10). There are two main sources of regular income, earned income and income from non-market sources. Earned income is defined as income earned from being employed or self-employed and represents income from salaries and wages or income from own business. Income from non-market sources includes income from grants and monthly transfers from people outside the household.

There are three main sources of irregular income - income from investments and property, income from non-market sources and income as a result of death. Income from property such as rental income is classified as irregular income because neither the amount nor the frequency is consistent or regular. Income from the disposal of assets is also regarded as irregular income from property. Income from non-market sources includes income for child maintenance, irregular transfers from relatives and non-relatives, once-off receipts for lobola, profit from the sale of home produced items, donations received, income from migrant workers, and income from gambling as well as funds received as a result of death which are once-off receipts.

Approximately 40% of all households receive earned income and the remainder rely totally on income from non-market sources. The main sources of regular non-market income for affected households are income from government grants such as disability (24%), old-age pension grants (18%) and income from child-support grants (22%) of households (see Table 7.10). The main sources of irregular non-market income for affected households are income from rentals (5%), child maintenance from spouse (5%) and income resulting from death which is either lump sum payments, income from burial societies or help from relatives and non-relatives (25% of households).

**Table 7.10: Sources of Income (Number of Households and Percentage of Households)**

| | Income Type | Non-Affected Households | | Affected Households | |
|---|---|---|---|---|---|
| | | Number of Households | Percent | Number of Households | Percent |
| **Earned Income:** | | | | | |
| Salaries | Regular | 123 | 27.2 | 152 | 33.6 |
| Perks | Regular | 3 | 0.7 | 4 | 0.9 |
| Net Profit from own business | Regular | 37 | 8.2 | 48 | 10.6 |
| **Income from Non-Market Sources:** | | | | | |
| Disability grant government | Regular | 18 | 4.0 | 106 | 23.5 |
| Child support grant | Regular | 56 | 12.4 | 97 | 21.5 |
| Government pension | Regular | 34 | 7.5 | 82 | 18.1 |
| Foster care grant | Regular | 0 | 0.0 | 8 | 1.8 |
| Care dependency grant | Regular | 1 | 0.2 | 2 | 0.4 |
| Employer pension | Regular | 0 | 0.0 | 2 | 0.4 |
| Disability from employer | Regular | 3 | 0.7 | 2 | 0.4 |
| Private maintenance from spouse | Irregular | 24 | 5.3 | 29 | 6.4 |
| Remittance in cash | Regular | 15 | 3.3 | 21 | 4.6 |
| Remittance in food | Regular | 6 | 1.3 | 10 | 2.2 |
| Remittance in clothing | Regular | 0 | 0.0 | 1 | 0.2 |
| Migrant workers | Irregular | 10 | 2.2 | 1 | 0.2 |
| Hobbies | Irregular | 7 | 1.5 | 5 | 1.1 |
| Unemployment insurance fund | Irregular | 1 | 0.2 | 0 | 0.0 |
| Education sponsorship/bursary | Irregular | 0 | 0.0 | 1 | 0.2 |
| Gratuities | Irregular | 1 | 0.2 | 4 | 0.9 |
| Donations received in food-irregular | Irregular | 0 | 0.0 | 2 | 0.4 |
| Donations received in housing - irregular | Irregular | 0 | 0.0 | 1 | 0.2 |
| Lobola | Irregular | 1 | 0.2 | 0 | 0.0 |
| Migrant workers | Irregular | 10 | 2.2 | 1 | 0.2 |
| **Income from Property and** | | | | | |

| | Income Type | Non-Affected Households | | Affected Households | |
|---|---|---|---|---|---|
| | | Number of Households | Percent | Number of Households | Percent |
| **Investments:** | | | | | |
| Income from boarders | Irregular | 3 | 0.7 | 3 | 0.7 |
| Rental income | Irregular | 20 | 4.4 | 34 | 7.5 |
| Income from stokvels | Irregular | 0 | 0.0 | 3 | 0.7 |
| sale of goods | Irregular | 1 | 0.2 | 4 | 0.9 |
| **Income as a result of Death** | Irregular | 28 | 6.2 | 115 | 25.4 |
| Total number of household all waves | | 452 | | 452 | |

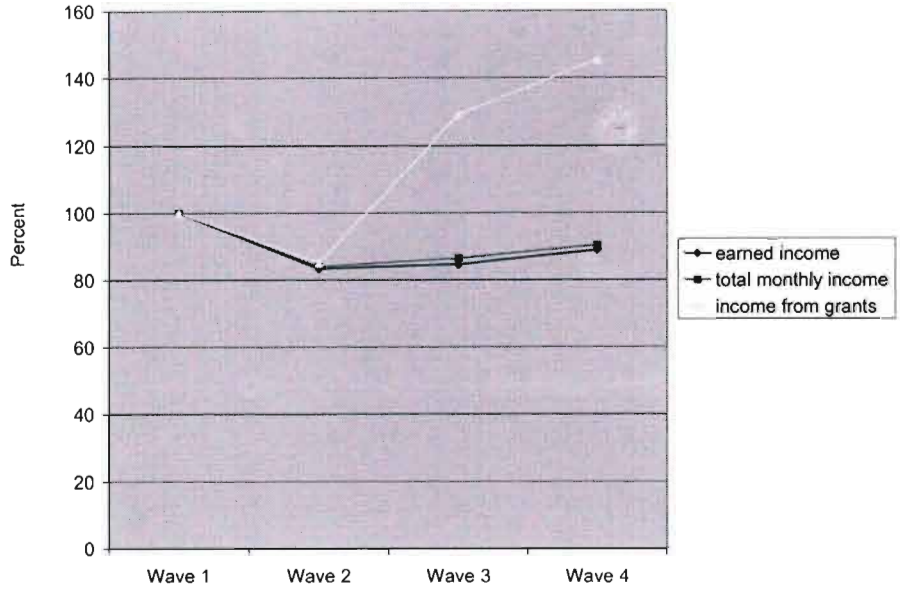
## 7.5 Analysis of Regular Monthly Household Income

Regular household income is analysed across cohorts and over the study period. The analysis compares the data of the affected cohort with that of the non-affected cohort using the balanced data set of 113 households (52 non-affected and 61 affected households) over the four waves. Due to the slow progression of the disease, the impact occurs slowly as seen in Figures 7.3 and 7.4. Since the changes over waves 2 and 3 are gradual, most of the analysis over the period of the study investigates the changes between waves 1 and 4.

Figure 7.3 shows the distribution of adult equivalent monthly household income for the non-affected cohort. The decline in earned income in wave 2 is caused by lost employment (see Table 7.2) or change in the mix of employment, that is, a reduction in the number of professional and skilled individuals with more semi-and unskilled workers being employed (See Figure 7.1).

There was a decrease in adult equivalent grant income in wave 2. From wave 3 there was an increase in adult equivalent grant income, however, the income from grants was not substantial enough to boost total monthly household income, leaving households poorer than they were a year ago.

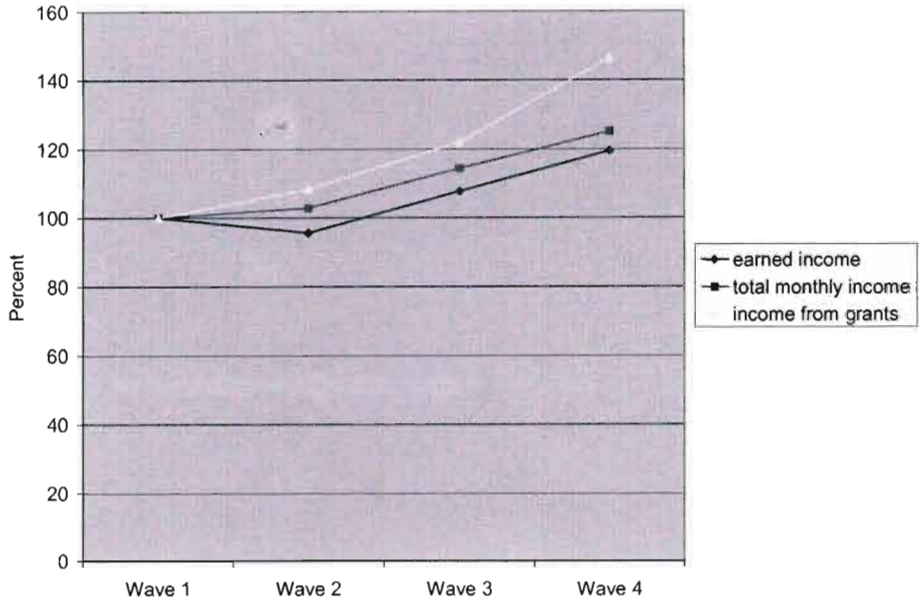
**Figure 7.3: Adult Equivalent Monthly Household Income Over Time for Non-Affected Households (Wave 1=100%)**




There was a slight decline in earned income in wave 2 due to changing levels of jobs from skilled to more semi-and unskilled positions in the affected cohort. The increase in earned income over time for the affected cohort is a result of non-economic members (number =12, see Section 7.2) entering the labour force through income-generation activities (see Section 7.2.1) as well as increases in grant income, resulting in the affected cohort being financially better off than a year ago.

However, the primary reason for showing Figure 7.3 and 7.4 is to illustrate that since the direction of change is similar between waves 2 and 3, the analysis over time will be conducted between waves 1 and 4.

**Figure 7.4: Monthly Household Income Over Time for Affected Households (Wave 1=100%)**




## 7.6 Composition of Regular Monthly Household Income

As mentioned earlier, regular monthly household income is made up of earned income and income from non-market sources, mainly from grants. Income from grants has been disaggregated and the difference between income from grants and income from non-market sources represents transfers into the household.

Table 7.11 shows the significant difference in how regular monthly household income is earned across cohorts[8]. The proportion of earned income in affected households is significantly lower than the proportion of earned income in non-affected households, for the following reasons:

- A higher proportion of females employed in affected households (see Table 7.2) and females earning less (in wave 1 males earned R1181 versus females R766).
- A higher proportion of semi-skilled and unskilled individuals employed (see Table 7.2).

[8] Total income in Table 7.8 does not add to 100% (1.00) because in 8 visits households did not receive any income.

- More individuals working part-time or casual (see Table 7.1).
- Increase in grant income (see Figure 7.4).
- Loss of income as a result of the sick person (see Table 7.18)
- Loss of caregiver income (see Table 7.18)
- Loss of employment for the sick person (see Table 7.18).

Between waves 1 and 4, affected households show a decline in reliance on earned income, despite the fact that there is an increase in the number of individuals employed in the affected cohort. This is because income from grants makes a significant contribution to household income in affected households. A change in the mix of occupational categories could also explain why earned income decreased despite more individuals being employed. It can be argued that affected households were poor to begin with, since their reliance on earned income was low at the start of the study (61%). However, this study did not obtain retrospective data on the unemployed to confirm this possibility.

**Table 7.11: Proportion of Regular Monthly Household Income by Wave *[9]**

| Composition of Income | All House-holds | Non-Affected House-holds | Affected House-holds | Percentage Difference Between Proportion (%) | T-stat | p-value |
|---|---|---|---|---|---|---|
| **Wave 1** | | | | | | |
| Earned Income | 0.70 | 0.80 | 0.61 | -23.7 | 2.86 | 0.0005* |
| Income from non-market sources | 0.29 | 0.20 | 0.37 | 85.0 | -2.63 | 0.0097* |
| Total Income | 0.99 | 1.00 | 0.98 | -2.0 | 1.00 | 0.3213 |
| Income from grants only | 0.24 | 0.15 | 0.33 | 120.0 | -3.08 | 0.0026* |
| **Wave 2** | | | | | | |
| Earned Income | 0.66 | 0.78 | 0.55 | -29.40 | 3.57 | 0.001* |
| Income from non-market sources | 0.33 | 0.22 | 0.42 | 90.0 | -3.09 | 0.003* |
| Total Income | 0.98 | 1.00 | 0.97 | -3.0 | 1.43 | 0.159 |
| Income from grants only | 0.25 | 0.14 | 0.34 | 142.8 | -3.75 | 0.000* |

[9] A negative t-stat value implies that mean costs in affected households exceeded those in non-affected households and * indicates significance at 5% level.

| Composition of Income | All House-holds | Non-Affected House-holds | Affected House-holds | Percentage Difference Between Proportion (%) | T-stat | p-value |
|---|---|---|---|---|---|---|
| **Wave 3** | | | | | | |
| Earned Income | 0.64 | 0.76 | 0.55 | -27.6 | 3.04 | 0.003* |
| Income from non-market sources | 0.34 | 0.23 | 0.43 | 86.9 | -3.16 | 0.002* |
| Total Income | 0.98 | 0.98 | 0.98 | 0.00 | -0.11 | 0.911 |
| Income from grants only | 0.26 | 0.15 | 0.36 | 140.0 | -3.68 | 0.000* |
| **Wave 4** | | | | | | |
| Earned Income | 0.65 | 0.76 | 0.56 | -26.3 | 3.19 | 0.002* |
| Income from non-market sources | 0.32 | 0.22 | 0.41 | 86.3 | -3.09 | 0.003* |
| Total Income | 0.97 | 0.98 | 0.97 | -1.0 | 0.45 | 0.652 |
| Income from grants only | 0.28 | 0.17 | 0.37 | 117.6 | -3.49 | 0.001* |
| **All Waves** | | | | | | |
| Earned Income | 0.66 | 0.77 | 0.57 | -25.9 | 6.36 | 0.0000* |
| Income from non-market sources | 0.32 | 0.22 | 0.41 | 86.3 | -6.02 | 0.0000* |
| Total Income | 0.98 | 0.99 | 0.98 | -1.0 | 1.24 | 0.2139 |
| Income from grants only | 0.26 | 0.15 | 0.35 | 133.3 | -7.02 | 0.0000* |

Measures of absolute, per capita and adult equivalent have been used to compare regular monthly household income across cohorts and over time. Affected households earn significantly less than non-affected households in earned income whether measured in absolute, per capita or adult equivalent basis. They earn significantly more in non-market income, using all three measures, because income from grants makes up a significant proportion of non-market income. The receipt of grants helped bridge the gap between earned income and total household income so much so that there are no significant differences in total regular monthly household income across cohorts. Adult equivalent regular monthly household income in affected households was 90% of the levels of total household income in non-affected households, while adult equivalent earned income was 72% of non-affected households (see Table 7.12).

**Table 7.12: Composition of Regular Monthly Household Income Across Cohorts (All Waves)**

| | Non-Affected Households | | Affected Households | | Percentage Difference Between Means (%) | | |
|---|---|---|---|---|---|---|---|
| **Income Type** | **Mean Income (Rand)** | **Median (Rand)** | **Mean Income (Rand)** | **Median (Rand)** | | **T- stat** | **p- value** |
| **Earned income** | 2371.62 | 1979.43 | 1721.14 | 1323.23 | -27.4 | 3.85 | 0.0001* |
| Per capita | 508.06 | 397.91 | 375.87 | 225.61 | -26.0 | 2.80 | 0.0053* |
| Adult equivalent | 903.00 | 747.09 | 650.19 | 432.42 | -28.0 | 3.71 | 0.0002* |
| **Income from non-market sources** | 373.34 | 132.63 | 812.19 | 753.62 | 117.5 | -7.37 | 0.0000* |
| Per capita | 61.72 | 23.18 | 144.23 | 108.68 | 133.6 | -6.04 | 0.0000* |
| Adult equivalent | 122.65 | 48.05 | 273.70 | 253.22 | 123.0 | -7.14 | 0.0000* |
| **Total income** | 2744.96 | 2290.36 | 2533.33 | 2174.33 | -7.7 | 1.20 | 0.2295 |
| Per capita | 569.79 | 442.98 | 520.10 | 357.90 | -8.7 | 1.05 | 0.2959 |
| Adult equivalent | 1025.65 | 875.99 | 923.89 | 764.67 | -9.9 | 1.50 | 0.1343 |
| **Income from grants only** | 260.82 | 0.00 | 691.79 | 646.43 | 165.2 | -8.40 | 0.0000* |
| Per capita | 35.91 | 0.00 | 115.90 | 90.49 | 222.7 | -8.54 | 0.0000* |
| Adult equivalent | 76.96 | 0.00 | 227.47 | 212.68 | 195.6 | -9.27 | 0.0000* |

Over time, the non-affected cohort demonstrates no significant changes to income whether measured in absolute, per capita or adult equivalent basis in earned income, income from non-market sources or income from grants, despite the fact that they experienced reduced employment (see Table 7.13). Over time, the affected cohort also demonstrates no significant changes to earned income but significant changes in non-market income due to the increase in income from grants.

**Table 7.13: Composition of Regular Monthly Household Income Over Time**

| | Wave 1 | | Wave 4 | | Percentage Difference Between Means | Absolute Difference | | |
|---|---|---|---|---|---|---|---|---|
| Non-Affected Households | Mean | Median | Mean | Median | | | | |
| | (Rand) | (Rand) | (Rand) | (Rand) | % | (Rand) | T-stat | p-value |
| **Earned Income** | 2536.21 | 2150.00 | 2420.23 | 2166.99 | -4.6 | -115.98 | 0.29 | 0.7736 |
| Per capita | 584.09 | 453.68 | 501.33 | 379.00 | -14.2 | -82.76 | 0.77 | 0.4404 |
| Adult equivalent | 1012.50 | 842.25 | 900.33 | 782.72 | -11.1 | -112.17 | 0.70 | 0.4851 |
| **Income from non-market sources** | 364.23 | 130.00 | 397.24 | 154.44 | 9.1 | 33.01 | -0.30 | 0.7623 |
| Per capita | 65.16 | 21.67 | 62.75 | 47.30 | -3.7 | -2.41 | 0.12 | 0.908 |
| Adult equivalent | 125.19 | 44.37 | 126.68 | 79.89 | 1.2 | 1.49 | -0.04 | 0.9675 |
| **Total Income** | 2900.44 | 2308.38 | 2817.46 | 2385.16 | -2.9 | -82.97 | 0.20 | 0.8401 |
| Per capita | 649.25 | 464.27 | 564.08 | 445.33 | -13.1 | -85.17 | 0.79 | 0.4289 |
| Adult equivalent | 1137.69 | 937.45 | 1027.00 | 889.05 | -9.7 | -110.69 | 0.69 | 0.4898 |
| **Income from grants** | 239.23 | 0.00 | 307.77 | 154.44 | 28.6 | 68.54 | -0.73 | 0.4667 |
| Per capita | 29.69 | 0.00 | 48.46 | 22.06 | 63.2 | 18.77 | -1.57 | 0.1195 |
| Adult equivalent | 67.01 | 0.00 | 97.35 | 48.05 | 45.3 | 30.34 | -1.23 | 0.2209 |
| | | | | | | | | |
| **Affected Households** | | | | | | | | |
| **Earned Income** | 1624.67 | 1266.12 | 1883.90 | 1833.98 | 16.0 | 259.23 | -0.91 | 0.3652 |
| Per capita | 351.93 | 250.00 | 438.81 | 260.93 | 24.7 | 86.88 | -0.94 | 0.3491 |
| Adult equivalent | 615.01 | 431.06 | 735.48 | 599.17 | 19.6 | 120.47 | -0.99 | 0.3255 |
| **Income from non-market sources** | 674.21 | 620.00 | 913.19 | 830.12 | 35.4 | 238.98 | -1.89 | 0.0606 |
| Per capita | 111.84 | 83.36 | 162.42 | 144.79 | 45.2 | 50.58 | -2.04 | 0.0436* |
| Adult equivalent | 220.28 | 178.05 | 310.35 | 309.09 | 40.9 | 90.07 | -2.17 | 0.0323* |
| **Total Income** | 2298.89 | 2095.16 | 2797.09 | 2606.18 | 21.7 | 498.20 | -1.62 | 0.1084 |
| Per capita | 463.77 | 310.00 | 601.23 | 500.07 | 29.6 | 137.46 | -1.53 | 0.1299 |
| Adult equivalent | 835.30 | 607.88 | 1045.82 | 891.56 | 25.2 | 210.52 | -1.79 | 0.0762 |
| **Income from grants** | 588.36 | 620.00 | 822.99 | 830.12 | 39.9 | 234.63 | -2.08 | 0.0395* |
| Per capita | 96.12 | 68.18 | 146.47 | 126.56 | 52.4 | 50.35 | -2.17 | 0.0321* |
| Adult equivalent | 190.82 | 165.90 | 279.25 | 283.30 | 46.3 | 88.43 | -2.35 | 0.0204* |

There are households that rely solely on earned income and households that rely solely on grants and other transfers. In this study there were 12 households (two

from the affected cohort and ten from the non-affected cohort) across both cohorts that relied solely on earned income over the 4 waves. On the other hand, there were seven households (four from the affected cohort) in total that were dependent totally on income from grants and transfers from family members outside the household. These seven households did have someone employed prior to wave 1. Individuals from four of these households stopped working because of ill-health, one stopped working to take care of a disabled child, one stopped working because of a new-born baby and one individual was conducting contract work fixing gutters but did not seem to find work throughout the year.

### 7.6.1 Income from Grants

Since grants make up a significant proportion of regular monthly household income, they are discussed in detail in this section. The three main sources of income from grants are child support grants, disability grants and old age pension grants. There was only one household that received the care dependency grant and three households that received foster care grants. The application process for the above two types of grants are more complex and is the reason why many households do not apply for them.

In terms of the composition of these grants, affected households relied more on disability and old age pension grants and non-affected households relied more on child support grants (see Table 7.14). The implication of relying more on disability or old age pension grants is that when the grantee dies, the grant ceases, with a resultant impact on household income.

**Table 7.14: Composition of Grants by Type (Percentage)**

| Grant Type | Affected Households | Non-Affected Households | % Point Difference |
|---|---|---|---|
| Disability | 43.0 | 13.8 | 29.2* |
| Pension | 32.0 | 33.0 | 1.0 |
| Child Support | 23.0 | 53.0 | 30.0* |
| Care Dependency | 0.4 | 0.2 | 0.2 |
| Foster Care | 1.6 | 0.0 | 1.6 |

## 7.7 Annual Income

Most studies report on monthly household income. However, since considerable irregular income is received, this study analyses annual income as well as monthly household income. The method of annual calculation of regular income by averaging the four visits and multiplying by 12 assumes that the economic behaviour of the four visits represents the economic behaviour for the unobserved periods. Total annual income was derived by adding the annualised regular income to the annualised irregular income.

With the incorporation of such income as grants and transfers in, renting out rooms and receipt of funds due to death, the total annual household income in absolute rand value or adult equivalent were slightly but not significantly higher in affected households (see Table 7.15).

**Table 7.15: Sources of Annual Household Income**

| | All Households | | Non-Affected Households | | Affected Households | | Percentage Difference Between Means | | |
|---|---|---|---|---|---|---|---|---|---|
| | Mean (Rand) | Median (Rand) | Mean (Rand) | Median (Rand) | Mean (Rand) | Median (Rand) | % | T-stat | p-value |
| Earned Income | 24245.72 | 19678.89 | 28459.45 | 24542.99 | 20653.70 | 14091.46 | -27.4 | 2.05 | 0.0004* |
| Income from property | 471.10 | 0.00 | 131.26 | 0.00 | 760.81 | 0.00 | 479.6 | -1.52 | 0.1300 |
| Income from non-market | 9876.70 | 7428.89 | 5235.80 | 2195.89 | 13832.88 | 10362.95 | 164.1 | -3.25 | 0.0000* |
| Income from death | 2702.60 | 0.00 | 375.21 | 0.00 | 4686.60 | 0.00 | 1149.1 | -1.71 | 0.0009* |
| Total income | 37296.12 | 29923.06 | 34201.72 | 29418.29 | 39933.98 | 30387.94 | 16.7 | -0.93 | 0.3500 |
| AE[2] earned income | 9293.60 | 7929.40 | 11098.22 | 9939.18 | 7755.24 | 4914.64 | -30.1 | 2.21 | 0.0029* |
| AE total household income | 13908.27 | 10520.89 | 13148.91 | 11320.95 | 14555.59 | 9804.96 | 10.6 | -0.67 | 0.5035 |

[2] AE means Adult Equivalent

Funds from other households are received in two major ways. Firstly through transfers (remittances) which are either regular (monthly) or irregular (ad hoc) during the course of the year. Secondly, funds enter through relatives and non-relatives when death occurs. The bulk of non-market income is income from grants in all households. While transfers[10] make up a small proportion of non-market income, it is important to understand further whether urban households in the presence of HIV/AIDS transfer more money out than receive money in. The study reveals that while the non-affected cohort transfers out almost twice the amount they receive in, the opposite is true for affected households (see Table 7.16). HIV/AIDS therefore has the potential to alter the pattern of transfers in urban households, with affected households drawing from other households.

**Table 7.16: Remittance In and Out (Real Absolute Annual Rand Value)**

| | Non-Affected Households (Rand) | Affected Households (Rand) |
|---|---|---|
| Remittance In | 737 | 1181 |
| Remittance Out | 1464 | 838 |

### 7.7.1 Proportion of Annual Household Income

According to the *Income and Expenditure Survey* in 2000 (Stats SA, 2002), the proportion of earned income is 85% (Gauteng 90%) of total annual income for all South African households. Since earned income represents 77% in the non-affected cohort and 51% in the affected cohort (see Table 7.17) of total household income, the households in Soweto that attend public antenatal and HIV clinics are poor and affected households are even poorer.

[10] This analysis has been done on inward transfers only, that is, regular and irregular transfers to help with general housekeeping, and not on funds from relatives and non-relatives specifically to help with funeral costs.

**Table 7.17: Proportion of Household Annual Income – Proportion**

| Type of Annual Income | All Households Mean (%) | Non-Affected Households Mean (%) | Affected Households Mean (%) | Percentage Difference Between Means (%) | T-stat | p-value |
|---|---|---|---|---|---|---|
| Earned Income | 0.63 | 0.77 | 0.51 | -33.7 | 4.60 | 0.0000* |
| Income from property | 0.01 | 0.00 | 0.02 | | -1.95 | 0.0558 |
| Income from non-market | 0.32 | 0.22 | 0.40 | 81.8 | -3.43 | 0.0009* |
| Income from death | 0.04 | 0.01 | 0.07 | 600.0 | -3.68 | 0.0005* |
| Total income | 1.00 | 1.00 | 1.00 | | | |

## 7.8 Changes in Income as a Result of Sickness and Death

This study has noted changes in income as a result of sickness and death since the start of the study in the affected cohort arising from the following sources (see Table 7.18):

- Grant income – from households applying for the grant during times of sickness and losing the grant after death (7 % of visits).
- Sick member losing income as a result of sickness (34% of visits).
- Sick member losing employment and therefore permanent loss of income to the household as a result of sickness or death (30% of visits).
- Caregiver losing income as a result of taking care of the sick person at home or accompanying the sick person to hospital (14% of visits).

**Table 7.18: Changes in Income Experienced Due to Sickness and Death in Households**

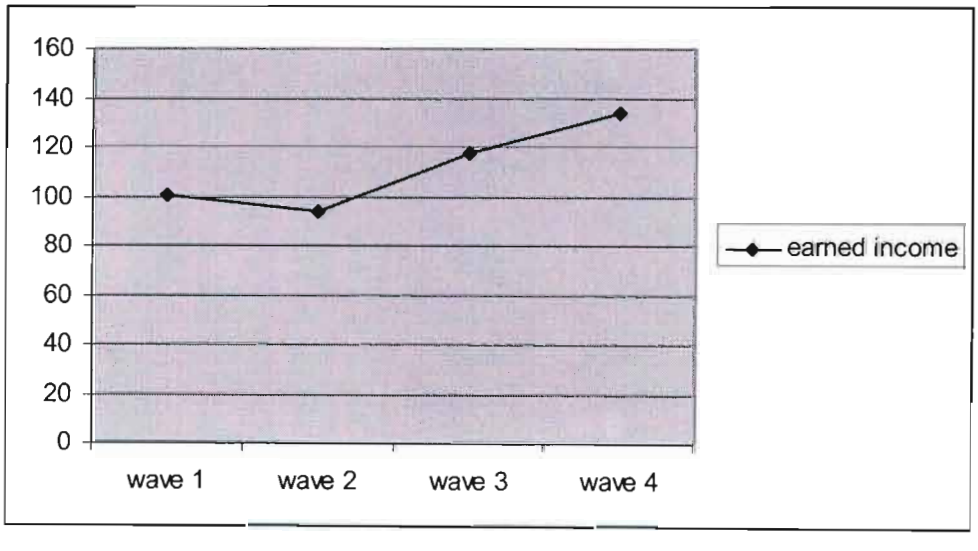
| | Non-Affected Households | Affected Households |
|---|---|---|
| Number of household visits | 44 | 131 |
| Households losing grant income after death | 1 | 9 |
| Sick member lost income | 6 | 45 |
| Sick person lost employment income | 2 | 53 |
| Caregiver lost income | 4 | 18 |
| Lost employment prior to wave 1 less than 2 years | 0 | 21 |

### 7.8.1 Tracking Monthly Adult Equivalent Income in Households

The data shows that adult equivalent earned income declined in wave 2 immediately after sickness and households then seemed to recover income from wave 3 (see Figure 7.6) as a result of:

- Other members of the household participating in income-generation activities.
- A reduction in household size over time.
- Individuals who are treated for opportunistic illness recover and rejoin the labour market.

**Figure 7.5: Household Monthly Income per Adult Equivalent Earned Over Time for Affected Households Sick in Wave 1 (Wave 1=100, n=47)**




Case study 7.1 illustrates how HIV/AIDS influences infected individuals to change place and type of employment.

**Case Study 7.1: Changing Occupations of Ill Members**

Petrus is a 27 year old male who is unemployed. He and his girlfriend, the mother of his two children live with his older brother. His girlfriend knows her status but they have not disclosed this to his brother or any member of their family. They are usually interviewed in their bedroom away from other family members. Petrus refuses to be tested as he does not believe that he is HIV positive or that he can get infected. He was counselled to use a condom as he has other girlfriends too.

Petrus used to work in his brother's bottle store but stopped working because of the high transport cost. The reward was too little for his effort. He is trying to start a Vodacom public phone business from home with a friend. His girlfriend worked as a domestic worker but had to leave work due to her illness. She started selling cool-drinks from home. They are surviving on the income from the sale of cool-drinks and from the child support grant they are collecting for their two children.

Petrus' girlfriend is worried about who is going to care for her children in the future. She fears that when she dies Petrus will bring a new woman into the house who will not care for her children. She is hoping that her in-laws will care for them but has not discussed the situation with them. She is planning to do so at the later stage of illness to avoid any discrimination.

From wave 3, Petrus started working as a technician after his brother taught him new skills that secured employment. They were delighted that they could now use the child support grant for the children and support the entire household with essentials such as food. Petrus' eldest son, who was staying with his grandparents in Estcourt, rejoined the household because they could now afford his upkeep.

## 7.9 Methodological Lessons

A detailed instrument to collect data on income was found to be valuable because respondents tend to forget about income from migrant workers, from non-resident family members or from home production. To calculate income from home produced items, detailed information on purchases of raw materials, cost of

overheads and sale of finished product is required. The profit or loss from home production was taken into the income calculation of net income. During the first visit, the study found that respondents did not keep records of income or expenditure on home produced items. They were then requested to keep a diary to record income and expenditure. Some respondents found that they were making a profit while others found they were making a loss even before labour costs were considered. With regard to this discovery, some respondents stated that although they were disappointed with the outcome they did not mind making a loss because they felt worthwhile as a result of the employment; others were disappointed to discover that they were making a loss.

This study further distinguished between net income and gross income. Both types of income were collected. Net income has been used in the analysis and represents gross income less deductions from employer for PAYE, trade union, medical aid, pension and UIF. If only net income (take-home pay) was collected then deductions made to insurance policies, burial funds and home loans (which are forms of savings and therefore part of net income) would not have been accurately recorded. One might argue that medical aid deductions is a form of insurance, however, in this study it was considered a deduction.

Recording net income from profit of own business was difficult to estimate in the absence of income and expenditure records. Respondents were encouraged to recall the amount they contributed to the household budget and this was used as a proxy for net income from own business. The previous months' income was recorded during each wave. If income was only captured for those individuals who were described as employed, the study would have not captured income from "non-employed" or other income-generating individuals.

The study found very little movement between waves two and three and therefore recommends that changes could be tracked every six months rather than every three months as tested in this study.

The study did not investigate reasons why individuals became unemployed nor did it collect income data from those who were unemployed. This would have made it

easier to distinguish loss of employment or change of skills due to HIV/AIDS or due to labour market conditions.

### 7.10 Summary

Chapter six has illustrated that morbidity causes ill individuals and their caregivers to lose income temporarily or permanently through the loss of employment as found in other studies (see Section 2.3.2). In addition, this chapter has shown that morbidity forces ill persons to replace full-time skilled jobs with part-time or casual work and skilled jobs with semi- or unskilled jobs. It forces economically active members to leave their formal full-time employment to collect the state disability, thereby taking a drop in income. It forces the elderly to continue working or to re-enter the workforce during their retirement years. If there are only females in the household, then these households can expect to earn less than households with male income-earners.

Affected households earned 72% of the levels of regular and irregular income of the non-affected cohort, similar to the proportion found in the Free State (Booysen et al., 2003:74). Affected households earn significantly less in earned income and significantly more in grants and other non-market income. Grant income however is an important contributor to total household income so much so that total household income is not significantly different across cohorts. Affected households make up this loss of income through activities such as:

- Receiving disability and other grants such as the child support grant and the old age pension grant
- Non-economically active members joining the labour force
- Other members of the household joining the labour force
- Employed members joining the household
- Diversifying income
- Renting out rooms
- Transfers from relatives in other households
- Income received as a result of death

Over time affected households showed no significant improvement in earned income even with more members entering the labour market. However, significant differences were found in non-market income due to increases in grant income. Some rural studies, on the other hand, found income dropping over time (Kongsin et al., 2000).

On an annual basis, the proportion of earned income to total household income is much lower than the national or Gauteng's average. Households affected by mortality receive funds from relatives and non-relatives as well as burial societies resulting in annual household income being slightly but not significantly higher than in the non-affected cohort. Lundberg et al., argues that this is a form of altruism that exists within communities (2000:961).

One of the key findings of this chapter is that while urban households in general transfer more money out than receive money in, this is not the case for affected households; affected households received more funds in than what they transferred out.

Not all affected households experience sickness all of the time. Following affected households that experienced sickness in wave 1 demonstrate that income drops immediately after sickness and then recovers as ill individuals get back to work and new members join the labour market.

The study collected data on income and was able to verify the difference between net and gross income and include income from all income-generating members. Future studies of this nature should collect data six monthly as well as collect retrospective data on the unemployed. Care-giving takes up a lot of time, preventing household members from joining the labour force even if there were more jobs available.

The impact that HIV/AIDS will have on household income will depend on:

- The employment status of the ill person and other members of the household

- The stage of HIV infection of the individual member
- The skill level of the ill person and other members of the household
- The employment status of caregivers
- The skill level of caregivers
- Whether or not the household has the opportunity to replace the loss of labour
- Transfers from other households
- Income from disability grants

# CHAPTER EIGHT
# CHANGING PATTERNS OF EXPENDITURE AS A RESULT OF HIV/AIDS

## 8.1 Introduction

There are two types of household expenditure analysed in this study - regular and irregular expenditure (see Table 8.1 and 8.2). Regular expenditure is expenditure that is spent on a monthly or regular basis from household income. Irregular expenditure is once off amounts paid on an irregular ad hoc basis. Annual expenditure is derived by multiplying the monthly average expenditure of the four waves by 12 and adding irregular expenditure. Data was collected on 19 items of regular monthly household expenditure (see Table 8.1) and seven items of irregular household expenditure (see Table 8.2) for which the diary method was used. The fieldworker assisted the respondent in cases where the respondent was not literate, or had forgotten to keep records or kept the receipts only.

As with the analysis on income, expenditure in this chapter is analysed on 113 households visited over 4 waves. All values have been adjusted to wave 1 using the CPI figures from Statistics South Africa. Measures of adult equivalents were used across cohorts and over time.

The study investigates differences in spending across cohorts and analyses annual expenditure patterns across cohorts using adult equivalent measures. Furthermore, the role of non-market income to pay for regular expenditure is explored. Finally, expenditure on food is investigated to uncover the importance placed on nutrition by households affected with HIV/AIDS.

