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Social networks and state grants:
sustaining the livelihoods of households
affected by HIV and AIDS in KwaZulu-
Natal, South Africa

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Thesis submitted to University of London for the degree of Doctor of Philosophy

May 2011

Abstract

The livelihoods of households in rural South Africa depend largely on formal and informal paid work, remittances and social security payments. Agricultural production is far less important than in other parts of sub-Saharan Africa. In addition, a turbulent social and political history has affected the composition, functioning and definition of rural households. This thesis explores in this context how illness caused by HIV, access to anti-retroviral therapy (ART) and the death of individuals change the experience of household members and their livelihoods.

The study is based on case studies of ten households and adopted a livelihoods conceptual framework. Data were collected both prospectively and retrospectively in a series of in-depth interviews supplemented by direct observation.

Social capital and state grants were particularly important in mitigating the effects of HIV and AIDS in affected households. Resident and non-resident members of the household provided each other with both valuable financial and material support and physical care. Access to this resource was underpinned by strong norms of obligation to family and generalised reciprocity within households. These findings highlight the importance of family or household-focussed interventions in alleviating the burden of HIV and AIDS. Norms of reciprocity also enabled affected households and individuals with sufficient social capital to secure support from kin outside the household and the wider community.

Although many affected households encountered difficulties accessing them, social grants were a major component of their livelihoods. A synergistic relationship existed between receipt of a disability grant and successful ART outcomes. This finding highlights the importance of providing social grants for those who become ill and have no other source of income. Unemployed people on ART should remain entitled to grant support even if they no longer qualify as disabled in order to assist them to continue treatment.

Acknowledgements

This study was supported by a UK Economic and Social Research Council (ESRC) postgraduate studentship linked to an ESRC/Department of International Development funded research project (grant number RES-167-25-0076). The fieldwork was conducted in the Africa Centre for Health and Population Studies research site in Mtubatuba. The Africa Centre is primarily funded by the Wellcome Trust. I would like to thank the following people who enabled this research project in many ways: my supervisors Ian Timæus and Vicky Hosegood for their support and encouragement; Marie-Louise Newell and the staff of the Africa Centre for their time and hospitality during the time the fieldwork was conducted; the VCT team; Patrick Gabela; Johan Viljoen and his staff at the Catholic Church home-based care team who introduced Zandile and I to our study households.

Special thanks to Zandile Gumede my research assistant for her willingness to learn and for her help, compassion and sense of humour, which were invaluable to me during the fieldwork. Thanks to Thom and my family for listening, reading and just being there through the process.

This thesis is dedicated to all the families who in spite of their own difficult and sometimes tragic personal experiences were still so willing to share of themselves, their homes and their stories with Zandile and I. I hope that some found solace in having someone to listen to their stories, even briefly.

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Abbreviations

ACDIS -	Africa Centre Demographic Information System
AIDS -	Acquired Immune Deficiency Syndrome
ART -	Anti-retroviral therapy
ASS -	Actuarial Society of Southern Africa
BIG -	Basic income grant
CAB -	Community Advisory Board
CBOs -	Community-based Organisation
DFID -	Department for International Development
DG -	Disability grant
CSG -	Child support grant
CDG -	Care dependency grant
FCG -	Family child grant
OAP -	Old age pension
DHS -	Demographic and Health Survey
DSS -	Demographic Surveillance Survey
EPWP -	Expanded Public Works Programme
GEAR -	Growth, Employment and Redistribution
HIV -	Human Immunodeficiency Virus
IDS -	Institute of Development Studies
JLICA -	The Joint Learning Initiative on Children and AIDS
KIDS -	KwaZulu-Natal Income Dynamics Study
NGO -	Non-governmental Organization
PLHIV -	People living with HIV
PSLSD-	Project for Statistics on Living Standards and Development
RDP -	Reconstruction and Development Programme
SALDRU-	South African Labour and Development Research Unit
SASSA -	South African Social Security Agency
SEF -	The Small Enterprise Foundation
SETAs -	Sector Education and Training Authorities
SRL -	Sustainable Rural Livelihoods
TB -	Tuberculosis
USA -	United States of America
VCT -	Voluntary counselling and testing
WHO -	World Health Organisation

Chapter 1: Introduction



1.1 Introduction

It is almost 30 years since the discovery of the Human Immunodeficiency Virus (HIV) and the scale of the Acquired Immune Deficiency Syndrome (AIDS) epidemic in Africa, specifically sub-Saharan Africa, is still enormous. The predominantly sexual transmission of HIV in Africa implies that the disease primarily affects adults in their reproductive and economic prime. Death or illness of these adults has a considerable social, demographic and economic impact, felt at both a macro and micro-level.

The focus of my thesis is on the effects of illness or death caused by HIV and AIDS on households and individual household members, but also the burden it has on related individuals and in some cases members of the wider community. The complex nature of the infection and its repercussions challenge the range of responses households typically draw on in order to survive crises and shocks (2002: 1086; Heuveline, 2004; Hosegood *et al.*, 2007b). The short and long-term impacts of this disease are felt by households both directly and indirectly (Barnett *et al.*, 1992). In this study, I explore some of the gaps identified in the literature concerning the social and economic implications of HIV and AIDS and its treatment with anti-retroviral therapy (ART) on rural South African households. Three key contextual factors shape the burden this disease has on rural South African households.

The first of these is the specific context in which the HIV and AIDS epidemic occurs in this country. In South Africa, the disease is characterised by its predominant heterosexual mode of transmission. It is a generalised epidemic, which has reached an alarmingly high prevalence in the general population and has a correspondingly high adult mortality. Despite more than 20

years of preventive interventions, there is still a persistently high incidence of new HIV infections particularly in the young (Department of Health, 2010).

Secondly, South African households and specifically rural black households have a distinctive social formation. They are characterised by the fluidity of their composition, and the relationships between household members, including both resident and non-resident members, are governed by obligations, reciprocal norms and distinctive cultural values. Household formation, composition and dissolution in rural South Africa have been influenced historically by socio-economic changes and political policy that in turn have influenced migration of household members and household development.

Thirdly, like household composition and formation, the livelihoods of South African households have been affected by similar historical factors and are, therefore, distinct in many ways from the livelihoods of most households in the other middle to low-income countries. Unlike the livelihoods of households in much of the rest of Africa, the livelihoods of rural South African households are dominated by social grants and income from formal and informal employment and remittances rather than agricultural activities.

1.2 Background and rationale for the study

South Africa has one of the most severe generalised HIV and AIDS epidemics in the world. The prevalence of HIV among pregnant women attending public antenatal clinics in 2008 was 29%¹, while in the general population the estimated prevalence was 19% (Department of Health, 2009). In the same year, it was estimated that about five million people (adults and children) were living with HIV in South Africa. Projections made with the Actuarial Society of Southern Africa (ASSA) model estimate that 36% of these people were already at World Health Organisation (WHO) stage three² of the illness, and 14% had reached stage four AIDS (Dorrington *et al.*, 2006). It was projected that HIV and AIDS accounted for 71% of deaths among adults 15 to 49 years of age in 2006.

This study was conducted in the Umkhanyakude district, a district in northern KwaZulu-Natal. According to national surveys, KwaZulu-Natal is the province with the highest prevalence of

¹ Figures are reported to closest percentage point.

² The various stages of HIV infection and AIDS disease have been classified by the WHO (Malamba *et al.*, 1999). Patients with stage 1 have asymptomatic HIV infection with normal ambulant activities. Stage 2 is symptomatic characterised by moderate weight loss and opportunistic infections with no effect on activity. Stage 3 is characterised by more serious weight loss, more extensive disease and infection and the sufferer has spent up to 50% of each day in the preceding month bedridden. Stage 4 is the most severe, wasting is severe and the person suffers extensive severe debilitating illness or disease and is bedridden for more the half of each day (Malamba *et al.*, 1999).

HIV among adults, 16% in 2008 (Shisana *et al.*, 2009). KwaZulu-Natal also had by far the highest HIV prevalence among women attending antenatal clinics in the country, estimated at 39% in 2008 (Department of Health, 2009). Provincial prevalence is highest in women aged 25 to 29 years (Department of Health., 2006). Estimates using the ASSA model suggest that in 2006, approximately 1.5 million people were living with HIV and AIDS in KwaZulu-Natal, about 12% of whom were estimated to have full-blown AIDS (stage 4) and thus eligible for ART (Dorrington *et al.*, 2006). In the last five years, there has been widespread free access to ART through the public health care system. Only 4% of people living with HIV and AIDS in South Africa were estimated to be receiving ART in 2006 (Dorrington *et al.*, 2006). ART has been shown to improve the physical and emotional quality of life of HIV-infected study participants in a study in the Free State province of South Africa (Wouters *et al.*, 2008).

By the time the fieldwork for this study was being conducted, ART was freely available through the public health services for those with a low CD4 count (<200 cells/mm³) or who had reached stage four AIDS (Department of Health., 2006; Lawn *et al.*, 2005a). A low CD4 count increases the risk of opportunistic infection, especially due to tuberculosis (TB), and progression to stage three or four disease (Lawn *et al.*, 2005a). In addition to the risk of worsening illness if ART is not started early, any changes to the therapeutic regimen or poor adherence to treatment can have negative health implications for people living with HIV (PLHIV) (Coetzee *et al.*, 2004b). In April 2010 the South African Department of Health Treatment Guidelines were changed, based on recommendations by a South African National AIDS Council Technical Task Team (Department of Health, 2010). The minimum CD4 count for commencement on ART were increased to 350 cells/mm³ for pregnant women and for those co-infected with HIV and TB. Children under the age of one year now automatically qualify for treatment but the guidelines for all other people still require the CD4 count to be less than 200 cells/mm³.

In South Africa, very high levels of circular migration³ from rural black African households to places of work, often urban centres, and back results in a considerable number of non-resident household members. Non-resident household members are defined by the authors as people who live apart from the household because of work, education or for other reasons (Hosegood *et al.*, 2006).

Demographic surveillance data in two rural areas of South Africa (Umkhanyakude in KwaZulu-Natal and Agincourt in Limpopo) have shown that many non-resident household members

³ Circular migration is a form of migration characterised by the migration between places of work, often urban or industrial centres, and the rural household. This migration is often part of a larger household strategy that is seeking to diversify income streams and maximise employment of adult household members who migrate for already secured work or in search of work.

living in urban areas return to live in the rural areas when they become ill. In both settings, the returning migrants were found to be more likely to die as a result of greater risk of infection in urban areas among short-term migrants than resident household members (Clark *et al.*, 2007; Welaga *et al.*, 2009). Booysen (2006) also observed returning migrants following a pattern of circular migration to their rural homes after they were diagnosed with HIV in a study conducted in the Free State.

Although, access to ART is free in South Africa, public-funded facilities have to follow strict treatment guidelines as to when PLHIV can commence ART. A WHO estimate based on 2005 data suggests that half of all provision at the time was through the private sector (Fields *et al.*). Although the commencement criteria have been relaxed recently, they still require the patient to have a relatively low CD4 count. The consequence of a conservative treatment commencement policy coupled with late presentation for medical care is that many PLHIV have advanced disease by the time they commence therapy (April *et al.*, 2009; Coetzee *et al.*, 2004b; Lawn *et al.*, 2006). Having advanced disease leads to many of those who were employed losing their jobs due to the disabling nature of the illness (Barnett *et al.*, 2001; Russell, 2004b). Hence, despite improved access to ART and better health and quality-of-life outcomes of those on treatment, there remain a large number of sick adults. Addressing the 2010 International AIDS Conference in Vienna, the South African Minister of Health stated that of the 5.5 million South Africans estimated to be living with HIV only 70 605 (1,3%) were receiving ART (Motsoaledi, 2010). Untreated PLHIV are likely at some point before and even after starting treatment to be disabled by the disease. As a result, they are likely to be unemployed or unable to earn income to sustain themselves, even if only in the short-term (Barnett *et al.*, 2001; Clark, 2006; Coetzee *et al.*, 2004b; Russell, 2004b; Saith, 2001). They may also require nursing care and other forms of economic, material and emotional support. The presence of a sick household member therefore exerts a number of demographic and socio-economic burdens on South African households (Booyesen, 2004a; Booyesen *et al.*, 2003; Booyesen *et al.*, 2002).