**Table 8.1: Items Classified as Regular Household Expenditure**

| |
|---|
| Housing – this entailed expenditure for mortgage, rent as well as for services such as electricity, water and refuse removal. |
| Food – this entailed food purchased for home consumption as well as food purchased and consumed outside the home such as take-aways. |
| Alcohol and cigarettes – this entailed items purchased and consumed at home or purchased and consumed outside the home. |
| Telephone – this was for cost of land line including calls or cost of pre-paid cards or cost of calls made from cellular telephones. |
| Groceries – this included all non-food items such as cleaning materials. |
| Personal care – this included items such as cosmetics, newspapers, hairdresser, entertainment, movie and other items of a personal nature requested by individual household members. |
| Clothing – this included clothing accounts but not school uniforms, clothing repairs as well as dry cleaning. |
| Gambling – this included all forms of gambling such as the lotto, horse racing, casinos, etc. |
| Public transport – this included payment for the use of taxis, trains, buses – all public transport but not for school. Transport for school was included under schooling and transport for medical purposes is included under medical expenses. |
| Vehicle instalments – repayments on vehicles purchased. |
| Petrol and vehicle maintenance – all running expenses of the vehicle was included. |
| Durables – these were repayments on furniture accounts, the purchase of electrical appliances and other household furniture accounts repaid on a monthly basis. |
| Insurance on possessions – this entailed insurance on all possessions such as motor vehicles, household contents as well as structural insurance on buildings. |
| Dependants at home – this entailed pocket money given to household members for their own consumption. |
| Dependants elsewhere – this entailed transfers out on a regular basis to members of other households. |
| Domestic workers – this included wages for child-minding, caring for the sick, domestic chores and gardening. |

**Table 8.1: Items Classified as Regular Household Expenditure (continued)**

| |
|---|
| Medical expenses – this included monthly regular expenses as well as cost of care for ill individuals. |
| Funeral donations – this was donations to relatives and non-relatives as a result of a funeral. |
| Regular schooling – this was pocket money and transport costs |

**Table 8.2: Items Classified as Irregular Household Expenditure**

| |
|---|
| Repairs to household goods – this entailed repairs to furniture and household appliances. |
| Housing repairs – this entailed repairs to the structure of the house internal or external including the building of extra rooms, plumbing, etc. |
| Irregular education – included the cost of school uniforms, school fees and stationery usually purchased on an annual or bi-annual basis. |
| Durables – purchased and paid for on a once-off basis. |
| Visits to rural areas/holidays – usually occurred once a year on vacation or visits as a result of funerals. |
| Transfers out - to relatives and non-relatives on a once-off basis were also recorded as irregular expenditure. |
| Funerals – since this cost was high and occur once-off these expenses were added to irregular expenditure. |

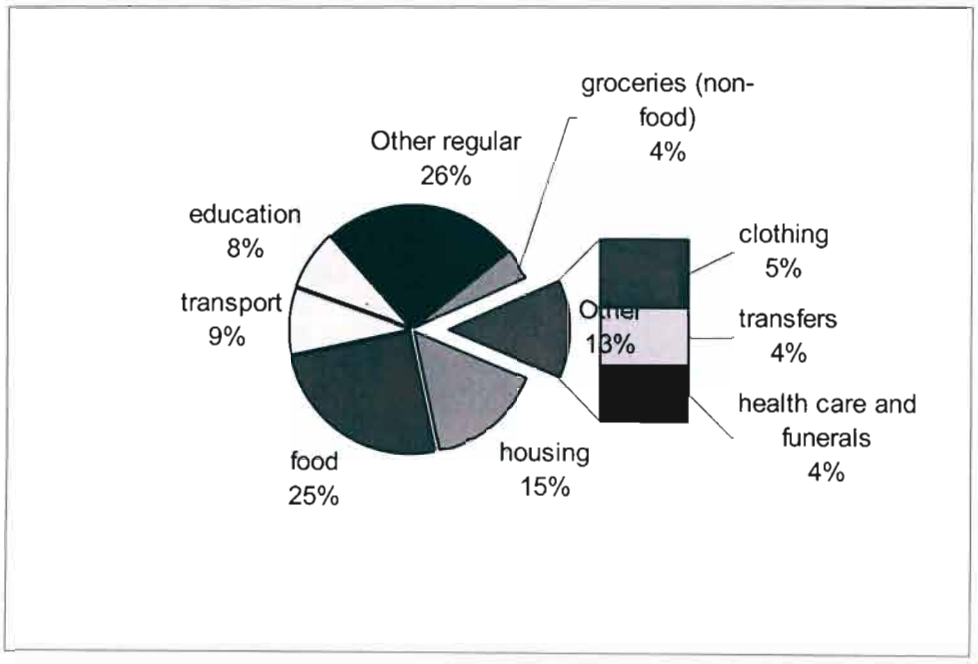
## 8.2 Proportion of Annual Expenditure Spends Across Cohorts

Approximately 61% of annual expenditure is made up of five expenditure categories in the non-affected cohort namely housing, food, transport, education, health care and funeral compared to 70% in the affected cohort (see Figure 8.1 and 8.2). This suggests that a large proportion of the household budget goes towards a few essential expenditure categories. Just under a third of the household budget goes towards the purchase of food[1] in both cohorts. Affected households spend proportionately more on funeral and health care expenditure and proportionately

[1] This survey separates the amount spent on food and non-food items. Non-food groceries include cleaning materials and other non-edible groceries.

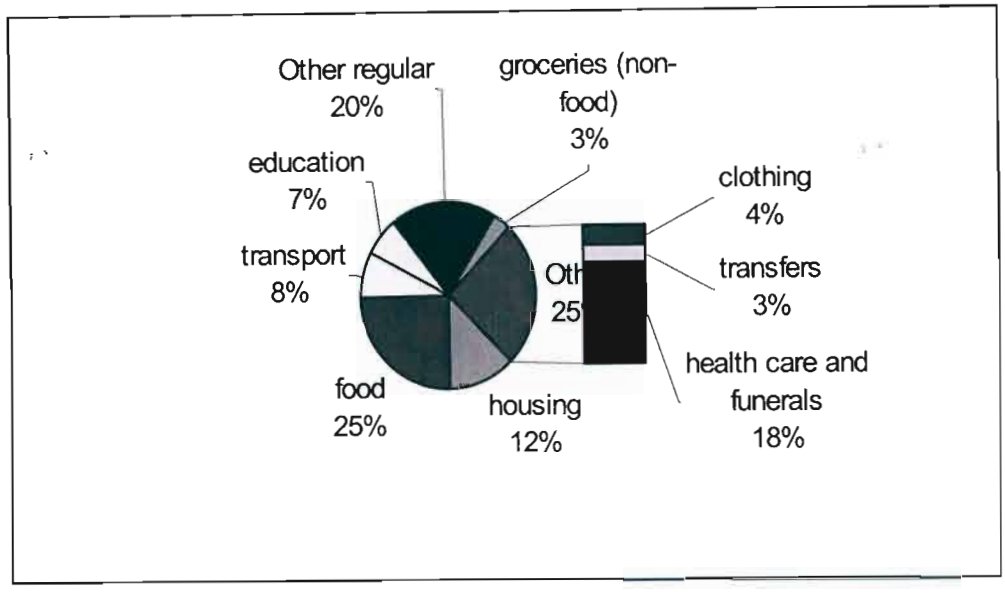
less on most other items of regular expenditure. This is because funeral and health care expenditures consume a large proportion of their annual expenditure (see Figure 8.2).

**Figure 8.1: Proportion of Annual Adult Equivalent Household Expenditure Across Cohorts – Non-Affected Cohort**




Source: Appendix Table 15

**Figure 8.2: Proportion of Annual Adult Equivalent Household Expenditure Across Cohorts - Affected Cohort**




Source: Appendix Table 15

### 8.3 Annual Household Expenditure Patterns (in Adult Equivalent)

Annual spending patterns for each of the expenditure categories are discussed in detail taking household economies of scale into account (see Appendix Table 16). Approximately 77% of annual household expenditure for all households consists of regular monthly household expenditure. It is interesting to note that a larger share of total expenditure is in the form of irregular expenditure for affected households (29% compared with 16%, half of the total irregular expenditure comprises the cost of funerals in affected households (see Table 8.3).

The affected cohort spent 8.8% less in regular annual adult equivalent expenditure (see Appendix Table 16) of the non-affected cohort. After funeral costs and other irregular annual expenditure are combined, the affected cohort spent 8.8% more per adult equivalent than the non-affected cohort (see Table 8.3) representing 91% of the levels of annual adult equivalent regular expenditure of the non-affected cohort (see Appendix Table 16) a similar trend to that found in the Free State study (Booysen et al., 2003:78).

Just as there are differences in the way income is earned across cohorts, there are differences in consumption. Table 8.3 derived from Appendix Table 16 show affected households spending significantly more per adult equivalent on irregular annual expenditure mainly on funeral and health care and significantly less on dependants at home, dependants elsewhere, and donations to the church.

Dependants at home were better off in non-affected households as they received more funds and on a regular basis than those from affected households. Dependants living elsewhere were also better off if they were related to non-affected households.

Health care and funeral costs were higher in affected households for obvious reasons. Medical costs are incurred by the household whether or not a person is sick. When a person is not sick, households still spend money on the purchase of vitamins for infected individuals or medicines for persons with chronic illness.

**Table 8.3: Adult Equivalent Annual Household Expenditure Across Cohorts**

| | All Households | Non Affected Households | Affected Households | Percentage Difference Between Means | | |
|---|---|---|---|---|---|---|
| | Mean (Rand) | Mean (Rand) | Mean (Rand) | (%) | T-stat | p-value |
| Dependants at home | 93.32 | 127.63 | 64.08 | -49.8 | 1.99 | 0.0491* |
| Dependants elsewhere | 349.67 | 567.01 | 164.40 | -71.0 | 2.60 | 0.0116* |
| Annual health care cost | 212.98 | 62.47 | 341.28 | 446.3 | -3.83 | 0.0003* |
| Funeral cost | 1180.19 | 355.27 | 1883.40 | 430.1 | -3.84 | 0.0002* |
| Church | 26.10 | 53.55 | 2.71 | -94.9 | 2.51 | 0.0151* |
| Total irregular Expenditure | 2489.07 | 1602.67 | 3244.69 | 102.5 | -2.50 | 0.0143* |
| Total regular plus Irregular Expenditure | 10623.75 | 10144.22 | 11032.52 | 8.8 | -0.58 | 0.5638 |

Overall the study found little difference (2.7%) in the annual consumption of basic essentials across cohorts (see Table 8.4), suggesting that households would have had similar expenditure patterns were it not for sickness and or death.

**Table 8.4: Adult Equivalent Annual Household Expenditure on Basic Essentials Across Cohorts**

| | Non-Affected Households | Affected Households |
|---|---|---|
| **Expenditure Category** | **Mean (Rand)** | **Mean (Rand)** |
| Housing (rent, electricity & water) | 1764.69 | 1328.01 |
| Food (takeaways included) | 2151.99 | 2327.21 |
| Groceries (non-food) | 361.57 | 314.50 |
| Clothing | 433.89 | 474.21 |
| Public Transport | 773.54 | 871.56 |
| Total | 5485.68 | 5336.28 |

### 8.3.1 The Role of Non-Market Income on Household Expenditure Patterns

Table 8.5 demonstrates that the non-affected cohort spends (R8 542) less per adult equivalent on annual regular expenditure than what they earn (R11 098). On the other hand, the affected cohort earn sufficiently to just cover regular expenditure and rely on the income from grants and other transfers help them survive the basic cost of living plus help them cope with the additional costs of health care and funerals (see Table 8.5).

**Table 8.5: Annual Adult Equivalent Regular Household Income and Expenditure**

| | Non-Affected Households | Affected Households |
|---|---|---|
| **Adult Equivalent Annual Income** | **Mean (Rand)** | **Mean (Rand)** |
| Total annual earned income (see Table 7.12) | 11 098 | 7 755 |
| Total annual regular expenditure (see Appendix Table 16) | 8 542 | 7 788 |
| Total annual household income (regular and irregular - see Table 7.12) | 13 149 | 14 556 |
| Total annual household expenditure (regular and irregular - see Table 8.3) | 10 144 | 11 032 |

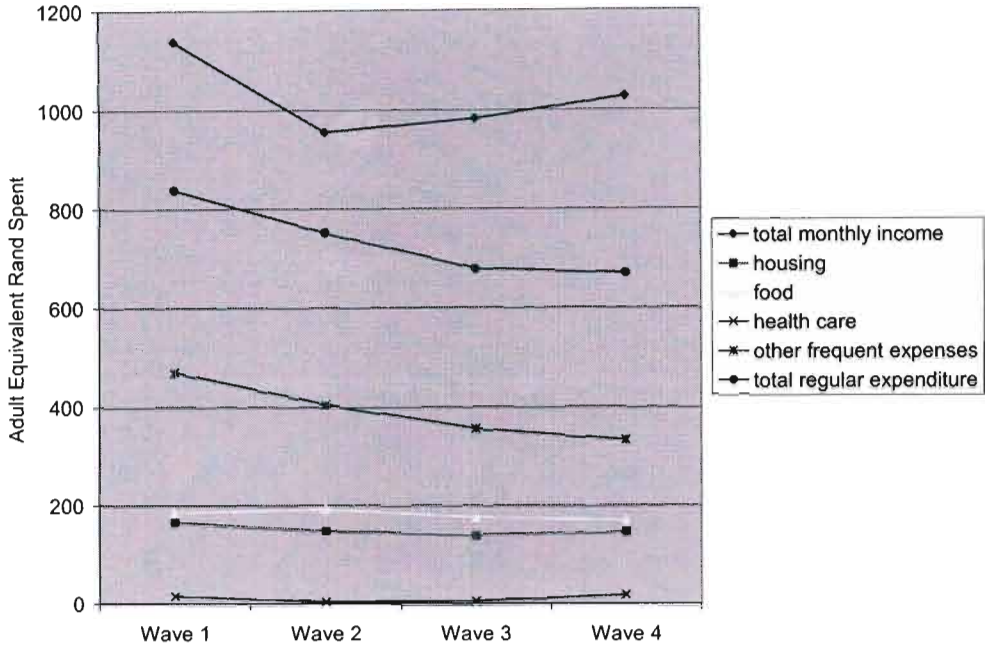
## 8.4 Determinants of Household Expenditure Patterns Over Time

Sickness or death may not be the only reason why expenditure declines in households over time. The general economic situation may result in new expenditure patterns. A question to consider is whether households recover from past expenditures and debts associated with health care and funerals when income increases in the future.

In wave 2, non-affected households experienced 16% fewer members being employed compared to wave 1 (see Section 7.2.3). Over time they also experienced a net gain of household members (see Table 5.1). This decline in income per adult equivalent in wave 2 (see Figure 7.3) caused monthly expenditure on certain regular items to decline over time despite the fact that income recovered in wave 3 due to increases in grant income.

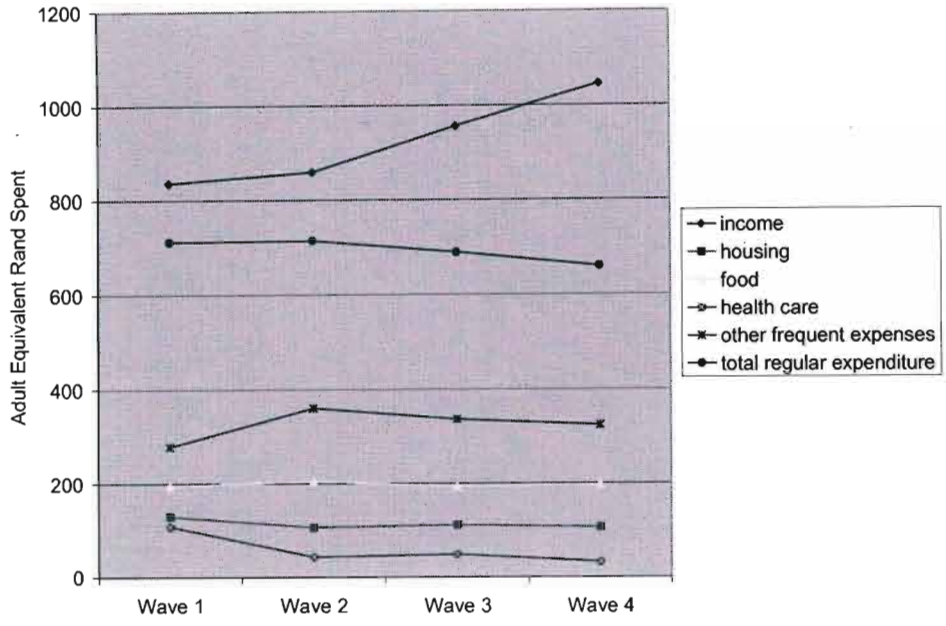
Furthermore, the evidence from Figure 8.3 shows that neither adult equivalent income nor expenditure recover to the levels of wave 1, suggesting that the non-affected cohort has become poorer in adult equivalent terms from baseline.

**Figure 8.3: Adult Equivalent Monthly Regular Household Expenditure in Relation to Income by Wave– Non-Affected Cohort**




The affected cohort responded to the reduced income by sending non-economically active members to work (see Section 7.2), by increasing their income from grants (see Figure 7.4) and by reducing household size (see Table 5.1). These resulted in an increase in adult equivalent income from wave 3 onwards. However, the increase in income was not sufficient for households to recover from past debt. The data also suggests that households in the affected cohort are also becoming poorer than at baseline.

**Figure 8.4: Adult Equivalent Monthly Regular Household Expenditure in Relation to Income by Wave– Affected Cohort**




### 8.4.1 Regular Monthly Adult Equivalent Household Expenditure Patterns Over Time (Wave 1 and Wave 4)

Changes across waves 1 and 4 are analysed using adult equivalent measures. Non-affected households earned 10% less in regular monthly household income and spent 20% less on regular monthly household expenditure over time (see Appendix Table 17). Over time the non-affected cohort had fewer household members participating in income-generating activities (see Table 7.2) and spent significantly less on personal care items and on donations to the church, changes of which were very small (see Appendix Table 17).

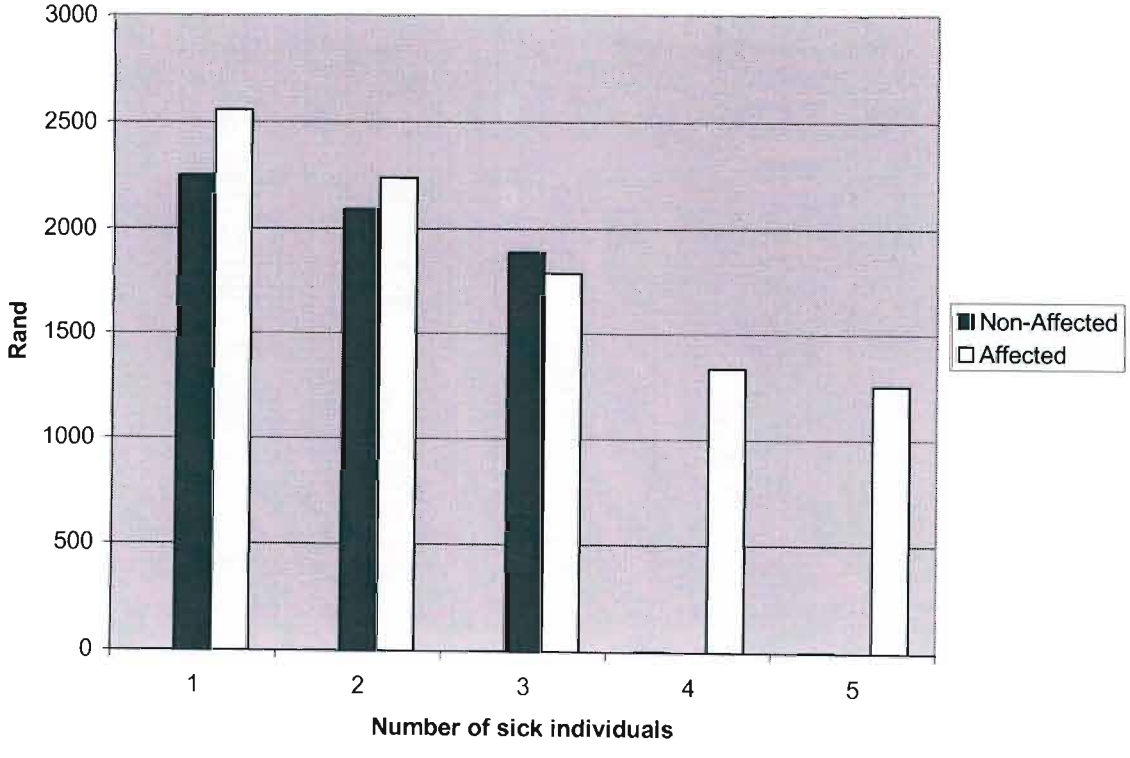
The affected cohort earned 25% more and spent 7% less in regular monthly household income (see Appendix Table 18). Over the period of the study affected households had more members participating in income-generation activities (see Table 7.2), fewer sick household members (see Section 6.2) or sick household members leave the household to be taken of elsewhere and some households experienced death (see Section 6.2). Financially, households do not recover immediately after sickness or death had occurred, as seen in chapter six (see Section

6.7). Households are therefore discretionary in their spending patterns. Due to fewer members attending health care facilities medical costs were reduced and expenditure on clothing increased.

### 8.5 Household Expenditure on Food

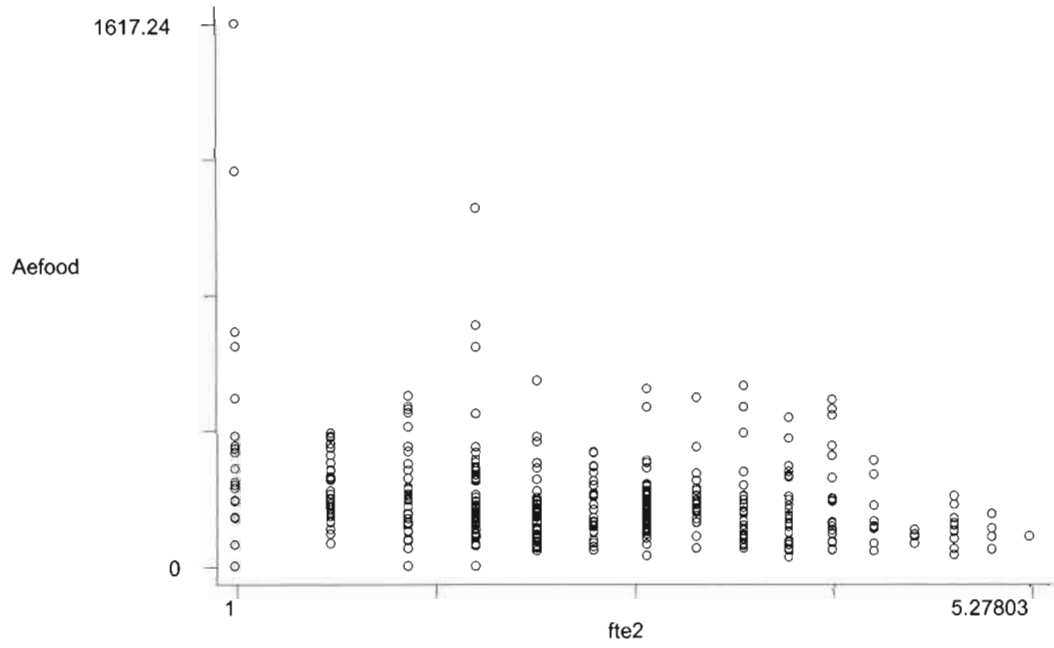
The data shows (see Figure 8.5) that as the number of sick members increases, there is a decline in per adult equivalent expenditure on food; the decline is more pronounced for affected households than for non-affected households. Even when more than one person was employed in a household, adult equivalent food expenditure still decreased when more individuals were sick in a household. This was true across both cohorts. For households experiencing death across cohorts, adult equivalent food expenditure increased. The most likely explanation is the need to purchase extra food to cater for visiting relatives. If there were more adults in the household, per adult equivalent food expenditure declined slightly; however, this was not the case if there were more children in the household.

**Figure 8.5: Per Adult Equivalent Annual Expenditure on Food Across Cohorts for Number of Sick Individuals per Household**



Expenditure on food did not decrease with reductions in household size. Figure 8.6 illustrates that the majority of households have small per adult equivalent expenditures on food irrespective of household size or household economies of scale.

**Figure 8.6: Adult Equivalent Monthly Household Expenditure on Food - Affected Cohort**



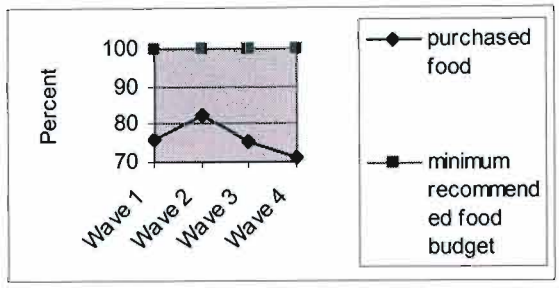

Households were asked what amount they felt was the minimum they should be spending on food (V147, Section 11.1, see Appendix 7). These figures were adjusted to account for household economies of scale and are hereafter referred to "Minimum Anticipated Food Budget." Actual adult equivalent food purchased across the waves was compared to adult equivalent Minimum Anticipated Food Budget. The non-affected cohort spent just under 80% of the levels of the Minimum Anticipated Food Budget in wave 1 and this declined to almost 70% by wave 4 (see Figure 8.7). The economic situation of these households compels them to routinely spend below their Minimum Anticipated Food Budget.

The affected cohort spent more than 90% of their Minimum Anticipated Food Budget in wave 1, increasing in wave 2 and then dropping slightly from wave 3

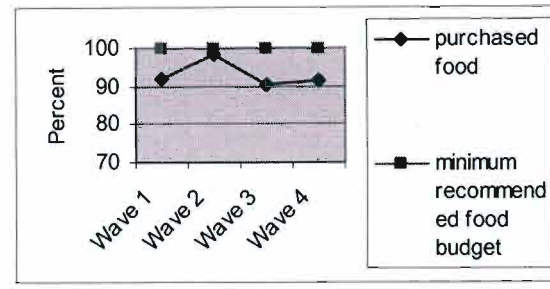
onwards; this confirms that the affected cohort assigns greater priority to the purchase of food.

**Figure 8.7: Difference between Adult Equivalent Monthly Food Purchased Versus Minimum Food Budget as Recommended by Respondents**

**Non-Affected Households**




**Affected Households**




## 8.6 Methodological Lessons

The use of the diary method as a data collection tool has been used to avoid over estimating or under estimating costs. The use of the diary complemented the respondent's memory. The study found certain costs recalled by the respondent but not recorded in the diary and vice versa. Households were informed regarding the use of the diary as a method of data collection. In approximately 15% of the cases, households had to be revisited and in all instances they were reminded at the beginning of the month to start recording expenses in the diary.

More pronounced differences were noted in six monthly or annual intervals, therefore it would be appropriate to conduct such household surveys on a six monthly basis.

Only expenditure from the pooled household budget was captured since only one respondent per household was requested to provide detailed information on expenditure for all household members. Expenditure on individual items spent by individual household members was not recorded.

Besides health care and funeral costs, there are certain expenditure categories associated with sickness and death. For example, special food items are purchased for the ill person either for consumption at home or at the hospital. Households spend more on telephone costs during death and during illness. Clothing is purchased for sick members to attend hospitals or for family members to attend funerals as well as for the deceased. Personal care items are also purchased for the ill person for hospital visits and during hospitalisation. These hidden costs should be captured as part of morbidity and mortality costs.

In some cases the costs of morbidity are transferred with the sick member who is sent to live elsewhere. This complicates the collection of data relating to sick members. Questions relating to morbidity and mortality costs should therefore be asked of all households irrespective of whether a sick person is a resident or not.

**8.7 Summary**

As with income there were two main types of expenditure - regular monthly expenditure and irregular once-off expenditure. For all households annual expenditure was made up of five key expenditure categories - housing, food, transport, education, health care and funerals with food being just over a quarter of the total expenditure. This confirms the findings of other general household surveys conducted in South Africa (see Section 2.5). Health care and funerals consumed a large proportion of the annual household budget for households affected by HIV/AIDS.

Approximately 77% of annual household expenditure for all households is regular compared to over 90% in the Free State study (Booysen et al., 2002:78). The Free State study also found about 5% of annual expenditure were transfers out in the form of remittances (Booysen et al., 2002:78), with more transfers taking place in the non-affected cohort due to higher disposable income.

This study found no significant differences in the levels of total household expenditure or the levels of food expenditure across cohorts. The study showed that there was a slight decline of food expenditure in the affected cohort per adult

equivalent as more members in the household became sick. Furthermore, the study confirms that the affected cohort spent close to their Minimum Anticipated Food Budget compared with the non-affected cohort.

While studies have found a decline in adult equivalent consumption of basic needs (see Section 2.5), this study has found a steady decline in consumption of basic essentials across both cohorts. This could be more a result of the economic position of households than a result of HIV/AIDS. However, we know from chapter seven that grants and transfers play an important role in the survival of affected households.

Affected households spent more on health care and funeral expenses and less on dependants whether they lived at home or elsewhere. Across the period of the study, expenditure on personal care declined as fewer members became sick. Depending on the cycle of HIV/AIDS at the household, the opportunity to receive treatment and whether or not households receive or transfer sick members out will determine whether the household's medical expenses increases or decreases over time. In addition to the cost of treatment, affected households incur health care cost for medicines, vitamins, personal care items including the cost of transport.

# CHAPTER NINE
# IMPACT ON SURVIVING FAMILY MEMBERS

## 9.1 Introduction

Members within households perform various functions so as to maximise personal and household utility. These activities include the allocation of work and non-work time within the household. Most previous studies focused on the impact the disease had on the health and welfare of children (see Section 2.6). This chapter focuses on the impact that sickness and death has on surviving household members, specifically on the care of children.

When specific events such as illness or death occur in a household, re-allocation of time takes place so as to accommodate these events. When a household member becomes ill, some members of the family allocate time to the sick person, many of which are classified as domestic duties, such as washing, cleaning and feeding the ill person (see Section 6.4). In cases where the ill person is AIDS-symptomatic, often the caregiver is on call "24 hours" per day (see Section 6.5.3). They do not sleep fully or sleep very lightly in case the ill person requires help during the night. Sometimes the care-giving function is shared with other members of the household so each member takes an eight hour shift.

Typically, a family would allocate time for domestic chores, production of income, schooling, working in the garden, helping neighbours or the community, visiting relatives and non-relatives, sleeping, leisure (TV or sport) and attending church. During times of illness or death, time is allocated to visit health care facilities, to care for ill persons (inter or intra-household) or to attend funerals. During the week-ends, the time spent on these activities differs. This study therefore investigates the time spent on activities during the week and on week-ends from wave 2 onwards because in wave 1 respondents were informed how to complete the time sheets. The activities of school-going children differs from that of adults, thus the analysis focuses on these groups separately.

## 9.2 Response Rate (Completion of Time Sheets)

All individuals in the household over the age of seven years were given time sheets to complete (see Section 4.9). Out of 1604 individuals in all waves, 439 individuals did not submit time sheets, a refusal rate of 27.4%. Some of the reasons for refusal were:

- They were forgetful, despite continuous telephonic reminders.
- Some children did not attend school and therefore could not read or write.
- Children were especially non-compliant. Approximately half of those who were non-compliant were school-going children.
- Approximately 6% of those who refused to complete the activity sheets were retired individuals over the age of 60.
- Approximately 54% of those who refused to comply were from the affected cohort (n=239) and 46% from the non-affected cohort (n=200).
- Respondents stated that it was a difficult task to complete because it reminded them of the sadness of the disease and the time that it consumed. For this reason only 4 caregivers from the affected cohort completed time sheets. However, caregivers did provide data on the time spent care-giving and the activity given up as a result of care-giving which was discussed in Section 6.4.

## 9.3 Time Allocation of Household Labour – Adults

Approximately 68% of the completed time sheets were from adults ranging from age 15 to 83 years. The activities most common for adults during weekdays were domestic chores, income-generation, sleeping and leisure (see Table 9.1 for actual hours spent).

On average, there were 68 individuals who were sick 21 out of 60 days in the two months preceding the interview and the average number of hours per day that they required caring was 16. Between caring for the sick member and sleeping, care-givers had no time left in the day. If one assumes the average length of sickness to

be 18 months (Rugalema, 1999:93), then on average an individual would be sick for 189 days. With 16 hours on average spent caring per day, care-givers would have spent 3 024 hours of caring over this period.

This section focuses on the reallocation of labour time for the sick member and other surviving household members. Since unemployment was high in Soweto (see Section 3.10), there was less opportunity for income-generation activities across both cohorts. Both cohorts spent more hours sleeping, performing domestic functions and on leisure than on income-generation activities.

However, as a result of sickness, there were some notable differences across cohorts. During the week, adults from the affected cohort spent proportionately less time working for wages (t-stat =2.25[1]), more time sleeping (t-stat =-3.88), visiting family and friends (t-stat =-2.41) than members from the non-affected cohort (see Appendix Table 22). This was to be expected since sickness in the household deters economically active members from working or seeking work. During sickness, sick members are expected to sleep more and there is also a tendency to receive visitors.

On Saturdays, adults from the affected cohort spent proportionately more time helping neighbours and family (t-stat =-2.28), on sleeping (t-stat =-2.72), and on attending church (t-stat =-2.17) at the expense of leisure time (t-stat =2.88) (see Appendix Table 22). It was evident from Appendix Table 22 that the affected cohort tended to help neighbours more than the non-affected cohort and that households affected by HIV/AIDS tended to seek comfort from the church.

On Sundays, adults from the affected cohort also spent proportionately more time helping neighbours and family (t-stat =-2.14) and on sleeping (t-stat =-5.64) thereby spending less time on home repairs (t-stat =3.35) or leisure (t-stat =2.83) (see Appendix Table 22).

Women across both cohorts spent more time on domestic chores than men during weekdays or on weekends. Care-giving is closely associated with domestic work,

[1] For all t-stats ==<0.05

hence women are tasked with care-giving. During week-days women spent on average 6.3 hours versus 3.3 hours spent by men on domestic chores (t-stat =12.12, p-value 0.0000).

**Table 9.1: Time Allocation of Daily Activities Across Cohorts – Adults (Hours)**

| | Week-day | | Saturday | | Sunday | |
|---|---|---|---|---|---|---|
| | Non-Affected | Affected | Non-Affected | Affected | Non-Affected | Affected |
| | n=337 | n=452 | n=337 | n=451 | n=337 | n=451 |
| Cooking, cleaning, domestic chores | 5.4 | 5.4 | 5.2 | 5.2 | 5.2 | 5.2 |
| Income-generation activity | 3.3 | 2.6 | 1.4 | 1.1 | 0.7 | 0.4 |
| Visiting friends and family and receiving visitors | 0.5 | 0.8 | 1.5 | 1.7 | 1.3 | 1.4 |
| Sleeping | 8.3 | 8.7 | 8.7 | 9 | 8.7 | 9.5 |
| Leisure hours | 4.9 | 4.5 | 5.3 | 4.6 | 5 | 4.4 |
| Travel time to and from work | 0.5 | 0.5 | 0.25 | 0.3 | 0.1 | 0.2 |
| Time spent shopping including travel time | 0.1 | 0.1 | 0.4 | 0.4 | 0.0 | 0.0 |
| Church (travel time plus at church) | 0.0 | 0.1 | 0.28 | 0.5 | 2.2 | 2.35 |
| Attending funerals | 0.0 | 0.0 | 0.43 | 0.5 | 0.2 | 0.1 |
| Caring for sick individuals | 0.05 | 0.7 | 0.05 | 0.2 | 0.0 | 0.11 |
| Other | 0.95 | 0.6 | 0.49 | 0.5 | 0.6 | 0.34 |
| Total daily hours | 24 | 24 | 24 | 24 | 24 | 24 |

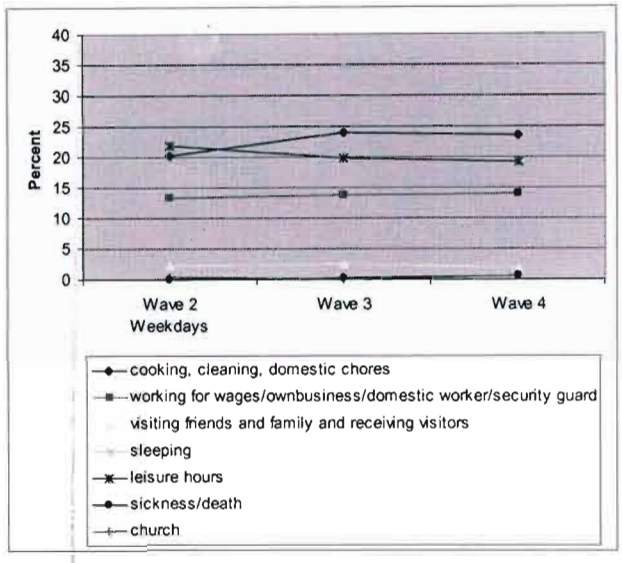
### 9.3.1 Time Allocation for Adults Across Waves

The analysis over time is illustrated in the proportion of time spent in each wave for the non-affected cohort and the affected cohort respectively.

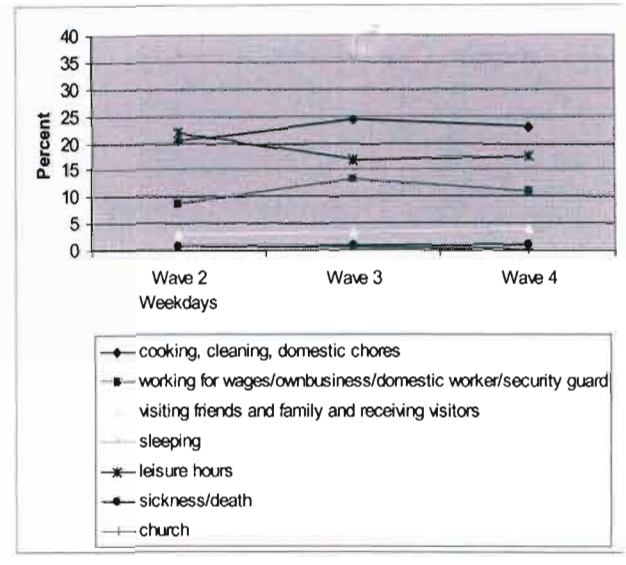
During week-days, by wave 4, both cohorts increased the proportion of time spent on income-generation and domestic work, reducing leisure time (see Figure 9.1). As employment opportunities emerge, more time can expect to be spent on income-generation.

**Figure 9.1: Non-Affected Cohort and Affected Cohort – Proportion of Time Allocated– Weekdays (Adults)**

**Non-Affected Households**



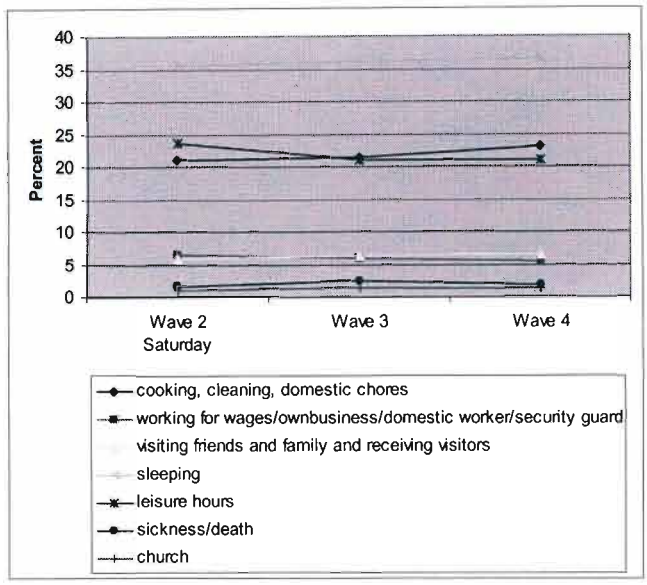

**Affected Households**

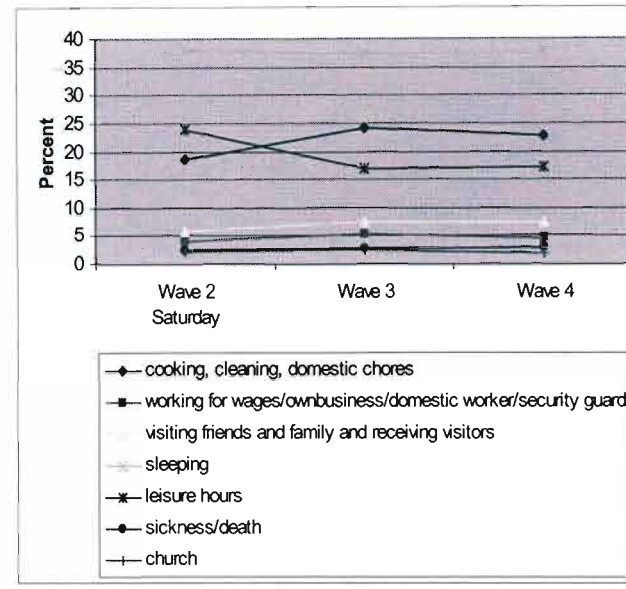



On Saturdays, by wave 4, both cohorts spent a higher proportion of time on domestic work, visits and attending funerals while reducing leisure time. By wave 4, as the number of sick individuals decreased (see Table 6.2), the affected cohort increased the proportion of time on income-generation and reduced the proportion of time spent on sleeping (see Figure 9.2). The non-affected cohort increased the proportion of time on domestic work sacrificing leisure time.

**Figure 9.2: Non-Affected Cohort and Affected Cohort – Proportion of Time Allocated– Saturday (Adults)**

**Non-Affected Households** **Affected Households**

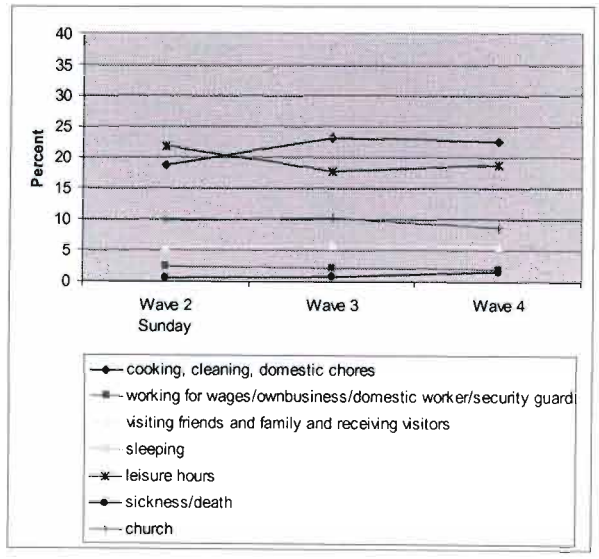


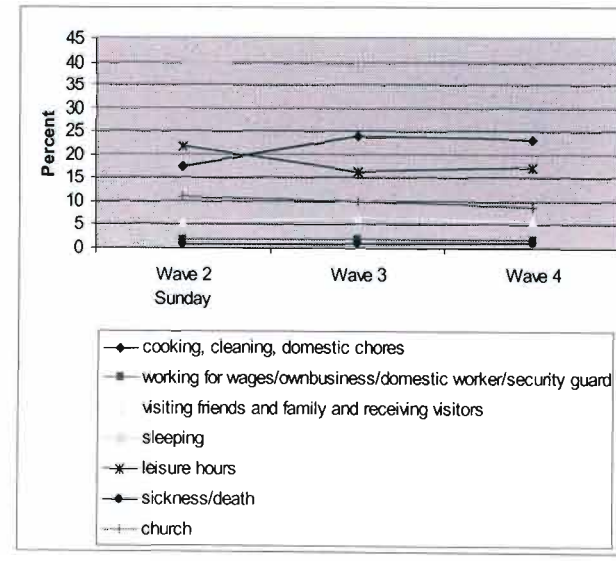




On Sundays by wave 4, a greater proportion of time was spent on domestic chores, attending funerals and visits reducing the proportion of leisure time or time spent attending church (see Figure 9.3). The evidence suggests that as the number of funerals increase more time would be spent attending funerals on week-ends.

**Figure 9.3: Non-Affected Cohort and Affected Cohort – Proportion of Time Allocated– Sunday (Adults)**

**Non-Affected Households** **Affected Households**



### 9.4 Time Allocation for School-Going Children Across Cohorts

Of the completed 1165 time sheets, 376 were from children attending school, their ages ranged from seven to 25 years. The most common activities (see Appendix Table 19) performed by children were related to schooling, domestic chores, visiting relatives and non-relatives (during weekends), sleeping, or leisure.

All children spend an average of just under seven hours per day at school and about half an hour travelling to school. Children were expected to spend at least three hours per day during the week performing domestic chores which increased over week-ends. During the week, there were no noticeable differences in the allocation of time for children across cohorts except that children from the affected cohort spent less time on leisure activities (see Appendix Table 21, t-stat =2.07).

On Saturdays, children slept for an extra hour. Children from the affected cohort spent more time visiting friends and relatives (see Appendix Table 21, t-stat = -2.73) and less time on school work (t-stat =2.32). More time was spent on Saturdays on visits because on Sundays more time was consumed attending Church. On Sundays, children slept nine hours on average, with children from the affected cohort being allowed to sleep 6% more (see Appendix Table 21, t-stat =-2.58).

The question is how does HIV/AIDS alters the time allocation of activities of children? It appears that children from affected households did not attend school any less due to illness in the household. However, they did spend proportionately less time on school work especially on Saturdays (see Appendix Table 21, t-stat =2.32). This could be as a result of receiving visitors.

Children from the affected cohort spent more time visiting relatives and non-relatives, presumably because their parents did more visiting and received more visitors as a result of illness in the household. Generally, children did not conduct care-giving functions. Only one child did not attend school for a few days because a parent was ill and only one child came home early from school to check on a sick parent. Due to high unemployment, household size and composition, care-giving is usually performed by the unemployed adults in the household (see Section 6.4).

Although sickness and death at households did not appear to significantly affect the time allocation of children's activities, further research should be conducted on the psychological aspects of children from households affected by HIV/AIDS, since school performance may be affected.

**Table 9.2: Time Allocation of Daily Activities Across Cohorts – Children (Hours)**

| | Week-day | | Saturday | | Sunday | |
|---|---|---|---|---|---|---|
| | Non-Affected n=145 | Affected n=231 | Non-Affected n=145 | Affected n=230 | Non-Affected n=145 | Affected n=230 |
| Studying, attending school or doing school work | 6.8 | 6.7 | 0.8 | 0.5 | 0.5 | 0.6 |
| Cooking, cleaning, domestic chores | 3.1 | 3.1 | 4.4 | 4.6 | 4.3 | 4.2 |
| Visiting friends and family and receiving visitors | 0.8 | 1.0 | 2.3 | 3.0 | 1.7 | 2.1 |
| Sleeping | 8.4 | 8.5 | 9.2 | 9.3 | 9.1 | 9.7 |
| Leisure hours | 4.3 | 3.8 | 6.6 | 6.2 | 4.8 | 4.5 |
| Travel time to and from school | 0.6 | 0.5 | 0.0 | 0.0 | 0.0 | 0.0 |
| Church (travel time plus at church) | 0.0 | 0.0 | 0.1 | 0.3 | 3.0 | 2.8 |
| Attending funerals | 0.0 | 0.0 | 0.0 | 0.1 | 0.1 | 0.1 |
| Other | 0.1 | 0.4 | 0.6 | 0.0 | 0.5 | 0.0 |
| Total Daily Hours | 24.0 | 24.0 | 24.0 | 24.0 | 24.0 | 24.0 |

### 9.4.1 Time Allocation for School-Going Children Across Waves

The analysis over time was analysed in the proportion of time spent in each wave for the non-affected cohort and the affected cohort respectively (see Appendix 20). Overall, the study showed no evidence of changes in children's activities as a result of illness. The study showed that children from the affected cohort spent proportionately more time sleeping as did adults from affected households and more time on visitors as did adults from affected households (see Section 9.3). The direction of change over time, across both cohorts was similar suggesting that illness in the household did not alter the time allocation of children's activities.

### 9.5 Impact on Surviving Household Members

In only 13% of the households was there more than one person infected. The fact that only 9% of all individuals that were ill were married or cohabited reduced the incidence of cross-infection at household level (refer to Section 6.2).

Strains on financial resources were caused by households purchasing healthier food, vitamins, clothing and other requirements for the sick person, especially in cases where the person had stopped working. Other members of the family sacrifice certain essential items in favour of purchases for the ill person. Some households stated that they rely on the disability grant income of the HIV/AIDS infected person and concerns were raised about their survival after the person's death because this source of income would cease. In terms of financial impact, the majority of respondents felt that the low cost of treatment from the public health care facilities helped relieve the financial burden somewhat.

Surviving family members felt they had to deal with the heavy truths about HIV/AIDS - that it is incurable, that treatment only extends life and that in the absence of proper treatment it is uncertain how long the ill person will live. In most households family members were greatly concerned about the person's illness, were depressed and felt helpless. They felt they had little knowledge of how to survive emotionally and were pressured by constant demands from relatives and non-relatives for information about the person's illness. Some isolated themselves as a result and also because of the stigma surrounding HIV/AIDS. Multiple deaths caused some families chronic depression especially when adult parents, siblings and spouses from the same household died. Some stated that they could not bear to see their loved ones in so much pain that they prayed for premature death. They faced the daily challenges and lived from moment to moment. They felt that there was no time to plan long-term or to think about the long-term effects of their actions.

Children did not know why the person was ill or if the person would be healthy again. The non-communication between adults and between adults and children further promoted stress within households.

Caregivers were concerned that they would be left with the burden of child-rearing after the death of their adult children in the time of their lives when they themselves required caring, being in their retirement phase.

In some cases, spouses and retired household members had to go out in search of work to contribute to household income as a result of sickness or death.

Respondents were asked if any expense had been cut back as a result of the additional costs and the value of the cut-back. Items mainly cut back were food and other essential items. Non-affected households cut back expenses to the value of R54.50 on average for all waves in the two months prior to illness, while affected household cut back on expenses to the value of R448.74.

HIV/AIDS may cause households to dissolve. Three households dissolved because the breadwinner died and children had to be placed with relatives in other households. In one case where the household was followed, the grandmother moved into an informal settlement with the children of the deceased. The grandmother also had a house in Soweto where she was regarded as the household head and had to share her old-age pension grant to run both households (see Case Study 9.1).

On the positive side some respondents stated that the illness had brought the family closer. Due to the love and support of family members and children, ill persons find reasons to live and fight the disease.

### 9.6 Impact on the Care of Children

While children's labour time may not be re-allocated as a result of sickness or death, the care of children is impacted. As a result of adult illness, one child was sent to live with relatives and as a result of adult death, three children were sent to live with relatives. Out of the 51 deaths, leaving aside two who were children, only 1 deceased person had a will. This has serious implications. In the absence of a will, adult members of the family informally inherit the belongings of the deceased. In one case where both parents died, the grandmother kept the family house intact

and moved in with the children. In another case the children relocated to the maternal aunt. The house remained unoccupied and the car unused. The aunt stated that she would prefer to keep these assets until the children grow up, although by the time the children grow up, the car might not be in a working condition and a few years rental income would have been forfeited. Poor financial planning and a lack of a will would leave children of HIV/AIDS families vulnerable.

There were no cash inheritances as a result of death by any household. The availability of cash is limited especially after funeral expenses have been paid. Fourteen households in the affected cohort inherited furniture, clothing, cars and houses of an average value of R25 000. These were items belonging to the deceased and were informally inherited by the household in the absence of a will.

Only 16 out of 43 households received lump sum payments as a result of death (see Section 6.5.4). These funds were used to pay for the funeral and the excess was either saved or used to run the household.

No children from the affected cohort were withdrawn from school as a result of death. Only four children from the non-affected cohort of school going age were not at school. This was due to one child being pregnant, one whose family could not afford school fees, one who was disabled and one was too ill to go to school. The study also found three children in the non-affected cohort whose school fees were not paid in a school in the suburbs; the mother did not want to enrol the children at a school in Soweto. The children were hidden because the mother was ashamed that she could not afford the fees after telling neighbours that education in Soweto was less than adequate.

Across both cohorts, the majority (85%) of children go to school by themselves, mostly (72%) on foot. Approximately 4% of children from the non-affected cohort and 10% of children from the affected cohort consume less than three meals per day. Supervision of children's homework is mainly done by other family members in the affected cohort and by the child's mother in the non-affected cohort (see Table 9.3).

**Table 9.3: Supervision of Children's School Work (Percentage of Households)**

| | Non-Affected | Affected | Percentage Difference |
|---|---|---|---|
| Nobody | 7.8 | 14.9 | 91.13 |
| Grandparent | 6.5 | 8.5 | 31.06 |
| Mother | 39.0 | 28.7 | -26.28 |
| Older child | 13.0 | 9.6 | -26.28 |
| Father | 5.2 | 2.1 | -59.04 |
| Other family members | 24.7 | 34.0 | 37.96 |
| Neighbour | 3.9 | 2.1 | -45.39 |
| | 100.0 | 100.0 | |

In one fifth of the households children from the affected cohort cared for themselves after school. Grandparents played a large role in after care across cohorts. The child's mother or father played much less of a role in after care for children from the affected cohort (see Table 9.4).

**Table 9.4: Care of Children after School (Percentage of Households)**

| | Non-Affected | Affected | Percentage Difference |
|---|---|---|---|
| Nobody | 11.1 | 23.5 | 111.7 |
| Grandparent | 22.2 | 24.5 | 10.4 |
| Mother | 39.5 | 23.5 | -40.5 |
| Older child | 6.2 | 5.1 | -17.7 |
| Father | 4.9 | 2.0 | -59.2 |
| Family members | 16.0 | 21.4 | 33.8 |

Table 9.5 shows the percentage of children in each cohort that had either lost one or both parents or had one or both their parents alive but living elsewhere and therefore were being cared for by someone in the sampled household. In the affected cohort there were significantly more children whose parents were alive and living

elsewhere and children were being cared for by members of the sampled households (t=-2.87, p=0.00). There were more children from the affected cohort that had either lost their mother or their father or both parents. The categories in Table 9.5 were not mutually exclusive. It was difficult to ascertain the percentage of children fostered because only households that received the foster care grant (three out of 318 children) described the child as a foster child. Other children were described as grandchildren, great-grandchildren or nieces and nephews. By drawing the kinship diagrams (see Section 5.4) it was possible to ascertain the percentage of children who were being cared for by the household in the absence of their parents. In this case, cared-for children could be used as a proxy for foster children. None of the households that housed cared-for children received child support grants. However, it was not established whether the living parent who lived elsewhere might be receiving the grant.

**Table 9.5: Categories of Children (Persons 15 years and younger)**

| | **All Households n=318** | **Non-Affected n=152** | **Affected n=166** | **Percentage Point Difference** |
|---|---|---|---|---|
| % of children under 7 years | 55 | 57 | 53 | 4 |
| % of children who did not have one parent live in the same household | 60 | 61 | 59 | 2 |
| % of cared-for children | 16 | 13 | 18 | 5 |
| % of children who lost their father, but mother alive | 16 | 9 | 23 | 14 |
| % of children who lost their mother but father alive | 8 | 3 | 11 | 8 |
| % of children who lost their mother and father | 21 | 11 | 31 | 20 |

### 9.6.1 Care of Children if Adults are too Sick

Respondents were asked who would take care of children in the household if adult members became too sick to do so. Two in five affected households stated that either they did not have anyone to take care of their children or that older siblings will take care of younger children. It was interesting to note that the child's surviving parent was expected to play a small role (see Table 9.6). This is because many children are raised by a single parent mainly the child's mother with little contact with the other parent. The fact that the child's maternal family plays a huge role in the raising of the child makes this an obvious choice for future care-giving. The government, through an orphanage or institution, is expected to carry the burden of care-giving in cases where there are no adults nominated to care for the child, or if the child is expected to be left at an orphanage or if older siblings are expected to take care of children. In three-quarters of the households, extended families were expected to carry the burden of fostering.

**Table 9.6: Care of Children in the Absence of Healthy Adults (Percentage of Households)**

| | All Households | Non-Affected | Affected |
|---|---|---|---|
| Paternal uncles/aunts | 4.2 | 5.8 | 2.6 |
| Maternal uncles/aunts | 25.8 | 24.6 | 26.9 |
| Mother's parents | 16.6 | 23.2 | 10.6 |
| Father's parents | 6.5 | 8.7 | 4.4 |
| Older or adult siblings of children | 17.9 | 17.9 | 18.1 |
| Clan, community, neighbours, etc | 1.4 | 1.0 | 1.8 |
| Orphanage/Institution | 7.4 | 7.3 | 7.5 |
| No-one | 15.9 | 9.2 | 22.0 |
| Child's surviving parent | 4.4 | 2.4 | 6.2 |

**Case Study 9.1: Split Household** [2]

Beatrice was the head of the household in Pimville and the mother of the deceased income-earner (Sally). Beatrice was retired and received an old age pension grant. When Sally's husband died, and after she became ill, she moved back to her family home in Pimville with her children. Besides Beatrice, no-one in this household knew of the cause of death of Sally's husband or that Sally was dying of AIDS.

After Sally's death, the household split and Beatrice moved to Orange Farm, a neighbouring settlement surrounding Soweto to take care of Sally's two children. Sally built this house for her children prior to her illness. Beatrice appointed another daughter of hers temporary head of the household in Pimville. Beatrice still considers herself the head of that household too since she is responsible to purchase the groceries for both households and takes care of all the expenses and the decisions surrounding the inhabitants of both households. The household size in wave 1 prior to the split was 7 members with Sally's death it would have been 6 members from wave 2. However, two new members joined one in each of the split household to help with child-care. This meant that each household had 4 members from wave 2. In wave 1, R750 was spent on regular expenditure; in wave 2 the same amount was spent but split over two households feeding more members than before. From wave 3, both households started spending to the previous level since Beatrice let out some of the rooms in the Orange Farm dwelling, borrowed money as well as received financial help from relatives.

Sally saved R7 438 towards her funeral. The funeral cost R7 835, a shortfall of R397. However, the family received R4 897 from relatives. After paying for funeral costs, the household saved R4 500 which they used to sustain themselves in the months following the death. The combined average monthly regular income for these two households was R1 343 and expenditure R1 605, a shortfall of R262 just on regular monthly expenditure alone. It would take these two households 17 months to deplete the savings notwithstanding the fact that there is irregular expenditure such as schooling that has to be paid.

[2] Both these households were followed during the period of the study. Names have been changed.

## 9.7 Methodological Lessons

The completion of time sheets was a lengthy exercise for respondents as well as for data capturing and analysing. It would have been easier to ask respondents how their time allocation had changed since the presence of illness and or death but such recall would probably have resulted in estimates of questionable accuracy. Almost a third of household members did not complete the time sheets.

For studies of this nature it is important to follow households that split. However, it is just as important to have the same fieldworker interview both households to ensure that remittances or transfers out from one household is recorded as a transfer in to the receiving household and that expenses or assets are not duplicated in the split household.

## 9.8 Summary

Adults from the affected cohort worked fewer hours, spent more time on visitors and on activities relating to sickness and or death. There was some evidence to suggest that the Church assumed a place of comfort for members from the affected cohort. As the number of people sick decreased in the affected cohort over time, the proportion of time spent on income-generation increased. In both cohorts, there was more time spent on domestic chores than on income-generation activities due to the high rate of unemployment.

Setting aside unemployment, care-giving do consume a lot of time as illustrated in this and other studies (Rugalema, 1995:93-95). Women play a key role in the provision of care for HIV/AIDS persons, as was found in the Rural Tanzanian study (Rugalema, 1999:95). It was not always easy to differentiate between domestic activities and care-giving because much of the care-giving was around domestic activity for the sick person as found in Rugulema (1999:96).

While care-giving consumed a lot of adult time, this was not the case with children. Children were not directly involved in care-giving although they appeared to have followed the same routine as adults, namely, they slept more and spent more time

with visitors. Children were not readily enlisted to help. This is as a result of urban households being in close proximity to each other enabling neighbours and friends to help especially with domestic work (see Figure 10.2). Although sickness and death at households did not appear to affect the re-allocation of children's time, future research should focus on the psychological implications and on school performance. Although no child was withdrawn from school (as occurred in other studies, see Section 2.5), it was unknown whether children were performing at their usual levels or not. Furthermore, this study has shown that the care of children was impacted by the disease and that children were being left to care for themselves. This has longer term implications on the education, health and welfare of children.

Poor financial planning on the part of adults would leave children in a less fortunate position in cases where assets would be under-utilised or abandoned. Even when there was income as a result of death, it was used not only for the funeral but for the household to sustain itself in the months following death (see Case Study 9.1). No formalised planning arrangements were made for children after their parents' death as found, for example, in the Uganda study (see Section 2.6). The extended family is assumed responsible irrespective of whether they wanted to or whether or not they had the financial resources. As found in other studies (see Section 2.6), affected and non-affected households were called upon to accept new members because of sickness or death or because they were better resourced to do so (see Section 5.3.2).

No HIV/AIDS economic studies focused on the psychological aspects of the disease. Surviving family members felt emotionally and financially drained by the epidemic. They were not sure how to deal with neighbours and relatives when they asked the reason for the illness. They were afraid of stigma and discrimination and felt isolated. Retired individuals were concerned with being left with the burden of child-rearing. As a result some households dissolved and the children were sent to live elsewhere while in other cases non-economically active members joined the labour force.

# CHAPTER TEN

# INTER-HOUSEHOLD CARE AND SUPPORT

## 10.1 Introduction

This chapter deals with the non-financial support and care of HIV/AIDS and other sick individuals which is provided by members of other households and organisations. The extent to which home-based care operates in an urban community is investigated and a description of the type of care provided and received relative to the needs of the households is studied, thereby uncovering unmet needs of affected households in terms of care and support. Moreover, the study analyses the quality of care and support received. The chapter complements the data on financial flows to affected households (see Section 11.5.2). The chapter also examines stigma and discrimination faced by households.

Approximately 41% of all respondents perceived that taking care of sick members of other households in the community was common, while the rest perceived it to be rare or not at all common. A higher percentage of non-affected households (50%) than the affected cohort (34%) perceived that helping other households during times of sickness was common. While sickness is very much a private event, death is a more public event and approximately 95% of respondents perceived that supporting other households during time of death was common.

## 10.2 Households Providing Care

Care and support is being provided by households in Soweto particularly those affected by HIV/AIDS (68% versus 56% respectively, see Table 10.2). However, when more households have individuals sick (see Table 10.1), as was the case in wave 1, fewer households provided care (see Table 10.2) to other households. This is understandable because ill individuals consume a lot of time, leaving fewer hours available to assist other households. However, as ill individuals recover, more time becomes available to assist other households (see Tables 10.1 and 10.2).

**Table 10.1: Percentage of Households with Sick Individuals**

| | Wave 1 | Wave 2 | Wave 3 | Wave 4 | All Waves |
|---|---|---|---|---|---|
| Non-Affected | 27.1 | 15.1 | 13.5 | 15.4 | 18.1 |
| Affected | 74.2 | 54.7 | 28.6 | 34.9 | 48.4 |

**Table 10.2: Percentage of Households Providing Care**

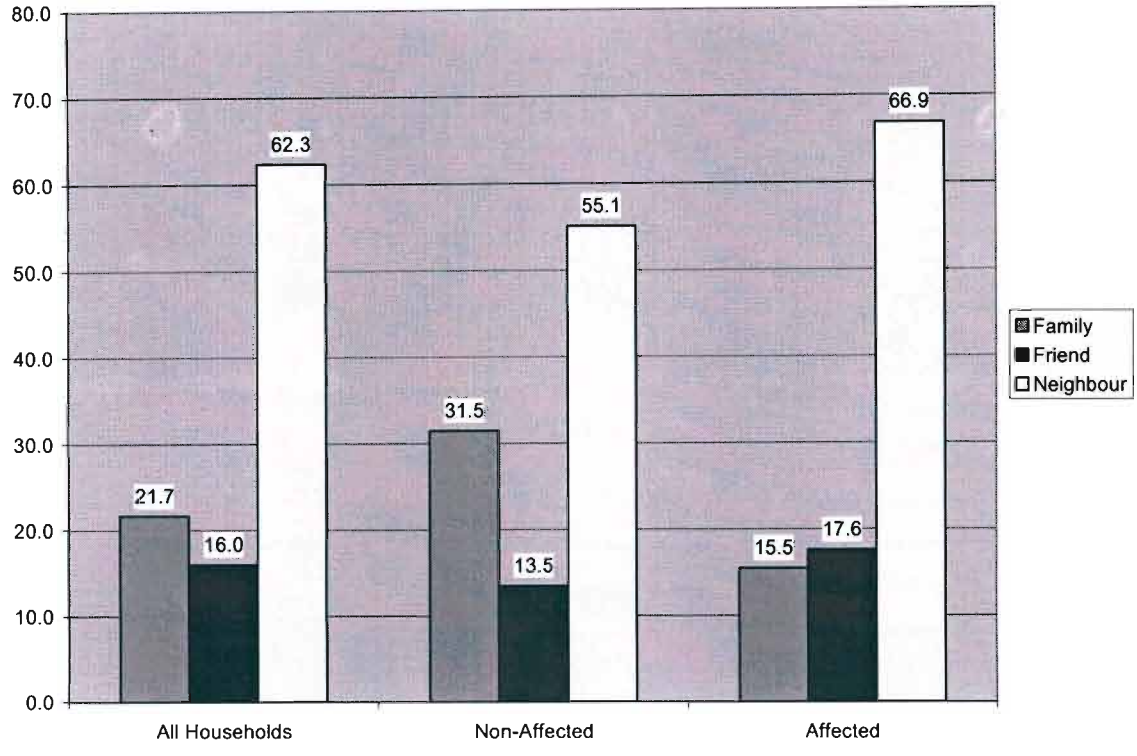
| | Wave 1 | Wave 2 | Wave 3 | Wave 4 | All Waves |
|---|---|---|---|---|---|
| Non-Affected | 52.5 | 54.7 | 61.5 | 53.8 | 55.6 |
| Affected | 47.0 | 67.2 | 76.2 | 81.0 | 67.6 |

Most of the care across cohorts is provided to neighbours (see Figure 10.1). This could be attributed to the fact that households in Soweto are in close proximity to each other due to small plots and because households in Soweto are well established and families have been living next door to each other for many years. The majority of household heads were born in Soweto (63%) and only 10% of those not born in Soweto had moved there less than 10 years before.

Twice the proportion of households from the non-affected cohort supported relatives. Just over half the non-affected households were engaged in the provision of care and support to neighbours, relatives and friends.

Methodologically, the perception of care and support in the community is not a good proxy for actual provision of care and support. The study found that a higher proportion of households provided care than the proportion of households which perceived that support in the community was common. However, it was interesting to note that a higher proportion of non-affected households thought that care and support was common and a high proportion of these households provided care and support.

**Figure 10.1: To whom is the Care Provided? (Percentage of Households) – All Waves**



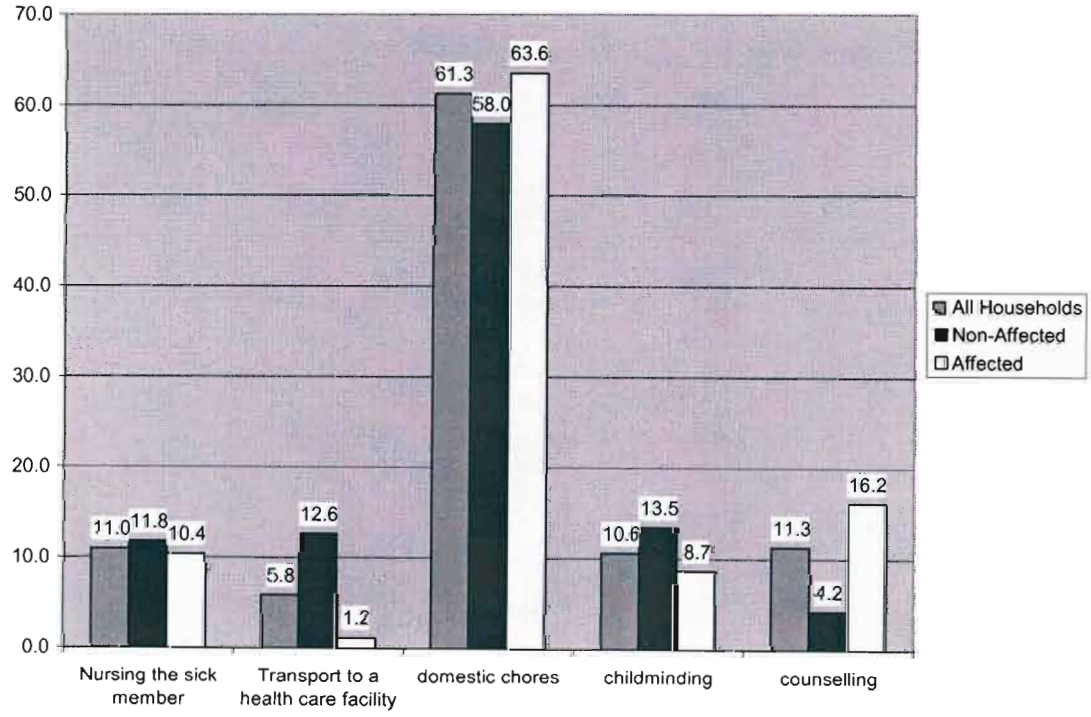

Most of the care provided involved helping households with domestic chores. On average the sick person consumes an average of 16 hours per day of care-giving. Given that caregivers sacrifice time they would have spent on domestic chores (see Section 6.4), most of the help provided was also in this area. Since sickness is more a private issue, sick individuals do not wish to be bathed, nursed or fed by neighbours. The caregivers of the household prefer to provide these functions and enlist help with domestic chores. Only about 11% of households provided nursing care to sick individuals, in other households.

It was interesting to note that counselling was more likely to be provided by members of affected households. This could be as a result of affected households receiving counselling at some point and therefore felt better equipped to provide such help.

Support in terms of child-minding is particularly required when adults have to attend or accompany sick individuals to public health care facilities. Almost 10% of households provided this type of support.

Non-affected households, possibly because of their greater wealth, were more likely to provide help with transport to health care facilities. This type of support is required during health care emergencies and during the latter phases of HIV/AIDS when the ill person is too ill to walk. Public transport is inadequate in these instances.

**Figure 10.2: Type of Care Provided by Cohort – Percentage of Households (All Waves)**




## 10.3 Households Receiving Care

In each wave, there were a higher proportion of households from the affected cohort receiving care and support. Approximately 40% of all households in the affected cohort received care and support from other households in the community at least once during the year of study.

It was interesting to note that a higher proportion of households reported providing support than receiving care and support (see Tables 10.2 and 10.3). It was also interesting to note that households continued to receive support even when individuals in the household were not sick.

Non-affected households appeared to have stronger safety networks because households that experienced sickness (see Table 10.1) received support (see Table 10.3). On the other hand, only half as many households in the affected cohort that was sick received care in waves 1 and 2. However, as the illness progressed more households received care and support.

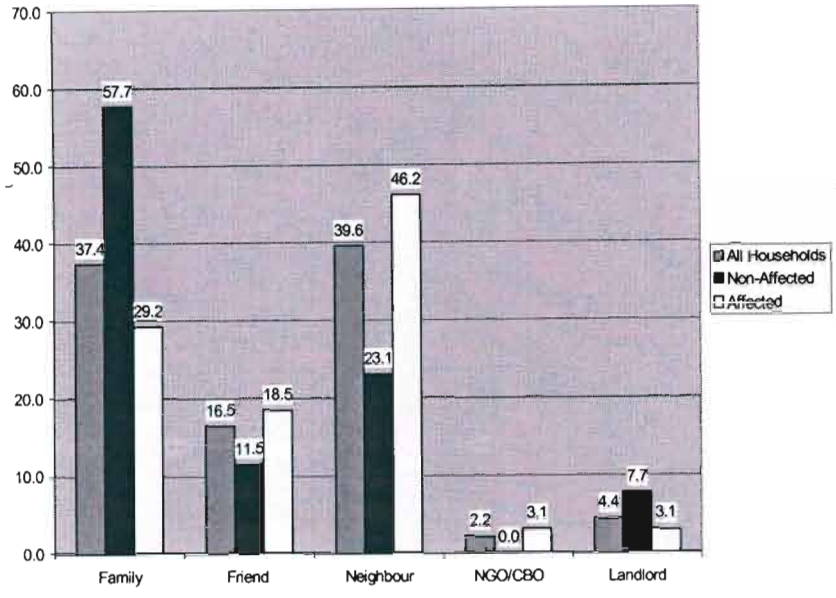
**Table 10.3: Percentage of Households Receiving Care**

| | Wave 1 | Wave 2 | Wave 3 | Wave 4 | All Waves |
|---|---|---|---|---|---|
| **Non-Affected** | 25.4 | 15.1 | 21.2 | 28.8 | 22.7 |
| **Affected** | 31.8 | 28.1 | 44.4 | 58.7 | 40.6 |

It is interesting to note that the affected cohort received very little support from non-governmental organisations or community based organisations although there is a high visibility of these organisations in Soweto. Non-governmental organisations mainly supported the affected households since their mandate is to provide support and help to households affected by HIV/AIDS. Since most of the help that they provide is with domestic chores their counselling functions were limited. Few individuals from the affected cohort stated that they were attending support groups and the individuals attending support groups did not see this as being part of counselling.

Twice as many households from the non-affected cohort were supported by family versus a third from the affected cohort (see Figure 10.3). The affected cohort relied more on support from friends and neighbours. This may be due to the fear of discrimination and lack of support from family should the true nature of illness become known.

**Figure 10.3: From whom is the Care Received?**




Most of the care received was in terms of childminding, with neighbours and family providing this function and more than half of the households from the affected cohort requested this type of help.

Very few households from the affected cohort received help with counselling and the majority of households saw this as an unmet need (see Table 10.4). Counselling is important not only for the HIV-infected individual but for all family members to provide them with tools to handle issues of grief, anger, stigma and discrimination resulting from the illness. Although few households from the non-affected households saw this as an unmet need, non-affected households also required counselling to prepare them to deal with HIV/AIDS in the community.

In terms of the quality of care received, approximately 98% of respondents stated that the quality of care was very good or good. Households are very appreciative of the care that is provided by neighbours and the community, although the type of care that is being received is not necessarily the type of care that is required by households (see Table 10.4).

## 10.4 Unmet Needs Identified by Households

Households were asked what help they expected to require in the next 12 months (see Table 10.4). The majority of households across cohorts were expected to need some form of help. However, there were a higher percentage of households from the affected cohort that expected to need help.

Since child-minding was the major support received by households, the unmet needs identified by affected households are in terms of counselling, financial help including food, domestic chores, nursing and transport.

Affected households requested financial help to cover the cost of basic essentials. Respondents felt that help with domestic chores would free up more time for them to perform care-giving functions to ill individuals. Domestic chores included bathing and performing other basic functions for the ill person. Furthermore, home-based care and nursing help was being requested. Many non-governmental organisations providing home-based care find that they spend most of their time performing domestic chores at the household. This is because the ill person consumes so much time of the caregiver that very little or no time is left for domestic chores. Help with transport costs were requested because the cost of transport to attend health care facilities in many cases exceeds the cost of attending the facility. This has implications for the roll-out of anti-retroviral therapy because the high cost of transport may prevent individuals adhering to therapy. It was interesting to note that very few households from the affected cohort requested help with employment. Care-giving consumes a lot of their time; moreover, they are aware of the difficulties of the sick individual finding employment.

Non-affected households mainly expected to require help with employment, food parcels and child-care which would allow the economically-active members to go out in search of work.

**Table 10.4: Help Required in the Next 12 Months (Percentage of Households)**

| | Non-Affected Households | Affected Households |
|---|---|---|
| Number of households | 52 | 63 |
| Percentage of households requiring help | 69 | 87 |
| **Type of Help Required:** | | |
| Childcare | 45.5 | 54.5 |
| Counselling | 17.4 | 82.6 |
| Financial | 21.9 | 78.1 |
| Employment | 83.3 | 16.7 |
| Food | 48.6 | 51.4 |
| Domestic chores | 20.0 | 80.0 |
| Nursing | 27.5 | 72.5 |
| Transport | 24.1 | 75.9 |

### 10.5 Stigma and Discrimination

Some households did not welcome help for fear of stigma and discrimination and the precise nature of illness remains very much a private issue. The fear of discrimination meant that households found it easier to send children to be minded by other households than to receive physical help in the household.

Stigma is described as a quality that discredits an individual or group in the eyes of others (Link, 2000). Discrimination is described as any "different or unequal" treatment that disadvantages a person (Crawford, 2002). The community that helps eradicate the impact of HIV/AIDS on households on the one hand is also a source of discrimination and stress.

To avoid stigma and discrimination, HIV/AIDS was referred to by many different names such as:

- Amagama amathathu
- Ingculaza
- Phamkati

- Z3
- Phungula
- Omo
- Icheese
- 5 to 12
- Mzala
- BioSlim
- Koloyi ya Eliya

The study found ten individuals who had disclosed their status and had volunteered their services to HIV/AIDS organisations. Disclosure allowed these individuals to become AIDS educators and activists which possibly may result in greater community acceptance.

The study found 13 households, all from the affected cohort, which reported being discriminated against as a result of illness in the household. The reason why the number is small is because the majority of households kept the illness private. In fact, within most households not even all members knew about the nature of the illness, particularly children. In some cases, interviews took place behind closed doors and when not all members of the household were present in order to maintain confidentiality.

Respondents were asked to describe the nature of the discrimination (see Table 10.5) and explain how it was handled. Discrimination involved negative comments from neighbours and a feeling of isolation by people not wanting to socialise with them. The community wanted to know the cause of illness and whether or not the person is going to die but were they ready to handle the truth about the person's HIV/AIDS status, deal with their fear of death and provide support to the sick person and the family? Individuals who showed visible signs of illness were often isolated by other households. The discriminated families and the ill individual prayed for comfort and appeared to be brave, but often felt sad and depressed.