Evidence from research in the study area has shown that while AIDS illness and death is very important it is not the only cause of illness or death in this community. This study is not calling for HIV exceptionalism but does argue that the widespread prevalence of HIV along with the implications of increased AIDS illness and death within this area specifically and in rural South Africa more generally justifies the in-depth study impacts of AIDS.

Infected household members present at different stages of HIV and AIDS to health facilities for care. The aim of this research was to include individuals at all stages of the disease including asymptomatic PLHIV, those PLHIV who were untreated and sick, those who were treated and

may be either feeling better or still be unwell. The research also addressed the implications for the household of those who had died or would die of AIDS. The diversity of PLHIV encountered, even within a household at various stages of infection and disease provided an opportunity to study how the households responded to these different situations. The study also presented an opportunity to investigate the ways in households reported that recent improvements in access to ART have changed how HIV and AIDS affect households.

In order to assess the different ways in which HIV and AIDS influence the household a livelihood conceptual framework was adopted. The livelihoods framework has been utilised elsewhere in similar research and was considered suitable to frame both the data collection and analysis phases of the research. This framework also facilitates an understanding and exploration of the response of the household to the variable effects of HIV and AIDS on the household.

Unless otherwise stated, any further reference to illness or disease within this thesis refers to opportunistic infections or disease caused because of an HIV or AIDS-related reduced resistance. Similarly, unless otherwise stated cause of death can be assumed by the reader to be a result of illness or disease caused by HIV-infection and progression to AIDS.

1.3 Aim and objectives

The aim of this study is to investigate the social and economic effects of HIV and AIDS on rural South African households in 2008, using a livelihood conceptual framework.

1.3.1 Objectives:

The objectives of this study are:

- To assess how various stages of HIV and AIDS, including ART, affect the livelihoods of their rural households;
- To describe using theories of social capital, family obligation and reciprocity how inter-personal relationships within households are changed by illness and death;
- To determine the way in which relationships that households have with other households or individuals influence the impact of illness and death on the household; and

- To explore how social grants, and especially disability grants, affect household experiences of illness and death caused by AIDS.

1.4 Outline of the thesis

This thesis consists of nine chapters. In Chapter 1, I have presented the background to the research project and the rationale for conducting the research.

The livelihoods framework and how it is used as the conceptual framework underpinning data collection and analyses, is presented in Chapter 2. In this chapter, I present the argument for adopting an extension of the livelihoods framework to conceptualise a framework of social relationships. These social relationships enable rural households in the South African context to make claims of assistance in times of crisis.

The international literature that covers the consequences of illness and death relating to HIV and AIDS, on the household livelihood is reviewed in Chapter 3.

Chapter 4 provides some context to the distinctive vulnerability of the household in South Africa. The theory, debate and rationale for using the household as the primary unit of study are presented along with a definition of the household and its relevance in the South African context. In addition, I discuss the background to social relationships and support within the rural black South African household through a discussion about kinship and family networks. In this chapter, I also discuss other sources of support for affected households outside of the family. The chapter contains a description and discussion of the social security system in South Africa. Finally, this chapter provides some background to the distinctiveness of the livelihood of the household in South Africa in the context of a high HIV and AIDS burden and particularly within the study setting.

The methodology used in the collection and analysis of the data for the research is presented in Chapter 5. The study involved the collection and analysis of in-depth qualitative data organised into case studies. In the chapter, I also discuss the strengths and limitations of the study methodology.

In the first results chapter, Chapter 6, I review the literature about the impact of illness and death on households in South Africa. The chapter contains a description of three case studies to illustrate the consequences of the various stages of illness and death on the livelihood of the households enrolled in this study in rural South Africa.

Chapter 7 contains a description of the framework of social relationships used to facilitate an in-depth analysis and interpretation of the benefits, motivations and complexities inherent in the social relationships and networks that individuals have in these households. Literature on the influence that social networks and social capital contribute to household wellbeing, inter-member assistance and care for the sick is reviewed. I then use the case studies to explore how social capital is used by the household as a whole, as well as individual household members, to access resources in order to alleviate the burden of illness and death.

The contribution social grants play in the household-level impact of HIV and AIDS in the rural South African context is reviewed in Chapter 8. I then present the evidence for the substantial contribution that social grants make on the livelihoods of affected households in rural South Africa. The synergistic relationship between receiving a disability grant and adherence to ART is also elucidated in this chapter.

In the final chapter, I summarise the main conclusions of my thesis and recommend a number of possible interventions and policy changes.

Chapter 2: Livelihood and social capital conceptual frameworks



2.1 Introduction

The sustainable livelihoods framework, adapted from the work of Chambers (1995) and Chambers and Conway (1991), conceptually frames the data collection and analysis for this study. Data were collected on all aspects of the livelihoods of the study households, in order to build up a holistic picture about the effects of illness and death caused by HIV and AIDS. In this chapter, I introduce and discuss the livelihoods framework adopted as the conceptual framework for this research. The livelihoods framework for households, its components, theoretical background and the rationale for using it to frame this research are presented. The concept of social capital and other closely related issues including reciprocity, family obligation and social exclusion are reviewed. I then combine some of these concepts to develop a conceptual framework of social relationships.

2.2 Livelihoods framework

The theoretical framework for the data collection for this study was a livelihoods framework, primarily adapted from the work of Robert Chambers and colleagues at the Institute of Development Studies (IDS) at the University of Sussex. Chambers and Conway (1991) proposed the framework for the analysis of the livelihoods of households as an alternative to

income-based descriptions and analyses of household poverty. Proponents of alternative measures of household vulnerability and risk critiqued these income-based methods of poverty analysis (Chambers, 1995). The livelihoods framework developed out of an understanding that poor households seldom rely on only one source of income for survival. Rather, households create and make use of a diverse livelihood repertoire to ensure that they make a living and therefore survive (Chambers *et al.*, 1991; Ellis, 1998; Moser, 1998).

2.2.1 Alternatives to Chambers' sustainable livelihoods framework

Alternatives to the livelihoods framework have also been proposed. Adams *et al.* (1998) propose the concept of coping as a framework for the study of food security and famine. These authors argue that this framework is necessary to understand how households mobilize and allocate resources in response to crises in order to develop programmes and policies to address these household crises adequately. The coping framework determines the process by which the household is enabled to respond to a crisis. In this framework, a factor triggers the crisis in the household. An example of a crisis used by the author is a famine, an immediate reality that exerts pressure on household food security. The crisis is affected by both endogenous factors (those internal to the household such as its demographic composition) and exogenous factors (those external to the household factors such as climate and ecology). These factors, in conjunction with the crisis, limit the options available to the household, which decisively affect their ability to cope. Based on these limited options and the overall objectives of the household, the household members make decisions and formulate coping strategies to survive the crisis. One of the difficulties with the coping framework Adams *et al.* (1998) propose is that much of the focus of the framework is on the development of a single livelihood outcome based on a crisis or shock. Another difficulty with this framework is the actual concept of coping that is central to the framework and is used extensively both in the livelihood and impact of AIDS literature.

Coping in this context, is defined as the way in which a household is able to rally together and allocate its resources in order for it to minimise the duration and intensity of stresses and shocks (Adams *et al.*, 1998; Barnett *et al.*, 1992). The concept and the appropriateness of using the coping framework are debated in the literature. The argument against using it stems from its essentially positive bias that assumes that the detrimental effect of the crisis or shock on the household can either be reversed or overcome. In some instances, the livelihoods of households actually collapse and the idea of 'coping' is misleading and even inappropriate (Leovinson *et al.*, 2003; Rugalema, 2000). It is argued by Leovinson and Gillespie (2003) that the positive associations of using the term directs attention away from the large costs that surviving a crisis

or shock impose on the household. Critics also argue that in many situations coping strategies are not actively adopted or planned for, as the phrase would suggest. People are caught unawares or are so focussed on surviving in the moment that they are unable to plan ahead. Alternatively, in the context of HIV, it is possible that people are becoming increasingly able to strategise as they find out and disclose their HIV status, are treated and, therefore, are forewarned about impending stresses and shocks. They would consequently be able to actively plan for the effects of impending illness and in some cases death. The literature suggests that being able to plan adequately may not be possible because of the relatively late presentation for testing and therefore treatment. The extreme vulnerability that exists in rural households often affected by complex crises may also affect households' ability to plan. In this chapter and further discussion, I will focus on how the livelihoods framework can be adapted to enhance the struggle for survival. The concept of 'coping' will only be used when contrasting and comparing the results of this study with previously published studies. Instead of referring to 'coping', I will refer to how households and household members respond to crises.

The Sustainable Rural Livelihoods (SRL) framework adopted by the United Kingdom Department for International Development (DfID) is a variation on the livelihoods framework of Chambers and Conway. These two frameworks share assumptions that are particularly relevant to both the process of data collection and analysis in this research dealing with the effect of HIV and AIDS. Both frameworks are people-centred and focus on the realities of those being studied (Carney, 2002; Murray, 2001; Scoones, 1998). Another important aspect of both these theoretical livelihoods frameworks relates to sustainability. In this context, sustainability is defined as the ability of the household to use its resources to maintain itself and survive despite the economic and social consequences of a range of shocks or stresses (Chambers, 1995; Chambers *et al.*, 1991). Sustainability is not always an easy concept to measure especially where the study period is relatively short. It is easier to measure in an agricultural context where the sustainability of natural resources can be observed or measured. The frameworks also both aim to provide a holistic and non-sectoral picture of livelihoods, while simultaneously being underpinned by the understanding that the livelihood is a dynamic process. This is important for the households in this study that experienced different stresses on their livelihoods at different times and stages of the illness trajectory. The Sustainable Rural Livelihoods (SRL) framework emphasises a strong macro-level element. The micro-level experience of the household and its members is the focus of my research (Carney, 2002; Murray, 2001). Although contextual factors are investigated in the review and contextual background, this thesis minimises the developmental focus of the SRL, which is more concerned with wider market forces and community-wide consequences of crises or shocks. Similarly, while policy and institutions may

determine the vulnerability of rural individuals and their households, and are closely related to aspects of their livelihood, these macro-level factors are not comprehensively addressed by this research. Although the SRL has aspects and assumptions that are common to Chambers' original sustainable livelihoods framework and relevant to this research, I have chosen to adopt Chambers and Conway's (1991) original livelihoods framework, which I will refer to in this thesis as the 'livelihoods framework'.

The components of a livelihood are conceptualised differently in the literature. Scoones (1998) refers to the components of a livelihood as natural, economic, human and social capital. Others, such as Bebbington (1999) and Carney (2002), refer to the components as 'assets' or 'capital assets', sub-dividing them into produced, human, natural, social and cultural assets. Although different terms are used in the literature to describe the elements of a livelihood, there is little substantive difference in their meaning.

2.2.2 Chambers' sustainable livelihoods framework

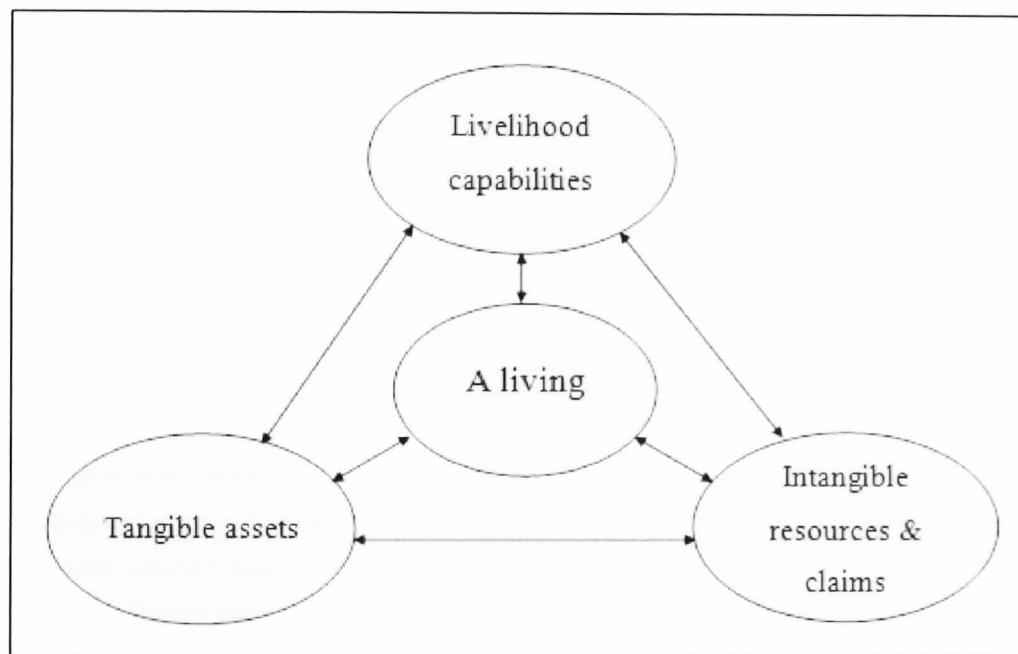
The original sustainable livelihoods framework proposed by Chambers is a useful research tool to analyse the effects of a crises such as illness and death on a household (Chambers *et al.*, 1991; Ellis *et al.*, 2004; Masanjala, 2007). This livelihoods framework is composed of three primary components that all combine to form an individual household's livelihood. These are the capability of household members to continue to function, how they use available resources and their ability to access a range of tangible assets and intangible resources and claims in the process of continued functioning (Chambers, 1995). The livelihoods framework is holistic in its approach and includes social, economic and demographic factors that influence the way in which a household generates resources. Unlike, the Sustainable Rural Livelihoods framework that considers five capital assets, this livelihoods framework does not differentiate between physical and natural capital assets. The need for these two different forms of capital is useful in the context in which rural agriculture and the use of natural resources dominate the livelihood of households, but that is not the case in rural South Africa.

The livelihoods framework utilised in this research includes the economic assets or resources available to a household and its demographic make-up, which are affected by the social, human and political resources available to and used by the household in order to survive (Chambers, 1995; Chambers *et al.*, 1991; Scoones, 1998). The shocks and stresses in this context are anticipated to have both short and long-term consequences. Therefore, the aim of my research is to assess, not merely one single outcome, success or failure of the livelihood, but the repercussions and responses over time to changes to the household, and specifically changes

caused by illness and death, on the livelihood of households. The original framework, as defined by Chambers and Conway (1991), remains the most applicable to use in this study. Rather than including and focusing on only one outcome of a single stress or shock, it provides a framework for the holistic analysis of repeated and ongoing changes to the livelihood in affected households.

Figure 1 depicts the way in which Chambers (1995) and Chambers and Conway (1991) conceptualised the components and flows of a livelihoods framework in a household. The three components of the framework are the livelihood capabilities, tangible assets and intangible resources and claims.

Figure 1: Components of and livelihood flow in household



Source: Adapted from Chambers (1995) and Chambers and Conway (1991)

The first component of the framework proposed by Chambers is the livelihood capability of the respective household members. Capabilities are defined by Sen (1993) as the ability of individuals to achieve a given functioning ('doing' or 'being'). The livelihood capabilities therefore refer to the ability of all members of the household to choose and perform particular activities as part of providing for their livelihood, along with their ability to "perceive, predict, adapt to and exploit changes in the physical, social and economic environment" (Chambers *et al.*, 1991: 16). One aspect of the capability of household members is their potential or ability to generate income.

The demographic structure and composition of households, including the age of household members and the dependency ratio, inform the capabilities of the household and its resulting ability to sustain a livelihood in the face of a crisis or stress. The demographic structure of households is particularly relevant in households where illness and death have the potential to affect the household composition and thus the potential of its members to function. The demographic consequences of the HIV and AIDS epidemics are explored in-depth in the review of the international literature in Chapter 3. The demographic impact of HIV and AIDS in South Africa is reviewed in the introduction to Chapter 6.

The second component of the livelihoods framework, access to intangible resources and claims, relates to the opportunities the household has to make claims on other people or the state for various types of support, assistance, and the use of resources, stores or services. This component includes the access household members have to opportunities for employment or earning an income and also the ability of a household to harness tangible assets, make use of natural resources and have access to opportunities (Chambers, 1995; Chambers *et al.*, 1991). This component also includes the range of claims for support a household can make, such as support from the state, including cash transfers and referred to in this thesis as social protection or support from within social networks. These form an important part of households' livelihoods in South Africa, where there is relatively good coverage of and access to a range of social services including grants. Finally, intangible claims by households come from their membership of social networks, and these relationships provide households and individuals with social capital.⁴

The claims made on social networks, an important part of which is social capital, are particularly important because they comprise both the relationships that a household and its individual members have with other people as well as their membership in social networks. The definition of social capital that I use in this thesis is that proposed by Bourdieu (1985). It is the potential that people have to benefit from trust and participation in social structures and networks. Social capital plays a role in providing access to economic and cultural assets and resources from individuals who are members of the household, kin or the wider community (Chambers, 1995; Chambers *et al.*, 1991). The concept of social capital, the controversy that surrounds it and its application in the context of households in rural South Africa are discussed further in Section 2.3 of this chapter.

⁴ Social networks are the primary social structure at work within social capital theory. While the extent of the group may vary depending on the definition and application of the theory, it is generally accepted that social networks are individuals tied or connected to one another by some sort of interdependency such as friendship, kinship, common interest or social exchange. This definition of social networks is widely accepted and used in the literature on social capital. There is a separate body of literature about social network theory and social network analysis but it will not be discussed further in this thesis.

The third component of the livelihoods framework relates to tangible assets. These include physical stores, household and individual possessions, and environmental or productive resources (Chambers, 1995; Chambers *et al.*, 1991). Agricultural products or assets that do not form part of the living or livelihood outcome, referred to in other frameworks as produced capital, also fall into this category (Bebbington, 1999; Scoones, 1998). Access to tangible assets, like intangible resources and claims, potentially assists households to make a living and therefore sustains the livelihood in the face of the crisis of illness, death or other shocks.

2.2.2.1 Diversity

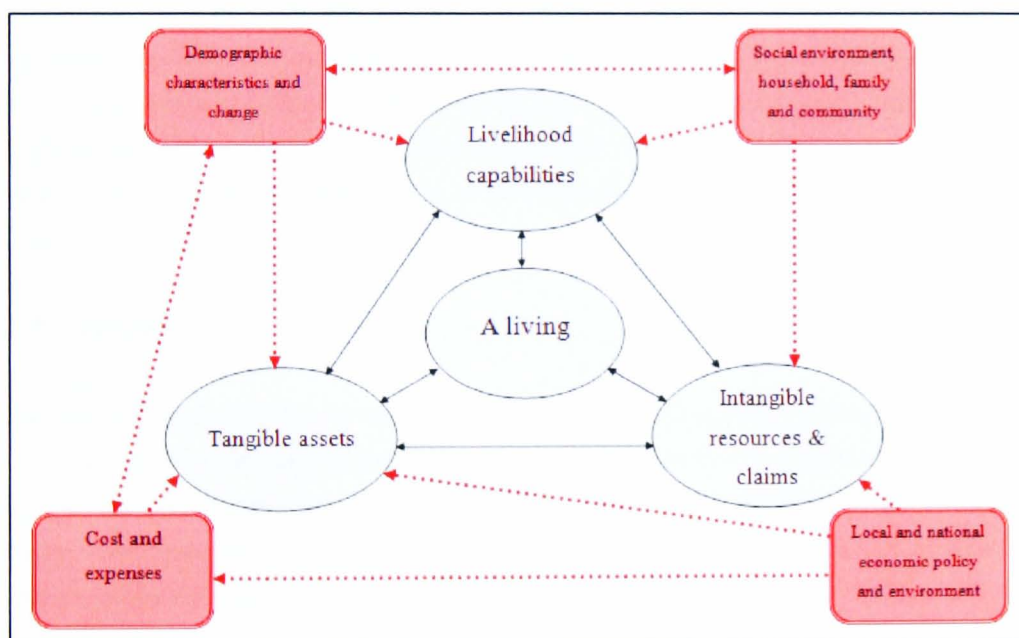
In addition to the basic livelihoods framework, a number of other concepts have specific relevance to this study. In a review of the relevant livelihoods literature, Ellis (1998) argued for the importance of considering the diversity of livelihood activities available to households. Households utilise a diverse and complex combination of capabilities, claims and assets to respond to the consequences of stresses and shocks caused by HIV and AIDS on their livelihood (Masanjala, 2007). Ellis (1998), defines the process of diversification as the way in which households “construct a diverse portfolio of activities and social support capabilities in their struggle to survive and improve their standards of living” (Ellis, 1998:4). He argued that diversification is undertaken by households in order to reduce or spread the risk involved in maintaining their livelihood. Diversification of the livelihood in a household can precede the stress, in order to manage the risk, or come after the stress or shock, to respond to it.

2.2.2.2 Vulnerability and resilience

Two other concepts linked to those of diversification and managing risk are those of vulnerability and resilience. Vulnerability is defined within livelihood theory as a lack of baseline resilience – ‘ability to recover’ - and defencelessness within the household, contributing to the risk of a crisis or threat having a negative impact (Barnett *et al.*, 2001; Leovinsohn *et al.*, 2003; Masanjala, 2007). Resilience is the converse of vulnerability. These concepts need to be considered when assessing the influence of a shock or stress on households’ livelihoods. Moser (1998) developed a similar argument to Ellis in her analysis of the asset vulnerability of urban households. She suggests that the portfolio of assets (in her framework defined as both intangible and tangible assets) to which the household has access can be arranged to help manage risk and, therefore, reduce household vulnerability. Hence, I would argue for an extension of the livelihoods framework adopted here to consider both the vulnerability of the geographical area and the vulnerability of the household.

The extension of the framework shows how certain factors endogenous and exogenous to the household and both related and not to illness combine to affect the livelihood components of the household. Social environment including household, family and community relationships and networks play an important role in both the accessibility the household has to social capital or claims on the social (see 2.3.1). The social environment and social organisation at this level also affect the demographic characteristics of the household both directly and indirectly through demographic factors influencing the household's livelihood capabilities. The demographic characteristics and changes to the household and possibly to the wider community are in turn affected by the costs and expenses to which the household is subject. In the case of households affected by illness and death, these may be increased because of related costs. In turn, these economic impacts affect the tangible assets that the household has. The economic implications are also affected by the local and national economic policy and environment.

Figure 2: Livelihoods framework and vulnerability context



Source: Authors additions in red, grey diagram adapted from Chambers (1995) and Chambers and Conway (1991)

Masanjala (2007) also raised the importance of this context of vulnerability in a review of the relevance of a livelihoods framework to the study of the relationship between AIDS and poverty. The examples of vulnerability in the African literature that describe the impact of AIDS by Masanjala (2007) and others focus largely on the disease occurring in an agricultural context. Vulnerable households are not necessarily poor but fall into this category because they

lack the tangible and intangible claims and access to resources or livelihood capabilities required to overcome the shocks they experience (Moser, 1998; Nkurunziza *et al.*, 2005). Chambers and Conway (1991) refer in their discussion of the livelihoods framework to the context of vulnerability in which the livelihood of the household operates. In this study, the high HIV prevalence, increased mortality and demographic consequences that these have for households influence their vulnerability. The degree of severity of the outcomes that illness and death causes depends on whether the household has the assets and capabilities to sustain their livelihood when it experiences the stressor (Adams *et al.*, 1998; Barnett *et al.*, 2001; Delor *et al.*, 2000).

In South Africa, the high burden of HIV and AIDS implies that households often have to survive multiple cases of illness or death within the household itself, or within the surrounding community. Exposure to repeated events of disease and death indirectly contributes to the increasing vulnerability of the household (Hosegood *et al.*, 2007b). South African rural households also have to confront other stresses such as high levels of unemployment, limited agricultural opportunities and high levels of household poverty. In many instances, households are already extremely vulnerable to the consequences of illness and death. In this study, I explore factors that contribute to household vulnerability to the effects of illness and death, in order to understand issues linked to inherent vulnerability such as social exclusion (see Section 7.9.5).

2.2.3 Summary

The importance of the context of vulnerability is sometimes underplayed and I will argue that it is essential to the understanding the livelihood of households in this area and provides important insights into these livelihoods are affected by HIV and AIDS. The livelihoods framework used in this study incorporates the key aspects of the vulnerability context (Figure 2). Demographic characteristics and changes have an important impact on livelihoods. In turn, the household encounters costs and expenses because of demographic characteristics or other reasons. In addition, the social environment has important implications for the social capital that the household can access. The local and national economic policy and environment are also very important considerations and determine the claims the household is able to make on the state but also shape the livelihood and the intangible opportunities available to the household.

The livelihoods framework was employed as a theoretical framework for the conceptualisation and planning of the study and in order to guide the collection of the data. The intangible component of the livelihoods framework including social capital, social relationships and social

welfare, emerged as a major theme in the collection of and preliminary analysis of the data. The comparative importance of this component for the rural households being studied led me to further develop and focus on this and tease out additional theoretical frameworks for the study and analysis of the intangible and social components of the livelihoods framework.