**Table 10.5: Discrimination against Households Experiencing Sickness**

| Nature of Discrimination | How was it Handled? |
|---|---|
| Accusations that the family cannot afford health expenses | Was counselled by family members, ignored comments and focussed on the funeral |
| Relatives and non-relatives wanted to know the diagnosis of the sick person and whether or not the person is going to die | Depressed, prayed a lot more for help to cope |
| Neighbours predicted the person was going to die because of the weight loss. Some friends stopped visiting the sick person for fear of what the illness might be | Avoided people with negative comments and welcome people who are supportive |
| Rumours were that the sick person was going to die so some friends stopped visiting | Forgave those people because they were ignorant |
| The sick person had accidentally killed his brother and had been ostracised ever since | Ignored the comments because he knew the truth |
| People wanted to know if the sick person had HIV/AIDS | Avoided these people |
| Neighbours passed comments that the ill person was going to die | Believed that everyone is going to die someday and that his time was sooner |
| People stayed away stating that everyone from this household was going to die | Reported to the local police |
| People stayed away because they were afraid the person was going to die | Ignored such people |
| Boyfriend's father called the sick person a whore stating that was how she contracted the disease | Got depressed and prayed a lot |
| People discussed HIV/AIDS and opportunistic illnesses in front of the sick person without the person disclosing their HIV status | Prayed and ignored the comments |
| People stated that weight loss = HIV/AIDS | Ignored the comments because she knew her family loved her with or without HIV/AIDS |
| Neighbours wanted to know the diagnosis and no longer associated with the sick person | Ignored the comments and stayed at home |

Families avoided disclosing the cause of death for fear of discrimination (see Table 10.6). Respondents stated that their families felt isolated. Households that experienced discrimination handled it by ignoring the comments, joining a support group or going to church which helped them through the difficult times. There was much ignorance surrounding the disease and how to support people infected and affected by HIV/AIDS.

**Table 10.6: Discrimination against Households Experiencing Death**

| Nature of Discrimination | How was it Handled? |
|---|---|
| Comments such as "she was a whore, therefore she died of HIV/AIDS" | Relied on some neighbours who were kind and supportive |
| The family was sworn at and there was gossip about the condition of the deceased prior to death | Joined a support group and associated with friends who are supportive |
| When people talked about her husbands death they directed comments to the ill person disclosing her status to everyone in her presence | Got support from the family of the landlord and ignore the neighbours comments |
| People talked about the cause of her husband's death, stating that she would follow soon | Ignored the comments |
| People passed comments about the husband's death | Ignored the comments |
| Neighbours passed negative comments | Went to Church and prayed more |
| Neighbours passed negative comments, stating she is going to die in 3 months | Ignored the comments |
| Community accused her of using her boyfriend to feed her family | Presented the case to the community forum |
| People wanted to know if she has HIV/AIDS | Stayed away from negative people |

## 10.6 Summary

No HIV/AIDS studies focussed on inter-household obligations of care and support prevalent in urban settings. This study found more households reported providing care than receiving care.

The main types of care provided was help with domestic chores, followed by counselling, nursing the sick member, providing transport to a health care facility or on child-minding (see Figure 10.2). This care was mainly provided to neighbours (see Figure 10.1).

On the other hand, the main type of care received in the affected cohort was on child-minding, mainly from neighbours. Although the study confirms that help was

requested on counselling, domestic chores, transportation finance and nursing (see Section 2.7).

Households found it easier to provide care than to receive care possibly due to fear of stigma and discrimination. Despite considerable criticism of those ill with HIV (if their status was known as noted by Bor et al., 1993:191), neighbours were an important source of support for many affected households. Households rated the quality of care received as good and were appreciative of the help provided by neighbours and the community at large.

Households with individuals who showed visible signs of disease were discriminated against while households with members in the earlier stages of illness were able to conceal it and therefore avoided discrimination. As found in other studies (see Section 2.7), some infected individuals disclosed their status publicly and joined volunteer organisations to promote wider acceptance of HIV/AIDS.

The needs of HIV/AIDS-infected individuals differ according to the stage of the disease. When the disease is at an advanced stage, home-based nursing care is required and caregivers are not trained or qualified to provide this function. It would be more appropriate to train caregivers from the affected households, given the limited community acceptance of HIV/AIDS.

# CHAPTER ELEVEN
# HOUSEHOLD SURVIVAL STRATEGIES

## 11.1 Introduction

Households attempt to survive the burden of HIV/AIDS costs by re-organising themselves and using of a number of survival strategies, which is discussed under four broad headings:

- Strategies aimed at alleviating the loss of income;
- Strategies aimed at surviving the financial cost;
- Strategies aimed at alleviating the loss of labour; and
- Strategies aimed at utilising safety networks.

In order to assess the survival strategies employed by households, it is appropriate to begin the discussion with the household's financial situation in terms of its assets, savings and debt. Furthermore, this chapter highlights the sequence in which financial strategies are employed and by applying the means test explores the take-up rate of state grants as a survival strategy. This chapter also attempts to answer whether the households' net worth is likely to increase or decrease after death. All values have been adjusted to wave 1[1].

## 11.2 Household Assets

Collecting data for an asset register was time consuming and tedious. Fieldworkers had to ensure that these assets were in working condition and document the year, brand and model. Often respondents forgot the year the asset was acquired. To help recall, respondents were asked to relate the asset to an event or time period. Data on assets were collected for wave one and new items added in subsequent waves. Respondents had little idea of the value of their assets. Hence, it was decided to obtain a retail price list for the year and model of the asset from a store

[1] Quarter 4, 2002 = 100

specialising in second hand furniture in Soweto. For assets greater than five years, the asset was valued at 50% of the lowest second hand price.

Only assets that are easily sold are captured in Table 11.1 herein termed marketable assets. Assets such as basic furniture were omitted since individuals for example, require a bed to sleep on. All new assets acquired after wave 1 were adjusted to wave 1 prices. All second hand assets were adjusted by age and model. Overall, there were no significant differences in marketable assets owned across cohorts. The only difference being the higher value of the fridge/freezer in the non-affected cohort.

During the first wave, respondents were asked for the market value of their house(s), both land and buildings. Overall, homeowners overestimated their properties by 10%. The average value of the 92 houses owned in Soweto was estimated at R57 337 compared to R52 139 given by the City of Johannesburg valuation services. This difference was not statistically significant. For consistency across households, the prices used in this study have been the prices of the market value of the properties as obtained from the City of Johannesburg. These prices were fixed as at 2 January 2001. These prices were not adjusted to wave 1 due to the fact that house prices had remained static in Gauteng between 2001 (R60 139) and 2002 (R60 038) (National Housing Finance Corporation, 2003). Houses owned by the sampled households elsewhere in the country have been included.

**Table 11.1: Value of Marketable Assets (Rand)**

| Assets | All Households | | Non-Affected Households | | Affected Households | | | |
|---|---|---|---|---|---|---|---|---|
| | Mean (Rand) | Number Owning Assets | Mean (Rand) | Number Owning Asset | Mean (Rand) | Number Owning Asset | T-stat | p-value |
| Motor vehicles | 2511.17 | 14 | 3705.58 | 8 | 1474.84 | 6 | 1.05 | 0.2971 |
| Bicycles | 21.806 | 14 | 26.48 | 6 | 17.74 | 8 | 0.56 | 0.5785 |
| Radio/tape/CD player | 565.79 | 77 | 741.67 | 41 | 413.19 | 36 | 1.63 | 0.1063 |
| Hi/fi music system | 209.16 | 18 | 296.44 | 12 | 133.43 | 6 | 1.26 | 0.2113 |
| Personal computer | 162.64 | 5 | 292.84 | 3 | 49.68 | 2 | 0.89 | 0.3761 |
| VCR | 166.03 | 28 | 203.65 | 14 | 133.40 | 14 | 0.98 | 0.3307 |

| Assets | All Households | | Non-Affected Households | | Affected Households | | T-stat | p-value |
|---|---|---|---|---|---|---|---|---|
| | Mean (Rand) | Number Owning Assets | Mean (Rand) | Number Owning Asset | Mean (Rand) | Number Owning Asset | | |
| TV | 954.74 | 105 | 1128.83 | 51 | 803.69 | 54 | 1.53 | 0.1300 |
| DSTV | 7.60 | 1 | 16.36 | 1 | 0 | 0 | 1.00 | 0.3215 |
| Camera | 9.12 | 2 | 0 | 0 | 17.03 | 2 | -1.18 | 0.2421 |
| Sewing machine | 117.57 | 18 | 208.73 | 9 | 38.46 | 9 | 1.11 | 0.1642 |
| Fridge/freezer | 1100.91 | 101 | 1429.04 | 47 | 816.20 | 54 | 2.47 | 0.0156* |
| House | 40153.24 | 95 | 38442.07 | 40 | 41637.92 | 55 | -0.46 | 0.6476 |
| Total | 45979.80 | 123 | 46491.74 | 59 | 45535.62 | 64 | 0.11 | 0.9109 |

### 11.3 Household Savings

Respondents were asked during each wave how much the households saved in the past month. Savings included amounts in:

- Burial and funeral cover
- Bank savings account
- Life policy
- Investment including fixed deposits
- Endowment policies including education policies
- Stokvel (informal savings schemes, see Section 3.7)

Non-affected households saved significantly more in wave 1 than affected households (see Table 11.2) however there was no significant difference in savings across the cohorts in subsequent waves. Funds received as a result of death complicate the analysis of savings. For example, in wave 3 two affected households, after paying funeral expenses, saved the excess which amounted to R25 000 and R4 500 respectively. In the first household, no one worked after wave 1 and therefore the funds saved in wave 3 were used to finance monthly household expenses. In the second household, the household split with the grandmother assuming care responsibilities for the deceased's children. She survived on her

retirement pension and used these "savings" to finance household expenses (see Case Study 9.1).

**Table 11.2: Average Household Savings per Wave Across Cohorts and Across Time (Rand)**

| Savings | All Households | Non-Affected Households | Affected Households | Percentage Difference Between Means (%) | T-stat | p-value |
|---|---|---|---|---|---|---|
| | Mean (Rand) | Mean (Rand) | Mean (Rand) | | | |
| Wave 1 | 171.38 | 232.51 | 119.27 | -48.7 | 2.46 | 0.0155* |
| Wave 2 | 93.59 | 91.08 | 95.73 | 5.1 | -0.14 | 0.8861 |
| Wave 3 | 399.72 | 234.42 | 540.63 | 130.6 | -0.75 | 0.4559 |
| Wave 4 | 166.36 | 150.36 | 179.99 | 19.7 | -0.80 | 0.4233 |
| All Waves | 207.76 | 177.09 | 233.90 | 32.1 | -0.55 | 0.5836 |

Over all 4 waves, there were 69% of households (n=289) that saved in some form of savings scheme (see Appendix Table 25). Table 11.3 excludes zeros and reflects the amount saved in each saving scheme. The saving type of choice for all households was burial and funeral cover. This was a higher percentage of households from the affected cohort that saved in burial and funeral cover, however, the amount saved across cohorts was not significantly different. In all waves almost a third of all households had a bank savings account (see Table 11.3). It was interesting to note that the non-affected cohort saved significantly more in life policies than the affected cohort (see Table 11.3). There were no other significant differences in the amount saved in each type of savings scheme.

**Table 11.3: Composition of Household Savings (See Appendix Table 25 for the number of households that saved in each savings scheme)**

| Type of Savings Account | All Households | | Non –Affected Households | | Affected Households | |
|---|---|---|---|---|---|---|
| | Percent of Households | Amount Saved (Rand) | Percent of Households | Amount Saved (Rand) | Percent of Households | Amount Saved (Rand) |
| Burial and funeral cover | 55.0 | 93.35 | 40.5 | 92.95 | 67.1 | 93.54 |
| Bank savings account | 27.0 | 635.07 | 35.9 | 326.45 | 19.6 | 1102.98 |
| Life policy | 20.1 | 121.41 | 17.6 | 150.79 | 22.2 | 102.10* |
| Investment | 2.4 | 449.59 | 2.3 | 435.33 | 2.5 | 460.28 |
| Endowment | 26.6 | 159.11 | 36.6 | 192.40 | 18.4 | 103.99 |
| Stokvel | 10.4 | 236.34 | 6.9 | 284.02 | 13.3 | 215.91 |
| **Total** | | 324.94 | | 281.18 | | 361.22 |

## 11.4 Household Debt

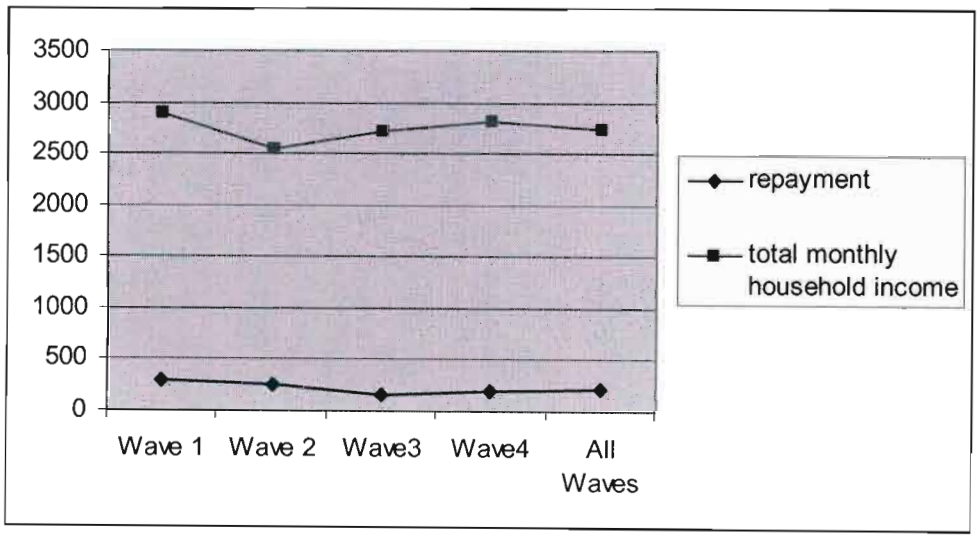
Average household debt was significantly lower in non-affected households with respect to electricity and water bills, for all waves. Affected households were mainly in debt and repaid amounts they felt they could reasonably afford. Wave three debt in affected households increased slightly before being reduced in wave 4. As can be seen by the medians in Table 11.4, there are some households that have high debts.

**Table 11.4: Average Total Household Debt**

| Debt | All Households | | Non-Affected Households | | Affected Households | | Percentage Difference Between Means (%) | T-stat | p-value |
|---|---|---|---|---|---|---|---|---|---|
| | Mean (Rand) | Median (Rand) | Mean (Rand) | Median (Rand) | Mean (Rand) | Median (Rand) | | | |
| Wave 1 | 10806.61 | 6000.00 | 7870.83 | 3895.50 | 13309.25 | 11100.00 | 69.1 | -2.25 | 0.0263* |
| Wave 2 | 11274.20 | 6569.66 | 9179.68 | 3500.49 | 13059.70 | 9302.65 | 42.3 | -1.44 | 0.1540 |
| Wave 3 | 12179.33 | 3526.57 | 9113.14 | 579.710 | 14793.12 | 13146.36 | 62.3 | -1.69 | 0.0934 |
| Wave 4 | 11127.53 | 4440.15 | 7985.14 | 1303.09 | 13806.29 | 9044.45 | 72.9 | -2.05 | 0.0427* |
| All Waves | 11346.92 | 5284.75 | 8537.20 | 1945.62 | 13742.09 | 11561.51 | 60.9 | -3.68 | 0.0003* |

The repayment of debt on average was the same across all waves. In two of the four waves, affected households repaid a higher amount of debt compared to non-affected households. As the household budget comes under financial pressure, the amount repaid towards debt decreases. The evidence in Figure 11.1 for the non-affected cohort suggests that repayment of debt occurs after income recovers and has a low positive correlation with income (r=0.35).

**Figure 11.1: Repayment of Debt in Actual Value in Relation to Total Household Monthly Income – Non-Affected Cohort**




The monthly repayment for all households represented only 2% of total debt. The monthly repayments for non-affected households represented 2.6% of total household debt compared with 1.6% for affected households (see Table 11.5). The implication is that affected households would take longer to recover from debt than non-affected households.

**Table 11.5: Average Monthly Repayment of Outstanding Household Debt as a Percentage of Debt**

| Time Period (Waves) | All Households | | Non-Affected Households | | Affected Households | |
|---|---|---|---|---|---|---|
| | Mean (Rand) | Percentage of Debt | Mean (Rand) | Percentage of Debt | Mean (Rand) | Percentage of Debt |
| Wave 1 | 296.98 | 2.7 | 284.94 | 3.6 | 307.74 | 2.3 |
| Wave 2 | 219.15 | 1.9 | 250.82 | 2.7 | 192.92 | 1.5 |
| Wave 3 | 183.58 | 1.5 | 157.27 | 1.7 | 205.21 | 1.4 |
| Wave 4 | 190.24 | 1.7 | 194.16 | 2.4 | 187.01 | 1.4 |
| All Waves | 224.22 | 2.0 | 224.29 | 2.6 | 224.17 | 1.6 |

## 11.5 Strategies Employed to Survive the Burden of HIV/AIDS Cost

This section examines strategies employed to survive the financial burden of HIV/AIDS and other illnesses in four categories – those aimed at alleviating the loss of income, at surviving the financial cost, at alleviating the loss of labour and at utilising safety networks.

### 11.5.1 Strategies Aimed at Alleviating the Loss of Income

The study found three instances of an employed person joining an affected household. The unemployment rate in Soweto was 57.3% (see Section 3.10) and in 99% of the cases across both cohorts, the employed had only one job. This was partly because those in employment worked long hours, spending on average 8.5 hours at work and another 2.5 hours travelling to and from work. Respondents were asked what the household did to make up the loss of the deceased's income. In 70% of cases, respondents stated that they did nothing to make up for the shortfall in income while in 30% of the cases, spouses or other members of the family diversified income by selling items such as cigarettes, sweets, ice-cream, vet-koeks, cool-drinks or renting telephones.

Some sick individuals remained employed for as long as possible. The study found individuals who had been sick (AIDS-symptomatic) for 60 days prior to the interview were still employed. The benefit of remaining employed for longer was

to keep future household income higher (salary compared to disability pension). The surviving spouse would receive higher benefits if the sick member died while in service as opposed to dying while on early retirement.

Table 11.6 shows that 65% of individuals in the AIDS-symptomatic phase that were employed were sick for 14 days or more in two months prior to the interview.

**Table 11.6: Number of Days Sick per Sick Employee**

| Number of Sick Days | Frequency | Percent |
|---|---|---|
| | | |
| 2 | 1 | 3.2 |
| 4 | 3 | 9.7 |
| 5 | 2 | 6.5 |
| 7 | 4 | 12.9 |
| 8 | 1 | 3.2 |
| 14 | 7 | 22.6 |
| 20 | 1 | 3.2 |
| 21 | 5 | 16.1 |
| 25 | 1 | 3.2 |
| 60 | 6 | 19.4 |
| Total | 31 | 100.0 |

Some studies have found households dissolve as a result of the loss of household income. This study found three households dissolved during the study period because both spouses died. Some households dissolved prior to wave 1 and the widowed spouse moved back to the family home.

### 11.5.2 Strategies Aimed at Surviving the Financial Cost

After utilising income or donations from relatives and non-relatives, households generally responded by employing one of three mechanisms; borrowing money, utilising savings or selling their assets. The frequency of their responses is used as an indication of the order in which they responded. The most frequent response for all households was to borrow money (58.3%). The second most frequent response

was to utilise savings, despite the fact that most households had very little savings to withdraw because most of the savings were in the form of burial funds. Sale of assets was the last resort (see Table 11.7).

**Table 11.7: Use of Financial Responses by Households to Help Survive (Percentage)**

| | All Households | Non-Affected Households | Affected Households |
|---|---|---|---|
| | Percent | Percent | Percent |
| **Borrowed money** | | | |
| In one wave only | 25.2 | 23.7 | 26.5 |
| In two waves | 17.3 | 10.2 | 23.5 |
| In three waves | 7.1 | 10.2 | 4.4 |
| In all four waves | 8.7 | 6.8 | 10.3 |
| **Total** | **58.3** | **50.9** | **64.7** |
| **Utilised savings** | | | |
| In one wave only | 15.0 | 22.0 | 8.8 |
| In two waves | 6.3 | 10.2 | 2.9 |
| In three waves | 0.8 | 1.7 | 0.0 |
| In all four waves | 0.0 | 0.0 | 0.0 |
| **Total** | **22.1** | **33.9** | **11.8** |
| **Sold assets** | | | |
| In one wave only | 6.3 | 3.4 | 8.8 |
| In two waves | 0.0 | 0.0 | 0.0 |
| In three waves | 0.8 | 0.0 | 1.5 |
| In all four waves | 0.0 | 0.0 | 0.0 |
| **Total** | **7.1** | **3.4** | **10.3** |

Non-affected households borrowed more money than affected households (see Table 11.8) although not significantly more. The money that was borrowed for home-improvements had been as a result of the World Summit on Sustainable Development held in 2002 when households improved their homes in the hope of

accommodating paid guests. This was evident in the borrowings recorded in wave 1[2].

**Table 11.8: Average Household Borrowing (Rand)**

| Borrowings | All Households Mean (Rand) | Non-Affected Households Mean (Rand) | Affected Households Mean (Rand) | Percentage Difference Between Means (%) | T-stat | p-value |
|---|---|---|---|---|---|---|
| Wave 1 | 1309.15 | 1780.76 | 907.13 | -49.1 | 1.09 | 0.2805 |
| Wave 2 | 562.35 | 1029.91 | 163.77 | -84.1 | 0.96 | 0.3433 |
| Wave 3 | 90.97 | 51.28 | 124.81 | 143.4 | -1.6 | 0.1131 |
| Wave 4 | 0.00 | 0.00 | 0.00 | . | . | . |
| All Waves | 490.62 | 715.48 | 298.92 | -.58.2 | 1.4 | 0.1745 |
| Total Borrowings – 4 waves | | 2861.95 | 1195.71 | | | |

The main purpose of borrowing was for food, funeral and transport. Repayment of previous debt and to cover the cost of funerals was additional reasons for borrowing money in the affected cohort (see Table 11.9).

**Table 11.9: Purpose of Borrowing (Percentage)**

| | All Households | Non-Affected Households | Affected Households |
|---|---|---|---|
| Food | 24.5 | 21.7 | 26.4 |
| General | 4.1 | 6.7 | 2.3 |
| Schooling | 6.8 | 6.7 | 6.9 |
| Rent | 1.4 | 0.0 | 2.3 |
| Transport | 19.7 | 25.0 | 16.1 |
| Health | 6.1 | 6.7 | 5.8 |
| Clothing | 4.1 | 3.3 | 4.6 |
| Services | 4.8 | 3.3 | 5.8 |
| Funeral | 10.9 | 5.0 | 14.9 |
| Debt | 7.5 | 6.7 | 8.1 |
| Home improvement | 8.2 | 10.0 | 6.8 |
| Wedding | 1.2 | 3.3 | 0.0 |
| Bail | 0.7 | 1.6 | 0.0 |
| **Total** | **100.0** | **100.0** | **100.0** |

The main source of borrowing for all households was from friends, micro lenders or the employer (see Table 11.10). Non-affected households appeared to have had

[2] Wave 1 borrowing reflected 12 months borrowing

greater access to banks than affected households who utilised micro lenders, co-workers, stokvels and insurers proportionately more than non-affected households.

**Table 11.10: Source of Household Borrowing**

| Source of Borrowing | All Households | Non-Affected Households | Affected Households |
|---|---|---|---|
| | Percent | Percent | Percent |
| Relatives/Friends | 60.0 | 56.0 | 62.9 |
| Bank | 7.5 | 12.0 | 4.3 |
| Micro lender | 15.8 | 14.0 | 17.1 |
| Employer | 11.7 | 18.0 | 7.1 |
| Co-worker | 2.5 | 0.0 | 4.3 |
| Stokvel | 1.7 | 0.0 | 2.9 |
| Insurer | 0.8 | 0.0 | 1.4 |
| **Total** | **100.0** | **100.0** | **100.0** |

There were no significant differences in the amounts withdrawn from savings across cohorts (see Table 11.11). Respondents found the question about how much they had in their bank accounts difficult to answer. They were asked if household members had a bank account. The study found that 28% of households from the affected cohort and 24.5% of households from the non-affected cohort did not have a bank account.

**Table 11.11: Average Withdrawal from Household Savings (Rand)**

| Withdrawal from Savings | All Households Mean (Rand) | Non-Affected Households Mean (Rand) | Affected Households Mean (Rand) | Percentage Difference Between Means (%) | T-stat | p-value |
|---|---|---|---|---|---|---|
| Wave 1 | 265.48 | 330.76 | 209.83 | -36.6 | 0.64 | 0.5211 |
| Wave 2 | 161.21 | 231.67 | 101.15 | -56.3 | 1.04 | 0.2997 |
| Wave 3 | 91.48 | 176.51 | 19.00 | -89.2 | 1.47 | 0.1483 |
| Wave 4 | 0.00 | 0.00 | 0.00 | . | . | . |
| All Waves | 129.54 | 184.73 | 82.49 | -55.3 | 1.63 | 0.1045 |

There were 26 households from the non-affected cohort and 9 households from the affected who withdrew from their savings account during the year. Multiple reasons were recorded for withdrawing from savings (see Table 11.12). The main reasons for the affected cohort withdrawing from savings were to pay for food, transport, and funerals compared to food, transport and clothing in the non-affected cohort (see Table 11.12).

**Table 11.12: Purpose of Withdrawal from Household Savings**

| Expenditure Items | All Households | | Non-Affected Households | | Affected Households | |
|---|---|---|---|---|---|---|
| | Frequency | Percent | Frequency | Percent | Frequency | Percent |
| Food | 14 | 21.5 | 10 | 20.8 | 4 | 23.5 |
| Schooling | 7 | 10.8 | 6 | 12.5 | 1 | 5.9 |
| Rent | 3 | 4.6 | 2 | 4.2 | 1 | 5.9 |
| Transport | 10 | 15.4 | 7 | 14.6 | 3 | 17.6 |
| Health | 1 | 1.5 | 1 | 2.1 | 0 | 0.0 |
| Clothing | 9 | 13.8 | 9 | 18.8 | 0 | 0.0 |
| Services | 5 | 7.7 | 3 | 6.3 | 2 | 11.8 |
| Funerals | 6 | 9.2 | 3 | 6.3 | 3 | 17.6 |
| Christening | 1 | 1.5 | 0 | 0.0 | 1 | 5.9 |
| Wedding | 2 | 3.1 | 2 | 4.2 | 0 | 0.0 |
| Business | 2 | 3.1 | 2 | 4.2 | 0 | 0.0 |
| Bills | 4 | 6.2 | 2 | 4.2 | 2 | 11.8 |
| Furniture maintenance | 1 | 1.5 | 1 | 2.1 | 0 | 0.0 |
| **Total** | 65 | 100.0 | 48 | 100.0 | 17 | 100.0 |

The final financial mechanism used by households was to sell off assets (see Table 11.13). Nine households from the affected cohort and two from the non-affected cohort sold assets over the period of the study. There were no significant differences noted in the disposal of assets across cohorts. The two non-affected households sold a stove and a cellular telephone to cover the cost of transport and child maintenance. The affected households sold a television, video cassette recorder, cellular telephone, home appliances and clothing to cover cost of health care and other basic essentials such as food. This could be because they owned very few marketable assets (see Table 11.1).

**Table 11.13: Disposal of Household Assets (Rand)**

| Time Period (Waves) | All Households Mean (Rand) | Non-Affected Households Mean (Rand) | Affected Households Mean (Rand) | Percentage Difference Between Means (%) | T-stat | p-value |
|---|---|---|---|---|---|---|
| Wave 1 | 23.62 | 9.61 | 35.57 | 269.9 | -0.90 | 0.3728 |
| Wave 2 | 25.65 | 30.13 | 21.83 | -27.5 | 0.26 | 0.8004 |
| Wave 3 | 7.26 | 0.00 | 13.46 | | -1 | 0.3213 |
| Wave 4 | 2.05 | 0.00 | 3.79 | | -1 | 0.3213 |
| All Waves | 14.65 | 9.94 | 18.67 | 87.8 | -0.76 | 0.446 |

Other financial strategies have been discussed elsewhere (see Section 7.8.1). Households did not stop children from going to school despite the hardships experienced. School fees were in arrears but the children were still at school. For evidence of reduction in consumption on certain expenditure categories, see section 8.3). There was no evidence of begging by any household despite the fact that there were seven households that did not receive any form of income in any of the waves over the 12-month period. Households across both cohorts sent household members to be taken care of by other households and this was far more common in the affected cohort.

Over the one year period of the study, almost all households borrowed money at least once. There were a higher number of households from the affected cohort that borrowed money although the amounts borrowed, withdrawn from savings or earned from the sale of assets, were not significantly different across both cohorts (see Table 11.14). The amounts reflected in Table 11.14 are for those households where amounts are greater than zero.

**Table 11.14: Summary of Household Financial Responses over the one year Period of the Study**

| Financial Responses | All Households | | Non-Affected | | Affected | | T-stat | p-value |
|---|---|---|---|---|---|---|---|---|
| | Frequency | Mean (Rand) | Frequency | Mean (Rand) | Frequency | Mean (Rand) | | |
| Borrowed Money | 109 | 2050.05 | 43 | 3489.30 | 66 | 1112.35 | 1.70 | 0.0967 |
| Utilised Savings | 35 | 1694.29 | 26 | 1500.00 | 9 | 2255.56 | -1.09 | 0.2953 |
| Sold Assets | 11 | 610.91 | 2 | 1050.00 | 9 | 513.33 | 0.94 | 0.5012 |

### 11.5.2.1 Social Grants

Households relied on state income, as discussed in chapter seven (see Section 7.6.1). The means test was applied to the old age and child support grant to determine whether or not the individual qualified for the grant.

- **Old Age Pension Grant**

The minimum age qualification for the old age grant is 65 for males and 60 for females (Department of Social Services, 2003). The maximum annual income that a person could have after the permissible deductions (pension, medical aid, tax and unemployment contributions) was R19 080 for a single person and R31 320 for a married person. The formula to conduct the means test is:

Single Person: D= (1,15 x R8 400) – (0,5 x annual income of applicant)
Married Persons: D= (1.075 x R8 400) – (0,5 x combined annual income of applicant)

Methodologically the data required to conduct such an analysis is net monthly income after deductions of applicant and spouse and marital status between partners and not just to the household head.

The analysis revealed that the take-up rate for old age grants was 100%. The one person from the affected cohort who was not receiving the old age grant had just turned 60 and the application was in process.

- **Child Support Grant**

Since the child support grant was available to children under the age of seven in 2002, the analysis was done using this age group. Families were in the process of re-applying for the child support grant to include children under the age of 9 from 2003. The means test of parental income not exceeding R800 per month for formal dwellings in an urban area was applied.

Of the 175 children under the age of 7, the study found 96 children (55%) receiving grants and 79 children (45%) not receiving grants. Not all those who receive grants in fact qualify for the grants (see Table 11.15). It was interesting to note that of all the children receiving child support grants, a higher proportion of children from the affected cohort qualified and received the grant. On the other hand, almost half of the children from the non-affected cohort received the grant but did not qualify for it. The study also found children qualifying but not receiving the child support grants. Of all the children not receiving grants from the affected cohort, almost half of the children qualified to receive it (see Table 11.16).

**Table 11.15: Receiving Child Support Grants (Percentage of Children)**

| | **All Households** | **Non-Affected** | **Affected** |
|---|---|---|---|
| Receiving and qualifying for child support grant | 70 | 55 | 81 |
| Receiving and not qualifying for child support grant | 30 | 45 | 19 |
| Total | 100 | 100 | 100 |

**Table 11.16: Not Receiving Child Support Grants (Percentage of Children)**

| | All Households | Non-Affected | Affected |
|---|---|---|---|
| Not receiving but qualifying for child support grant | 41 | 35 | 47 |
| Not receiving and not qualifying for child support grant | 59 | 65 | 53 |
| Total | 100 | 100 | 100 |

The take-up rate was calculated by first establishing the percentage of children who qualified for the grant. The next step was to establish from those who qualified for the grant, the percentage of children who received and did not receive the child support grant. The take-up rate was higher for children from the affected cohort (see Table 11.17). As households become cash strapped, they would turn to social welfare.

**Table 11.17: Take-up Rate of Child Support Grant (Percentage of Children)**

| | All Households | Non-Affected | Affected |
|---|---|---|---|
| Qualified and received child support grant | 68 | 61 | 72 |
| Qualified but did not receive the child support grant | 32 | 39 | 28 |

Furthermore, there were 18 children in total whose parents lived elsewhere and who were cared-for by members of the studied households. It might be that these parents were collecting the child support grant. It was difficult to establish whether or not these children qualified for the child support grant because their parents' income was unknown.

- **Disability Grant**

This grant was eligible only to those who produced a medical report that p individual was unable to provide a livelihood. Four out of the 43 indivi[illegible] classified themselves as disabled were not receiving a disability grant. The take-up rate was high in this survey because all of the identified HIV infected individuals were chosen with a CD4 cell count of 200 and below and the medical practitioner used this as a benchmark to decide on disability status. Those who did not receive the disability grant were either in the process of applying or waiting for their CD4 cell counts to drop further before applying.

### 11.5.3 Strategies Aimed at Alleviating the Loss of Labour

Caregivers from the affected cohort gave up most of their leisure and time performing domestic chores to care for sick adults (see Section 6.4). Non-economically active members were encouraged to find work (see Section 7.2). There was only one child who stopped going to school to assist with domestic chores. Most households were structured in extended family set ups and therefore there were other adults in the household available to perform care-giving functions. Because of the long hours already spent at work or travelling to work, extra hours could not be worked.

### 11.5.4 Strategies Aimed at Utilising Safety Networks

Although some studies have found the poor having less access to social support networks (see Section 2.8.4), this study found those in greater need accessing a wider range of social networks (see Figure 11.2). To borrow money, the affected cohort accessed their friends and relations, and then institutions such as micro lenders and their employers (see Table 11.10).

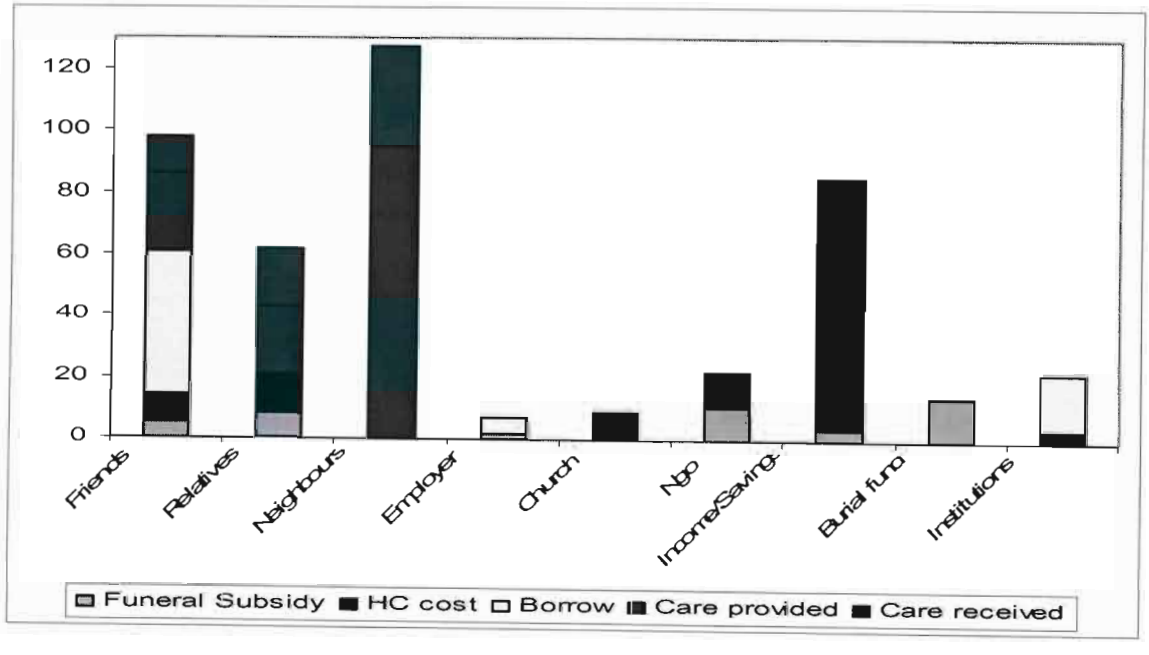
Funerals were subsidised with money from burial funds, non-governmental organisations, relatives, friends, employers, churches, income and savings. It was interesting to note that funerals were not subsidised by neighbours but either by

institutions or by people the family considered relatives or friends. Previously, contributions were made in cash or kind by neighbours. More recently, the bereaved family is expected to fund the cost of funerals. This is the reason why families emphasised that funeral practices had changed and become more expensive for them. However, discussions with respondents revealed that if the bereaved family did not have sufficient money to cover the cost of the funeral, a street collection in the community would take place. This may result in the family being ostracised for not having sufficient money to bury their dead.

Out-of-pocket health care costs were mainly subsidised from household income or savings (see Figure 11.2).

The affected cohort received care mainly from neighbours, relatives and friends and provided care mainly to neighbours, friends and relatives located in close proximity. Relatives still played an important role in monetary support during times of sickness and death while friends and neighbours play a larger role in non-monetary support and care.