2.3 Social capital, reciprocity and family obligation: developing a conceptual framework for social support in the context of rural black South African households

Social capital is one of the primary intangible claims identified in the livelihoods framework. Given the potential for adverse repercussions of illness and death on the rural livelihood, there is a need to understand better the ability of individuals and households to make claims on the time, energy and resources of others. These 'claims' are described by Burger and Booysen (2006) as being central to the concept of social capital. The resources that households and individuals can rely on vary and are referred to in different ways in the literature. In this thesis I distinguish between three types of resource provisioning, namely financial assistance, material support and physical care. Financial assistance refers to the financial help that the household or individual receives predominantly in the form of cash transfers. Material support incorporates in-kind help either through the provision of goods, such as food or building materials, domestic help and services, or involving another's time, such as time spent in preparing food. The third type of support involves the provision of personal care, which is distinct from other services. It refers to care work, such as nursing a sick person or contributing physical care such as washing and feeding a child.

Social capital theory has particular relevance to the understanding of aspects of social relationships between individuals, within and between households and the way in which these relationships facilitate or detract from assistance being offered to affected individuals and households. The theory of social capital is underpinned by social norms including reciprocity and the familial obligations that facilitate better family functioning. These theories have all been combined to create a framework applicable for this thesis that can be utilised to investigate how households and their livelihoods function in the context of illness and death.

2.3.1 Social capital

Social capital has been extensively debated, and the concept modified so it can be used in different disciplines and applied to a range of research and policy questions. Broadly, social

capital is understood to provide an explanation of the benefits or beneficial outcomes people can negotiate from within the social groups to which they belong. However, unless clearly articulated with reference to each application, there is a tendency for social capital to become rather a diffuse concept (Portes, 1998). The use and application of social capital as a theoretical concept applied to economics, to explain all social aspects has been criticised by Fine (2002). He acknowledges that Bourdieu first conceptualised the term social capital, but argues that its current use has almost nothing to do with Bourdieu's original definition and understanding of the concept.

Different commentators including Putnam, Coleman and Bourdieu consider that social capital theory operates at different levels (Portes, 1998). Putnam proposes that it is a societal-level characteristic that reflects civil and political participation. Putnam and Fukuyama's interpretation of social capital have been criticised for their focus on large aggregate groups of people, communities, regions or even nations (Edwards *et al.*, 2003; Fine, 2002). The assumption in the definition Putnam provides, that social capital is homogeneously available at a community or societal-level of analysis, has been widely criticised (Edwards *et al.*, 2003; Fine, 2002). It has been argued that this interpretation of the concept is not applicable to the study of either families or in the South African context (du Toit *et al.*, 2007; Edwards *et al.*, 2003). I have therefore decided that Putnam's concept of social capital is not applicable to the household and individual level data collected in this study.

In contrast, Bourdieu and Coleman argue that social capital operates at an individual or household level (reciprocal or trust relationships). They therefore both put families at the centre of their conceptual constructs (Edwards *et al.*, 2003; Portes, 1998). Although the focus in this study is on the household, the relevance of family-focussed theories such as social capital is justified because the family is of great importance to the household, both within the household, where links are largely familial and external to the household where kin may play a role on the household's response to illness or death. Bourdieu (1985: 456) defines social capital, as the "potential people have to benefit from the trust developed through participation in social structures and networks." Although also based at the individual or household level, Coleman's (1988) definition of the concept is different to that of Bourdieu and describes it as "a variety of entities with two elements in common: they all consist of some aspect of social structures, and they facilitate certain actors - whether persons or corporate actors - within the structure." (Coleman, 1988: S98). Coleman has been criticised by Portes (1998) for including and confusing, within his definition, those factors and mechanisms through which social capital is

created and accessed, such as expectations of reciprocity, social norms and motivations, and the resources that influence access to social capital.

Bourdieu (1985) makes a distinction between the building blocks and the repercussions of social capital. Edwards *et al.* (2003), in their review argue that while the focus of Coleman's work is on the deterioration of social capital, Bourdieu focuses on the development and spread of social capital and the way in which it reinforces social inequalities. Coleman and Bourdieu also differ in their argument that the family is central to their theory of social capital. Coleman is concerned about the family as the centre of all social capital accumulation and the breakdown of the western traditional notion of a nuclear family as a deterioration of social capital. Bourdieu's interest while family-centred does stretch to other social networks and he has a more flexible idea of family and social networks. As conceptualised by Bourdieu, social capital is considered to work in relation to other forms of capital, this therefore fits well within the livelihoods framework that considers other livelihood components. Bourdieu's treatment of the concept and the social relationships and networks that are required, therefore, are more adaptable and flexible than Coleman's more fixed ideas (Edwards *et al.*, 2003). Although Bourdieu sees the family as constituting a key source of social capital, he also conceives of social capital as something which people invest in and, therefore, is further adaptable to other types of social relationships and changing family structures unlike the focus on the traditional family as proposed by Coleman (Edwards *et al.*, 2003).

Despite criticisms levelled at the concept, a recent literature by South African academics working on studies of social and economic development demonstrates the value of social capital theory for examining issues such as food security, livelihoods and the burden of HIV and AIDS (Burger *et al.*, 2006; Misselhorn, 2009; Vermaak, 2009).

In this thesis, I am interested in exploring the way in which households and individuals can make use of social capital in order to alleviate the consequences of HIV and AIDS. With this construct in mind I have chosen an adaptation of Bourdieu's definition of social capital, proposed by Burger and Booysen (2006), for use in the South African context. They differentiate between the claims people have on resources and support, and the building blocks of social capital including the norms of reciprocity, trust and social networks. Bourdieu defined social capital as the benefit people can claim from the trust engendered through participation in social structures and networks (Bourdieu, 1985). Social capital, as defined by Bourdieu (1985), includes a distinction between the various elements of social capital and therefore frames this study well. It allows for an analysis of the way in which households or individuals negotiate, construct and maintain social relationships and ties that lead to the creation of social capital. It

also facilitates an analysis of the way in which people form essential trust and bonds and, therefore, qualify for membership in social networks or groups. Membership in social groups or networks, in turn, means that individuals can rely upon other members to share their resources during times of need.

Another important but often overlooked aspect of social capital is the possibility of negative social capital. Portes (1998) argues that downward levelling norms can be associated with membership of social networks with similar social and economic characteristics. For example, demands of successful people by less successful members of their social network results in the levelling of people within the network. Portes (2000) also gives an example of the detrimental control that a social network may exert over its members manifesting as negative social capital.

Portes (1998) identifies social capital in modern society as the accumulation of obligations derived from others according to the norms of reciprocity. Alternatively, he suggests that social capital can be determined purely by obligations directed by internalised norms and family values with no expectation of some form of return. I would argue that, like Burger and Booyen (2006), that social capital is created and maintained by the norms of reciprocity, different types of which operate within different social networks. It also incorporates other important aspects of social interaction and trust that underpin specific relationships such as those dealing with family obligations. These different theoretical concepts are used to demonstrate the way in which affected individuals and households are able to negotiate social support from within different social networks.

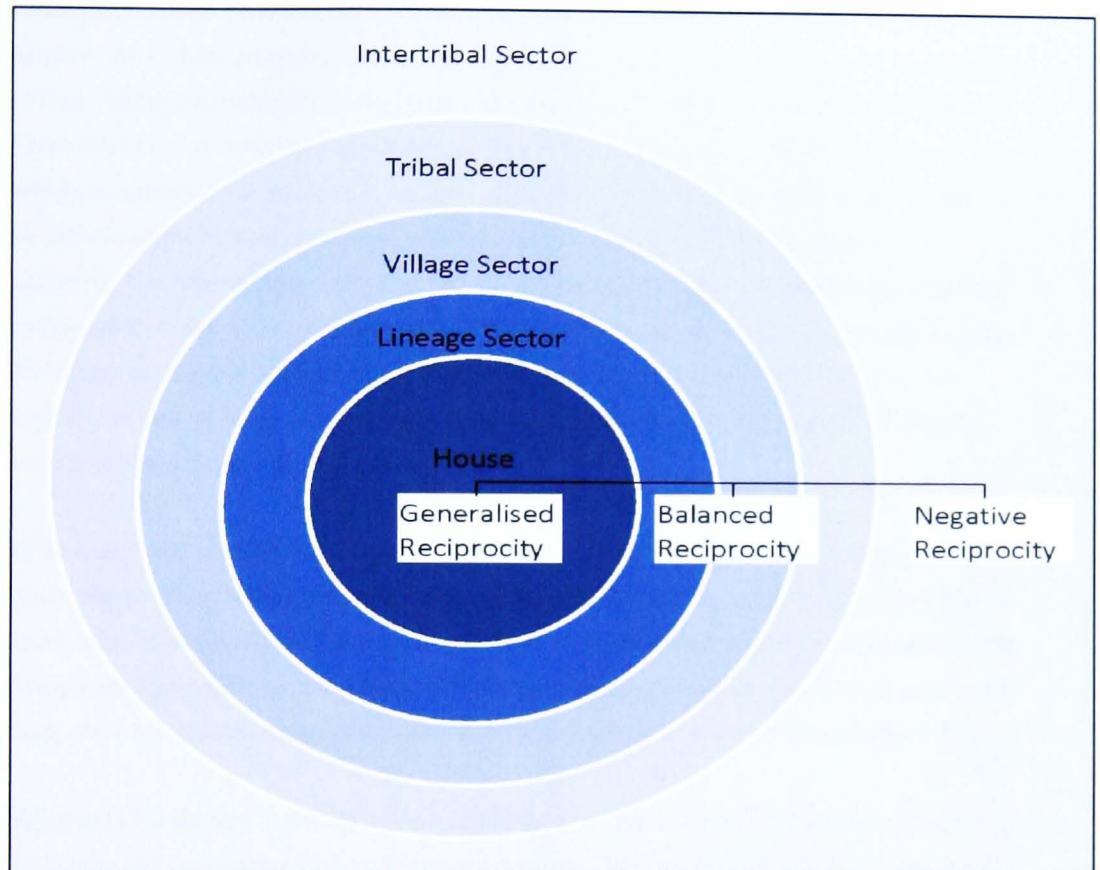
2.3.2 Reciprocity

Reciprocity is a concept explored by Sahlins (1972) based on earlier work by social anthropologists including Mauss, Malinowski, Radcliffe-Brown and Levi-Strauss. Mauss (1954) argued that there was no such thing as a 'free gift', and that every time something was given, it was with an expectation of some form of return. Reciprocity is defined by Sahlins (1972) as a mutual exchange of obligations between people within an economic system and he identified three types of reciprocity namely, generalised, balanced and negative reciprocity.

Generalised reciprocity is defined as the general giving of goods or services without the expectation of a direct, immediate return of equal value. It relates to the fact that something is done for those in need, with the knowledge that the favour, service, good or money provided will be reciprocated in some way at some time in the future by someone within the applicable social network, if possible and where necessary. This level of reciprocity requires a high level of

trust and Sahlins (1972) suggested that the relationships and social networks within which generalised reciprocity operate are generally personal and familiar.

Figure 3: Reproduction of reciprocity and kinship sectors diagram



Source: From Sahlins (Sahlins, 1972)

Balanced reciprocity is an exchange of goods, materials or services in direct (although not necessarily immediate) exchange for something of equal value (Barnard *et al.*, 1996). The social expectations associated with balanced exchanges are of a less binding nature than those which exist in the extended family or kin group and, therefore, as Sahlins (1972) suggests less personal. Negative reciprocity is getting something for nothing or at the expense of the other party and is often used to characterise unfair trade or credit relationships. These definitions of balanced and negative reciprocity as defined by Sahlins are the extreme of these relationships. In reality, all reciprocal relationships are harder to define clearly and are based more on a continuum.

Sahlins (1972) based his conclusions about the different types of reciprocity on work conducted in Fiji. In his analysis of the local economic systems, he developed a continuum that described the three key types of reciprocity associated with different sectors of Fijian society. These sectors were based on kinship and community organisational structures specific to the study community. Figure 3 illustrates the relationships originally produced by Sahlins in 1972. The diagram shows how generalised reciprocity operated in kinship-orientated spheres, a particular example being the house and lineage sector networks where there is social familiarity, based on either kinship or geographical proximity. There is some overlap with balanced reciprocity which, in Sahlins' (1972) diagram, operates within the village, tribal and inter-tribal sectors. Negative reciprocity operated at the inter-tribal level. The model and key assumptions underlying the different types of reciprocity do not necessarily represent all possible economic exchanges that operate in contemporary rural South Africa. Nevertheless, it is possible to adapt this theory to interpret some of the exchange, gift-giving and dynamics of social care and support relevant to the social relationships, interactions and networks that operate within the rural South African context.

In his analysis of economic exchanges in Fiji, Sahlins (1972), also identified a *richesse oblige*. This concept of sanctioned obligations by which the better-off share some or all of their assets and wealth, allows those from poorer households to secure resource benefits from neighbouring households without the need to reciprocate. This relationship is largely charitable in nature and takes place between members of the same community but of different socio-economic status.

Sahlins (1972) showed that the networks available to the Fijians in his study were contracted to the family and even to the nuclear family level when generalised stresses and crises occurred within communities. He also argued that, as positive reciprocal relations were contracted, negative reciprocity could increase. Negative reciprocity is particularly relevant in the context of HIV and AIDS, where the socio-economic effects of illness are both widespread and devastating to both the households and individuals involved.

2.3.3 Family obligation

Kinship and membership in networks, based on kinship or kin-like relationships, has certain moral obligations and duties attached to it. As Fortes states "...kinship is binding; it creates inescapable moral claims and obligations." (Fortes, 1969: 242). This moral obligation to help or support kin has been referred to by Finch (1987) and Finch and Mason (1991, 2005) as a family obligation. In their analyses of family obligation in Britain, they argue that while family obligations are social norms they are also commitments that are constantly renegotiated with

other members of the family group, depending on the circumstances and interpretations of the people involved. Given the South African rural context of fluid and extended family households, family obligation if normative within the family or kin network, has the potential to operate within the household as well as within the wider family network.

The family obligation is complex as it may occur because of a socially sanctioned obligation to family, a desire to help family based on the quality of a relationship, sometimes referred to in the literature as affective ties, bonds or love, or a result of self-interest and, therefore, simplified to a generalised reciprocal exchange. The assumption is that family obligatedness operates in close family social networks and within the household, between members. However, even in kinship relationships, reciprocal arrangements may be equally as relevant.

2.3.4 Social exclusion

Social exclusion is defined as “the process through which individuals or groups are wholly or in part excluded from full participation in the society in which they live” (de Haan, 1998: 10). In another sense, social exclusion is the individual or households inability to make claims on or access opportunities. Therefore, these people could be excluded from wider society and unable to take or access employment opportunities, be excluded from state benefit systems or excluded from smaller social networks they are reliant on to build social capital such as the family (Adato *et al.*, 2006). De Haan (1998) argued that along with concepts such as vulnerability and social capital, already included in the frameworks presented in this chapter, social exclusion provides a multi-dimensional characteristic to deprivation or poverty. In keeping with Bourdieu’s focus on the inherent inequalities in society and the potential that social capital has to reinforce these inequalities, the consideration of a concept such as social exclusion as part of the framework of social relationships is important (Edwards *et al.*, 2003). Social exclusion must, de Haan (1998) argued, only be interpreted in context and cannot be measured without an analysis of the broader social reality. Therefore, exclusion within this study will be measured in relation to the individual or household reality.

2.3.5 Conceptual framework: building blocks of social capital

The concepts of social capital, the continuum of reciprocity and family obligation can all be incorporated into a conceptual framework for use in analysing the factors affecting the benefits and support affected individuals and households are able to rely on because of membership in social relationships. These social relationships may be within or between households, and

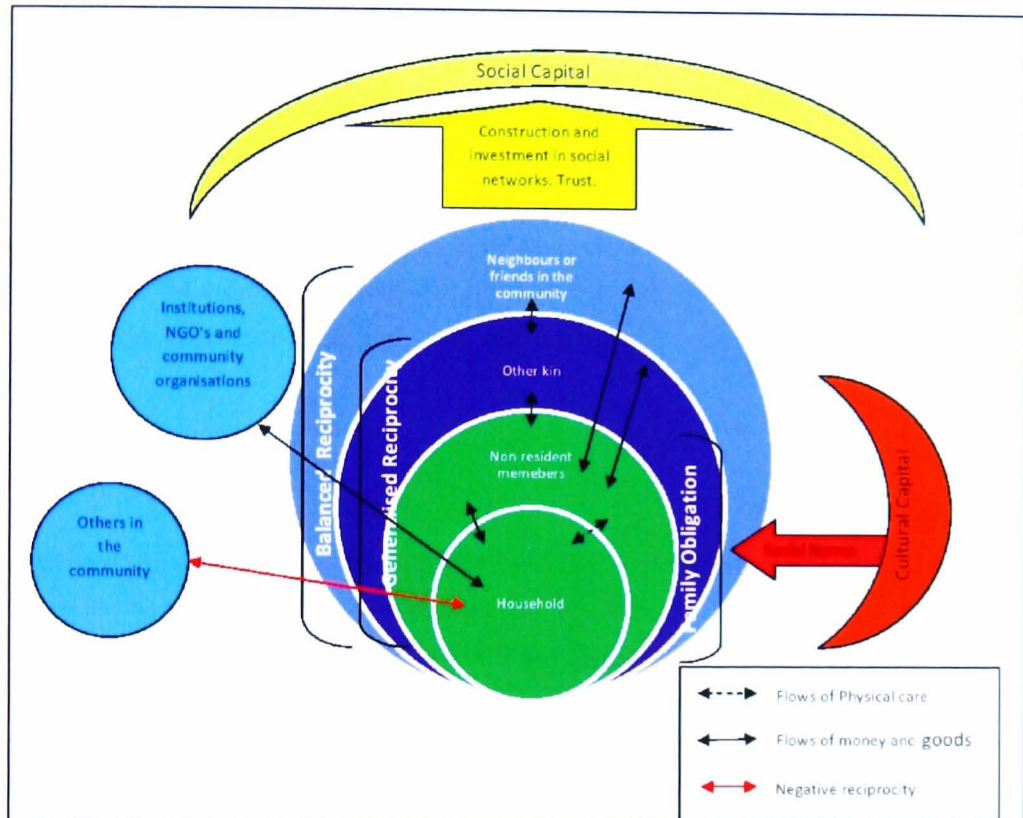
between individuals networked through kinship or other types of social networks such as tribal groups or religious congregations.

Burger and Booysen (2006) and Bourdieu (1985), suggested that the norms of reciprocity and family obligations are the building blocks of social capital. The conceptual framework in Figure 3 illustrates how the social networks that individual household members and households participate in, with either other members of the household, kin who live independently outside of the household, or the households of friends and neighbours within the wider community, are governed by norms of reciprocity and family obligation. Community is defined for the purpose of this conceptual model and this thesis as a group of people who are linked through geographical proximity to one another, either they are neighbours and share a location, are tied together through social bonds of friendship or common interest. Although the social relationships on which balanced reciprocity are based are less personal than those involved in generalised reciprocity or family obligation, there is still a level of proximity and membership in common networks or groups that foster some degree of trust. The trust required for both generalised and balanced reciprocity demonstrates that participation in reciprocal relationships is a means by which individuals and households can build social capital. Generalised and balanced reciprocity are, therefore, linked to, and reliant upon, a relatively good relationship between people, commonly operating, within the same social network. In this way, social relationships function as a mechanism by which social capital is negotiated. The quality of relationships, social and geographical proximity within different social networks implies that individuals or households are able to secure a range of resources or assistance facilitated through different reciprocal relationships. These diverse aspects of social relationships are encompassed in the theory of social capital. For example, membership in a community network and good relationships with other members of the group may allow members of affected households to negotiate balanced reciprocal arrangements, such as waged seasonal labour and other examples of relatively equal exchange relationships. In practice, this investment in social networks and consequent building of trust and fostering of norms around sharing and assistance within these networks leads to the construction of social capital. Therefore, social capital is the accumulation of benefits that result from the investment in norms of reciprocity.

Individuals who have built up strong social capital or have because of their membership in a network able to negotiate access to additional resources, assistance and care than those with weak or no social capital. The conceptual framework depicted in Figure 4 suggests that the level of social capital and ability to negotiate support, because of either balanced or generalised reciprocity or family obligation, differs according to the type of social relationship indicated

within the central circle by the different colours. I therefore, suggest that with all forms of positive reciprocity, the quality of this relationship is particularly important, because of the different levels of trust in these relationships.

Figure 4: Conceptual framework of social capital influencing the support households affected by HIV and AIDS receive in rural South Africa.



In this conceptual framework social capital is assessed at household level, this includes non-resident household members and is indicated in green, as the collection of individual benefits. While generalised reciprocity and family obligatedness tend to have communal benefits for the household they are often built on, developed by the individuals within the household, and vary depending on the individual and their interpersonal relationships.

In the theory of family obligation, sub-groups within a household may exist with even closer ties (Finch, 1987; Finch *et al.*, 1991, 2005). For example, family ties between partners, or between parents and children, strengthened by love, may suggest that the internalised or socially sanctioned obligations to help these close family members are even stronger than the obligations to assist other members of the household. The social capital that households or individuals are

able to access is also determined through norms of reciprocity that, depending on the type of reciprocity, are reliant on the ability to return the favour immediately or being in a suitable position to return a favour to someone in the network in the past or future. Relationships within, and membership of wider social networks such as the community or neighbourhood, may be more reliant on the quality of a relationship or the benefits other members of the group may be able to secure in the future, if they provide help. The reality though for affected households is that support is not guaranteed and is highly dependent on their ability to secure social capital.

The conceptual framework also suggests that the household or individual may be able to rely on a range of support from various sources. For example, the framework suggests that physical care is more easily secured from relationships in closely-knit families. The flow of money and other resources can be secured from a range of sources and are not dependent on close relationships or an obligation. Nevertheless, the amount and type of support the household or individual is able to secure may vary depending on the source and the motivation behind the provision of the support.

2.4 Summary

The primary conceptual framework adopted for this study is the livelihoods framework. It offers a basis for the holistic analysis and interpretation of the impact of illness and death on rural households in South Africa. It incorporates a range of components that may be affected by or mitigate the harmful effects on the household of a stress or crisis. The three principal components of the framework include access to intangible resources and claims, tangible assets, and livelihood capabilities. In conjunction with the livelihoods framework in this chapter the concept of vulnerability, especially the context of vulnerability both existing before and created by the burden of HIV and AIDS on the household, is considered. The vulnerability of the household and the resilience of the livelihood are crucial to the household being able to continue making a living and, therefore, the survival and sustainability of the livelihood.

The relative importance of social capital as the claims made from social relationships or networks and as part of the intangible claims and resources component of the livelihoods framework emerged during data collection. I therefore decided to further explore some of the issues and theories contributing to the support people are able to access because of social capital. A framework has therefore been conceptualised to understand the building blocks of social capital. The framework incorporates ideas of reciprocity and family obligation to help

explain what motivates people to provide different types of support. Another important concept addressed in the analysis of social relationships and social capital is that of social exclusion.

Chapter 3: Review of the impacts of illness and death on livelihoods



3.1 Introduction

The livelihoods framework was adopted as the primary conceptual framework for the collection and analysis of the data for this study. The three main components of the framework; livelihood capabilities, intangible resources, claims and tangible assets, are used as a theoretical basis for the review of the international literature about the impacts of HIV and AIDS on affected households and individuals. The literature review also provides some critiques of the framework and shows how it is relevant to the issues under study. The framework of social relationships is considered part of the intangible assets component of the livelihoods framework and the review will begin to address issues of social support and social relationships within households affected by HIV and AIDS.

The livelihood conceptual framework introduces the internal working components of the household's livelihood considered necessary for its functioning, the exploration of which is the primary aim of this study. A number of factors, both endogenous and exogenous to the household, including those related to HIV and AIDS may affect the pre-existing vulnerability of the household and its livelihood. These factors may also act independently as shocks and stresses on the livelihood of the household. Chambers and Conway (1991) suggest the significant role that the context of vulnerability, referred to by the authors as the vulnerability context, plays in the livelihood. So important is this role that I would argue that it is not feasible to review the existing literature about the impacts of illness and death on the three primary

livelihood components without providing some analysis of the factors that influence the livelihood and its vulnerability. This chapter therefore aims to provide a review of the literature along with an analysis of the context both external and internal to the households and individuals under study, generally.