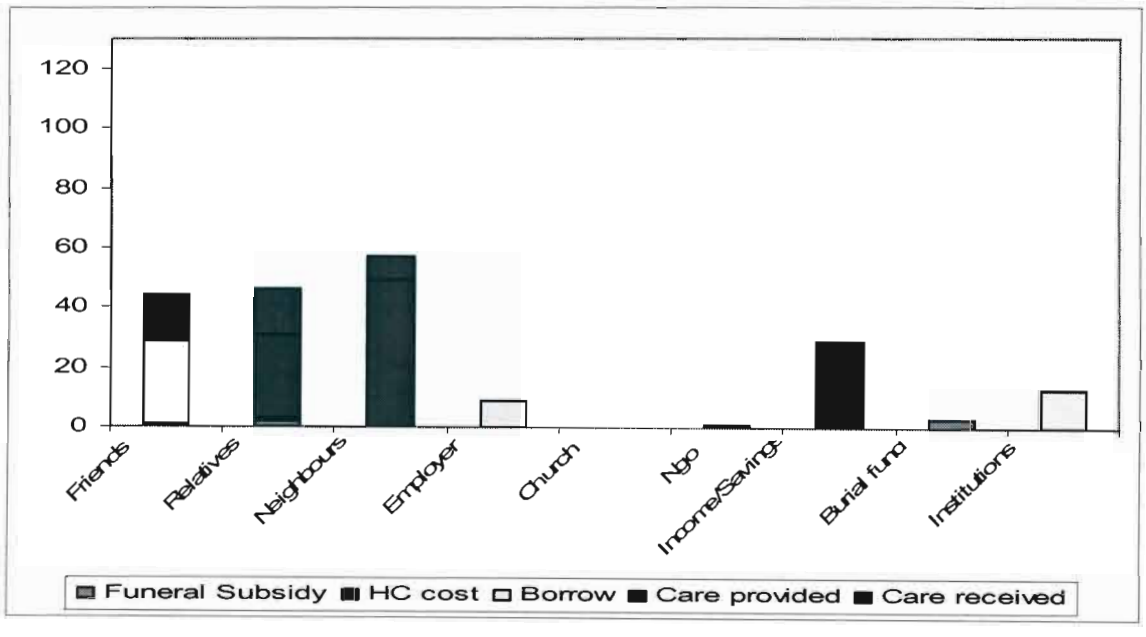
**Figure 11.2: Sources of Social Networks – Affected Cohort**




Non-affected households appeared to be more independent, having less need for social networks (see Figure 11.3). Funerals were subsidised by relatives, friends,

non-governmental organisations and the burial fund. They subsidised their health care costs mainly from income and savings and to a lesser extent from relatives. They borrowed money mainly from friends, institutions or their employer. They appeared to have had easier access to borrow funds from employers or from institutions. They provided care to neighbours, relatives and friends and received care from neighbours, relatives and friends.

**Figure 11.3: Sources of Social Networks – Non-Affected Cohort**




In terms of job searches, more than one option was pursued at any one time. The evidence suggests that social networks play a large role in job searches. Approximately 60% of all those who sought work in the non-affected cohort and 79% from the affected cohort relied on social networks for employment. The second option of choice was the word of mouth route which was to talk to everyone they came into contact with. The third option was via job advertisements in the newspapers (see Table 11.18).

**Table 11.18: Sources of Job Searches (Percentage)**

| | Non-Affected Households | Affected Households |
|---|---|---|
| | n=229 | n=216 |
| Relying on networks of relatives and friends | 60 | 79 |
| Employment agencies | 10 | 6 |
| Advertisements in newspapers | 42 | 60 |
| Word of mouth | 56 | 79 |
| Door to door company searches | 1 | 0 |

### 11.5.4.1 Private Transfers

Almost twice as many households from the affected cohort received transfers on an annual basis (see Table 11.19). Approximately 42% of households from the non-affected cohort (25/59) and 74% from the affected cohort (49/66) received transfers (for amount transferred in and out refer to Table 7.14).

The bulk of the transfers in were used to contribute to the welfare of all household members (78% of non-affected households and 72% of affected households used the transfers for all household members). The rest of the households used the transfers in for specific members. In most cases the transfers were designed for children who were cared for by the household, or for retired parents. Across both cohorts and across all waves the transfers were used for basic essentials such as food, rent, clothing, schooling and electricity and water bills.

**Table 11.19: Purpose of Transfers in (Percentage of Households)**

| | Non-Affected Households | Affected Households |
|---|---|---|
| | n=74 | n=147 |
| Food | 45.9 | 53.7 |
| Schooling | 6.8 | 8.2 |
| Rent | 9.5 | 2.7 |
| Transport | 6.8 | 6.8 |
| Health | 4.1 | 6.2 |
| Clothing | 21.5 | 15.6 |
| Services (electricity and water) | 5.4 | 6.8 |

In terms of annual transfers out, 46 households (78%) from the non-affected cohort and 49 households (74%) from the affected cohort transferred funds out (see Section 7.7). There were almost twice as many households from the non-affected cohort that transferred money out than received money in. There was the same number of households from the affected cohort that transferred money in and out. The transfers out were generally for children or retired parents living elsewhere.

The evidence suggests that fostering of children is being carried out on an informal basis mainly by the maternal family (see Section 9.6). Households rely on safety networks to help survive. While social networks are very helpful and support households during times of economic and health shocks, they can be the cause of much social distress due to their ignorance about HIV/AIDS (see Section 10.5).

### 11.5.5 How Are Households Surviving Financially?

The affected cohort earned less than the non-affected cohort but as mentioned in chapter seven, they make up their income from grants, transfers in as well as income from death through burial societies and from relatives and non-relatives. After expenses for health care and funeral are paid for, they had a positive gap between income and expenditure. In the meantime, debt has accumulated. After debt was

taken into account, the affected cohort returned to a similar financial position as the non-affected households (see Table 11.20).

**Table 11.20: Financial Position of Households**

| Annualised Absolute Values | Non-Affected Household n=52 (Rand) | Affected Household n=61 (Rand) |
|---|---|---|
| Total household income including income as a result of death (see Table 7.12) | 34 202 | 39 934 |
| Less: household expenditure including health care and funeral | 27 206 | 29 092 |
| Net disposable income | 6 996 | 10 841 |
| Less: debt and borrowings (see Table 11.4 and 11.8) | 11 399 | 14 938 |
| Net financial position | -4 403 | -4 097 |

The financial position of affected households were aided by grants and transfers in but, without the help of funds entering the household as a result of death, affected households would have been worse off financially (see Table 11.21).

**Table 11.21: Financial Position of Households Excluding Income as a Result of Death**

| Annualised Absolute Values | Non-Affected Household n=52 (Rand) | Affected Household n=61 (Rand) |
|---|---|---|
| Total household income excluding income as a result of death (see Table 7.12) | 33 827 | 35 247 |
| Less: household expenditure including health care and funeral | 27 206 | 29 092 |
| Net disposable income | 6 621 | 6 154 |
| Less: debt and borrowings (see Table 11.4 and 11.8) | 11 399 | 14 938 |
| Net financial position | -4 778 | -8 784 |

To survive the burden of sickness and disease the affected cohort would need to earn at least R3 000 per month after deductions. In this study 37% of households from the non-affected cohort and 29% of households from the affected cohort earned R3 000 or more per household per month.

## 11.6 Methodological Lessons

Information relating to borrowings and savings were collected for a 12 month period in wave 1 and in subsequent waves for a period of three months. A better reflection of trends would have been if the question was asked for the same time period for all waves. Alternatively, an additional question should have been asked for the 12 month prior and for three months prior for comparative purposes.

The drawing of kinship diagrams to link parents to children was a lengthy exercise. If the information is required only for calculating take-up rates for grants only, then it is recommended that future surveys insert a column on the instrument for identity code of the spouse and a column for the identity code of the parents.

Instead of drawing up a lengthy register of assets, it would be cost-effective to choose ten to 12 key assets and obtain data on these items only. To avoid the embarrassment of asking how much money is in the bank account, a proxy for having saved in the last three months or having a positive bank balance could be used to determine whether or not households have money in their savings account.

The study found that children were being sent to live with relatives outside Soweto as a result of illness and death. However, the survey did not capture households that had dissolved as a result of illness or death prior to the first visit or since. It would be appropriate to ask household members if they had joined the household in the last five years and reasons for joining and establish whether household members left the household in the last five years and reasons for leaving. In this way, the survey would have captured the movement of household members due to illness prior to the first visit. Due to the fact that most household surveys did not follow households or families in households that moved away or dissolved, it was difficult to measure the full impact of children being sent elsewhere. The study found in one household that had split, all the children had moved to another household and the grandmother moved with the children to take care of them. In another household, the household moved out of Soweto so the family from Soweto moved in with the children of the deceased to live with them and take care of them. Although children were not displaced in these examples, adults displaced themselves to live with children in their parental home after their parents had died. Household surveys that do not follow split or dissolved households will under-estimate the movement of children.

### 11.7 Summary

Overall, there were no significant differences in the total marketable assets owned across cohorts. The affected cohort saved significantly less (as found in the Free State Survey, Booysen et al., 2001) but in wave one only. In the other waves income received as a result of death complicated the analysis on savings. The affected cohort had significantly more debt and was expected to take twice as long to repay debt compared to the non-affected cohort even without taking into account future health care and funeral expenses.

Four key household survival strategies were investigated. To alleviate the loss of income, the study found that employed members joined the household, members' diversified income either by selling items from home or through renting rooms or telephones, while widows returned to their family home, all of which confirm the findings of other studies (see Section 2.8.1). Furthermore, this study found sick members remaining employed for as long as possible to avoid the premature loss of earnings. In cases where both parents died, households dissolved while there were other households that felt that they could do nothing about alleviating the loss of income. The study did not find children dropping out of school (see Section 9.6).

To survive the financial cost after income was used, households first borrowed money, then utilised savings and lastly disposed of assets in the same order as found in the Free State study (Booysen et al., 2003:86). The main purpose of borrowing was to subsidise basic essentials as well as the cost of funerals. The main source of borrowings was from relatives and non-relatives. There were no significant differences in amounts withdrawn from savings or from the sale of assets across cohorts. The study uncovered the increase in the take-up rates of grants which could account for the loss of earned income. The take-up rates in the affected cohort for old-age pension and disability grants was almost 100% and for child-support grants 72%. In the future, as households become cash strapped, the take-up rate on grants will continue to increase.

To alleviate the loss of labour, household members re-organised their productive activities, non-economically active members were encouraged to join the labour market (as found in Thailand, Pitayanon et al., 1995:8), one child was stopped from school to assist with domestic chores and because of the long hours already at work or travelling to and from work, individuals could not work extra hours.

Safety networks were built with friends, relatives and neighbours. They provide a huge source of strength to households either to borrow money or to assist with care and support of sick adults and children. Safety networks were also used for job searches. It was interesting to note that twice as many households in the non-affected cohort transferred money out than received money in. Although the same

number of households from the affected cohort transferred money out as well as transferred money in the amounts transferred out were almost half of what was transferred in, suggesting that the affected cohort relied more on transfers-in than the non-affected cohort. Fostering of children was being carried out on an informal basis, mainly by the maternal family. The study found safety networks extremely useful in helping households cope but at the same time these were a source of stigma and discrimination.

As opposed to another study that found poor households constrained in their choice of coping mechanisms (Mutangadura, 1999:19), this study found members of the affected cohort extremely resourceful in accessing a broad range of safety networks, without which these households would have collapsed financially even with the help of grants. Affected households with the help from safety networks therefore organised themselves so as to bring themselves into a similar financial position to non-affected households.

# CHAPTER TWELVE
# CONCLUSIONS AND RECOMMENDATIONS

## 12.1 Introduction

The overall objectives of the study (see section 1.4) were to analyse the economic impact of HIV/AIDS on income-earning South African urban households and in so doing to develop a methodology for HIV/AIDS household surveys. This chapter discusses the key methodological contributions of the study and concludes with the key findings and recommendations by addressing each of the research questions. A distinguishing feature of this study is that it covered 17 different aspects of the household (as illustrated in Table 4.6) which enabled it to draw relationships between these various aspects and HIV/AIDS. Most HIV/AIDS studies covered only one or a few aspects with the exception of the Free State study in South Africa (urban and rural) and the Kagera study in Tanzania (rural) which were more comprehensive in nature.

## 12.2 Methodological Contributions

This objective was achieved by initially reviewing 33 household studies (see Section 4.1) which investigated the socio-economic impact of HIV/AIDS on individuals and households in order to develop the best possible methodology for this study (see chapter four). HIV/AIDS is a sensitive issue for many individuals and households and it was necessary to spend time in the community understanding their level of acceptance and openness about certain sensitive topics and building trust to enable the study to be carried out. For a study of this nature, this study found and recommends that at least nine months of planning time is required before field work commences. This period of time is necessary to understand the local community, design the methodology, obtain support and input from local and regional structures and field test the instrument.

The study developed a training manual (see Appendix 6) and a training programme that can be replicated by other household surveys investigating the economic impact

of HIV/AIDS on households. Furthermore, the study developed tools such as the kinship diagrams (see Section 5.4), an expenditure diary (see Appendix 26), allocation of time diary (see Appendix 27), and a consent form (see Appendix 2) as well as the sample selection and screening form (see Appendix 3).

The use of local people in conducting the fieldwork was very effective because of their understanding of the local languages, subtle nuances, and non-verbal communication and their "prior knowledge" of how to approach households. The field team underwent a training programme, received on-the-job training, and also underwent psycho-therapy (see Section 4.3.1). They found the psycho-therapy useful (see Section 4.10) and showed a great interest in the research. Furthermore, the study offered local people the opportunity to develop research skills (see Section 4.10, and Case Study 6.1 for an example of a story written by a fieldworker).

This survey experienced no problems in obtaining sensitive data, probably due to the time spent on building rapport with respondents (see Section 4.4). The research team was in constant contact with the households in-between visits, so much so (see Section 4.4) that when changes occurred at the household respondents often took the initiative to inform the research team. The longitudinal design of the research made it easier to build rapport and to amend the instrument as and when was required.

The drawing of kinship diagrams (see Section 5.4) is not a common tool used in household surveys because it is time-consuming. This study found it useful in establishing biological relationships without the use of confusing and inaccurate labels often used at household level. For subsequent waves, new members were easily incorporated into the kinship diagram and members who left were easily deleted. No previous household study investigating the impact of HIV/AIDS has been able to apply the means test to establish eligibility for state grants (see Section 11.5.2.1). This study was able to do so because of the use of kinship diagrams.

Although the instrument was semi-structured and collected vast amounts of quantitative data, certain questions were asked in a qualitative manner allowing respondents time to express themselves. Respondents felt free to explain

themselves and in this way helped to clarify confusing numbers. Following this method, a story was written about each household in a qualitative way some of which was illustrated by way of case studies in the various chapters. Due to space considerations, the use of these stories was limited.

The study found that households often split due to the death of one spouse. It also found that sick individuals already lost employment prior to the start of the study. This makes it imperative in studies of this nature to collect retrospective data relating to sickness and death. Future studies should follow split households throughout the period of the study.

The study found it necessary to collect morbidity data for sick individuals as well as individuals who died due to illness so that data could be compared and combined to calculate the combined cost of morbidity and mortality to households (see Section 6.5). Most previous studies estimated either the cost of morbidity or the cost of mortality. It is necessary to understand the combined cost since it has a joint impact on the household. When costs of morbidity and mortality were obtained, households' under-estimated total costs because of certain "hidden" costs (see Section 6.8).

A detailed instrument for income is appropriate (see Appendix 7, Section 10) because household members often do not consider themselves generating income if they classify themselves as unemployed or retired. It is also necessary to examine payslips so as to avoid confusion between gross and net income (see Section 4.16). For net profit from own business, the amount brought into the household budget is a good proxy for income since detailed accounts of income and expenditure relating to own businesses are not kept. Future studies may want to consider investigating income and expenditure from pooled resources. Regular and irregular income needs to be accounted for since some types of income come into the household on an ad hoc irregular basis such as income as a result of death. It is appropriate to define employment to capture all forms of income-generation/productive activity since not all productive activity converts to cash during the period of employment (see Section 1.2.3).

The study tested the collection of data every three months but more pronounced changes were noted every six months (see Section 7.5). It is recommended that future household surveys of this nature collect data every six months for a period of five to ten years since HIV/AIDS is a long-term illness with longer-term impacts.

The use of the diary to collect data on expenditure complemented the respondents' memories and it is recommended that future studies use this method. The reminders to the household to complete the diary also served as a contact between the fieldworkers and the respondents. It is important to collect data on all cost items during the study so as to avoid mistakes based on poor memory. An extensive tool is required to capture all forms of regular and irregular expenditure.

The completion of time sheets (see Section 9.2) is time-consuming with less compliance and the results not particularly illuminating. Future household surveys investigating the allocation of labour should choose key household members only (such as sick individuals and their caregivers), to complete time sheets.

The key items recommended in drawing up an asset register are house, vehicles, bicycle, radio, television, cellular telephone, video cassette recorder, camera, sewing machine and fridge/freezer. These items are sufficient to develop a wealth index for households. The prices of houses can be obtained from the local municipality and the prices of assets either from a new store or a second-hand store in the study site area. Household surveys should also take into account houses and assets owned in other provinces (see Section 11.2).

### 12.2.1 Overcoming Sampling Bias in HIV/AIDS Household Surveys

One method of overcoming sampling selection bias is to randomly select households in a study area and to encourage individual members to submit to an oral HIV test. To undertake such as study would require extensive, community, local and national political buy-in. Another method is to have a longitudinal study that extends over 10 years. In this way, all women from public antenatal clinics (HIV positive and negative) could be selected irrespective of CD4 cell count.

Households could be followed prospectively over a long period of time which would capture changes in HIV status of household members.

### 12.2.2 Methodological Questions for Future HIV/AIDS Household Surveys

This study raises a number of questions about what constitutes HIV/AIDS cost and the definitions of some key concepts which should be addressed in future household surveys of this nature. Firstly, the definition of what constitutes an HIV/AIDS household should be re-evaluated. The study has shown that almost all households directly or indirectly are affected by HIV/AIDS. Should future surveys distinguish between households where at least one member presents with an HIV/AIDS defining illness versus households where there are no members presenting with an HIV/AIDS defining illness? Unless individuals are selected from health care facilities, it is not possible to categorically assign individuals' HIV status. Should future surveys therefore not opt to randomly select households and then assign them according to a set of questions relating to chronic illness?

What then should constitute chronic illness? The study found that respondents do not classify a person sick unless they were unable to perform usual functions. As a result, total costs relating to illness may not be captured since the household may be incurring medical costs due to chronic illness. In the future, questions relating to the number of days a person was sick, whether the person was receiving treatment and whether or not costs were incurred, be used as indicators to classify whether or not the household has a member presenting with chronic illness.

Is it necessary to distinguish between HIV/AIDS deaths or not? The study found that the funeral cost did not differ whether or not someone died of HIV/AIDS. Therefore should households be classified as those that experienced death versus those that experienced no death? Future household surveys may classify households on the basis of "chronic illness" only without consideration of death because death would occur naturally in the one group and more frequently in the other.

In longitudinal surveys, it is not possible that the "control" group would continue to have all members not presenting with an HIV/AIDS defining illness. Should these households be removed from the "control" group and analysed separately? Should the "control" group be over-sampled to take these factors into account? Should these households be moved from the "control" group into the "sampled group?"

Studies investigating economic impact of HIV/AIDS should be aware that it is not easy to distinguish between what costs directly arise as a result of HIV/AIDS. For confidentiality reasons, these surveys do not ask questions directly of the HIV/AIDS-infected person or questions directly relating to the illness and therefore only costs influenced by HIV/AIDS can only be assumed. For example, even if a member was sick and lost employment, it cannot be categorically stated that this person lost employment due to HIV/AIDS because that fact can only be proven or disproven in a court of law. The sick member could have lost employment for a number of other reasons related to performance, absence from work without notification and so on. Studies of this nature could only establish from respondents whether or not they believed that the loss of employment was due to the members' illness.

It was not easy to distinguish between what portion of the costs would not have been incurred had it not been for infection in the household. For example, during illness and death telephone costs escalate but what proportion can be attributed to HIV/AIDS unless a household is followed on a monthly basis and illness is documented against costs prior to illness or death, during illness or death and after illness or death. There could be various other reasons why telephone costs escalated and the presence of illness or death could have been a mere co-incidence.

The concept of "disability" should be addressed especially in the light of the anti-retroviral roll-out plan. A person may classify themselves as unfit to perform their usual job function yet the person's CD4 cell count status is used as a measure to determine whether or not that person is fit to perform their usual job function. If a person receives treatment and their CD4 cell count rises, should the person be re-classified?

## 12.3 Profile of Sample Households

Affected households were often headed by single (never married) older women as young adult infected members moved back home to be taken care of (see Section 5.2). They brought with them their illegitimate children whom after death are often left in the care of the grandparent (see Section 5.2). The infected member usually collected a state disability grant of R700 and child support grant of R160 for each child. The former cease upon the death of the infected person (see Section 6.3) and grandparents (see Section 5.2) were expected to take care of children without this additional income. In the longer-term children may be forced to drop out of school since, beside school fees, there are other expenses such as uniforms, transport, books and pocket money for school-related activities. It costs R1 500 on average to keep a child at school for a year, equating to more than two months old age pension grant income of the grandparent.

Grandparents would be eligible for the foster care grant but this requires intervention of the courts and therefore most of them do not apply for this type of grant. Besides the financial drain, they are left in their old-age to take up the responsibility of child-rearing.

Approximately 60% of all children are raised by a one parent (see Table 9.5). The implication is that if the single parent dies prematurely, the child is left in the care of other family members not necessarily those from the same household or people that the child is familiar with. No formal arrangements are made with future guardians of children should their parents die prematurely (see Section 9.6.1). Parents could be encouraged at family planning clinics to make alternative arrangements for their children should they not be in a position to do so in the future.

## 12.4 Changing Household Size, Composition and Structure

Over time, affected households, despite new additions, may reduce in household size due to (see Section 5.3):

- Fewer births
- More deaths
- Children sent to live elsewhere
- Adults sent elsewhere to be taken care of or to seek traditional treatment (see Section 5.3.2)

Thus in the long-term and beyond the scope of this study, affected households are expected to reduce the number of dependants to the levels of the non-affected households, via migration (see Section 5.3).

HIV/AIDS is one of the main reasons why individuals leave or join a household (see Section 5.3.2). Extended families still appear to be the norm with over 40% of households containing three or more generations of inhabitants (see Section 5.4). HIV/AIDS causes household structures to change easily from nuclear to single to extended family structures and vice versa. It will cause nuclear and extended families to decrease over time and single persons with children and cohabiting structures to increase (see Section 5.4). When a spouse dies and there are children in the household, the household is reclassified as single with children; if the remaining spouse brings in a partner, the household is reclassified as cohabiting.

Households affected by HIV/AIDS had more dependants and a higher dependency ratio. It is expected that the dependency ratio will decrease over time due to fewer births and more deaths (see Section 5.3). Alternative methods of calculating the dependency ratio could be considered in the presence of high unemployment and high reliance on non-market income.

### 12.5 The Cost Impact of HIV/AIDS on Households (Research Question One)

The first research question was about the cost of HIV/AIDS morbidity and mortality to an urban household. This question was addressed in three parts, namely, the cost of morbidity, the cost of mortality and the combined cost. The reason for disaggregating the costs was for comparison purposes since most other studies reported either the costs of morbidity or the costs of mortality. Another point to

note is that most surveys did not take into account incoming funds received as a result of death and therefore reported only the total costs of morbidity or mortality. This study summarised the total costs (see Table 6.5) and deducted incoming funds resulting in net cost of morbidity or net cost of mortality.

In regions with good access to public health care such as Soweto, the direct cost to the household is reduced since the public health care system absorbs the majority of the cost of illness. The total net cost of HIV/AIDS morbidity to affected households was R4 984 (see Table 6.5) for an eight month period excluding expenses incurred outside of the pooled household budget. A limitation in the methodology was that it did not take into account costs paid for by other household members outside of the pooled budget as well as from non-household members (as explained in Section 6.8). Systemic costs were higher than indirect costs, because many of the caregivers and sick members were not employed. However, if more of the caregivers and sick individuals had been employed, then indirect costs and subsequently the total cost of morbidity would have been higher.

The total net cost of HIV/AIDS mortality to households was R33 832 (see Table 6.5) for an eight month period, with an average of one death per household. The total net cost of mortality to a household, even when incoming funds were taken into account, was 6.8 times the total net cost of morbidity. Households spent 30 (see Section 6.5.1) times more on funerals than they did on health care. Mortality resulted in permanent loss of income to the household.

The combined net cost of HIV/AIDS morbidity and mortality to an urban household was approximately R21 810 (see Table 6.5) for an eight month period, after deducting incoming funds. Since households are affected by either morbidity or mortality or both during the observed period of the study, it is necessary to report the combined cost of morbidity and mortality.

The total combined net cost of HIV/AIDS morbidity and mortality for an eight month period represents 62% of annual household income in the affected cohort (see Section 6.7). Taking just the direct combined cost of morbidity and mortality into account, it would take affected households 25 months to recover without help

from relatives for funerals; with their help, it would take 6 months to recover from these costs at their current level of savings. This is because more than 75% of the cost of funerals is covered by incoming funds (see Section 6.5.4). As the number of funerals increase, it is unknown whether households would be able to sustain the level of funeral contributions. Encouraging households to insure against the cost of funerals might be less severe on the resources of other households.

The above costs are an under-estimate because they take into account only the cost of the funeral day itself. The study found that there are pre-funeral and post-funeral costs incurred up to a year after the funeral that need to be covered (see Section 6.6.1).

The majority of individuals living with HIV/AIDS require home-based care (see Section 6.2) especially in the AIDS-symptomatic phase of a patients' life. Generally, caregivers were unemployed female members of the household (see Section 6.4). These caregivers provided home-based care to people living with HIV/AIDS without any form of training. They themselves are in need of counselling and help on handling neighbours and relatives in the presence of stigma and discrimination (see Section 10.5). There are home-based care organisations in Soweto, but because of stigma and discrimination, members of the household prefer to take on the responsibility of care-giving. It would be appropriate for these organisations to train members of the household to perform care-giving functions.

The health care treatment of choice has been the public health care facilities (see Section 6.2) due to cost and accessibility. However, in extreme cases of illness where nothing could be done for the sick person at the public health care facilities, some families have sent ill relatives to the rural areas to seek traditional methods of treatment. The cost of traditional methods of treatment exceeded the cost of treatment at public health care facilities.

## 12.6 Changing Patterns of Income for HIV/AIDS Affected Households (Research Question Two)

The second question investigated income-shifts for households where there was at least one person infected with HIV/AIDS. The study found that ill members not only lost income due to taking sick leave but also as a result of changing jobs. As individuals became sick and left formal full-time employment, they tried to participate in alternative income-generation activities or took up less demanding jobs to supplement income (see Section 7.2.1). The provision of anti-retroviral therapy would contribute to individuals remaining in full-time employment for longer. Some households tried to compensate for lost income by having other family members seek work (see section 7.2.3).

Over time, the affected cohort showed no significant improvement in earned income and relied more on non-market income, that is, income from grants and transfers in. If it were not for non-market income bridging this gap between earned income and total household income, affected households would not be in a position to finance the costs of morbidity and mortality. Care-giving consumes a lot of labour time in the AIDS-symptomatic phase of a person's life, preventing more household members from seeking employment even if there were more employment opportunities available.

Annually, affected households earned significantly less per adult equivalent (see Section 7.7) but do not spend significantly less per adult equivalent on regular expenditure (see Section 8.3.1) because of health care expenditure.

On an annual basis, funds enter the affected households as non-market income in the form of transfers in from other households, from grants and as a result of death so much so that total household income is similar to that of non-affected households (see Section 7.7).

The proportion of earned income became smaller over time in the affected cohort and was supplemented by non-market income, particularly income from grants (see Section 7.7.1). This has serious implications for policy because it can be expected

in the short-term that the affected cohort will apply for all available grants. Due to high unemployment, most if not all of these households qualify for the grants.

## 12.7 Changing Patterns of Expenditure for HIV/AIDS Affected Households (Research Question Three)

The third question investigated how expenditure patterns changed especially basic needs as a result of increased health care and funeral costs. The study showed no significant differences in adult equivalent annual household expenditure on basic essentials across cohorts (see Table 8.4). This could be because total household income across cohorts was not significantly different when non-market income and income from death was taken into account (See Table 7.15). Over time, the study showed that economic pressures cause all households to spend less not only on essential expenditure categories but also on total regular expenditure (see Section 8.4).

Annually, there were no significant differences in per adult equivalent regular or total expenditure across the cohorts despite remittances, grants and other income that entered the households (see Section 8.3.1). However, significant differences in spending were noted in annual health care and funeral costs in the affected cohort (see Appendix Table 16). This is so not just because of the presence or absence of HIV/AIDS but due to the frequency of occurrence. Due to the higher proportion of spending on health care and funeral costs, affected households spent significantly less on dependants whether they lived in the household or elsewhere (see Section 8.3).

Grants play a huge role in the survival of households affected by HIV/AIDS (see Section 8.3.1). However, even when income recovered, consumption did not resume to previous levels due to households dealing with past debt (see Section 8.4).

Besides health care and funeral costs, there were other expenditure categories associated with sickness and death. For example, special food items were purchased for the ill person either for consumption at home or at the hospital. The extra cost of food was not maintained when more than one person was sick in the

household (see Section 8.5). Per adult equivalent rand spent on food declined as more members in the household became sick.

A few items of expenditure make up the majority of the regular household expenditure across both cohorts (see Section 8.2). When households are cash strapped, they reduced payment of their services bill (see Section 11.4). They felt they could do this because their electricity and water supply would not be cut if they were contributing something however small, towards the bill. If it were not for this, most households would find themselves without water and electricity, making the problem of caring for the sick person even greater.

### 12.8 Impact on Surviving Family Members (Research Question Four)

Question four investigates the social and economic impact of HIV/AIDS of surviving household members. Adults from the affected cohort worked fewer hours (see Section 9.3) because many had already stopped working due to illness (see Section 7.3). In many cases, their household labour was not replaced due to a scarcity of jobs. More time was spent visiting relatives to maintain social networks (see Section 9.3).

Individuals across both cohorts spent time on Sundays at church (see Section 9.3.1), which they felt helped with the healing process (see Section 10.5).

Surviving family members were emotionally and financially drained from the effects of HIV/AIDS (see Section 9.5). They felt the need for knowledge and skills to cope emotionally within the household and also with outsiders. Stigma and discrimination prevented many families from being open about HIV/AIDS. They therefore isolated themselves (see Section 9.5).

Surviving family members went without certain essentials in favour of the ill person (see Section 9.5). Upon death of one or both spouses, most households dissolved and children were sent to live elsewhere. Grandparents were concerned about being left with child-rearing duties in their retirement years (see Section 9.5).

The psychological impact that HIV/AIDS has on children is unknown. Children from affected households spent a similar proportion of time attending school (see Section 9.4), but school performance, not just school attendance and hours at school or doing school work, is the more important indicator. The implication is that if children start performing poorly at school, the likelihood of dropping out of school in the future is high. Children were not withdrawn from school because there were adult members of the household focusing on care-giving functions (see Section 9.6). Future research should examine the impact of HIV/AIDS on orphans, cared-for children, children who lost one parent and children who do not live with both their parents versus children living with both parents. Moreover, research should be carried out on how households handle the unconditional burden of fostering children in the absence of any formal or financial arrangement.

Adults did not generally leave a will (see Section 9.6), even when there were assets such as houses owned by the deceased. Excess funds remaining after funerals were used for daily subsistence in the months following death (see Section 11.3).

## 12.9 Inter-Household Obligations of Care and Support (Research Question Five)

This question investigated the role of inter-household obligations of care in the survival of AIDS-survivors. More households reported providing care (see Section 10.2) than receiving care (see Section 10.3). This is because affected households isolated themselves and found it easier to provide care than to receive care due to stigma and discrimination (see Section 10.5). The type of support most often received from neighbours was child minding (see Section 10.3). However, affected households had unmet needs in the way of counselling, financial support, domestic chores and with transport for health care visits (see Section 10.4). The provision of anti-retroviral therapy should include the provision of transport to and from the health care facility, especially for those who are unemployed. Counselling support was offered to the infected person during and after diagnosis, but there was no follow-up during sickness. There was also no counselling support for surviving family members.

More research is required on the effectiveness of home-based care provided by governmental and non-governmental organisations versus training family members to provide such service. Access to home-based care organisations has been limited because households isolated themselves or because these organisations could only reach a limited number of households.

While households provided a great source of comfort to affected households, they were also a cause of stress and discrimination especially when the cause of illness or death became known or was suspected to be linked to HIV/AIDS (see Section 10.5). Neighbours can be a good resource for home-based care. More research is required to establish ways to encourage broader community acceptance of HIV/AIDS. On the other hand, some individuals who disclosed their status joined volunteer organisations to promote wider acceptance of HIV/AIDS (see Section 10.5).

### 12.10 Household Survival Strategies (Research Question Six)

The final question investigated how HIV/AIDS affected households survive the extra burden of HIV/AIDS costs. Both cohorts owned assets in similar value (see Section 11.2). The non-affected cohort favoured more medium to long-term investment schemes while the affected cohort favoured more short-term investment schemes where the access to funds would be easier. The affected cohort saved similarly to the non-affected cohort despite lump sum receipts as a result of death (see Section 11.3). As the affected household came under financial pressure, smaller amounts were paid for services such as electricity and water and debt escalated (see Section 11.4).

To alleviate the loss of income, households tried to diversify income. They remained employed for as long as possible and to a lesser extent some employed persons joined the households. Despite these strategies, the majority of households felt that they did not make up the loss of the deceased's income. Households that were destitute were forced to dissolve (see Section 11.5.1).

To survive the financial cost after utilising income, households tended to borrow money, then utilise savings and, as a last resort sold assets (see Section 11.5.2).

Very few households sold assets only because they had very few assets besides the dwelling in which they lived. Money was borrowed mainly from friends and relatives and to a lesser extent from micro-lenders. Households relied heavily on social grants. In the short-term, the Department of Social Development can expect a very high up-take on old age pension grant, disability grant and child support grants.

To alleviate the loss of labour, non-economically active members went out in search of work and care-giving was performed mainly by unemployed adult members of the household.

The affected cohort accessed a wide range of safety networks (see Section 11.5.4), such as relatives and non-relatives, employer, church, non-governmental organisations, burial funds and other institutions to help with the costs of funerals, health care and general subsistence.

Non-affected households transferred money out more than they received money in which is expected to be the case for an urban household. Affected households received more transfers in than they transferred out. This is apart from the funds donated to help with funeral costs.

Affected households organised themselves such that financially they were similar to non-affected households (see Section 11.5.5). This occurred through the receipt of grant income, funds as a result of death from relatives, burial societies and other insurance schemes, and from transfers into the household. Without this help, affected households would have been in a far worse financial situation (see Section 11.5.5).

### 12.11 Overall Conclusion

In the end, there are only two types of households - those with an infected member and those affected. There is no household untouched by HIV/AIDS directly or indirectly. This may be through taking care of sick members of other households,

taking care of children of sick members, caring for the sick, donating funds towards a funeral, subsidising funeral costs or through just listening to the neighbour.

Households that attend public antenatal care facilities are poor and can barely afford required regular monthly household expenditures. Across time they have become poorer with regular spending declining, even with the help from safety networks including government grants. With less money transferred out of urban households, there are other households, particularly in the rural areas which suffer in consequence.

This study has raised various issues for government, the church and for organisations to help bring about change to improve the quality of lives of people in households infected and affected by HIV/AIDS. It is clear that without the help from various sources the affected cohort would not survive the costs of HIV/AIDS morbidity and mortality (see Case Study 12.1).

**Case Study 12.1: Story Written by an Infected Household Member**

My name is Noluthando[1]. I am 28 years of age and grew up in Soweto. I was brought up by a single mother who used to work as a housekeeper (maid). I too am a single mother of three who is unemployed. In 1999, I got pregnant with my third child and visited the antenatal clinic who offered voluntary counselling and testing. After a blood test, I discovered that I was HIV positive. I was confused and did not know what to do. I cried, and cried and cried. The counsellor comforted me. I wanted to tell my mother but I was scared because the whole world would know about my HIV status if I told my mother. My mother is an alcoholic and I did not feel safe telling her my secret in case she mentioned it to anyone when she got drunk. The baby was born HIV positive last year and died when she was only one month old. I knew that my baby died of AIDS but I kept the secret to myself because I was afraid of people finding out that I too was HIV positive.

Late last year my mother got very sick and was hospitalised. She lost weight and coughed through the night. She was diagnosed as having TB and took treatment for six months. This year, she got sick again and went to the clinic. They conducted more tests and admitted her to hospital. When I went to visit her she cried and told me that she was HIV positive. I was in a state of shock and thought I was dreaming. I cried not because of what she told me but I

[1] Name has been changed

was thinking more about who would care for my children and whether I should tell her about my status or should I wait, is it the right time or not? I decided not to tell her then because I did not know whether the time was right or not.

One thing that did enter my mind was that I thought I infected her because I did not know much about HIV. When she got discharged from hospital and returned home, she told me that she had an affair with a married man who used to work in the mines. She suspected she got it from him. I was so relieved that I did not infect her.

Since we were both sick and not working, I kept many boyfriends to generate income so that I could have money to take her to hospital. She got admitted in July and died in hospital the same month. Being unemployed, I did not have any money for the funeral. I had to ask my neighbours for help and with their help I went to Jozi FM (Soweto community radio) to ask for help. Jozi FM arranged with one of the local undertakers who donated a coffin and transport. The neighbours went from door to door asking for donations. The neighbours managed to raise R1000 but this was not sufficient to cover the cost of the funeral. This money was used to purchase tea and cakes for the people who attended the funeral. Even though it was a sad funeral, everyone could tell that that I was brought up in a very poor family because I didn't even have money to bury my mother. But I still say thanks to everyone who helped me. I wish they would do this to others who are in need.

Knowing that I am going to die brings pain and sorrow to me especially when I look at my kids. I feel sorry for them because they will grow up without a mother or a family. I am sorry things turned out to be like this. I had a dream, that one day I will get a better job save money so that I can give them a better education. Unlike me I left school at standard 8. I do not want them to be like me.

Unfortunately, I am also starting to get sick and starting to lose weight. I have diarrhoea that doesn't stop. I went to the clinic to see a doctor and she advised me to attend a support group and to meet other people who were also HIV positive. She gave me medication and then she took my blood to check my CD4 count and my viral load. When I came back for my results my CD4 count was 148 and she told me that I could apply for a disability grant. I obtained the forms from Rissik Street and the good doctor helped me complete the form and I received R1250.00 for the first payment (including back payment). I used R400 to buy food, R500 to buy the kids clothes. Then I took R60 to join a burial society called Tshebedisano. The other money that was left I bought vitamins (R10 a bottle) and I use R24 for transport to go to the support group every month. Thanks to our government for the money. At least we can do something with it.

I pray to God that one day the doctors will get a cure for AIDS. Our brothers, sisters, mothers and children are dying. The cemeteries are so full in such a way that when we die they will be bury us standing inside the coffins because there will be no enough space to fit all of us.

To my brothers and sisters out there I want to tell you that AIDS is real it doesn't choose, you will get it whether you are beautiful or ugly if you practice unsafe sex. If you are still negative say thanks to God and always remember to use condoms.

I feel bad about myself because I have AIDS today. This was because of my poor financial position that forced me to have boyfriends to put food on the table for my family. If it were not for poverty I may be negative. I still blame myself for being positive but I cannot change that.