Certain of the gaps that exist in the literature about how the shocks and crises of adult illness and death influence livelihoods in households, are assessed. Previous research has focused on a few specific themes. Very few studies have attempted to holistically assess the impact on the livelihood and the responses of household members to these effects. In addition, very few consider the importance of the definition of the household and how changing household structure and composition may contribute to the impacts of illness and death. Chapter 4 will continue this contextual theme and analyse the factors that affect the South African rural household specifically. Chapter 4 begins to develop the argument for the distinctiveness of the household formation and livelihood of rural black South African households.

3.2 Livelihood capabilities

The illness or death of an adult household member results in a number of changes to the demographic structure and composition of the household. These changes have the potential to change the roles and responsibilities of household members, which in turn, can directly or indirectly affect the potential of the households to function and the household members to work. This chapter reviews the largely African literature dealing with the impacts of illness and death caused by AIDS. The focus in this research is on adult illness and death so limited literature is reviewed on the impacts of child illness or death but the impacts of these events or episodes for the household are also important.

Death of an adult changes the livelihood capabilities of the household because of the loss of a potentially economically active household member, this loss of an adult can have direct implications for the functioning of the livelihood. This is particularly through the loss of income and the costs associated both with illness prior to death and the repercussions of the death, such as funerals. Gregson *et al.* (2007) using data from Zimbabwe found that the costs associated with illness and death were significantly higher in households with an AIDS death than in households where the death was from another cause. Death has a direct impact on the livelihood in addition to costs, including limiting the household's livelihood capabilities. Death also has potential indirect implications for some of the other aspects of the livelihood and the contextual factors. The evidence for this in the literature is presented throughout this chapter.

An indirect demographic impact of adult AIDS death is the orphaning of children. Studies in Malawi, South Africa and Tanzania have employed longitudinal Demographic Surveillance Site (DSS) data to investigate the changes in the number of orphaned children between 1998 and 2004. The results suggest that there was an increase in maternal, paternal and double orphans in all settings. The increase in paternal orphans is demonstrably greater than that in maternal orphans (Hosegood *et al.*, 2007a). The increases were particularly marked in severely affected communities in rural KwaZulu-Natal, South Africa, where 25% of all children were paternal orphans (Hosegood *et al.*, 2007a).

Rather than households being headed by children as is sometimes assumed within the literature, in many cases the elderly care for children. This argument is corroborated by evidence from studies using Demographic and Health Survey (DHS) data from across sub-Saharan Africa (Bicego *et al.*, 2003; Monasch *et al.*, 2004). The analysis of the DHS data suggests that countries with higher HIV prevalence have higher rates of AIDS orphans. Double orphans were found to live in households with higher dependency ratios than households without orphans. Bicego (2003) found that between 20 and 50 % of double orphans included in the sub-Saharan countries they were studying were living in households headed by their grandparents. Monasch and Boerma (2004) found that approximately half of double orphans were cared for by grandparents. The extended family network is shown to facilitate the fostering out of children, 90 % of all double orphans were cared for by the extended family. Child fostering by family because of orphaning by HIV and AIDS has also been demonstrated to be of importance in the Zimbabwean and the South African contexts (Foster, 2007; Foster *et al.*, 1995; Hosegood *et al.*, 2007a). Whether as a historically entrenched practice of fostering or because of increased numbers of orphans because of AIDS, family other than parents have a large responsibility for the care of children in sub-Saharan Africa. Given the burden of this care on the elderly, they may experience care for orphaned children as a physically taxing task (Dayton *et al.*, 2004; Orner, 2006).

Care requirements of children may affect the functioning of the households' livelihood as those providing care have their livelihood capabilities limited by their care responsibilities or in the case of the elderly may be forced to undertake activities beyond their ability (Nyambetha *et al.*, 2003a; Nyambetha *et al.*, 2003b). The literature about fostering provides little analysis and evidence for the factors which motivate or underpin the care and movement of children.

The impact of illness and death is different depending on the household's economic context. For example, a lot of research addresses the impacts of illness and particularly death on households in developing countries where agriculture is the primary livelihood activity. In sub-Saharan

countries dominated by agriculture such as Kenya, research into the impacts of adult mortality, reveal that the loss of human capital through death may cause negative changes to crop cultivation and land productivity (Yamano *et al.*, 2004). A number of other studies also focus on factors that directly or indirectly affect food security by affecting productivity and labour available for production in the household. Curry *et al.* (2006) compare the findings of four different baseline studies in Uganda, Namibia and two in Zambia designed to analyse the gender differentiated impacts of illness and death on livelihood and food security in households. The studies generally, and specifically the northern Zambian study, found that affected households headed by women were generally likely to have less labour available than households headed by men (Curry *et al.*, 2006; Wiegers *et al.*, 2006). The Namibian and Kenyan research shows that affected households had reduced the size of the area of land they cultivated and that households identified illness or death as a cause of reduced soil fertility. Affected Zambian households also invested less in the cultivation of their land and the authors suggest that the limited labour available in female and elderly-headed households contributed to both the decreased cultivation and ability to invest in agriculture. The evidence from these studies emphasizes the significance of agricultural activities for affected households and the consequences for household productivity, the livelihood capabilities and the way the household's livelihood is affected by illness and death (Wiegers *et al.*, 2006).

Analysis of evidence gathered in a study of sick Kenyan farm labourers, shows that productivity decreased in the final two years of employment. These sick workers picked less tea, took more time off, undertook less strenuous work and earned about 17 % less than healthy labourers (Fox *et al.*, 2004). Decreased productivity and employment capabilities of sick household members may influence the livelihood of their households, with corresponding negative impacts on the other household members. This is a reflection of the individuals' reduced livelihood capabilities defined by Chambers (1995) and Chambers and Conway (1991).

The death or illness of a potentially economically productive adult can have significant outcomes for the household's livelihood. This is the case even if the household livelihood is not dominated by agriculture. The income reduction because of the inability to work either indirectly through reduced livelihood capability or directly through job loss by the sick person is described in a number of studies in Africa (Gregson *et al.*, 2007; Menon *et al.*, 1998; Russell, 2004b; Wyss *et al.*, 2004). Qualitative research conducted in Botswana established that the illness of a household member affected their ability to earn an income through employment. The authors found that, sick people with jobs lost income because of having to take unpaid sick

leave. The lost income reported in this study resulted in extreme food shortages within their households and an inability to meet their own pressing basic needs (Rajaraman *et al.*, 2006).

Another demographic change to the rural household observed because of HIV and AIDS is the migration of new members or previously non-resident sick members into the household. Thai research shows that unmarried young adults are likely to return to their parental households because of illness in order to be physically cared for (Knodel *et al.*, 2003). The in-migration of a sick person into the household has important implications for the household, not least for the potential functioning and livelihood capabilities of the other household members. The need for household members to provide care for those who were ill had a negative impact on the ability of the caregiver to earn an income in the Botswanan study. Some also ultimately lost their jobs. One in five caregivers in the study lost income because of the need to care for another person (Rajaraman *et al.*, 2006). Care requirements of the ill may necessitate household members giving up employment or schooling to provide care. Inevitably, this may result in loss of income or the future benefits of education (Barnett *et al.*, 2001; Ngalula *et al.*, 2002; Russell, 2004b). The demographic impacts of HIV and AIDS therefore have the potential to affect the livelihood capabilities of other household members. The impact is not limited to those directly affected by illness but the livelihood capabilities of other household members may be affected indirectly through the impacts. These impacts may not be felt equally by gender and findings from other studies in South Africa suggest that for example caring is done more often by women than men (Bond *et al.*).

Access to ART has the potential to change the capabilities of those who were previously sick. Some preliminary findings from ongoing research in Uganda amongst those receiving ART suggest that there was a significant improvement in the health and physical strength of those on treatment. Despite this the qualitative assessment of the functioning of treated individuals suggests that their ability to undertake completely normal activity was still compromised (Kyegombe *et al.*, 2010a, b). Russell *et al.* (2007) in a commentary paper argue that the contextual challenges that those receiving treatment face are very important to consider. Health as a result of treatment may be meaningless for the livelihood where households and affected individuals are still faced with poverty and are unable to rebuild their economic and social lives (Russell *et al.*, 2010).

Two papers present the results of qualitative data from a sample of 70 people on ART since 2003 (Russell *et al.*, 2010; Seeley *et al.*, 2010). In response to a very small literature on the adjustment to life on treatment, these papers assess the way in which treatment facilitates a transformation to living with HIV as a chronic condition. The first paper highlights the

transition to 'normal' life for those that receive ART. The study participants' return to health was viewed as a normalisation. A number of different factors facilitated the transformation to dealing with their HIV as a chronic illness. The paper focuses on the personal effects and struggle to 'self-manage' one's condition and life. The ability to return to a productive life and take control of the resources available to individuals helped to give them a sense of control (Russell *et al.*, 2010). The authors argue for the importance of a return to a fulfilling social and economic life in supporting transition to life with illness.

The other paper explores the ways in which individuals receiving treatment respond to life on ART. One response was to have a social rebirth or transformation where they undergo a change in social life because of their experience. Alternatively, some people were able to return to a pre-illness 'normal' social life (Seeley *et al.*, 2010). Neither of these changes was easy and both papers highlight the important role played by close family, friends and support groups, CBOs and NGOs in providing emotional and livelihood support. While these papers point to the personal changes in terms of health, social life and improved livelihood capabilities, they do not assess the wider impact of these changes and access to ART for the livelihood and for the other members of the household.

3.3 Intangible claims, access and tangible assets

The intangible claims and access to resources and tangible assets that a household has forms an important part of its livelihood. In this section I provide evidence from the literature of the range of claims households affected by illness are able to make and that they use to make a living. These tangible assets and intangible resources and claims are closely linked to one another and, like livelihood capabilities, it is also not possible to discuss them without assessing the vulnerability context and existing vulnerability of the household. The bulk of the international literature about the impacts of illness and death on households and aspects of the livelihood is from research in the rest of Africa (see Section 3.1 for example).

The impacts of illness and death have the potential to affect the functioning and capability of individuals and indirectly on the ability of household members to work or participate in economic activities that contribute to households' livelihoods. The resulting changes in capability, access to employment and the ability to participate in economic activities and the effect these have on income loss for the household have already been discussed. The costs that occur because of illness and death have been studied extensively and much of the literature considers these impacts. Costs that are a direct result of illness and death, although not part of

the livelihoods framework, can be considered an important part of the vulnerability context of the household. In response to the pressure on the resources the household may be forced to change their portfolio of assets and this may in turn affect their ability to efficiently utilise the opportunities they have to make a living through the use of tangible assets.

3.3.1 Health care and funeral costs

The costs of health care during periods of illness are high in many developing countries. The findings of a small-scale longitudinal study of spending on health care in AIDS-affected households in Cote d'Ivoire found that households with a person with AIDS spent twice the amount on health care related costs as those without an ill member. Almost 80% of this spending was on health costs for the sick person (Bechu, 1998). Evidence from a relatively small purposively selected sample of individuals with AIDS in Chad, explored the household-level cost attributable to AIDS by matching affected households with unaffected control households (Wyss *et al.*, 2004). The study found that health care costs made up more than 50% of the total costs in AIDS-affected households.

Ngalula *et al.* (2002) explored health care costs of illness in Tanzanian households that had recently experienced an AIDS death. Verbal autopsies were used to identify affected households and their expenditure was compared to households with deaths from other diseases. The findings concur with those in Cote d'Ivoire and confirm that household health care expenditure for affected households was higher than in households with a death from other causes. Although those with AIDS spent less time in hospital, they consulted health carers more often and used a greater range of health care services in the period preceding death than adults with other diseases. The authors attributed this increased spending to the longer periods of illness associated with AIDS compared with those who died of other causes. Health care costs are important but are context specific and costs vary depending on what is available within the health care system.

In a review of the costs related to illness in developing countries Russell (2004b) found that illness generally, especially as a result of HIV and AIDS, had catastrophically high costs for affected households. Direct costs of seeking health care, such as transport to the health facility, contributed to health care costs along with the substantial direct costs of repeat visits to the health service. Reports from case study research, in Sri Lanka, provided evidence for the complexity and dynamic nature of health care costs associated with illness and shows how underlying vulnerability of the household may lead the cost burden of illness to be compounded (Russell, 2005). The direct and indirect costs of health care have a relationship to the income of

the household and the other costs with which the household is faced. Therefore, there is an interplay between the severity of the demographic impact and the vulnerability context.

In the Core d'Ivoire study households experienced a reduction in health care expenditure over the 24-month study period, suggesting that the ability of households to consume scarce resources was affected. The consumption patterns of directly-affected households have also been observed to decrease in a number of settings (Bechu, 1998; Janjaroen, 1998). It is not just the direct demographic impact of HIV and AIDS that affects the livelihood but other factors affecting vulnerability also affect one another and influence the livelihood.

The costs of a funeral for a member who has died is another important cost or expense, it depends on the existing cultural and religious beliefs of the household. Kenyan research suggests that this is an essential social event and is the primary and largest cost associated with the death of a household member (Lundberg *et al.*, 2000). Tanzanian and Zimbabwean findings demonstrate that funeral expenditure was significantly higher than costs related to health care for a PLHIV (Gregson *et al.*, 2007). The authors also found that households in the Tanzanian context were provided with very limited support from outside the household, in the event of a death in the household. In Zimbabwe, the cause-of-death did not affect the costs associated with a funeral. These findings suggest that the costs associated with illness and death are dependent on the context in which they occur.

Russell (2004b) suggests that, while understanding these costs is important, their measurement is difficult. He levels one of the key critiques of those who attempt to quantify the costs of illness and death. He suggests that population-level quantitative analysis of costs fails to provide adequate perspective of the impacts of costs at the household –level, specifically for the livelihood. He argues that small-scale case study research helps generate knowledge about affected household's responses to illness and death and the impacts thereof. I would agree with this argument and this study therefore aims to explore the way in which increased costs and loss of income because of illness and death form part of the household's vulnerability context and therefore affect the household's economic activity, functioning potential and livelihoods capabilities.

3.3.2 Tangible assets and economic opportunities within the African rural economy

Section 3.1 shows the way in which the demographic impacts of illness and death affect the livelihood capabilities available to affected households. The section points to the close ties

between livelihood capabilities and intangible claims defined by Chambers and Conway (1991) as the opportunities to use resources, stores or services. This is therefore the opportunities for employment and other economic activities. The results from Kenya, Uganda, Namibia and Zambia all show that the effects that illness and or death have on the opportunities the household has to make a living through agricultural activities (Curry *et al.*, 2006; Wieggers *et al.*, 2006; Yamano *et al.*, 2004). In contexts such as those discussed in these three papers where the livelihood is dominated by agriculture and particularly subsistence agriculture the importance of access to employment opportunities is not as pronounced as in contexts dominated by waged employment. Where the local economy is dominated by small-scale agriculture then factors such as access to land, labour as discussed with reference to the livelihood capabilities and the environmental context are particularly important for the livelihood. These factors contribute to the ability of the household to be agriculturally productive and therefore to make a living and ensure the household's food security.

The evidence from a number of African studies conducted within communities largely reliant on agriculture suggest that illness and death affect the ability of those who have land to make good use of it, in order to maximise the livelihood benefit (Curry *et al.*, 2006; Drimie, 2002; Mather *et al.*, 2004; Wieggers *et al.*, 2006). Those who through HIV and AIDS had reduced access to or no land had no opportunity to make use of it, therefore affecting their livelihood. Seeley *et al.* (2008) conducted an analysis of qualitative data from a sample of 26 household affected by HIV and AIDS in Uganda. The authors followed up from a study originally conducted in 1991. The results demonstrate the significance of access to land for making a living in affected households within the study. The study provides examples of conflict over land as well as problems with inheritance once someone dies of AIDS. Seeley *et al.* (2008) show how important land was to maintain livelihoods in households by either working the land themselves or paying others to assist with this task. Without their own capability to use the land or financial resources to pay for other labour, these households were unable to take advantage of an opportunity for an economic activity and struggled to survive.

Land is therefore an important tangible asset and, in settings where agriculture is the primary source of income or main livelihood activity access to it is key to the household's ability to participate in this livelihood activity. In Uganda, two thirds of affected households sold property to pay for death-related costs including for funeral expenses (Menon *et al.*, 1998). This finding shows the significance of land not only as a physical resource for use in making a living but also as a tangible asset for sale to respond to the economic costs associated with illness or death.

In addition to land, the literature suggests that other assets may also be important for the household to continue making a living from the land. The economic pressure of dealing with illness can precipitate the sale of durable goods in order to finance everyday and illness-related expenses (Bechu, 1998; Booysen *et al.*, 2002; Menon *et al.*, 1998; Yamano *et al.*, 2004). For example, Gregson *et al.* (2007) found that one in nine people in their study in Zimbabwe sold assets to pay to cover costs incurred due to illness in household members. Similar examples of the sale of assets have been reported from Kenya, Chad and Mozambique (Mather *et al.*, 2004; Wyss *et al.*, 2004; Yamano *et al.*, 2004). In the Kenyan study, death in a household was found to be followed by the sale of cattle and also equipment; this would have affected the households' ability to make a living from farming (Yamano *et al.*, 2004). These findings give an indication of the importance of access to and ownership of tangible assets such as livestock, equipment and land by rural households. The literature also suggests that the demographic impact, reduced livelihood capabilities, loss of income and expenses are all closely interlinked and affect each other and the tangible assets, intangible opportunities and the vulnerability context in which affected households make a living.

HIV and AIDS is not the only event or episode with the potential to have a negative impact on the livelihood of a household, specifically households whose livelihoods are dominated by agriculture. The land and natural resources necessary for agricultural productivity are also at risk of other shocks and crises, particularly those with environmental causes such as drought (Topouzis, 1999). Therefore, affected households are potentially faced by complex or multiple crises that affect their access to tangible assets.

Except for, Gregson *et al.* (2007) and Rajaraman *et al.* (2006) whose research used data from Zimbabwe and Botswana respectively where rural households were also reliant on employment, the large majority of the literature from the rest of Africa addresses communities where the primary rural economic activity was small-scale or subsistence farming. Even in contexts where informal work was considered an important activity it was often tied to farm activities and something undertaken in response to problems with agricultural production caused by HIV or AIDS, such as the increase in casual labour to supplement household income cited by Masanjala (2007) in his analysis of coping strategies. Alternatively, informal trading or other activities, linked to either the actual produce of farming or linked to capital from farming, may be reduced as a result of increased labour requirements, lack of capital or produce (Mutangadura, 2005; Rugalema, 2000).

Many of those conducting cross-country analyses of the impact of HIV and AIDS acknowledge the significant differences in terms of both economic context and policy that exist within and

between African countries (Drimie, 2002; Masanjala, 2007). I would suggest that, although there are some themes and issues in the literature common to all contexts, an in-depth household or individual-level analysis and comparison of the impacts of HIV and AIDS, is not possible. Instead, I would argue that the international literature highlights the significance of the vulnerability context and, in the case of the analysis of the impact of HIV and AIDS the specific policy and economic context in which the affected households operate. The relationship between tangible assets and the intangible claims in rural economies in Africa dominated by farming or the use of natural resources is very important, as the access to opportunities for employment and a productive livelihood activity are often dependent on intangible resources and claims.

3.3.3 Intangible claims: social protection

Unlike tangible resources, intangible claims are defined as demands and appeals made for material, moral or practical support from people or the state, largely external to the household. In the livelihoods framework adopted for this study social protection is one of the primary components I am choosing to focus on. Social protection is a claim that either can be made on the state in the form of social security measures or from other sources such as NGOs, donors or multinational aid agencies. Social protection encompasses a range of possible interventions to provide protection to the most vulnerable and poor, that are provided to individuals or households. It is broadly defined as the provision of formal safety nets (Devereux, 2001; Ellis *et al.*, 2008). Formal safety nets are defined by Devereux (2001) as public transfers and take a range of forms. In Malawi, Zambia, Mozambique and Kenya examples of social protection programmes exist but are targeted at specific groups or communities. The examples provided in the context of high HIV prevalence are targeted to communities affected by illness and death. The mechanisms include agricultural support for households involved in farming, food aid provided directly to household affected by illness and or death such as in Malawi or unconditional⁵ transfers of cash to the poor. Unconditional cash transfers are available nationally in South Africa but there are no other national programmes for social security in Africa.

The evidence for the impact of social protection interventions on households affected by HIV and AIDS is very limited outside of South Africa. While there is evidence from programme and intervention evaluations and assessments of the effectiveness of targeting methodologies, in other words assessment of whether interventions reach their targets, there is little evidence of

⁵ Unconditional transfers have eligibility requirements but no conditionalities. An example of a conditional transfer is a cash transfer for children that requires school registration and attendance in order for qualification.

the actual impacts of interventions at the household-level directed at households affected by illness and death. The literature that does provide evidence of a household-level impact of social protection activities focuses on the effects on household poverty by cash transfers targeted at children regardless of health or death. In particular these studies assess whether these cash transfers affect children's education and health outcomes, both of which are discussed in a review by Adato and Bassett (2007). Poverty outcomes resulting from cash transfers provide some evidence for the potential impact social protection could have on households affected by illness and death. For example, an unconditional cash transfer programme, for the poor and destitute in an urban area of Mozambique, was able to reduce the severity of poverty, and narrow the gap between rich and poor (Datt *et al.*, 1997).

Adato and Bassett (2007) also highlight the positive effect that conditional cash transfers, targeted mainly at children, had on households in South America, where there are relatively well-established programmes of such transfers. Programmes in Nicaragua, Colombia, Brazil and Mexico show that cash transfers have had a positive impact on overall household poverty, although this was measured slightly differently in all cases. Such evidence therefore suggests that conditional or unconditional cash transfers could have a positive impact on the livelihoods of poor households affected by illness, death and their accompanying social and economic repercussions for those households.

3.3.4 Intangible claims: social capital and informal safety nets

The literature largely focuses on two major sources of support for HIV and AIDS-affected households; support from within the extended family and support from the neighbourhood or community. This section reviews the international evidence for types and patterns of social support for households affected by HIV and AIDS. Firstly, I focus on familial support, from both within and external to the household, I then move on to support from outside of the family, most commonly from the neighbourhood or community.

Writing in 1993, Ankrah (1993) suggested that illness and death would affect the ability of the African family, both nuclear and extended, to respond to the needs of those affected. She argued that the family and household were becoming increasingly nuclear in nature and, therefore, the obligations to support and care for members of the extended family were steadily being reduced and would be ultimately lost. She furthermore suggested that, in undermining the familial survival strategies, illness and death might result in the development of new social associations and networks of sick people, located outside of the family, but rather linked through common experience. Also writing in the early nineties, Seeley *et al.* (1993) cautioned against

assumptions that African families possessed the capability or willingness to provide unlimited support and care to people affected by HIV and AIDS. They also expressed concern about the impacts of a more widespread epidemic on the ability of the family to respond to the needs of the sick. They suggested that, although the findings of their research highlighted the importance of the family in the care of those who have illness, the extended family provides a “safety net with holes” (Seeley *et al.*, 1993: 117).

A sample of 27 households enrolled in the 1991/92 ethnographic study was chosen to represent a cross-section of households in Uganda. The study found that barriers to affected households securing support from family members included fear of witchcraft and stigma. The Ugandan results also suggest that family members refused requests for support from other family members because of their own poverty or more urgent or prioritised needs of their own closer family members. Other limitations to securing support from relatives were relatively weak kinship ties (Seeley *et al.*, 1993).

The households enrolled in the early Ugandan study were followed up again in 2006/07 (Seeley *et al.*, 2008). The data from four affected households were used to provide insight into the findings from a large-scale quantitative longitudinal study about the impacts of HIV and AIDS. The authors show that small-scale qualitative data has the benefit of providing evidence for the impacts of HIV and AIDS on changing socio-economic circumstance observed in the longitudinal study. In terms of evidence concerning support from within the household and family, the results showed that rural households were able to rely on support from members of their immediate family, specifically adult children who were resident elsewhere, although this was often limited. Familial relationships were complex and the paper provides evidence of conflict within the family, as well as examples of family members actively working against the communal success of the household. For example, a dead man’s mother, who was caring for his children and his late wife, disputed the ownership and use of the man’s land. In another example, a man was beaten up and robbed by one of his sons.

The findings about the limits to familial support in the early Ugandan study are echoed by evidence from Tanzania and Zambia where, although support from kin was very important, there were limitations specifically where family members were limited by their own resources (Baylies, 2002; Nombo, 2007). Baylies (2002) suggested that the monetization and privatization of the production economy in Zambia may have resulted in reductions in reciprocity and claims within the extended family.