I wrote a letter to everyone as I am writing to you, especially my 8 and 10 year old daughters telling them that I have died of AIDS, and that I have joined a burial scheme called Tshebedisano.

I am sorry because they don't know about my HIV status. They only know that I am sick and I will be better soon. I don't want to hurt them or disturb their studies by telling them that I am dying. When I die, I am hoping my children will be taken care of by an orphanage because I lost contact with my family in the Transkei. A letter would be given to my neighbour who only knew about my status because her daughter attends the support group with me. She agreed to bury me if I die because I don't have family here; my mother was originally from Transkei. I never got a chance to go there. She never went to visit also because of family problems.

Dear God, please send down the Holy Spirit to heal us. AIDS is killing us. God Bless
Noluthando

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# APPENDICES

## Appendix 1: Annotated Questionnaire

### Section 1 to 4: Administrative Functions

Sections one to four are administrative questions to guide the interviewer in planning and executing the survey.

### Section 5: Demographic Profile of the Household

The objective of this is to establish who regularly resides at the household to identify household members, their status and role within the household structure. This section will collect the names of the household members, their relationship with the head of the household, their age, gender, education current and planned, marital status, parentage of children, school attendance and health care status. Changes in household composition over time will be reflected in changes in the demographic profile across waves of the survey. The relationship to the household head will detect any fostering of children and other dependents. Section 1 will be rechecked during each wave of the survey to document changes in structure, size and composition of household. New members entering the household in subsequent waves will be given a new identification code. The current education level will give an indication of the quality of skills that exist. This section will also guide the interviewer in identifying the relevant sections of the questionnaire to be completed and will help the interviewer in planning. Kinship diagrams will be drawn for each household to establish the relationship between parents and children and not just to the household head.

The data from this section will inform users about the socio-economic status of households that utilise the VCT service centres.

### Section 6: Migration

The objective of this section is to establish the length of time that the household has been residing in Soweto and the reasons for leaving the last place of residence. Lack of work in the rural areas and family economic crisis force people to migrate to the urban areas in search of work. Migration contributes to household formation and dissolution.

Policy-makers will be informed about the reasons for migration to urban areas such as Soweto.

### Section 7: Main Activities of the Household (Time Allocation)

The purpose of this section is to analyse the productive allocation and use of time at household level by all members over the age of 7 years. This section analyses the economic activities of all household members, their employment status, who is supported

by whom and who requires support. It also investigates whether household members are included in household economic activities. This section is divided into four parts.

The first part will collect information on the number of hours per day spent by each household member in the past 7 days on the following activities: attending to school or to school work; domestic chores, supervising childrens' school work, working, looking for a job, off sick, caring for sick members, attending funerals, working for neighbours or relatives for pay, working for neighbours or relatives for no-pay, working in the garden, home production, repairs and maintenance, sleeping and on leisure. This part will improve an understanding of the changes that will take place in the allocation of time in households that experience HIV/AIDS sickness or death and will help answer research question one (time allocation of activities) as well as research question four (effects on remaining household members). This information will be obtained via the use of the diary method. It may never be 100% accurate; however, it will provide a good guide to the allocation of time by individual household members.

The second part deals with how the household supports itself financially. It also deals with what types of income sources the household relies on. In cases of sickness and death, certain income sources will be more vulnerable than others. It will in part deal with research question 1.

The third part deals with the employment status of household members 15 years and older as well as their employee benefits and establish whether they are self employed or work for others in either the formal or informal sectors. It also establishes whether business skills are transferred to other household members and highlights vulnerable employment areas in cases of sickness or death. It will help partly answer research question 1.

The fourth part deals with obligations of care for sick household members of other households and children of the interviewing household if adult members become sick. This section contributes to answering part of research question 5.

This section will inform the allocation of time by household members, what productive activities have to be sacrificed, and by whom, as a result of HIV/AIDS. The main sources of financial support are important to inform how people are surviving without formal employment. It is not known whether inter-household obligations of care still exist within urban areas or the extent of this care.

**Section 8: Migrant Workers**

These are the people not classified as household members unless they are household heads because their work takes them away from home for more than a month each year. Generally migrant workers send money and gifts home thereby contributing to the household economy. Migration has been identified as a high risk factor in the transmission of the HIV virus as migrant workers are away from their families for

lengthy periods of time. An understanding of migrant workers and its effects on the household is therefore of importance.

This section will inform us about the extent of migrant workers that seek work outside of Soweto, their responsibility to send money or in-kind transfers to households in Soweto and the extent of reliance on migrant support. This section contributes to answering research question 1.

**Section 9: Remittances In**

The purpose of this section is to record assistance from other relatives, friends and neighbours beside migrant workers. In addition, it establishes for what purpose the money or gifts were given and for what purpose it was used. This section will highlight the value of social capital that exists in urban communities. The data could be used to calculate how many of the survey households would dissolve in the absence of these remittances.

This section informs us about inter-household financial support to answer research question 1.

**Section 10: Income from Market and Non-Market Activities**

This section will help answer research question 1, which deals with income shifts where at least one of the primary income-earners is infected. This section will collect information on income, from market activities (employment or self-employment) and from non-market activities such as government grants, remittances in from relatives, neighbours and friends and migrant workers and assistance from non-governmental organisations. It will also record the income from home production activities. This section breakdowns the income by income-earner and will be completed by the income-earner to enhance reliability. Income will be recorded before deductions and taxes to better assess what households contribute to the tax system as well as to highlight the funds that households contribute to. All income and assistance in cash and in-kind will be recorded. For those who do not wish to disclose their income, a card will be shown of income categories, for them to choose one of the categories.

This section will help us understand at what income levels people are surviving in Soweto and at what income levels households are not able to fulfil basic economic needs.

**Section 11: Household Expenditure**

This section will help answer research question 3, which is to investigate how households experience change and how basic economic needs are being sacrificed to accommodate increased HIV/AIDS costs. This section is divided into four parts, regular household expenses, irregular household expenses, expenses on education and transfers out. Expenditure on HIV/AIDS related costs will be explored in sections 14 and 15 (Morbidity and Mortality) and will be transferred to this section during analysis.

Households will be requested to keep a diary of expenditure. However, the interviewer will confirm and record expenditure during household visits. Twenty-two regular expenditure groups have been identified. Since many people in Soweto leave home very early for work, many purchase food for consumption outside the home. It is therefore important to record food consumed at home and out of home. People frequent taverns and shebeens especially during crises, hence it is important to record alcoholic beverages consumed at home and outside the home.

Irregular once-off expenditure such as weddings, dowries/lobola's, funeral expenses and durables will be recorded separately. The third part deals with expenditure on education, which includes transportation to school, meals, school fees, books, uniforms as well as pocket money. The fourth part deals with transfers to relatives, which are sometimes the major source of income for destitute relatives. Transfers out may also take place because children, the elderly or the sick may be sent to relatives to be cared for. Reasons and value of the transfers out will be recorded.

This section will inform what expenditure categories are sacrificed as a result of increased health care and funeral costs (research question 3). What is no longer afforded at household level and what the long-term economic consequences will be for survivors? (research question 4).

**Section 12: Household Assets**

The households' ability to cope with sickness and death is linked to the value of assets the household possesses. A recording of assets is important to assess household wealth. It is an important starting point since households that are in a wealthier starting position will be able to cope better with sickness and death than households without assets. Assets especially durable goods and current assets can be liquidated for cash, which can be used to finance health care costs. The biggest asset for most households is home ownership. A separate section 12.1 focuses on home acquisition, mortgage payments, rent received or rent paid. Households that pay rent are more vulnerable to dissolution when household members become sick and die than households who own their homes.

Section 12.2 deals with an inventory of household assets and section 12.3 investigates what assets were disposed of during the past month and for what purpose. Changes to the asset base will be tracked over time to establish the impact of HIV/AIDS on household wealth. This section will help partly answer research question 4.

Assets are a better representation of household wealth. Households with assets may be in a better position to manage increased costs in the short-term. Assets may also be used in the production of income and this study may inform the extent to which this is done or not done. This section will contribute to answering research question 6.

**Section 13: Savings, Investment, Borrowings and Debt**

This section assesses the economic strength or weakness of the household. For households to be sustainable in the long-term more savings and less debt are required. Sickness and death consume savings and increase debt. Participation in formal and informal savings and investment schemes will be recorded. Households that experience sickness or death may utilise their savings to pay for these additional expenses. Households that do not have savings may borrow money from a variety of sources to pay for these added expenses or they may go into debt. Households pay a higher interest rate when borrowing money from money-lenders or informal sources which may force them further into debt. Details about who the lenders are, the interest rates when the household anticipates repaying the debt are recorded. This section will help partly answer research question 6.

**Section 14: Morbidity**

This section is divided into two parts. The first section contributes to answering research question three by monitoring the direct and indirect costs of HIV/AIDS. This section measures the cause of sickness, the health seeking behaviour of the sick persons and the costs associated with sickness. It records indirect costs such as transportation to and from hospital and clinic visits, consultation fees paid and cost of medicines. Indirect costs include loss of income for the deceased as well as for the carers.

The second part partly answers research question four by delving into expenditure cut-backs as a result of sickness and who was affected by this cut-back. It also deals with household discrimination as a result of sickness within the household and the community.

This section will inform us about the cost of health care including the loss of earnings for the sick individual and the caregiver (research question 2). It will also inform us how households cope with these increased costs (research question 6).

**Section 15: Mortality**

This section contributes to answering research question 2 by monitoring the direct and indirect costs of death. It measures the cause of death, the health seeking behaviour of the deceased persons and the costs involved in sickness and in death. It records direct costs for medical and funeral costs relating to the deceased. In terms of indirect costs it measures loss of income for the deceased and for the carers. It also records assistance received from outside sources and any cultural changes related to funeral practices. It also deals with household discrimination as a result of the death within the household and the community.

This section will inform us about the loss of income in households as a result of death, whether this loss is made up from another source and what the impact is on surviving members (research question 4). It will explore the cultural aspects and cost of funerals.

**Section 16: Home Production and Consumption**

Where unemployment is high, home production increases. This section will investigate and quantify household produce consumed at home and household produce sold. The total value of home produced goods will be recorded as income. Home produced goods consumed at home will be recorded as expenditure. If all home produced goods were consumed at home, income will be balanced with expenditure.

This section will inform us whether home production takes place in Soweto and to what extent (research question 1).

**Section 17: Anthropometry**

In this section, the interviewer records the height and weight of all household members under the age of 5 years. These measures of well-being are indicators of health and nutritional status of children. An important impact of sickness and death is the deterioration of the health status especially of children. This section will also collect data on the immunisation of children since these aspects are neglected during family crises. This section will contribute to answering research question four.

This section will inform us about the vulnerability of children's health as a consequence of sickness or death at household level and will contribute to answering research question 4.

**Adapting the Questionnaire for Subsequent Waves**

The information from the first wave will generate data on the economic differences in households experiencing sickness and death and households that do not experience sickness and death. The questions and the subjects covered in the first wave will remain the same. Reviewing the demographic profile of households in subsequent waves will capture changes to the household composition, size and structure. A new section will be added to the questionnaire for subsequent waves to capture who has moved, who has entered and the reasons for the movement. This section will also contribute to answering research questions four and five. The changes in economic well-being will be captured in the sections on main activities of the household, income, expenditure, savings, investment, borrowings and debt, disposal of assets, changes in home production as well as health and nutritional status of children. The questionnaire of the first wave will represent a cross-sectional survey. The subsequent waves will represent a longitudinal survey in which data can be compared.

For the second wave, all questions with a 12-month reference period will be modified to 2-months (since the last interview). The reference section for the time allocation that measures time use in the past 7 days will remain the same.

The data programme will generate a form for the demographic profile of the household that can be carried by the interviewer to subsequent visits to check any inconsistencies

and to capture movements. A form will also be generated on the ownership of assets to record any disposal of assets during subsequent visits. A time use form will be carried to subsequent visits to confirm any changes to the time allocation of economic activities as a result of sickness and death.

## Appendix 2: Details of Primary Research on the Socio-Economic Impact of HIV/AIDS on Households and Individuals

| Country and Research Title/ Design | Themes | Urban /Rural | Period of data collect ion | Method of data collect-ion | Sample size | Sampling method and selection criteria | Stratification parameters | Respondent | Reference |
|---|---|---|---|---|---|---|---|---|---|
| 1. Tanzania (Kagera district)<br><br>"Transfers and household welfare in Kagera"<br>"Financial Assistance to Bereaved households: Lessons from Kagera"<br>"Sources of Financial Assistance for Households suffering an Adult Death in Kagera"<br>"The impact of adult mortality on primary school enrolment in Northwestern Tanzania"<br>"Coping with the AIDS Epidemic in Tanzania: Survivor Assistance"<br>"The Impact of the AIDS "Epidemic on the Health of Older Persons in Northwestern Tanzania"<br>Longitudinal panel household survey<br><br>No control group | Coping abilities across households poor versus rich<br><br>Private transfers to households as part of a coping strategy<br><br>Withdrawal of children from school as a coping mechanism<br><br>Economic impact of mortality on the BMI (body mass index) of older persons | rural | 1990-1994<br><br>4 rounds/ waves | Combinati on of structured household questionn aire (interview ed every six or seven months) and set of five questionn aires collecting data on communit y, prices, clinics, primary schools and traditional healers. | Total of 816 rural household s first sampled, with 757 household s completin g all four waves and 915 household interviewe d in total after replacing household s that moved out of the area over the study period. | A so-called quick health survey was administered to 8386 households in four selected villages, checking for the presence of illness and death within the household, after which a random sample of 816 households was drawn from this sampling frame. | Villages were selected so as to reflect differences in geographical location and mortality rates. | Household head and individual members of the household.<br><br>Interviewers: 4 mobile teams each with a trained supervisor and 2 trained interviewers plus an anthropomet rist and a driver<br><br>Incentive: None reported | Lundberg and Over (2000),<br><br>Lundberg, Over and Mujinja (2000),<br><br>Lundberg, Over and Mujinja (2000),<br><br>Ainsworth *et al.* (2000), Ainsworth and Rwegarulira (1992),<br><br>Ainsworth and Dayton, 2002 |

| Country and Research Title/ Design | Themes | Urban /Rural | Period of data collect ion | Method of data collect-ion | Sample size | Sampling method and selection criteria | Stratification parameters | Respondent | Reference |
|---|---|---|---|---|---|---|---|---|---|
| 2. Zimbabwe (Mutare (urban) and Marange (rural)<br><br>"Household welfare impacts of mortality of adult females in Zimbabwe: Implications for policy and program development"<br><br>cross-sectional household survey<br><br>no control group | Mortality impact of adult females on food security, child schooling, health and asset base.<br>Household responses including social support | Urban and Rural | Februar y and March 2000 | Combinati on of structured questionn aires, focus group sessions and interviews with key informant s in the communit y. | 215 household s fostering maternal orphans were interviewe d<br>Mutare n=101<br>Marange n=114 | Purposively selected households supplied by Family AIDS Caring Trust (FACT) orphan assistance programme, of households that had experienced an adult death in the past two years. | Urban versus rural households | Foster parent (in many cases a relative) or surviving husband with the help of the deceased's children<br><br>Interviewer: Unknown<br><br>Incentive: None reported | Mutangadura (1999/2000) |
| 3. Zambia<br>2 urban residential areas Zambia compound and Kafue Estate<br><br>Cross-sectional survey<br><br>No control-group | AIDS Morbidity and Mortality in the formal and informal sector | Urban | End of 1997 beginni ng of 1998 | In-depth interviews using structured questionn aire<br>+ 5 focus group discussion s were held. | 177 residents of Zambia compound and 168 residents of Kafue Estates in 15 household s in each area (total 30 household s) | Chronically ill patients and those households who experienced death in the past 24 months | Urban residential areas | Unknown<br><br>Interviewer: Unknown<br><br>Incentives: None reported | Mutangadura ,G. and Webb, D. in Everybody's Business (2000) |

| Country and Research Title/ Design | Themes | Urban /Rural | Period of data collect ion | Method of data collect-ion | Sample size | Sampling method and selection criteria | Stratification parameters | Respondent | Reference |
|---|---|---|---|---|---|---|---|---|---|
| 4. Zambia (Lusaka (urban) and Chikankata (rural) district)<br><br>"Social and Economic Risk Factors for HIV/AIDS affected Families in Zambia"<br><br>Economic impact study<br><br>Longitudinal household survey<br><br>No control group | Coping mechanisms<br><br>Income, educational outcomes, health outcomes and nutritional status of children under 5 years of age | Urban and Rural | January 1991-December 1995<br><br>5 years | Structured interviews by trained interviewers | Total of 333 households, 232 urban and 101 rural families in low income areas<br><br>Purposive sampling | Five year retrospective study of employees of which one or both parents or the major breadwinner had died of AIDS in the past five years. Urban households selected with the help of NGOs involved in provision of services to HIV/AIDS affected families. Rural households selected with the co-operation of the Community AIDS Management and Counselling team based at a mission hospital. | Urban versus rural households | Caregivers<br><br>Interviewer: Trained interviewers<br><br>Incentives: None reported | Nampanya-Serpell (2000) |
| 5. Uganda (Hoima, Iganga, Kabale, Masaka, Mbale and Mbarara)<br>"AIDS Morbidity and the role of the family in patient care in Uganda"<br>"AIDS in Uganda: how has the household coped with the epidemic?"<br>"Changes in household composition and family structure during the AIDS epidemic in Uganda"<br>cross sectional household survey | Care and support for HIV/AIDS patients<br><br>Families coping mechanism<br><br>Orphan care, behaviour patterns of widowed persons, attitudes towards death and sexual behaviour | | 1991-1996<br><br>Phase 1 (mid 1992)<br>Phase 2:late 1992 early 1993<br>Follow up: July/August | Phase 1: Ethnographic data and Focus groups with elders and youth structured interviews with elders<br>Phase 2: Baseline survey | 1 797 households<br><br>143 households in the elders survey phase 2 and 3 same instrument with 1797 household | Random sample of 1 797 households with self reporting of illness in the past four weeks | Aids patients (92)<br>AIDS-related patients (290)<br>Patients ill from other causes (938) | Patients, care providers or heads of households<br><br>Interviewer: None reported<br><br>Incentives: none reported | Ntozi, JPM (1997), Ntozi and Nakayiwa (1999)<br>Ntozi and Zirimenya (1999) |

| Country and Research Title/ Design | Themes | Urban /Rural | Period of data collect ion | Method of data collect-ion | Sample size | Sampling method and selection criteria | Stratification parameters | Respondent | Reference |
|---|---|---|---|---|---|---|---|---|---|
| no control group | Household structure and dependency burden | | 1995 Multi-phase study of 6 districts | Phase 3: follow-up survey Phase 4: complete household survey and registratio n of vital events | s | | | | |
| 6. Uganda (districts of Soroti, Lira and Arua)<br><br>"The effect of the AIDS epidemic on widowhood in Northern Uganda"<br><br>"Orphan care: the role of the extended family in northern Uganda"<br><br>Cross-sectional survey<br><br>No control group | Widowhood, Changes in funeral practices as a coping strategy orphans, mortality | | 1997 | Structured questionn aire | 1206 household s | Purposive sampling technique.<br>First selected the two counties with the highest HIV/AIDS prevalence from each district, after which randomly selected two parishes from each county. Five villages were then randomly selected in each parish, after which 20 households where a death had occurred since 1982 were interviewed. | unknown | Head of household or spouse<br><br>Interviewer: None reported<br><br>Incentives: none reported | Ntozi et al., (1999), |

| Country and Research Title/ Design | Themes | Urban /Rural | Period of data collect ion | Method of data collect-ion | Sample size | Sampling method and selection criteria | Stratification parameters | Respondent | Reference |
|---|---|---|---|---|---|---|---|---|---|
| 7. Thailand (Chiangmai province)<br><br>"The Economic Impact of HIV/AIDS Mortality on Households in Thailand"<br><br>Cross-sectional household survey<br><br>Control group<br><br>Qualitative and Quantitative | Impact of adult death on poverty of households<br>household coping mechanisms<br>Household structure<br>Changing consumption patterns | Rural | 1994 | Combination of structured questionnaire administered to households, interviews with key informants (community leaders), and questionnaire administered to children in interviewed households. | Total of 324 households, consisting of 116 households that recently experienced an HIV/AIDS-related death, 100 households where a non-HIV/AIDS related death had occurred, and 108 households with no death in the household | AIDS rural households were selected from hospital records because the number of reported deaths were small, all the cases from the hospital records were included either as interviewing households or as substitutes. The study was designed to be a random selection from hospital records. | Sample stratified by presence or absence of AIDS-related and non-AIDS-related deaths. | Heads of household or others who could provide the information<br><br>Interviewers: Public health interviewers<br><br>Incentives: None reported | Pitayanon *et al.* (1994), UNAIDS (1995). |

| Country and Research Title/ Design | Themes | Urban /Rural | Period of data collect ion | Method of data collect-ion | Sample size | Sampling method and selection criteria | Stratification parameters | Respondent | Reference |
|---|---|---|---|---|---|---|---|---|---|
| 8. Thailand (two districts Mueng and Pong in Phayao province)<br><br>Cross-sectional survey plus<br>Case studies (10)<br><br>Control group | Economic Impact of Morbidity – Methodological issues<br>Hh income and expenditure, transfers in and out, assets and savings, direct and indirect cost of HIV/AIDS<br>Household debt | Rural | 1999<br><br>Betwee n April and Decemb er | Combinati on of structured questionn aire administer ed to household s, interviews with key informant s and focus groups | 600 rural household s | Key informants (community leaders, health personnel) identified household where someone was chronically ill. | 300 households recently experienced chronic morbidity and 300 households not experiencing morbidity or mortality | Household Head or care-givers<br><br>Interviewers: Health personnel who spoke the local language<br><br>Incentives: None reported | Kongsin, S and Watts, C.H. (2000). |
| 9. Tanzania (Bukoba district)<br><br>Adult mortality as Entitlement Failure – AIDS and the crisis of rural livelihoods in a Tanzanian Village<br><br>case study village<br><br>longitudinal survey<br><br>no control group | Labour diversion from productive activities to care giving activities<br>Time allocation of labour within a household<br>Changes in household composition<br>Household survival strategies | Rural | 1996 seven months from Februar y to Decemb er | In-depth interviews | | A census was first conducted collecting detailed information about each household(164 households) including illness to identify the households affected by HIV/AIDS | Affected versus non-affected households | Household head or spouse<br><br>Interviewer: Researcher<br><br>Incentives: None reported | Rugalema, G (1999) |

| Country and Research Title/ Design | Themes | Urban /Rural | Period of data collect ion | Method of data collect-ion | Sample size | Sampling method and selection criteria | Stratification parameters | Respondent | Reference |
|---|---|---|---|---|---|---|---|---|---|
| 10. Zaïre (Kinshasa)<br><br>Longitudinal Survey<br><br>Case-control study | Socio-economic consequence on Orphans | | 1986-1990 | Structured questionn aire | 466 HIV-positive women and 26 AIDS orphans (cases) and 606 HIV-negative mothers and 52 non-AIDS orphans (controls). | Nested case-control study within a cohort of HIV-positive mothers attending the obstetric ward and follow-up clinic at two hospitals. Longitudinal cohort study consisting of monthly visits over a three year period. Verbal informed consent was obtained from mothers. | Infected versus non-infected mothers | Mother, children and father of the children<br><br>Interviews took place at the place of residence<br><br>Incentives: none reported | Ryder *et al.* (1994) |
| 11. Burkina Faso (Seriba and Bourasso)<br><br>"Household Strategies to cope with the economic costs of illness"<br><br>Longitudinal Survey | Household coping strategies | Rural | 1992 | Combinati on of qualitative interviews , structured interviews , and household time allocation mapping. | 566 household s were visited 6 times between March and October 1992 to cover both the dry and rainy season | Households were selected using a theoretical sampling approach that sought to include households representing a wide variety of characteristics deemed to influence coping behaviour. | Sample was stratified so as to be representative of rural households of different size composition, wealth, severity of disease, age and gender, and the seasonality of illness episodes. | Household head, sick individual or caregiver in case of sick children<br><br>Interviewer: None reported<br><br>Incentives: None reported | Sauerborn et al. (1996) |

| Country and Research Title/ Design | Themes | Urban /Rural | Period of data collect ion | Method of data collect-ion | Sample size | Sampling method and selection criteria | Stratification parameters | Respondent | Reference |
|---|---|---|---|---|---|---|---|---|---|
| 12. Uganda<br><br>"Methods used to study household coping strategies in rural South West Uganda"<br><br>Longitudinal study – observation over a one year period | Household coping mechanisms | Rural | 1991-1992 | Combination of structured interviews conducted with households during monthly visits spread over one year, rapid appraisal techniques and focus groups. | 27 rural households living in 3 villages (two pilot studies preceding study included 24 households, 4 of whom was included in the study) | Purposive sampling to represent different household types and socio-economic status | household composition and socio-economic status | Individual household members<br><br>Interviewer: 9 local people were trained as interviewers | Seeley *et al.* (1995) |
| 13. Ivory Coast (Cote d'Ivoire)<br><br>"Socio-economic dynamics within families affected by HIV/AIDS"<br>First sample – cross-sectional survey<br>Sub-sample – longitudinal survey<br><br>Multi-centre study with Haiti below.<br><br>No control group | Impact on Families<br>Economic activities within the household<br>Extended family and community networks | Rural | Early 1990s | Structured questionnaire | Phase 1: 200 households were visited once off<br>Phase 2: subsample of 120 households was visited every 2nd month. | Household containing at least one adult with an HIV-related disease, who had been informed of their HIV status, and who had one or more dependent children. The sub-sample was chosen on the basis of educational background, socio-economic status and level of integration with the extended family | Sub-set of households visited in second survey selected on basis of education, socio-economic status and extent of integration with extended family and community networks. | Unknown<br><br>Interviewer: None reported<br><br>Incentives: None reported | Chevallier, E., Bechu, N., Cayemittes, M., UNAIDS (1995) |

| Country and Research Title/ Design | Themes | Urban /Rural | Period of data collect ion | Method of data collect-ion | Sample size | Sampling method and selection criteria | Stratification parameters | Respondent | Reference |
|---|---|---|---|---|---|---|---|---|---|
| 14. Haiti<br>"Socio-economic dynamics within families affected by HIV/AIDS"<br><br>Longitudinal study<br><br>No control group | Impact on Families<br>Economic activities within the household<br>Extended family and community networks | 1/3 urban 2/3 rural | Early 1990s | 6-monthly interviews with household (period uncertain) | 107 household s | Households with at least one household member who is HIV-positive and whose status is known. | Urban (1/3) versus rural (2/3) households | Unknown<br><br>Interviewer: None reported<br><br>Incentives: None reported | Chevallier, E., Bechu, N., Cayemittes, M., UNAIDS (1995) |
| 15. Sri Lanka<br>"Socio-economic impact of HIV/AIDS on households"<br><br>Cross-sectional survey<br><br>No control group | Direct and indirect cost<br><br>Household responses | | Early 1990s | Semi-structured questionn aire | 34 household s | Household with at least one HIV-positive member that are aware of their HIV-status. | | infected individual and their relatives<br><br>Interviewer: None reported<br><br>Incentives: None reported | Jayasinghe, S., UNAIDS (1995) |
| 16. India (Bombay), Tanzania (Kyela district), and Thailand (Chiangmai province)<br><br>cross-sectional survey<br><br>no control group | Household and community responses to HIV/AIDS | Urban and rural | 1993-1995 | Data collected using combinati on of individual and household interviews , focus | The India study sampled 24 men and 3 women with HIV/AID S, including | Respondents were sampled from hospital outpatient departments and belonged mainly to lower income groups. | | Household members and women as providers and receivers of care<br>Interviewer: None reported | Bharat (1995/96), UNAIDS (1995). |

| Country and Research Title/ Design | Themes | Urban /Rural | Period of data collect ion | Method of data collect-ion | Sample size | Sampling method and selection criteria | Stratification parameters | Respondent | Reference |
|---|---|---|---|---|---|---|---|---|---|
| | | | | group discussion s and observatio ns. | their spouses and other family | | | Incentives: None reported | |
| 17. South Africa (Welkom and Qwa Qwa – Pilot Study)<br><br>Longitudinal survey + focus groups<br><br>Control group of non-affected households | Aids morbidity and mortality and associated costs<br>Income, expenditure, household coping strategies migration | Urban and Rural | 2001 to 2004 | Structured questionn aires | 100 urban household s and a control group<br>100 rural household s and a control group | Sampling was done through NGO networks | HIV Affected versus non-affected households | Financial Head of Household<br>Interviewer: Trained interviewers from the local community<br>Incentive: R100 per household | Booysen, et al (2001) |
| 18. Kenya (8 districts, Coastal, Eastern, Nyanza, Kisumu, Kisii, Western, Central and Rift Valley)<br><br>Panel household survey | Changes in household size and composition<br>Agricultural production<br>Asset levels<br>Household income | Rural | 1997 and 2000<br><br>3 year survey period | | 1422 household s | Random selection of households with a prime age adult death | Households afflicted by adult mortality versus households not afflicted by adult mortality | Unknown<br><br>Interviewer: None reported<br>Incentives: None reported | Yamano and Jayne (2002) |
| 19. Kenya (Kisumu and Siaya districts)<br><br>"From single parents to child-headed households: The case of children | Food security, production and coping mechanisms of Orphans | Rural | 1997 | Combinati on of structured questionn aires, interviews | 1101 household s headed by children or elderly | Purposive and convenience sampling of households with orphans with the help of local village chiefs and trained research | Two districts | Caregivers, orphans and terminally ill parents<br>Local people trained in | Ayieko (1998) |

| Country and Research Title/ Design | Themes | Urban /Rural | Period of data collect ion | Method of data collect-ion | Sample size | Sampling method and selection criteria | Stratification parameters | Respondent | Reference |
|---|---|---|---|---|---|---|---|---|---|
| orphaned by AIDS in Kisumu and Siaya Districts"<br><br>cross sectional survey<br><br>no control group | | | | with key informant s, focus group sessions, personal observation | grandpare nts | assistants. Due to limited resources only 9 EA's were relatively well covered, 3 partially covered. | | interviewing techniques and HIV/AIDS prevention Incentives: None reported | |
| 20. India (Mumbai)<br><br>Cross-sectional survey<br><br>No control group | Care and support by family members | Urban | 1999 | Combinati on of semi-structured interviews and observatio ns.<br><br>In-depth individual and couple interviews | Total of 58, including 26 infected individual s, 4 couples in which both partners were infected, and 24 other members of infected household s. | Recruited from outpatient departments of two public hospitals and from those visiting a homeopathic AIDS research centre. | | Patient<br><br>Interview was done at people's homes, clinical setting or the project office<br><br>Interviewer: Team of one interviewer and one recorder/obs erver who also focused on body language Incentives: none reported | Bharat and Aggleton (1999) |

| Country and Research Title/ Design | Themes | Urban /Rural | Period of data collect ion | Method of data collect-ion | Sample size | Sampling method and selection criteria | Stratification parameters | Respondent | Reference |
|---|---|---|---|---|---|---|---|---|---|
| 21. New Zealand (Auckland, Hamilton, Wellington and Christchurch)<br><br>Cross-sectional survey<br><br>No control group | Private costs of HIV/AIDS | Urban | 1994 | Structured questionn aire used in combinati on with personal diary kept by patients to document HIV/AID S related costs over a period of one month. | 25 people living with HIV/AID S | Participants were recruited via local branch of the national union of PWLA, using a snowball sampling technique. | Patients were classified as asymptomatic, symptomatic without AIDS and symptomatic with AIDS. | Individual patient or caregiver<br><br>Interviewer: Trained co-ordinators associated with the national people living with AIDS<br><br>Incentives: none reported | Bowie *et al.* (1996) |
| 22. South Africa (Mount Frere)<br><br>"HIV/AIDS and Poverty in households with children suffering from Malnutrition"<br><br>Cross-sectional household survey<br><br>No control group | Impact on children's education, health, nutritional status and social security | Rural | Betwee n Septem ber to Decemb er 2001 | Structured in-depth interviews | 30 household s | Purposive sampling Households in which a child suffered from severe malnutrition and was admitted to a local hospital | | Household head<br><br>Interviewer: trained interviewer<br><br>Incentives: None reported | Samson, M. (2002) |
| 23. South Africa (Limpopo)<br><br>"The Economic Impact of | Impact on household income, expenditure, | Rural | Betwee n July and Septem | Structured questionn aire plus focus | 140 affected household s and 435 | Randomised sample of households using the 1996 census data with respondents self-report | Affected households versus unaffected | Household head<br><br>Interviewers | Oni, et al., (2002) |

| Country and Research Title/ Design | Themes | Urban /Rural | Period of data collect ion | Method of data collect-ion | Sample size | Sampling method and selection criteria | Stratification parameters | Respondent | Reference |
|---|---|---|---|---|---|---|---|---|---|
| HIV/AIDS on rural households in Limpopo"<br><br>cross-sectional household survey<br><br>control group of non-affected households | household coping mechanisms | | ber 2001 | groups | unaffected household s | whether or not the household was affected or non-affected by HIV/AIDS | households | : Trained post-graduate students<br><br>Incentives: none reported | |
| 24. Zimbabwe (Mutare) "Orphan prevalence and extended family care in a peri-urban community in Zimbabwe"<br><br>Cross-sectional household survey<br><br>No control group | Coping mechanisms of Orphans discrimination | Peri-urban | 1992 surveye d over a two-month period | Combinati on of structured questionn aire)and focus group | 570 household s over a two month period | Clustered stratified sampling using a simple verbal autopsy method to determine case of parental death | Not Aids<br>Possible Aids<br>Probable Aids<br>Undetermined | Caregivers<br><br>Trained interviewers community development workers and community volunteers associated with AIDS organisation<br>Incentives: none reported | Foster et al., (1995) |
| 25. Zimbabwe (Mutare)<br><br>"Supporting children in need through a community based orphan visiting programme"<br><br>Case Study<br><br>No control group | Orphans | Peri-urban | 1995 | Combinati on of structured questionn aires and narrative histories of household s | 292 orphan household s | Records of the FOCUS program supporting orphans were reviewed and orphan households known to the program were interviewed. | | Caregivers<br><br>Interviewer: Programme evaluators and Orphan volunteers<br>Incentives: none | Foster and Mukufa (1996) |

| Country and Research Title/ Design | Themes | Urban /Rural | Period of data collect ion | Method of data collect-ion | Sample size | Sampling method and selection criteria | Stratification parameters | Respondent | Reference |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | reported | |
| 26. United States (cities in South West)<br><br>Cross-sectional individual study<br><br>No control group | Disclosure and Social Support from Family | Urban | 1996 | Self-administer ed questionn aire | 77 people diagnosed HIV-positive and/or living with AIDS | Participants were recruited from two non-profit community-based organisations aimed at servicing the informational, educational, counselling and referral needs of persons living with AIDS. | | Patients<br><br>Self-administered instrument<br><br>Incentive: None reported | Kimberley and Serovich (1996) |
| 27. South Africa (Northern Province)<br><br>cross-sectional household survey<br><br>no control group | Education on sex and sexuality | Rural | 2000 | Workshop s where sex education was openly discussed to the entire family | 147 homestead s in three villages | Systematic sampling | | Family members of selected homes<br>Interviewer: Community educators<br>Incentive: None reported | Ngwenya *et al.* (2001) |
| 28. United States (Los Angeles and San Francisco Bay)`<br><br>Cross sectional individual survey<br><br>No control group | Utilisation of support services by persons living with HIV/AIDS | Urban | 1995 | Structured interviews | 472 caregivers | Recruited through mass media, AIDS service agencies, doctors rooms, clinics, health fairs, gay pride festivals, etc. | | Caregivers and people living with HIV/AIDS<br>Interviewer: None reported<br>Incentive: none reported | Wight, R.G. and LeBlanc, A.J. (1995) |

| Country and Research Title/ Design | Themes | Urban /Rural | Period of data collect ion | Method of data collect-ion | Sample size | Sampling method and selection criteria | Stratification parameters | Respondent | Reference |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | |
| 29. South Africa (Soweto)<br><br>"The impact of morbidity and mortality on the welfare of children"<br><br>cross sectional survey<br><br>no control group | Impact on children's education, health, nutrition, discrimination and stress | Urban | 2002 | Structured interviews | 5000 household s | Two-stage stratified sampling using the 1996 census enumerator areas | | Caregivers<br>Interviewer: Trained interviewers from the local community<br>Incentive: R20 Telkom voucher | Naidu, et al., (2003) |
| 30. United States<br><br>cross-sectional survey<br><br>no control group | | | 1994 | Standardis ed self-report measures and in-depth interviews . | 63 people living with AIDS, including 7 individual s living in a residential centre for people living with AIDS | Recruited from health care clinics and HIV-AIDS service organisations. Flyers announcing the study were distributed and interested persons phoned in for appointment. | | Patients<br><br>Interviewer: Male doctoral-level clinical psychologist<br><br>Incentives: US$25 per participant | Kalichman and Sikkema (1996) |
| 31. United States (two urban areas in west Texas) | | | 1995 | Structured questionn aire used in combinati on with | 28 people who had an immediate family member | Convenience sample selected from members of two AIDS support organisations that serve persons with HIV/AIDS and their | Diagnosed persons who are homosexual and ones that are heterosexual | | Smith and Robinson (1995) |

| Country and Research Title/ Design | Themes | Urban /Rural | Period of data collect ion | Method of data collect-ion | Sample size | Sampling method and selection criteria | Stratification parameters | Respondent | Reference |
|---|---|---|---|---|---|---|---|---|---|
| | | | | two psycholog ical scales. | diagnosed with HIV infection or AIDS | families. | | | |
| 32. South Africa (Gauteng (urban), Mpumalanga (rural) , Free State (urban) and 2 sites in Kwa-Zulu Natal – one rural and one urban)<br><br>"How Households cope with the impact of the HIV/AIDS epidemic"<br><br>cross-sectional survey<br><br>no control group | Impact on income, expenditure, cost of death, food expenditure, family breakdown, orphans, gender impact and household coping strategies | Urban and Rural<br><br>Incent ive: Unkn own | 2001 | Structured instrument plus the writing of stories by the fieldwork ers | 771 HIV/AID S affected household s in different parts of South Africa | Random selection from an NGO list of HIV/AIDS affected households | None reported | Individual sick with AIDS or someone this individual appointed if the index case was too sick to be interviewed<br><br>Interviewer: fieldworkers were recruited from employees of different HIV/AIDS organization s<br><br>Incentives: Help provided to households as and when required | Steinberg, et al., (2002) |

| Country and Research Title/ Design | Themes | Urban /Rural | Period of data collect ion | Method of data collect-ion | Sample size | Sampling method and selection criteria | Stratification parameters | Respondent | Reference |
|---|---|---|---|---|---|---|---|---|---|
| 33. South Africa "Study of HIV/AIDS – South African National HIV Prevalence, Behavioural Risks and Mass Media Household survey 2002" cross-sectional survey<br><br>no control group | HIV prevalence HIV education and awareness Identify the social cultural contexts with which behaviour occurs | Urban and Rural | 2002 | Phase 1: structured instrument Phase 2: test kits as well as structured instrument | 8 840 individual s in xx of household s | Random selection using the 1996 census enumerator areas | None<br><br>Incentive: R50 paid to household head and R20 to hostel dweller | Household head and tests were conducted on adults, children and youth within the household<br><br>Fieldworker s for phase 1: 15 interviewers in the process of completing their masters degrees in various disciplines were chosen Phase 2: 171 recently retired nurses were used to administer the HIV test | Shisana and Simbayi (2002) |

**Appendix 3: Characteristics of Non-Affected Households**

| Non-Affected Households | Wave 1 n=59 | Wave 2 n=53 | Wave 3 n=52 | Wave 4 n=52 | All Waves n=216 |
|---|---|---|---|---|---|
| Number of individuals | 331 | 309 | 301 | 297 | 1238 |
| % of all females | 55.3 | 57.9 | 56.5 | 57.6 | 56.8 |
| % of adults- married/living together | 31 | 30 | 28 | 27 | 30 |
| % widowed | 5 | 5 | 5 | 5 | 5 |
| % divorced | 3 | 3 | 3 | 3 | 3 |
| % single | 61 | 62 | 64 | 65 | 62 |
| % of Female Household Heads | 39 | 37 | 39 | 39 | 39 |
| Average age of household head | 45 | 45 | 46 | 45 | 45 |

**Appendix 4: Characteristics of Affected Households**

| Affected Households | Wave 1 n=64 | Wave 2 n=64 | Wave 3 n=63[1] | Wave 4 n=63[3] | All Waves n=256 |
|---|---|---|---|---|---|
| Number of individuals | 429 | 404 | 375 | 368 | 1576 |
| % of all females | 56.6 | 56.9 | 55.7 | 55.7 | 56.3 |
| % of adults married/living together | 15 | 13 | 14 | 14 | 14 |
| % widowed | 6 | 6 | 6 | 6 | 6 |
| % divorced | 5 | 5 | 5 | 5 | 5 |
| % single | 74 | 76 | 75 | 75 | 75 |
| % of Female Household Head | 73 | 73 | 73 | 73 | 73 |
| Average age of household head | 52 | 52 | 52 | 51 | 52 |

[1] One household split in wave 3

## Appendix 5: Mobility of Household Members Across Cohorts and Across All Waves

| Left | Non-Affected | Affected |
|---|---|---|
| went in search of work | 4 | 2 |
| care of sick member of other households | 2 | 1 |
| to be taken care of by another household | 15 | 26 |
| family could not afford the exp | 1 | 3 |
| parents died | 1 | 3 |
| found own accommodation | 18 | 1 |
| person died | 1 | 16 |
| education purposes | 1 | 10 |
| Total | 43 | 62 |
| | | |
| **Joined** | **Non-Affected** | **Affected** |
| work related | 6 | 5 |
| No option – household refused no longer able to look after child | 0 | 4 |
| parents deceased/divorced | 0 | 5 |
| attend school | 0 | 5 |
| to take care of someone sick | 1 | 2 |
| new born | 30 | 5 |
| was sick came for treatment | 1 | 0 |
| can now afford to take care of children | 5 | 4 |
| new partner | 1 | 1 |
| to be taken care of | 7 | 1 |
| Total | 51 | 32 |
| Net migration | 8 | -30 |

**Appendix 6: HIV/AIDS Morbidity Costs Across Cohorts (8 months cost averaged over households)**

| Morbidity costs | All Households | | Non-Affected Households | | Affected Households | | Percentage Difference Between Means (%) | T-Stat | p-value |
|---|---|---|---|---|---|---|---|---|---|
| | Mean (Rand) | Median (Rand) | Mean (Rand) | Median (Rand) | Mean (Rand) | Median (Rand) | | | |
| **DIRECT COSTS** | | | | | | | | | |
| Consultation | 116.27 | 13.00 | 96.23 | 26.00 | 124.48 | 13.00 | 29.4 | -0.45 | 0.6527 |
| Medicine/drugs | 86.34 | 0.00 | 27.57 | 0.00 | 110.43 | 0.00 | 300.5 | -1.88 | 0.064 |
| Medical -self treated costs | 56.98 | 0.00 | 16.92 | 0.00 | 73.40 | 0.00 | 333.9 | -1.82 | 0.0728 |
| Hospitalisation | 6.68 | 0.00 | 0.50 | 0.00 | 9.21 | 0.00 | 1733.1 | -1.64 | 0.1056 |
| Physiotherapy | 0.15 | 0.00 | 0.00 | 0.00 | 0.21 | 0.00 | 0.0 | -1.00 | 0.3213 |
| Transport/food | 45.33 | 7.00 | 19.17 | 0.00 | 56.05 | 14.00 | 192.4 | -2.37 | 0.0206* |
| Laboratory costs | 1.35 | 0.00 | 4.00 | 0.00 | 0.27 | 0.00 | -93.3 | 0.93 | 0.3608 |
| Disposable nappies | 5.06 | 0.00 | 0.00 | 0.00 | 7.13 | 0.00 | 0.0 | -1.00 | 0.3213 |
| **Total Direct Costs** | **318.15** | **107.96** | **164.39** | **100.00** | **381.17** | **117.39** | 131.9 | **-1.69** | **0.0946** |
| **INDIRECT COSTS** | | | | | | | | | |
| Loss of income -sick member | 353.61 | 0.00 | 138.03 | 0.00 | 441.97 | 0.00 | 220.2 | -2.19 | 0.0316* |
| Loss of income - caregiver | 55.97 | 0.00 | 56.89 | 0.00 | 55.59 | 0.00 | -2.3 | 0.02 | 0.9825 |
| Foregone earnings - sick member | 399.24 | 0.00 | 93.15 | 0.00 | 524.69 | 0.00 | 463.3 | -2.17 | 0.0373* |
| **Total Indirect Costs** | **808.82** | **0.00** | **288.06** | **0.00** | **1022.24** | **0.00** | 254.9 | **-2.63** | **0.0101*** |
| **Total Financial Costs** | **1126.97** | **344.28** | **452.45** | **137.64** | **1403.41** | **432.43** | 210.2 | **-2.92** | **0.0045*** |
| **SYSTEMIC COSTS** | | | | | | | | | |
| Foregone cost of earnings - caregivers | 2984.34 | 1403.51 | 1880.69 | 385.50 | 3436.65 | 2023.90 | 82.7 | -2.21 | 0.0307* |
| Foregone cost of earnings - sick member | 1719.68 | 1006.39 | 1379.09 | 685.71 | 1859.27 | 1068.53 | 34.8 | -1.14 | 0.26 |
| **Total Systemic Costs** | **4704.02** | **2409.90** | **3259.79** | **1071.22** | **5295.92** | **3092.43** | 62.5 | **-1.98** | **0.0524** |
| **Total Costs of Morbidity** | **5830.99** | **4926.11** | **3712.24** | **4225.10** | **6699.33** | **4926.11** | 80.5 | **-2.66** | **0.0099*** |

*Notes*:*p=<0.05

**Appendix 7: HIV/AIDS Morbidity Costs Across Cohorts (with adjusted hours of caring -8 months cost averaged over households)**

| Morbidity costs | All Households | | Non-Affected Households | | Affected Households | | Percentage Difference Between Means (%) | T-Stat | p-value |
|---|---|---|---|---|---|---|---|---|---|
| | Mean (Rand) | Median (Rand) | Mean (Rand) | Median (Rand) | Mean (Rand) | Median (Rand) | | | |
| **DIRECT COSTS** | | | | | | | | | |
| Consultation | 116.27 | 13.00 | 96.23 | 26.00 | 124.48 | 13.00 | -22.7 | -0.45 | 0.6527 |
| Medicine/drugs | 86.34 | 0.00 | 27.57 | 0.00 | 110.43 | 0.00 | -75.0 | -1.88 | 0.064 |
| Medical -self treated costs | 56.98 | 0.00 | 16.92 | 0.00 | 73.40 | 0.00 | -77.0 | -1.82 | 0.0728 |
| Hospitalisation | 6.68 | 0.00 | 0.50 | 0.00 | 9.21 | 0.00 | -94.5 | -1.64 | 0.1056 |
| Physiotherapy | 0.15 | 0.00 | 0.00 | 0.00 | 0.21 | 0.00 | -100.0 | -1.00 | 0.3213 |
| Transport/food | 45.33 | 7.00 | 19.17 | 0.00 | 56.05 | 14.00 | -65.8 | -2.37 | 0.0206* |
| Laboratory costs | 1.35 | 0.00 | 4.00 | 0.00 | 0.27 | 0.00 | 1386.4 | 0.93 | 0.3608 |
| Disposable nappies | 5.06 | 0.00 | 0.00 | 0.00 | 7.13 | 0.00 | -100.0 | -1.00 | 0.3213 |
| **Total Direct Costs** | **318.15** | **107.96** | **164.39** | **100.00** | **381.17** | **117.39** | -56.9 | **-1.69** | 0.0946 |
| **INDIRECT COSTS** | | | | | | | | | |
| Loss of income -sick member | 353.61 | 0.00 | 138.03 | 0.00 | 441.97 | 0.00 | -68.8 | -2.19 | 0.0316* |
| Loss of income - caregiver | 55.97 | 0.00 | 56.89 | 0.00 | 55.59 | 0.00 | 2.3 | 0.02 | 0.9825 |
| Foregone earnings - sick member | 399.24 | 0.00 | 93.15 | 0.00 | 524.69 | 0.00 | -82.2 | -2.12 | 0.0373* |
| **Total Indirect Costs** | **808.82** | **0.00** | **288.06** | **0.00** | **1022.24** | **0.00** | -71.8 | **-2.63** | **0.0101*** |
| **Total Financial Costs** | **1126.97** | **344.28** | **452.45** | **137.64** | **1403.41** | **432.43** | -67.8 | **-2.92** | **0.0045*** |
| **SYSTEMIC COSTS** | | | | | | | | | |
| Foregone cost of earnings - caregivers | 1458.62 | 766.93 | 816.90 | 144.56 | 1721.62 | 1069.57 | -52.6 | -3.65 | 0.0004* |
| Foregone cost of earnings - sick member | 1719.68 | 1006.39 | 1379.09 | 685.71 | 1859.27 | 1068.53 | -25.8 | -1.14 | 0.26 |
| **Total Systemic Costs** | **3178.31** | **2214.00** | **2196.00** | **1371.43** | **3580.89** | **2350.98** | -38.7 | **-2.17** | **0.0335*** |
| **Total Costs of Morbidity** | **4305.28** | **2712.17** | **2648.45** | **2168.46** | **4984.30** | **3365.93** | -46.9 | **-3.08** | **0.003*** |

*Notes*: * p=<0.05

## Appendix 8: HIV/AIDS Mortality Costs Across Cohorts (8 months cost averaged over households)

| | All Households | | Non-Affected Households | | Affected Households | | Percentage Difference Between Means (%) | T-stat | p-value |
|---|---|---|---|---|---|---|---|---|---|
| | Mean (Rand) | Median (Rand) | Mean (Rand) | Median (Rand) | Mean (Rand) | Median (Rand) | | | |
| **DIRECT COSTS** | | | | | | | | | |
| Consultation | 54.10 | 0.00 | 1.86 | 0.00 | 64.25 | 0.00 | 33.6 | -2.01 | 0.052 |
| Medicine/drugs | 20.93 | 0.00 | 0.00 | 0.00 | 25.00 | 0.00 | 0.0 | -1.36 | 0.183 |
| Hospitalisation | 1.98 | 0.00 | 6.68 | 0.00 | 1.07 | 0.00 | -0.8 | 1.14 | 0.295 |
| Transport | 197.37 | 0.00 | 12.51 | 0.00 | 233.32 | 0.00 | 17.7 | -1.62 | 0.11 |
| **Total Direct Costs** | **274.38** | **13.00** | **21.05** | **0.00** | **323.64** | **19.50** | **14.4** | **-2.17** | **0.037** |
| Funeral Cost | 9485.05 | 8000.00 | 7413.00 | 6000.00 | 9887.95 | 8500.00 | 0.3 | -0.99 | 0.352 |
| **Total Direct Cost including Funerals** | **9759.43** | **8013.00** | **7434.05** | **6000.00** | **10211.59** | **8519.50** | **14.7** | **-1.11** | **0.3006** |
| **INDIRECT COSTS** | | | | | | | | | |
| Loss of employment - deceased member | 5620.25 | 675.68 | 2285.71 | 0.00 | 6268.63 | 1896.45 | 1.7 | -1.40 | 0.184 |
| Loss of earnings - caregiver | 1731.31 | 0.00 | 0.00 | 0.00 | 2067.95 | 0.00 | 0.0 | -1.48 | 0.147 |
| **Total Indirect Costs** | **7351.56** | **1236.72** | **2285.71** | **0.00** | **8336.58** | **2196.20** | **2.7** | **-1.90** | **0.072** |
| **Total Financial Cost (Direct and Indirect)** | **17110.98** | **11757.49** | **9719.76** | **6000.00** | **18548.17** | **12809.02** | **0.9** | **-2.13** | **0.05** |
| **SYSTEMIC COSTS** | | | | | | | | | |
| Foregone cost of earnings - caregivers | 564.42 | 720.00 | 261.43 | 150.00 | 623.33 | 720.00 | 1.4 | -2.68 | 0.0263 |
| Foregone cost of earnings - sick member | 20672.23 | 26568.00 | 9518.37 | 5535.00 | 22841.03 | 26568.00 | 1.4 | -2.72 | 0.0247 |
| **Total Systemic Costs** | **21236.65** | **27288.00** | **9779.80** | **5685.00** | **23464.37** | **27288.00** | **1.4** | **-2.72** | **0.0247** |
| **Total Costs of Mortality** | **38347.63** | **36268.00** | **19499.56** | **29142.00** | **42012.53** | **38281.71** | **1.3** | **-3.51** | **0.0042** |
| **Incoming Funds** | | | | | | | | | |
| Cash | 2892.47 | 1500.00 | 1264.22 | 1000.00 | 3209.07 | 1740.19 | 1.6 | -2.48 | 0.018 |
| Goods | 282.75 | 0.00 | 111.87 | 0.00 | 315.98 | 0.00 | 1.8 | -1.51 | 0.140 |
| Total cash and Goods | 3105.48 | 1689.19 | 1376.09 | 1300.00 | 3441.76 | 1895.59 | 1.5 | -2.54 | 0.0161 |
| Lump Sum receipts | 4196.62 | 0.00 | 1411.20 | 0.00 | 4738.23 | 0.00 | 2.4 | -0.78 | 0.437 |
| **Total Incoming Funds** | **7302.10** | **2000.00** | **2787.28** | **1700.00** | **8179.99** | **2000.00** | **1.9** | **-1.27** | **0.213** |
| **Net Effect of Mortality** | **31045.53** | **32769.19** | **16712.27** | **23385.00** | **33832.55** | **34127.84** | **1.0** | **-2.38** | **0.0276** |

**Appendix 9: HIV/AIDS Morbidity and Mortality Costs Across Cohorts (8 months cost averaged over households)**

| Type of Cost | All Households | | Non-Affected Households | | Affected Households | | | |
|---|---|---|---|---|---|---|---|---|
| | Mean (Rand) | Median (Rand) | Mean (Rand) | Median (Rand) | Mean (Rand) | Median (Rand) | T-Stat | p-value |
| **DIRECT COSTS** | | | | | | | | |
| Consultation | 128.39 | 13.00 | 80.63 | 12.87 | 150.10 | 13.00 | -1.12 | 0.2675 |
| Medicine/drugs | 86.72 | 0.00 | 22.97 | 0.00 | 115.70 | 0.00 | -2.24 | 0.0279* |
| Hospitalisation | 6.87 | 0.00 | 1.98 | 0.00 | 9.10 | 0.00 | -1.41 | 0.1617 |
| Physiotherapy | 0.13 | 0.00 | 0.00 | 0.00 | 0.19 | 0.00 | -1.00 | 0.321 |
| Transport/food | 129.01 | 7.25 | 18.89 | 0.00 | 179.07 | 23.58 | -2.11 | 0.0387* |
| Lab costs | 1.21 | 0.00 | 3.33 | 0.00 | 0.25 | 0.00 | 0.92 | 0.363 |
| Disposable nappies | 4.53 | 0.00 | 0.00 | 0.00 | 6.59 | 0.00 | -1.00 | 0.321 |
| Medical -self treated | 51.04 | 0.00 | 14.10 | 0.00 | 67.84 | 0.00 | -1.89 | 0.062** |
| **Total Direct Costs** | **407.91** | **109.37** | **141.91** | **44.72** | **528.82** | **127.28** | **-2.70** | **0.0086*** |
| Funeral Costs | 4248.51 | 0.00 | 1729.70 | 0.00 | 5393.43 | 3344.66 | -3.29 | 0.0015* |
| **Total Direct costs including funerals** | **4656.42** | **567.63** | **1871.6** | **128.822** | **5922.25** | **4727.63** | **-3.60** | **0.0005*** |
| **INDIRECT COSTS** | | | | | | | | |
| Loss of income -sick member | 316.78 | 0.00 | 115.02 | 0.00 | 408.49 | 0.00 | -2.33 | 0.0218* |
| Loss of income - caregiver | 825.62 | 0.00 | 47.41 | 0.00 | 1179.35 | 0.00 | -1.47 | 0.1452 |
| loss of employment - sick and deceased | 2875.06 | 0.00 | 610.96 | 0.00 | 3904.19 | 0.00 | -2.87 | 0.0051* |
| **Total Indirect** | **4017.45** | **24.13** | **773.38** | **0.00** | **5492.03** | **950.00** | **-3.32** | **0.0013*** |
| **Total Financial Cost (direct and indirect costs)** | **8673.87** | **1966.3** | **2645** | **201.315** | **11414.3** | **7609.15** | **-4.25** | **0.0001*** |
| **SYSTEMIC COSTS** | | | | | | | | |
| Foregone earnings - caregivers | 505.63 | 0.00 | 122.00 | 0.00 | 680.00 | 0.00 | -4.69 | 0.000* |
| Foregone earnings - sick member | 10799.98 | 2686.82 | 3370.20 | 896.36 | 14177.16 | 5514.13 | -4.93 | 0.000* |
| **Total Systemic Costs** | **11305.61** | **2686.82** | **3492.20** | **896.36** | **14857.16** | **5634.13** | **-4.92** | **0.000*** |
| **Total Morbidity and Mortality Costs** | **19979.5** | **5350.8** | **6137.2** | **2191.23** | **26271.4** | **14145.7** | **-5.25** | **0.000*** |
| **Incoming Funds** | | | | | | | | |
| Cash | 1295.585 | 0.00 | 294.984 | 0.00 | 1750.403 | 0.00 | -3.37 | 0.0012* |
| Goods | 126.6481 | 0.00 | 26.1031 | 0.00 | 172.3505 | 0.00 | -2.19 | 0.0317* |
| Total Cash & Goods | 1390.998 | 0.00 | 321.087 | 0.00 | 1877.321 | 0.00 | -3.52 | 0.0007* |
| Lump Sum Receipts | 1879.736 | 0.00 | 329.279 | 0.00 | 2584.489 | 0.00 | -0.99 | 0.3278 |
| Total Incoming Funds | 3270.734 | 0.00 | 650.366 | 0.00 | 4461.81 | 0.00 | -1.63 | 0.1078 |
| **Net Impact from Mortality** | **16708.8** | **4704.5** | **5486.8** | **2144.28** | **21809.6** | **9601.85** | **-4.18** | **0.0001*** |

# Appendix 10: Proportion of Adult Equivalent Annual Household Expenditure to Total Expenditure

| | | | | | | Non-Affected Households | | | | | | Affected Households | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Variable | Obs | Mean | Std. Dev. | Min | Max | Variable | Obs | Mean | Std. Dev. | Min | Max | Variable | Obs | Mean | Std. Dev. | Min | Max | % Diff | T-stat | p-value |
| housing (re | ppahousing | 113 | 0.132807 | 0.118708 | 0 | 0.495786 | ppahousing | 52 | 0.151366 | 0.139071 | 0 | 0.495786 | ppahousing | 61 | 0.116985 | 0.096497 | 0 | 0.443194 | -0.227136 | 1.5011 | 0.1369 |
| food (takea | ppafood | 113 | 0.249908 | 0.101969 | 0.069686 | 0.590736 | ppafood | 52 | 0.253498 | 0.103778 | 0.080296 | 0.590736 | ppafood | 61 | 0.246848 | 0.101162 | 0.069686 | 0.517865 | -0.026233 | 0.3434 | 0.7319 |
| alcohol & c | ppaalcocig | 113 | 0.013219 | 0.027286 | 0 | 0.144751 | ppaalcocig | 52 | 0.01808 | 0.034399 | 0 | 0.144751 | ppaalcocig | 61 | 0.009075 | 0.018602 | 0 | 0.088692 | -0.498067 | 1.6889 | 0.0954 |
| telephone | pparv164 | 113 | 0.031415 | 0.037847 | 0 | 0.261837 | pparv164 | 52 | 0.029655 | 0.025465 | 0 | 0.095546 | pparv164 | 61 | 0.032915 | 0.046017 | 0 | 0.261837 | 0.109949 | -0.4747 | 0.6361 |
| groceries (i | pparv167 | 113 | 0.037457 | 0.018107 | 0.00928 | 0.103224 | pparv167 | 52 | 0.041854 | 0.01933 | 0.014303 | 0.103224 | pparv167 | 61 | 0.033709 | 0.016228 | 0.00928 | 0.085817 | -0.194594 | 2.4014 | 0.0182 |
| personal c | pparv168 | 113 | 0.026757 | 0.021431 | 0 | 0.115922 | pparv168 | 52 | 0.023757 | 0.019257 | 0 | 0.08139 | pparv168 | 61 | 0.029314 | 0.022971 | 0 | 0.115922 | 0.233885 | -1.3987 | 0.1647 |
| clothing | pparv169 | 113 | 0.041945 | 0.056795 | 0 | 0.272153 | pparv169 | 52 | 0.046891 | 0.068817 | 0 | 0.272153 | pparv169 | 61 | 0.037729 | 0.044232 | 0 | 0.177131 | -0.195394 | 0.8256 | 0.4113 |
| gambling | pparv172 | 113 | 0.004092 | 0.007129 | 0 | 0.032036 | pparv172 | 52 | 0.00522 | 0.007549 | 0 | 0.032036 | pparv172 | 61 | 0.00313 | 0.006662 | 0 | 0.031353 | -0.400341 | 1.5476 | 0.1248 |
| public trans | pparv173 | 113 | 0.083687 | 0.056652 | 0 | 0.247645 | pparv173 | 52 | 0.085722 | 0.05816 | 0 | 0.247645 | pparv173 | 61 | 0.081953 | 0.05576 | 0 | 0.230861 | -0.043976 | 0.35 | 0.727 |
| vehicle cos | pparv174 | 113 | 0.002494 | 0.016312 | 0 | 0.16317 | pparv174 | 52 | 0.004153 | 0.023186 | 0 | 0.16317 | pparv174 | 61 | 0.00108 | 0.00594 | 0 | 0.042905 | -0.739923 | 0.93 | 0.3563 |
| petrol and | pparv175 | 113 | 0.008669 | 0.038643 | 0 | 0.290664 | pparv175 | 52 | 0.015834 | 0.053984 | 0 | 0.290664 | pparv175 | 61 | 0.002562 | 0.015095 | 0 | 0.115858 | -0.838224 | 1.7166 | 0.0914 |
| durables | pparv176 | 113 | 0.043297 | 0.059184 | 0 | 0.260629 | pparv176 | 52 | 0.042417 | 0.059687 | 0 | 0.232323 | pparv176 | 61 | 0.044048 | 0.059237 | 0 | 0.260629 | 0.038447 | -0.1453 | 0.8848 |
| insurance | pparv179 | 113 | 0.000816 | 0.005028 | 0 | 0.043396 | pparv179 | 52 | 0.000855 | 0.004353 | 0 | 0.025045 | pparv179 | 61 | 0.000783 | 0.005575 | 0 | 0.043396 | -0.083967 | 0.0768 | 0.9389 |
| dependant | pparv180 | 113 | 0.009646 | 0.018354 | 0 | 0.108349 | pparv180 | 52 | 0.014904 | 0.024048 | 0 | 0.108349 | pparv180 | 61 | 0.005164 | 0.00964 | 0 | 0.043742 | -0.653511 | 2.7391 | 0.0079 |
| dependant | pparv181 | 113 | 0.025695 | 0.055009 | 0 | 0.312022 | pparv181 | 52 | 0.042853 | 0.071149 | 0 | 0.312022 | pparv181 | 61 | 0.011068 | 0.029546 | 0 | 0.197698 | -0.741734 | 3.008 | 0.0037 |
| domestic | pparv182 | 113 | 0.003277 | 0.01044 | 0 | 0.062411 | pparv182 | 52 | 0.002687 | 0.009449 | 0 | 0.049427 | pparv182 | 61 | 0.00378 | 0.01127 | 0 | 0.062411 | 0.406669 | -0.5606 | 0.5762 |
| funeral dor | pparv184 | 113 | 0.007809 | 0.019861 | 0 | 0.13934 | pparv184 | 52 | 0.003978 | 0.00961 | 0 | 0.040646 | pparv184 | 61 | 0.011075 | 0.025185 | 0 | 0.13934 | 1.784342 | -2.0341 | 0.0453 |
| regular sch | pparv185a | 113 | 0.050514 | 0.059434 | 0 | 0.288631 | pparv185a | 52 | 0.056927 | 0.061867 | 0 | 0.288631 | pparv185a | 61 | 0.045047 | 0.057222 | 0 | 0.272815 | -0.208692 | 1.053 | 0.2947 |
| church | pparv185b | 113 | 0.00293 | 0.010766 | 0 | 0.070395 | pparv185b | 52 | 0.005967 | 0.015202 | 0 | 0.070395 | pparv185b | 61 | 0.000341 | 0.002257 | 0 | 0.017339 | -0.942835 | 2.6438 | 0.0108 |
| annual hc | ppannhcco | 113 | 0.020277 | 0.035931 | 0 | 0.275823 | ppannhcco | 52 | 0.008148 | 0.018315 | 0 | 0.118902 | ppannhcco | 61 | 0.030617 | 0.043458 | 0 | 0.275823 | 2.757797 | -3.6736 | 0.0004 |
| total regula | ppatotrege | 113 | 0.796711 | 0.173752 | 0.299347 | 1 | ppatotrege | 52 | 0.854765 | 0.12596 | 0.512719 | 0.993589 | ppatotrege | 61 | 0.747223 | 0.19354 | 0.299347 | 1 | -0.125815 | 3.5472 | 0.0006 |
| schooling | ppanneduc | 113 | 0.020204 | 0.019704 | 0 | 0.114841 | ppanneduc | 52 | 0.020514 | 0.016426 | 0 | 0.060321 | ppanneduc | 61 | 0.01994 | 0.022253 | 0 | 0.114841 | -0.027971 | 0.1573 | 0.8753 |
| purchases | ppannpur | 113 | 0.02738 | 0.060605 | 0 | 0.29818 | ppannpur | 52 | 0.02689 | 0.062459 | 0 | 0.268337 | ppannpur | 61 | 0.027796 | 0.059497 | 0 | 0.29818 | 0.033692 | -0.0785 | 0.9375 |
| transfers o | ppannremc | 113 | 0.015062 | 0.028461 | 0 | 0.254558 | ppannremc | 52 | 0.013107 | 0.020268 | 0 | 0.089765 | ppannremc | 61 | 0.016729 | 0.03401 | 0 | 0.254558 | 0.276294 | -0.6987 | 0.4863 |
| housing re | ppannirrho | 113 | 0.014933 | 0.049167 | 0 | 0.337571 | ppannirrho | 52 | 0.015524 | 0.053522 | 0 | 0.337571 | ppannirrho | 61 | 0.014429 | 0.045575 | 0 | 0.309516 | -0.070512 | 0.1159 | 0.9079 |
| visits/holid | ppannrv19 | 113 | 0.028463 | 0.059226 | 0 | 0.29235 | ppannrv19 | 52 | 0.037485 | 0.067431 | 0 | 0.29235 | ppannrv19 | 61 | 0.020772 | 0.050519 | 0 | 0.289661 | -0.445867 | 1.4699 | 0.1449 |
| funeral cos | ppannfun | 113 | 0.097247 | 0.158446 | 0 | 0.695188 | ppannfun | 52 | 0.031714 | 0.094277 | 0 | 0.381057 | ppannfun | 61 | 0.153111 | 0.180038 | 0 | 0.695188 | 3.82781 | -4.5808 | 0.0000 |
| total irregul | ppanntotir~ | 113 | 0.203289 | 0.173752 | 0 | 0.700653 | ppanntotir~ | 52 | 0.145235 | 0.12596 | 0.006411 | 0.487281 | ppanntotir~ | 61 | 0.252777 | 0.19354 | 0 | 0.700653 | 0.740468 | -3.5472 | 0.0006 |
| total regula | ppanntotex | 113 | 1 | 0 | 1 | 1 | ppanntotex | 52 | 1 | 0 | 1 | 1 | ppanntotex | 61 | 1 | 0 | 1 | 1 | 0 | | |

**Appendix 11: Adult Equivalent Annual Household Expenditure Across Cohorts**

| | All Households | Non Affected Households | Affected Households | | | |
|---|---|---|---|---|---|---|
| | Mean (Rand) | Mean (Rand) | Mean (Rand) | Difference (%) | T-stat | p-value |
| Housing (rent, electricity &water) | 1528.96 | 1764.69 | 1328.01 | -0.25 | 1.1174 | 0.2667 |
| Food (takeaways inc) | 2246.58 | 2151.99 | 2327.21 | 0.08 | -0.7139 | 0.4768 |
| Alcohol & cig | 127.51 | 183.90 | 79.45 | -0.57 | 1.6138 | 0.1117 |
| Telephone | 294.65 | 297.97 | 291.82 | -0.02 | 0.1008 | 0.9199 |
| Groceries (non-food) | 336.16 | 361.57 | 314.50 | -0.13 | 1.2027 | 0.2319 |
| Personal care | 246.58 | 214.96 | 273.54 | 0.27 | -1.3058 | 0.1944 |
| Clothing | 455.66 | 433.89 | 474.21 | 0.09 | -0.2327 | 0.8165 |
| Gambling | 41.81 | 60.40 | 25.96 | -0.57 | 1.9231 | 0.0586 |
| Public transport | 826.45 | 773.54 | 871.56 | 0.13 | -0.7548 | 0.452 |
| Vehicle costs repayments | 83.36 | 162.55 | 15.86 | -0.90 | 0.945 | 0.3491 |
| Petrol and maintenance | 141.88 | 282.95 | 21.61 | -0.92 | 1.9957 | 0.0512 |
| Durables | 490.94 | 379.19 | 586.20 | 0.55 | -1.5044 | 0.1357 |
| Insurance assets | 15.62 | 22.30 | 9.93 | -0.55 | 0.6175 | 0.539 |
| Dependants at home | 93.32 | 127.63 | 64.08 | -0.50 | 1.9946 | 0.0491* |
| Dependants elsewhere | 349.67 | 567.01 | 164.40 | -0.71 | 2.5973 | 0.0116* |
| Domestic | 64.02 | 72.06 | 57.17 | -0.21 | 0.2874 | 0.7745 |
| Funeral donations | 70.66 | 34.00 | 101.91 | 2.00 | -1.907 | 0.0602 |
| Regular schooling | 481.77 | 534.92 | 436.46 | -0.18 | 0.838 | 0.4042 |
| Church | 26.10 | 53.55 | 2.71 | -0.95 | 2.5132 | 0.0151* |
| Annual health care cost | 212.98 | 62.47 | 341.28 | 4.46 | -3.8262 | 0.0003* |
| Total regular expenditure | 8134.68 | 8541.55 | 7787.84 | -0.09 | 0.6925 | 0.4901 |
| Schooling | 209.17 | 212.66 | 206.19 | -0.03 | 0.1104 | 0.9123 |
| Purchases | 415.74 | 338.97 | 481.19 | 0.42 | -0.5727 | 0.5681 |
| Transfers out | 180.05 | 138.27 | 215.66 | 0.56 | -1.0897 | 0.2785 |
| Housing repairs | 205.98 | 185.24 | 223.66 | 0.21 | -0.2221 | 0.8246 |
| Visits/holidays | 297.94 | 372.25 | 234.59 | -0.37 | 1.0231 | 0.3092 |
| Funeral cost | 1180.19 | 355.27 | 1883.40 | 4.30 | -3.8421 | 0.0002* |
| Total irregular | 2489.07 | 1602.67 | 3244.69 | 1.02 | -2.4976 | 0.0143* |
| Total regular + irregular | 10623.75 | 10144.22 | 11032.52 | 0.09 | -0.579 | 0.5638 |

## Appendix 12: Adult Equivalent Regular Monthly Expenditure Over Time (W1 versus W4) – Non-Affected Cohort

**Non Affected**

| | Wave 1 | | | | | | Wave 4 | | | | | | % | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Variable | Obs | Mean | Std.Dev | Min | Max | Variable | Obs | Mean | Std.Dev | Min | Max | Difference | T-stat | p-value |
| total inc | ae158reg | 52 | 1137.689 | 919.2918 | 147.0808 | 4788.028 | ae158reg | 52 | 1027.003 | 693.0326 | 0 | 3707.403 | -0.09729 | 0.6933 | 0.4898 |
| housing (rent, elec&water) | aehousing | 52 | 165.5861 | 221.3641 | 0 | 904.5999 | aehousing | 52 | 146.5263 | 183.2689 | 0 | 724.312 | -0.115105 | 0.4783 | 0.6335 |
| food (takeaways inc) | aefood | 52 | 187.4694 | 127.6328 | 62.2259 | 718.2042 | aefood | 52 | 172.6491 | 96.1379 | 49.534 | 551.2512 | -0.079055 | 0.6688 | 0.5052 |
| alcohol & cig | aeralcocig | 52 | 19.64555 | 51.23342 | 0 | 303.4868 | aeralcocig | 52 | 8.122038 | 28.0256 | 0 | 181.1808 | -0.586571 | 1.423 | 0.1587 |
| telephone | aev164 | 52 | 21.80301 | 29.72863 | 0 | 108.8188 | aev164 | 52 | 27.37146 | 30.99337 | 0 | 135.1351 | 0.255398 | -0.935 | 0.352 |
| groceries (non-food) | aev167 | 52 | 35.79855 | 33.95224 | 0 | 217.6376 | aev167 | 52 | 28.94861 | 20.07287 | 0 | 98.8259 | -0.191347 | 1.2524 | 0.214 |
| personal care | aev168 | 52 | 22.10243 | 32.95424 | 0 | 224.3163 | aev168 | 52 | 9.947743 | 12.83699 | 0 | 45.57026 | -0.549925 | 2.4783 | 0.0158* |
| clothing | aev169 | 52 | 37.69108 | 103.6041 | 0 | 620.7382 | aev169 | 52 | 31.65198 | 59.28386 | 0 | 247.0647 | -0.160226 | 0.3648 | 0.7162 |
| gambling | aev172 | 52 | 9.652678 | 32.06364 | 0 | 217.6376 | aev172 | 52 | 1.580166 | 3.517777 | 0 | 18.94163 | -0.836298 | 1.8047 | 0.0769 |
| public transport | aev173 | 52 | 76.52692 | 86.94692 | 0 | 527.8032 | aev173 | 52 | 66.69071 | 53.79898 | 0 | 212.3552 | -0.128533 | 0.6937 | 0.4897 |
| vehicle costs repayments | aev174 | 52 | 20.9267 | 150.9046 | 0 | 1088.188 | aev174 | 52 | 11.10489 | 80.07847 | 0 | 577.454 | -0.469343 | 0.4146 | 0.6796 |
| petrol and maintenance | aev175 | 52 | 36.35516 | 109.5538 | 0 | 600 | aev175 | 52 | 11.82916 | 51.73212 | 0 | 308.8803 | -0.674622 | 1.4598 | 0.1487 |
| durables | aev176 | 52 | 48.99675 | 78.50082 | 0 | 324.2148 | aev176 | 52 | 26.39891 | 44.79991 | 0 | 199.7227 | -0.461211 | 1.8029 | 0.0751 |
| insurance assets | aev179 | 52 | 0 | 0 | 0 | 0 | aev179 | 52 | 0 | 0 | 0 | 0 | #DIV/0! | . | . |
| dependants at home | aev180 | 52 | 8.699486 | 27.8596 | 0 | 159.9069 | aev180 | 52 | 9.288438 | 14.17069 | 0 | 42.01499 | 0.0677 | -0.1359 | 0.8923 |
| dependants elsewhere | aev181 | 52 | 66.09452 | 129.3448 | 0 | 522.3303 | aev181 | 52 | 34.24415 | 74.41478 | 0 | 386.1004 | -0.481891 | 1.5391 | 0.1276 |
| domestic | aev182 | 52 | 3.178431 | 21.16755 | 0 | 152.3464 | aev182 | 52 | 8.027848 | 36.88434 | 0 | 220.5005 | 1.525727 | -0.8223 | 0.4133 |
| funeral donations | aev184 | 52 | 0.129394 | 0.745016 | 0 | 5.172819 | aev184 | 52 | 7.084532 | 30.69985 | 0 | 210.2226 | 53.7518 | -1.6332 | 0.1086 |
| regular schooling | aev185a | 52 | 44.22256 | 72.43762 | 0 | 380.7308 | aev185a | 52 | 49.85494 | 78.77645 | 0 | 441.0009 | 0.127364 | -0.3795 | 0.7051 |
| church | aev185b | 52 | 18.27992 | 49.92501 | 0 | 218.724 | aev185b | 52 | 0 | 0 | 0 | 0 | -1 | 2.6403 | 0.011* |
| medical costs | aehccost | 52 | 14.8326 | 47.27646 | 0 | 326.686 | aehccost | 52 | 18.15127 | 54.97566 | 0 | 377.9753 | 0.223742 | -0.3301 | 0.7421 |
| total regular expenditure | aetotregex | 52 | 837.9912 | 687.6345 | 110.0734 | 4439.373 | aetotregex | 52 | 669.4722 | 398.6344 | 92.13325 | 2169.822 | -0.201099 | 1.5289 | 0.1301 |

# Appendix 13: Adult Equivalent Regular Monthly Expenditure Over Time (W1 versus W4) – Affected Cohort

**Affected**

| | Wave 1 | | | | | | Wave 4 | | | | | | % | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Variable | Obs | Mean | Std.Dev | Min | Max | Variable | Obs | Mean | Std.Dev | Min | Max | Difference | T-stat | p-value |
| total inc | ae158reg | 61 | 835.2968 | 632.9094 | 0 | 3041.928 | ae158reg | 61 | 1045.823 | 666.7761 | 0 | 2895.753 | 0.252038 | -1.7885 | 0.0762 |
| housing (rent, elec&water) | aehousing | 61 | 129.5161 | 150.1261 | 0 | 879.3792 | aehousing | 61 | 106.2391 | 152.1465 | 0 | 823.8563 | -0.179723 | 0.8505 | 0.3967 |
| food (takeaways inc) | aefood | 61 | 195.3773 | 145.5291 | 0 | 700 | aefood | 61 | 197.5454 | 153.9629 | 60.61502 | 1177.606 | 0.011097 | -0.0799 | 0.9364 |
| alcohol & cig | aeralcocig | 61 | 7.651509 | 24.20534 | 0 | 143.5873 | aeralcocig | 61 | 4.431329 | 21.89018 | 0 | 144.7876 | -0.420856 | 0.7706 | 0.4424 |
| telephone | aev164 | 61 | 20.2149 | 41.74051 | 0 | 300 | aev164 | 61 | 29.68239 | 39.74655 | 0 | 209.4595 | 0.468342 | -1.2829 | 0.202 |
| groceries (non-food) | aev167 | 61 | 30.35772 | 27.69093 | 0 | 124.1477 | aev167 | 61 | 26.64112 | 20.83306 | 0 | 125.4551 | -0.122427 | 0.8377 | 0.404 |
| personal care | aev168 | 61 | 22.80975 | 21.87431 | 0 | 100 | aev168 | 61 | 27.74177 | 41.69726 | 0 | 225.2385 | 0.216224 | -0.8181 | 0.4155 |
| clothing | aev169 | 61 | 10.61664 | 39.17033 | 0 | 263.9016 | aev169 | 61 | 40.13352 | 78.63931 | 0 | 459.3623 | 2.780247 | -2.624 | 0.0102* |
| gambling | aev172 | 61 | 1.181253 | 3.259885 | 0 | 15.51846 | aev172 | 61 | 2.231633 | 8.253795 | 0 | 59.46297 | 0.889208 | -0.9244 | 0.3581 |
| public transport | aev173 | 61 | 76.79541 | 97.52179 | 0 | 527.8032 | aev173 | 61 | 73.35803 | 65.09761 | 0 | 222.8898 | -0.04476 | 0.229 | 0.8193 |
| vehicle costs repayments | aev174 | 61 | 0 | 0 | 0 | 0 | aev174 | 61 | 1.763252 | 13.77144 | 0 | 107.5584 | #DIV/0! | -1.0000 | 0.3213 |
| petrol and maintenance | aev175 | 61 | 0.205892 | 1.60807 | 0 | 12.55943 | aev175 | 61 | 0.984649 | 7.690357 | 0 | 60.06361 | 3.782351 | -0.7742 | 0.4416 |
| durables | aev176 | 61 | 46.78803 | 105.9428 | 0 | 521.2056 | aev176 | 61 | 43.22218 | 77.90568 | 0 | 318.4141 | -0.076213 | 0.2118 | 0.8327 |
| insurance assets | aev179 | 61 | 1.883112 | 14.70758 | 0 | 114.8698 | aev179 | 61 | 0 | 0 | 0 | 0 | -1 | 1.0000 | 0.3213 |
| dependants at home | aev180 | 61 | 7.164874 | 29.33804 | 0 | 206.9128 | aev180 | 61 | 6.873176 | 19.97448 | 0 | 126.045 | -0.040712 | 0.0642 | 0.9489 |
| dependants elsewhere | aev181 | 61 | 13.72629 | 42.35176 | 0 | 214.0644 | aev181 | 61 | 11.27212 | 35.94945 | 0 | 173.7452 | -0.178793 | 0.345 | 0.7307 |
| domestic | aev182 | 61 | 0.816077 | 6.373768 | 0 | 49.78072 | aev182 | 61 | 13.06011 | 61.02139 | 0 | 453.668 | 15.00352 | -1.5587 | 0.1242 |
| funeral donations | aev184 | 61 | 1.945025 | 7.433972 | 0 | 50 | aev184 | 61 | 5.594776 | 12.76977 | 0 | 77.4847 | 1.876455 | -1.9292 | 0.0566 |
| regular schooling | aev185a | 61 | 36.86998 | 68.64149 | 0 | 339.1311 | aev185a | 61 | 36.95861 | 53.95866 | 0 | 199.7227 | 0.002404 | -0.0079 | 0.9937 |
| church | aev185b | 61 | 0 | 0 | 0 | 0 | aev185b | 61 | 0 | 0 | 0 | 0 | #DIV/0! | . | . |
| medical costs | aehccost | 61 | 107.8188 | 268.0143 | 0 | 1649.742 | aehccost | 61 | 32.52783 | 53.01489 | 0 | 270.2863 | -0.69831 | 2.1524 | 0.0351* |
| total regular expenditure | aetotregex | 61 | 711.7387 | 555.8912 | 80.67068 | 2864.652 | aetotregex | 61 | 660.261 | 420.3581 | 122.3302 | 2236.487 | -0.072327 | 0.5769 | 0.5652 |

## Appendix 14: Time Allocation of Daily Activities Across Cohorts - Children (Proportion of Time)

| | Week-day | | | Saturday | | | Sunday | | |
|---|---|---|---|---|---|---|---|---|---|
| | All House holds | Non-Affected | Affected | All House holds | Non-Affected | Affected | All House holds | Non-Affected | Affected |
| | n=363 | n=142 | n=221 | n=362 | n=142 | n=220 | n=362 | n=142 | n=220 |
| Studying, attending school or doing school work | 28.19 | 28.35 | 28.10 | 2.49 | 3.38 | 1.94* | 2.39 | 2.21 | 2.50 |
| Cooking, cleaning, domestic chores | 13.02 | 12.89 | 13.10 | 18.23 | 18.39 | 18.13 | 17.71 | 18.03 | 17.50 |
| sleeping | 35.39 | 35.09 | 35.58 | 38.57 | 38.30 | 38.73 | 39.35 | 37.99 | 40.21* |
| leisure hours | 16.54 | 17.80 | 15.75* | 26.41 | 27.50 | 25.72 | 19.04 | 19.86 | 18.53 |
| visiting friends and family and receiving visitors | 3.96 | 3.28 | 4.39 | 11.53 | 9.58 | 12.75* | 8.13 | 7.14 | 8.75 |
| Church (travel time plus at church) | 0.08 | 0.00 | 0.14 | 1.13 | 1.15 | 1.11 | 11.82 | 12.36 | 11.49 |
| Total | 97.19 | 97.41 | 81.31 | 98.36 | 98.30 | 83.70 | 98.44 | 97.59 | 58.77 |

## Appendix 15: Time Allocation of Daily Activities Over Time - Children (Proportion of Time)

| Non-Affected Households | Weekdays | | | Saturday | | | Sunday | | |
|---|---|---|---|---|---|---|---|---|---|
| | Wave 2 | Wave 3 | Wave 4 | Wave 2 | Wave 3 | Wave 4 | Wave 2 | Wave 3 | Wave 4 |
| | n=45 | n=47 | n=50 | n=45 | n=47 | n=50 | n=45 | n=47 | n=50 |
| Studying, attending school, doing school work including travel time | 30.76 | 29.37 | 32.23 | 3.70 | 4.43 | 2.29 | 3.89 | 1.42 | 1.50 |
| Cooking, cleaning, domestic chores | 10.97 | 13.92 | 14.00 | 17.18 | 19.06 | 19.50 | 15.09 | 21.59 | 18.04 |
| Visiting friends and family and receiving visitors | 2.22 | 3.19 | 4.50 | 7.04 | 9.66 | 12.21 | 6.11 | 6.83 | 8.63 |
| Sleeping | 35.14 | 35.46 | 34.90 | 38.80 | 37.85 | 38.17 | 36.06 | 37.94 | 39.67 |
| Leisure hours | 20.21 | 18.02 | 14.38 | 31.16 | 26.20 | 24.13 | 23.70 | 16.58 | 18.21 |
| Church (travel time plus at church) | 0.00 | 0.00 | 0.00 | 1.34 | 0.22 | 1.92 | 10.79 | 13.96 | 12.46 |
| | | | | | | | | | |
| Affected Households | Weekdays | | | Saturday | | | Sunday | | |
| | Wave 2 | Wave 3 | Wave 4 | Wave 2 | Wave 3 | Wave 4 | Wave 2 | Wave 3 | Wave 4 |
| | n=73 | n=73 | n=75 | n=73 | n=73 | n=75 | n=73 | n=73 | n=75 |
| Studying, attending school or doing school work | 29.98 | 31.10 | 29.14 | 2.52 | 1.34 | 2.22 | 3.41 | 1.88 | 2.56 |
| Cooking, cleaning, domestic chores | 11.67 | 13.44 | 13.64 | 14.47 | 19.83 | 19.61 | 13.89 | 19.46 | 18.31 |
| Visiting friends and family and receiving visitors | 3.00 | 4.20 | 5.81 | 10.65 | 13.44 | 13.58 | 7.12 | 8.62 | 10.14 |
| Sleeping | 36.22 | 35.64 | 34.92 | 38.66 | 38.53 | 38.97 | 40.65 | 39.75 | 40.00 |
| Leisure hours | 17.94 | 14.91 | 15.33 | 30.41 | 24.66 | 22.92 | 23.52 | 17.61 | 15.78 |
| Church (travel time plus at church) | 0.00 | 0.31 | 0.11 | 1.45 | 0.80 | 1.25 | 9.87 | 11.93 | 12.28 |

# Appendix 16: Proportion of Time Across Cohorts – Children

| Proportion of time allocated: | | Across Cohorts | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Children | | Week-day | | | | | Saturday | | | | | Sunday | | | |
| | All Households | Non-Affected | Affected | | | All Households | Non-Affected | Affected | | | All Households | Non-Affected | Affected | | |
| | n=376 | n=145 | n=231 | t-stat | p-value | n=375 | n=145 | n=230 | t-stat | p-value | n=375 | n=145 | n=230 | t-stat | p-value |
| Studying, attending school or doin | 28.19 | 28.35 | 28.10 | | | 2.49 | 3.38 | 1.94 | 2.3198 | 0.0209 | 2.39 | 2.21 | 2.50 | | |
| Cooking, cleaning, domestic chore | 13.02 | 12.89 | 13.10 | | | 18.23 | 18.39 | 18.13 | | | 17.71 | 18.03 | 17.50 | | |
| Supervising children's schoolwork | 0.03 | 0.07 | 0.00 | 2.1138 | 0.0352 | 0.02 | 0.06 | 0.00 | | | 0.07 | 0.00 | 0.12 | | |
| Working for wages/ownbusiness/o | 0.28 | 0.00 | 0.46 | | | 0.19 | 0.29 | 0.13 | | | 0.00 | 0.00 | 0.00 | | |
| Hours off sick or didn't go to work | 0.08 | 0.00 | 0.13 | | | 0.09 | 0.00 | 0.15 | | | 0.04 | 0.00 | 0.07 | | |
| Looking for a job | 0.00 | 0.00 | 0.00 | | | 0.00 | 0.00 | 0.00 | | | 0.00 | 0.00 | 0.00 | | |
| Caring for sick members of the ho | 0.00 | 0.00 | 0.00 | | | 0.00 | 0.00 | 0.00 | | | 0.00 | 0.00 | 0.00 | | |
| Caring for sick members of other h | 0.00 | 0.00 | 0.00 | | | 0.00 | 0.00 | 0.00 | | | 0.00 | 0.00 | 0.00 | | |
| Attending funerals | 0.00 | 0.00 | 0.00 | | | 0.23 | 0.13 | 0.30 | | | 0.17 | 0.32 | 0.07 | | |
| Working for neighbours/friends for | 0.00 | 0.00 | 0.00 | | | 0.00 | 0.00 | 0.00 | | | 0.01 | 0.00 | 0.02 | | |
| Helping neighbours/friends/relative | 0.04 | 0.00 | 0.06 | | | 0.08 | 0.00 | 0.13 | | | 0.08 | 0.00 | 0.14 | | |
| Working in the garden | 0.00 | 0.00 | 0.00 | | | 0.28 | 0.16 | 0.36 | | | 0.14 | 0.04 | 0.21 | | |
| Home production of clothing, bakir | 0.07 | 0.13 | 0.03 | | | 0.03 | 0.00 | 0.05 | | | 0.17 | 0.33 | 0.07 | | |
| Visiting friends and family and rec | 3.96 | 3.28 | 4.39 | | | 11.53 | 9.58 | 12.75 | -2.7302 | 0.0066 | 8.13 | 7.14 | 8.75 | | |
| Repairs and maintenance to home | 0.00 | 0.00 | 0.00 | | | 0.06 | 0.00 | 0.09 | | | 0.66 | 1.57 | 0.09 | 2.8375 | 0.0048 |
| Sleeping | 35.39 | 35.09 | 35.58 | | | 38.57 | 38.30 | 38.73 | | | 39.35 | 37.99 | 40.21 | -2.5772 | 0.0103 |
| Leisure hours | 16.54 | 17.80 | 15.75 | 2.0661 | 0.0395 | 26.41 | 27.50 | 25.72 | | | 19.04 | 19.86 | 18.53 | | |
| Travel time to and from school | 2.20 | 2.36 | 2.10 | | | | | | | | | | | | |
| Visiting clinic/hospital | 0.00 | 0.00 | 0.00 | | | 0.01 | 0.03 | 0.00 | | | 0.04 | 0.00 | 0.06 | | |
| Time spent shopping including tra | 0.03 | 0.00 | 0.05 | | | 0.39 | 0.40 | 0.38 | | | | | | | |
| Church (travel time plus at church) | 0.08 | 0.00 | 0.14 | | | 1.13 | 1.15 | 1.11 | | | 11.82 | 12.36 | 11.49 | | |
| Community projects | | | | | | | | | | | 0.06 | 0.10 | 0.03 | | |
| Total hours per week-day | 99.91 | 99.97 | 99.87 | | | 99.74 | 99.37 | 99.98 | | | 99.89 | 99.94 | 99.86 | | |

# Appendix 17: Proportion of Time Across Cohorts – Adults

| Proportion of time allocated: | | Across Cohorts | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Adults | Week-day | | | | | Saturday | | | | | Sunday | | | | |
| | All Households | Non-Affected | Affected | | | All Households | Non-Affected | Affected | | | All Households | Non-Affected | Affected | | |
| | n=789 | n=337 | n=452 | t-stat | p-value | n=788 | n=337 | n=451 | t-stat | p-value | n=788 | n=337 | n=451 | t-stat | p-value |
| Studying, attending school or do | 0.84 | 0.90 | 0.79 | | | 0.79 | 0.93 | 0.67 | | | 0.45 | 0.38 | 0.49 | | |
| Cooking, cleaning, domestic cho | 22.55 | 22.52 | 22.58 | | | 21.82 | 21.81 | 21.83 | | | 21.50 | 21.49 | 21.50 | | |
| Supervising children's schoolwo | 0.45 | 0.57 | 0.36 | | | 0.09 | 0.15 | 0.05 | | | 0.07 | 0.09 | 0.05 | | |
| Working for wages/ownbusiness | 12.13 | 13.70 | 10.95 | 2.2529 | 0.0245 | 5.26 | 5.98 | 4.73 | | | 2.19 | 2.76 | 1.77 | | |
| Hours off sick or didn't go to wor | 0.13 | 0.00 | 0.23 | -1.7057 | 0.0885 | 0.10 | 0.15 | 0.06 | | | 0.04 | 0.00 | 0.07 | | |
| Looking for a job | 0.88 | 1.03 | 0.76 | | | 0.08 | 0.13 | 0.05 | | | 0.01 | 0.01 | 0.00 | | |
| Caring for sick members of the h | 0.07 | 0.00 | 0.12 | | | 0.06 | 0.00 | 0.10 | 1.1893 | 0.2347 | 0.06 | 0.00 | 0.10 | | |
| Caring for sick members of othe | 0.07 | 0.02 | 0.10 | | | 0.09 | 0.07 | 0.11 | | | 0.03 | 0.02 | 0.03 | | |
| Attending funerals | 0.01 | 0.00 | 0.02 | | | 1.93 | 1.79 | 2.04 | | | 0.69 | 0.88 | 0.55 | | |
| Working for neighbours/friends f | 0.06 | 0.00 | 0.10 | | | 0.11 | 0.07 | 0.13 | | | 0.03 | 0.00 | 0.06 | | |
| Helping neighbours/friends/relat | 0.50 | 0.24 | 0.69 | -1.7564 | 0.0794 | 0.34 | 0.13 | 0.50 | -2.2751 | 0.0232 | 0.20 | 0.00 | 0.34 | -2.1489 | 0.0319 |
| Working in the garden | 0.41 | 0.42 | 0.41 | | | 0.24 | 0.38 | 0.14 | 2.0180 | 0.0439 | 0.27 | 0.35 | 0.21 | | |
| Home production of clothing, ba | 0.04 | 0.02 | 0.06 | | | 0.12 | 0.05 | 0.18 | | | 0.12 | 0.20 | 0.06 | | |
| Visiting friends and family and re | 2.87 | 2.22 | 3.36 | -2.4163 | 0.0159 | 6.61 | 6.19 | 6.93 | | | 5.63 | 5.38 | 5.83 | | |
| Repairs and maintenance to hor | 0.07 | 0.00 | 0.12 | | | 0.13 | 0.12 | 0.14 | | | 0.47 | 1.05 | 0.03 | 3.3472 | 0.0009 |
| Sleeping | 35.44 | 34.49 | 36.14 | -3.8826 | 0.0001 | 37.00 | 36.13 | 37.65 | -2.7157 | 0.0068 | 38.13 | 36.21 | 39.57 | -5.6431 | 0.0000 |
| Leisure hours | 19.46 | 20.35 | 18.79 | 1.7617 | 0.0785 | 20.43 | 21.93 | 19.30 | 2.8761 | 0.0041 | 19.49 | 20.85 | 18.48 | 2.83 | 0.0048 |
| Travel time to and from school | 0.26 | 0.25 | 0.26 | | | | | | | | | | | | |
| Travel time to and from work | 1.92 | 1.93 | 1.91 | | | 1.19 | 1.06 | 1.28 | | | 0.70 | 0.59 | 0.77 | | |
| Visiting clinic/hospital | 0.70 | 0.41 | 0.92 | -1.8030 | 0.0718 | 0.23 | 0.09 | 0.34 | | | 0.17 | 0.17 | 0.17 | | |
| Time spent shopping including t | 0.72 | 0.59 | 0.83 | | | 1.64 | 1.68 | 1.61 | | | | | | | |
| Church (travel time plus at churc | 0.43 | 0.32 | 0.51 | | | 1.72 | 1.17 | 2.13 | -2.1732 | 0.0301 | 9.52 | 9.15 | 9.80 | | |
| Community projects | | | | | | | | | | | 0.24 | 0.40 | 0.12 | 1.8039 | 0.0716 |
| Total hours per week-day | 100.00 | 100.00 | 100.00 | | | 100.00 | 100.00 | 100.00 | | | 100.00 | 100.00 | 100.00 | | |

**Appendix 18: Time Allocation of Daily Activities Over Time – Adults in Non-Affected Households (Proportion of time)**

| | Weekdays | | | Saturday | | | Sunday | | |
|---|---|---|---|---|---|---|---|---|---|
| Non-Affected Households | Wave 2 | Wave 3 | Wave 4 | Wave 2 | Wave 3 | Wave 4 | Wave 2 | Wave 3 | Wave 4 |
| | n=120 | n=107 | n=110 | n=120 | n=107 | n=110 | n=120 | n=107 | n=110 |
| Studying, attending school or doing school work | 0.97 | 0.84 | 0.89 | 1.32 | 0.86 | 0.59 | 0.73 | 0.33 | 0.26 |
| Cooking, cleaning, domestic chores | 20.21 | 24.03 | 23.58 | 20.99 | 21.42 | 23.09 | 18.85 | 23.17 | 22.62 |
| Supervising children's schoolwork | 0.83 | 0.47 | 0.38 | 0.14 | 0.00 | 0.30 | 0.05 | 0.07 | 0.09 |
| Working for wages/own business/domestic worker/guard | 13.37 | 13.73 | 14.03 | 6.51 | 5.94 | 5.44 | 2.37 | 2.13 | 2.07 |
| Hours off sick or didn't go to work | 0.00 | 0.00 | 0.00 | 0.00 | 0.47 | 0.00 | 0.00 | 0.06 | 0.06 |
| Looking for a job | 1.60 | 0.82 | 0.63 | 0.35 | 0.02 | 0.00 | 0.02 | 0.00 | 0.00 |
| Caring for sick members of the household | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.02 | 0.00 | 0.15 |
| Caring for sick members of other households | 0.00 | 0.00 | 0.08 | 0.00 | 0.23 | 0.00 | 0.03 | 0.05 | 0.00 |
| Attending funerals | 0.00 | 0.00 | 0.00 | 1.58 | 2.16 | 1.65 | 0.42 | 0.38 | 1.28* |
| Working for neighbours/friends for pay | 0.00 | 0.00 | 0.00 | 0.00 | 0.23 | 0.00 | 0.00 | 0.00 | 0.10 |
| Helping neighbours/friends/relatives for no pay | 0.00 | 0.23 | 0.51 | 0.07 | 0.06 | 0.27 | 0.18 | 0.33 | 0.08 |
| Working in the garden | 0.59 | 0.10 | 0.55 | 0.33 | 0.31 | 0.49 | 0.27 | 0.41 | 0.14 |
| Home production of clothing, baking, food | 0.00 | 0.00 | 0.08 | 0.00 | 0.00 | 0.15 | 0.18 | 0.00 | 0.18 |
| Visiting friends and family and receiving visitors | 2.33 | 2.51 | 1.82 | 5.85 | 6.31 | 6.44 | 5.48 | 5.84 | 5.59 |
| Repairs and maintenance to home/business | 0.00 | 0.00 | 0.00 | 0.21 | 0.00 | 0.13 | 1.03 | 0.27 | 0.06 |
| Sleeping | 34.27 | 34.72 | 34.51 | 35.73 | 36.20 | 36.52 | 37.69 | 38.01 | 38.71 |
| Leisure hours | 21.89 | 19.84 | 19.17 | 23.58 | 20.93 | 21.12 | 21.90 | 17.72 | 18.72 |
| Travel time to and from school | 0.50 | 0.12 | 0.09 | | | | | | |
| Travel time to and from work | 2.20 | 1.77 | 1.80 | 1.41 | 1.13 | 0.61 | 0.63 | 0.61 | 0.85 |
| Visiting clinic/hospital | 0.31 | 0.43 | 0.51 | 0.00 | 0.23 | 0.04 | 0.26 | 0.25 | 0.00 |
| Time spent shopping including travel time | 0.59 | 0.41 | 0.76 | 0.95 | 2.16 | 1.99 | | | |
| Church (travel time plus at church) | 0.33 | 0.00 | 0.63 | 0.99 | 1.34 | 1.19 | 9.73 | 10.16 | 8.68 |
| Community projects | | | | | | | 0.15 | 0.21 | 0.35 |
| Total hours per week-day | 100.00 | 100.00 | 100.00 | 100.00 | 100.00 | 100.00 | 100.00 | 100.00 | 100.00 |

**Appendix 19: Time Allocation of Daily Activities Over Time – Affected Households Adults (Proportion of Time)**

| | Weekdays | | | Saturday | | | Sunday | | |
|---|---|---|---|---|---|---|---|---|---|
| Affected Households | Wave 2 | Wave 3 | Wave 4 | Wave 2 | Wave 3 | Wave 4 | Wave 2 | Wave 3 | Wave 4 |
| | n=153 | n=148 | n=151 | n=152 | n=148 | n=151 | n=152 | n=148 | n=151 |
| Studying, attending school or doing school work | 1.35 | 0.68 | 0.34 | 1.41 | 0.17 | 0.43 | 0.95 | 0.17 | 0.36 |
| Cooking, cleaning, domestic chores | 20.28 | 24.45 | 23.07 | 18.56 | 24.07 | 22.93* | 17.56 | 23.85 | 23.17* |
| Supervising children's schoolwork | 0.76 | 0.06 | 0.25 | 0.07 | 0.08 | 0.00 | 0.10 | 0.00 | 0.06 |
| Working for wages/own business/domestic worker/guard | 8.77 | 13.36 | 10.80 | 4.11 | 5.43 | 4.65 | 1.75 | 1.77 | 1.79 |
| Hours off sick or didn't go to work | 0.37 | 0.00 | 0.32 | 0.00 | 0.00 | 0.19 | 0.00 | 0.10 | 0.11 |
| Looking for a job | 0.69 | 0.63 | 0.95 | 0.00 | 0.14 | 0.00 | 0.00 | 0.00 | 0.00 |
| Caring for sick members of the household | 0.10 | 0.04 | 0.21 | 0.27 | 0.00 | 0.03 | 0.03 | 0.00 | 0.26 |
| Caring for sick members of other households | 0.00 | 0.11 | 0.19 | 0.00 | 0.32 | 0.00 | 0.00 | 0.08 | 0.00 |
| Attending funerals | 0.05 | 0.00 | 0.00 | 1.55 | 2.10 | 2.48 | 0.55 | 0.25 | 0.84 |
| Working for neighbours/friends for pay | 0.18 | 0.13 | 0.00 | 0.00 | 0.23 | 0.18 | 0.00 | 0.00 | 0.18 |
| Helping neighbours/friends/relatives for no pay | 0.64 | 0.66 | 0.76 | 0.60 | 0.34 | 0.57 | 0.32 | 0.58 | 0.14 |
| Working in the garden | 0.44 | 0.62 | 0.17 | 0.12 | 0.20 | 0.10 | 0.18 | 0.34 | 0.12 |
| Home production of clothing, baking, food | 0.00 | 0.00 | 0.18 | 0.00 | 0.15 | 0.39 | 0.03 | 0.00 | 0.17 |
| Visiting friends and family and receiving visitors | 3.01 | 3.21 | 3.85 | 5.89 | 7.39 | 7.52 | 5.36 | 6.32 | 5.81 |
| Repairs and maintenance to home/business | 0.37 | 0.00 | 0.00 | 0.42 | 0.00 | 0.00 | 0.00 | 0.00 | 0.08 |
| Sleeping | 36.34 | 35.73 | 36.34 | 38.08 | 37.19 | 37.68 | 39.99 | 39.22 | 39.49 |
| Leisure hours | 21.88 | 16.82 | 17.59* | 23.88 | 16.81 | 17.15* | 21.85 | 16.29 | 17.23* |
| Travel time to and from school | 0.19 | 0.11 | 0.48 | | | | | | |
| Travel time to and from work | 1.84 | 1.49 | 2.40 | 1.30 | 0.80 | 1.74 | 0.45 | 0.65 | 1.21 |
| Visiting clinic/hospital | 1.35 | 0.48 | 0.91 | 0.34 | 0.61 | 0.08 | 0.16 | 0.35 | 0.00 |
| Time spent shopping including travel time | 0.60 | 0.86 | 1.02 | 1.37 | 1.55 | 1.92 | | | |
| Church (travel time plus at church) | 0.80 | 0.56 | 0.17 | 2.01 | 2.42 | 1.97 | 10.73 | 9.90 | 8.77 |
| Community projects | | | | | | | 0.00 | 0.14 | 0.21 |
| Total hours per week-day | 100.00 | 100.00 | 100.00 | 100.00 | 100.00 | 100.00 | 100.00 | 100.00 | 100.00 |

**Appendix 20: Composition of Savings Across all Waves**

| Type of Savings Account | All Households | | | Non-Affected | | | Affected | | | T-stat | p-value |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | Number of Households | Percentage of Households | Mean Amount Saved | Number of Households | Percentage of Households | Mean Amount Saved | Number of Households | Percentage of Households | Mean Amount Saved | | |
| Burial and funeral cover | 159 | 55.0 | 93.35 | 53 | 40.5 | 92.95 | 106 | 67.1 | 93.54 | -0.04 | 0.9665 |
| Bank savings account | 78 | 27.0 | 635.07 | 47 | 35.9 | 326.45 | 31 | 19.6 | 1102.98 | -1.00 | 0.3252 |
| Life policy | 58 | 20.1 | 121.41 | 23 | 17.6 | 150.79 | 35 | 22.2 | 102.10 | 1.94 | 0.0601 |
| Investment | 7 | 2.4 | 449.59 | 3 | 2.3 | 435.33 | 4 | 2.5 | 460.28 | -0.07 | 0.9449 |
| Endowment | 77 | 26.6 | 159.11 | 48 | 36.6 | 192.40 | 29 | 18.4 | 103.99 | 3.22 | 0.002* |
| Stokvel | 30 | 10.4 | 236.34 | 9 | 6.9 | 284.02 | 21 | 13.3 | 215.91 | 0.92 | 0.3709 |
| Total | 289 | 100.0 | 324.94 | 131 | 100.0 | 281.18 | 158 | 100.0 | 361.22 | -0.50 | 0.6149 |

# Appendix 21: Annual Household Expenditure – Absolute Real Values

| | All Households - n=113 | | | | Non-Affected Households n=52 | | | | | Affected Households n=61 | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Mean | Std. Dev. | Min | Max | Variable | Mean | Std. Dev. | Min | Max | Variable | Mean | Std. Dev. | Min | Max | % Diff | T-stat | p-value |
| Housing (rent, elec&water) | 4131.017 | 5595.425 | 0 | 33108.68 | ahousing | 5002.51 | 6964.365 | 0 | 33108.68 | ahousing | 3388.105 | 3999.586 | 0 | 19510.78 | -0.322719 | 1.4768 | 0.1437 |
| Food (takeaways inc) | 6157.638 | 3179.588 | 1875.86 | 23005.19 | afood | 5930.688 | 2774.239 | 1875.86 | 16641.61 | afood | 6351.104 | 3499.565 | 2198.647 | 23005.19 | 0.070888 | -0.7119 | 0.478 |
| Alcohol & cig | 333.8428 | 825.5129 | 0 | 6185 | aalcocig | 467.6517 | 1083.439 | 0 | 6185 | aalcocig | 219.7763 | 495.5512 | 0 | 2673.893 | -0.530043 | 1.5198 | 0.1331 |
| Telephone | 762.0765 | 700.23 | 0 | 2990.804 | arv164 | 797.7363 | 757.6268 | 0 | 2990.804 | arv164 | 731.678 | 652.1716 | 0 | 2579.806 | -0.082807 | 0.4922 | 0.6236 |
| Groceries (non-food) | 918.7911 | 500.8497 | 121.5972 | 3395.562 | arv167 | 997.521 | 568.204 | 235.0215 | 3395.562 | arv167 | 851.677 | 428.807 | 121.5972 | 2199.605 | -0.146206 | 1.5186 | 0.1322 |
| Personal care | 653.3981 | 526.8777 | 0 | 3205.499 | arv168 | 572.8053 | 432.3124 | 0 | 1876.674 | arv168 | 722.1002 | 590.6768 | 0 | 3205.499 | 0.260638 | -1.547 | 0.1248 |
| Clothing | 1092.353 | 1467.376 | 0 | 9089.223 | arv169 | 1070.178 | 1358.085 | 0 | 4613.514 | arv169 | 1111.256 | 1565.493 | 0 | 9089.223 | 0.038384 | -0.1494 | 0.8815 |
| Gambling | 110.3583 | 222.939 | 0 | 1557.915 | arv172 | 154.701 | 287.3004 | 0 | 1557.915 | arv172 | 72.55803 | 139.4977 | 0 | 602.3506 | -0.530979 | 1.8813 | 0.064 |
| Public transport | 2248.573 | 1653.701 | 0 | 7181.904 | arv173 | 2237.488 | 1578.206 | 0 | 5794.565 | arv173 | 2258.023 | 1728.439 | 0 | 7181.904 | 0.009178 | -0.066 | 0.9475 |
| Vehicle costs repayments | 188.2714 | 1743.662 | 0 | 18517.14 | arv174 | 376.288 | 2567.057 | 0 | 18517.14 | arv174 | 27.99485 | 131.4031 | 0 | 741.3127 | -0.925603 | 0.9773 | 0.333 |
| Petrol and maintenance | 327.2457 | 1458.658 | 0 | 11132.59 | arv175 | 624.3385 | 2071.784 | 0 | 11132.59 | arv175 | 73.98635 | 426.0567 | 0 | 3203.744 | -0.881496 | 1.8819 | 0.0652 |
| Durables | 1292.068 | 1879.191 | 0 | 8225.496 | arv176 | 1079.49 | 1441.993 | 0 | 5031.512 | arv176 | 1473.281 | 2179.88 | 0 | 8225.496 | 0.364794 | -1.1469 | 0.254 |
| Insurance assets | 37.63054 | 241.8266 | 0 | 2203.722 | arv179 | 53.68041 | 314.7327 | 0 | 2203.722 | arv179 | 23.94868 | 156.688 | 0 | 1200 | -0.553866 | 0.619 | 0.5379 |
| Dependants at home | 249.1788 | 417.925 | 0 | 2028.706 | arv180 | 343.1017 | 499.6848 | 0 | 2028.706 | arv180 | 169.1135 | 315.6576 | 0 | 1200 | -0.507104 | 2.1689 | 0.0329 |
| Dependants elsewhere | 721.6932 | 1488.649 | 0 | 9690.756 | arv181 | 1146.754 | 1898.84 | 0 | 9690.756 | arv181 | 359.346 | 884.2223 | 0 | 4947.409 | -0.686641 | 2.7471 | 0.0076 |
| Domestic | 141.1373 | 549.3182 | 0 | 4686.12 | arv182 | 153.9483 | 693.254 | 0 | 4686.12 | arv182 | 130.2164 | 393.0562 | 0 | 2499.785 | -0.154155 | 0.2187 | 0.8275 |
| Funeral donations | 177.6173 | 493.1759 | 0 | 4117.971 | arv184 | 109.2624 | 327.5996 | 0 | 2144.559 | arv184 | 235.887 | 596.0626 | 0 | 4117.971 | 1.158904 | -1.4257 | 0.1572 |
| Regular schooling | 1465.184 | 1798.661 | 0 | 10214.14 | arv185a | 1607.913 | 1985.652 | 0 | 10214.14 | arv185a | 1343.513 | 1629.389 | 0 | 6701.897 | -0.164437 | 0.7653 | 0.4459 |
| Church | 78.78613 | 310.474 | 0 | 2109 | arv185b | 161.0872 | 442.5389 | 0 | 2109 | arv185b | 8.62789 | 50.95569 | 0 | 367.6333 | -0.94644 | 2.4704 | 0.0168 |
| Annual hc cost | 573.4413 | 1236.904 | 0 | 10162.97 | annhccost | 164.7785 | 322.5347 | 0 | 1755.855 | annhccost | 921.8095 | 1580.925 | 0 | 10162.97 | 4.594234 | -3.6519 | 0.0005 |
| Total regular expenditure | 21660.3 | 13065.71 | 3980.411 | 91616.36 | atotregexp | 23051.92 | 15164.53 | 4098.689 | 91616.36 | atotregexp | 20474 | 10958.39 | 3980.411 | 47802.29 | -0.111831 | 1.0197 | 0.3106 |
| Schooling | 625.9393 | 888.8282 | 0 | 6290.069 | anneduc | 613.9866 | 809.5619 | 0 | 4893.718 | anneduc | 636.1285 | 957.8018 | 0 | 6290.069 | 0.036063 | -0.1332 | 0.8943 |
| Purchases | 914.5173 | 2606.485 | 0 | 19794.32 | annpur | 833.6621 | 2156.013 | 0 | 10958.3 | annpur | 983.443 | 2952.975 | 0 | 19794.32 | 0.179666 | -0.3107 | 0.7566 |
| Transfers out | 404.3875 | 794.4797 | 0 | 5950 | annremout | 316.7655 | 569.2892 | 0 | 3155.384 | annremout | 479.0818 | 943.6278 | 0 | 5950 | 0.512418 | 0.1318 | 0.8954 |
| Housing repairs | 600.579 | 2568.284 | 0 | 19000 | annirrhous· | 635.3707 | 2649.136 | 0 | 18119.81 | annirrhous· | 570.9205 | 2519.029 | 0 | 19000 | -0.101437 | -1.1247 | 0.2634 |
| Visits/holidays | 704.568 | 1623.718 | 0 | 11765.25 | annrv191 | 756.1592 | 1398.779 | 0 | 7830.918 | annrv191 | 660.5885 | 1803.892 | 0 | 11765.25 | -0.12639 | 0.3169 | 0.7519 |
| Funeral cost | 3314.35 | 5721.475 | 0 | 22000 | annfun | 997.9036 | 3311.26 | 0 | 20000 | annfun | 5289.026 | 6570.486 | 0 | 22000 | 4.300137 | -4.4773 | 0.0000 |
| Total irregular | 6564.341 | 7704.219 | 0 | 41337.84 | anntotirrex | 4153.848 | 5498.175 | 77.97102 | 23544.4 | anntotirrex | 8619.188 | 8704.713 | 0 | 41337.84 | 1.074989 | -0.2155 | 0.8298 |
| Total regular + irregular | 28224.64 | 16562.91 | 4280.988 | 113483.7 | anntotexp | 27205.77 | 17974.47 | 5585.279 | 113483.7 | anntotexp | 29093.19 | 15355.67 | 4280.988 | 66383.75 | 0.069376 | -0.5945 | 0.5535 |