Nombo (2007) describes a small-scale qualitative study in Tanzania. She argues that the weakening of family ties led to declining transfers from family members. Her results suggest that although a moral obligation to assist operates within kinship networks, the support provided by relatives was limited. The study context described by Nombo (2007) was of largely immigrant communities. The immigrants were already excluded from informal support networks, because of their relatively short-term settlement in the area, they were also potentially far away from their family members and not well known to people within the community. The findings suggest that factors such as accusations and assumptions of witchcraft and conflict within social networks had a negative impact on the social support people within the study were able to rely upon. It can be argued that accusations of witchcraft could be a reflection of low levels of trust within the community.

A synthesis paper using studies from Botswana and Malawi assesses childcare following parental death. In Botswana, the fostering and care of orphaned children was identified as an important source of support from family members (Heymann *et al.*, 2009). The role of the family in fostering is also identified in the Ugandan study, where nine of the 24 households enrolled in the qualitative study had fostered children who had been orphaned by HIV and AIDS (Seeley *et al.*, 2008). The Botswanan findings suggest that other household members cared for 43% of orphaned children. In the same study, relatives outside of the household cared for 39% of orphans. The type of care from these relatives varied greatly from economic assistance, material help, educational and emotional support and childcare. The evidence for support in the form of food, cash or gifts to the households of orphans in Malawi did not differentiate between the source of support and it could have been provided by family and kin or friends and neighbours (Heymann *et al.*, 2009).

Zambian findings from mixed methods research into the impacts of AIDS on food access and security by Wieggers *et al.* (2006) also found that the social network was a source of child support and care. The paper did not indicate who within the social network was actually providing the care. Like many of the papers examining social capital and social support for households affected by AIDS, the authors suggest that there has been a “general weakening of social cohesion and erosion of reciprocal relations” (Wieggers *et al.*, 2006) within the social network with affected households increasingly unable to rely on social support.

Research from Thailand finds that there is substantial return migration of sick adults, during the final stages of illness, into the household of their parents because of the severity of their illness and their need for care. The Thai findings suggest the importance of close family relationships for the support of those young adults who were unmarried, became sick and required care and

support from their parents (Knodel *et al.*, 2003). In an earlier analysis of the implications of death of adult children for parents, Knodel and Im-Ew (2004) describe the norms of obligation for care of parents for the children and particularly of adult children for their parents. The authors also suggest that proximity between children and their parents, particularly co-residence was an important factor in determining whether parents provided care for their children, took responsibility for orphaned grandchildren or helped pay for their children's treatment.

The literature suggests that the family is an important potential source of support for households or individuals affected by illness and death. Despite the observed role of the family as a source of social support or assistance in the form of informal safety nets, some of the literature still suggests that the impacts of illness and death along with other factors influencing household and family vulnerability may lead to weakening social and reciprocal relations between family members. These arguments were made in the early nineties by Ankrah (1993) and by Seeley *et al.* (1993) and more recently the likes of Nombo (2007), Wiegers *et al.* (2006) and Baylies (2002) who suggest there are limitations to and potential erosion in the reciprocal relationships within families. I would argue that although the literature provides examples of changes in the support those affected are able to rely on from within the extended family social network the role of the context is very important and may affect the support households are able to rely on. Recent evidence from a qualitative study of the personal adjustment to life on ART in Uganda suggests that the family is still the most important source of support for those directly affected by illness (Russell *et al.*, 2010; Seeley *et al.*, 2010). Based on this and other international evidence, I would propose that despite arguments to the contrary and the burden and pressure placed on the family by the impact of illness and death, families still play an important role in supporting affected households and individuals and in the resilience of the livelihood.

The family and kin network is not the only source of support, and affected households may be able to rely on different types of support from people external to the household. The findings of Nombo (2007) in Tanzania echo findings about social networks by Wiegers *et al.* (2006) that suggest that affected households are less able to secure financial support from within their social networks, particularly family or kin networks, because they are less able to reciprocate than non-affected households. Moser (1998), in her analysis of the assets urban poor households in Ecuador, the Philippines, Zambia and Hungary require, suggests that access to social capital may help to mitigate the impact of a negative shock or prevent vulnerability. She goes on to suggest that, as other assets are used up or access to them is reduced, so too is the households' ability to participate in reciprocal exchanges.

Baylies (2002) argues that AIDS can weaken community ties much like the erosion of the support within family networks, thereby affecting the support that affected households are able to access. Much of the literature precedes the roll out of treatment and emphasises community support to households related to funerals and funeral costs. Funerals cost a lot of money in most countries and there may be specific expectations for social support at that time. In Kagera, resource- poor households were much less able to secure financial assistance for the funeral in the form of private transfers than better off households because they were clearly unable to reciprocate the support with which they would have been provided (Lundberg *et al.*, 2000). Although friends and neighbours were a source of support for affected households in Tanzania, this was largely unreliable and also quite short-term (Nombo, 2007). Nombo (2007) suggests that trust was vital to the support households were able to secure from other members of the community. Trust was affected negatively given the context of poverty, high ethnic diversity within the study area, HIV stigma and fears about witchcraft. None of these examples comes from countries with widespread ART rollout and access such as South Africa.

The local community and Non-Governmental Organisations (NGOs) were found to be an important source of support at the time of a death for affected households in a Ugandan survey assessing the impacts of an AIDS death (Menon *et al.*, 1998). Nombo (2007) also found that voluntary organisations and groups were another source of potential support for affected households and she suggests that this may be another measure of social capital. The Tanzanian study suggested that community groups were more important for women, but that in many cases those who were the most poor or affected by HIV were excluded because of stigma or their inability to pay for membership. Men were better able to participate in formal savings and credit groups because of their dominant role in agriculture and production. However, in general, the support from the range of groups the households could rely on was limited and the affected households and individuals in the study were seldom able to access support more than once.

Russell and Seeley (2010) and Seeley and Russell (2010) in their analysis of the reintegration of sick people receiving ART into the economy and society found that, next to the family, post-test support groups were the most important source of support for individuals receiving treatment. The assumption within some of the literature is that, in a similar way that it is argued that the support by the family is being degraded, the support households are able to rely on from within the community is also being reduced. I would argue that like the family, and despite weaknesses and potential barriers, the community and particularly groups might play an important role in supporting households and individuals affected by illness and death.

3.4 Summary

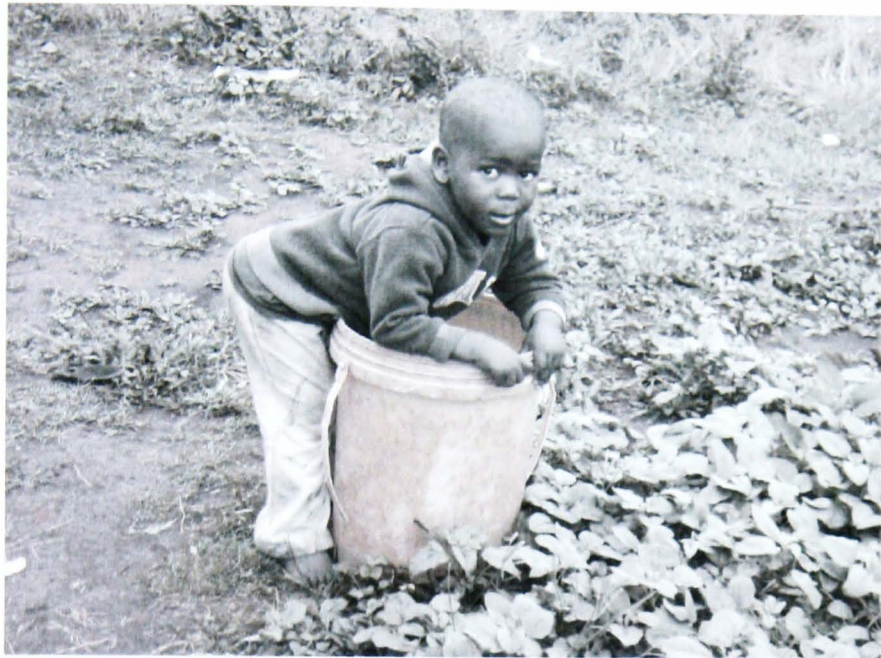
In sub-Saharan African households, livelihoods, although no longer completely reliant on agriculture and subsistence farming, are still dominated by these activities. The international literature that explores the impact of HIV and AIDS illness and death reflects this agricultural context. The economic context is shown by this review to have important implications for the focus of the research in terms of the impact on the components and outcomes of the livelihoods of affected households. Much of the research therefore has focussed either on the implications of illness and death on food security in the event of illness and death or on agricultural production.

The livelihoods framework highlights the significance of the context in which affected individuals and households find themselves and the influence this has on the households' existing vulnerability. I would argue therefore that not only the economic and economic policy context in which the livelihood of the household operates is important but so are all other aspects of the vulnerability context. The literature review shows that, even where the rural economy may operate and be conceptualised in a very similar way, health, social and economic policy play an important role in determining affected households' responses to illness and death. Examples of this are the varying access that people have to health care and ART and the different role that social relationships play in different types of communities. In addition, the impact of HIV and AIDS varies both within and between countries and may affect the vulnerability of affected households. This study therefore analyses the impacts of the various stages of HIV and AIDS; illness, death and treatment on rural households in South Africa within the very particular context in which they operate.

In addition to the importance of the contextual differences between studies, there are some potential similarities. The research to date shows that, despite arguments to the contrary and pressures exerted by a number of different shocks and stresses including illness and death, that the family (both nuclear and extended) is an important informal safety net for households and particularly for individuals affected by HIV and AIDS. In addition to families, there is a range of other sources of support available to affected households within the community including formal and informal groupings of people. In keeping with the argument for the significance of context presented above, the sources of support external to the family seem to vary with context. The following chapter provides an analysis of the South African rural context and shows that the significance of context would suggest that it is not necessarily possible to draw conclusions

about the social support that rural households in South Africa are able to secure based on the international literature.

Chapter 4: External and internal factors contributing to vulnerability in rural South African households



4.1 Introduction

While some information about the context of the study has been provided in Chapter 1, in this chapter I describe the circumstances of households in rural South Africa. One consequence of the adoption of the livelihoods framework and evidence from the literature review is the need to describe both the external and internal context of households in this study community. Contextualising the study is important as it highlights areas of potential vulnerability in the households enrolled in it. It also provides a basis for the argument about the distinctiveness of the household formation and livelihoods of rural black South African households.

4.2 Context of vulnerability for poor rural households in South Africa

The livelihood conceptual framework introduces the components of a household livelihood necessary for making a living, the exploration of which is the primary aim of this study. The concept of household vulnerability was discussed in Section 2.3. In the rural South African context, the household livelihood faces a number of endogenous and exogenous factors, excluding those related to HIV and AIDS that affect their pre-existing vulnerability. These

factors may themselves act independently as shocks and stresses on the livelihood of the household. Chambers and Conway (1991) refer to the substantial role that the 'vulnerability context' plays in households' livelihoods.

The vulnerability context of households and their livelihoods in relation to the burden of illness and death requires further analysis. In this chapter, I describe some of the factors that may affect the vulnerability of rural livelihoods in South Africa, this includes but is not exclusively illness and death.

The first of these that is reviewed is the way in which history, politics, social and economic factors have shaped the formation of the household. The formation of the household has also influenced the way in which the household is conceptualised and I discuss some of the theoretical debate surrounding this. An evaluation of the role of social networks both within and outside of the household, and how these facilitate the development of social capital, follows. Social capital provides the household with informal resource safety nets in times of need. Another formal safety net for households is social security and a description of the system of social security in South Africa provides some evidence for the benefit that social grants have on poor households. An analysis of the South African rural economy follows. The chapter is concluded with a summary of household composition, livelihood and vulnerability in the study population.

4.3 The household: definition, debate and the applicability of the concept In South Africa

In this study, the primary unit of analysis is the household. The definition of a household is constantly revisited, considered and open to a range of interpretations and measurements within the literature. Definitions vary, depending on the particular discipline or field of study concerned and on the country context. The debate is wide-ranging and in this thesis, I have used a definition that is relevant to the analysis of the livelihoods of households in the South African context.

There are two primary areas of debate about the conceptualisation of the household. The first debate relates to whether the household is changing from an extended family composition to a nuclear formation. This argument limits the definition of households in South Africa that are complex and follow no one particular formation. The second area of debate is whether the household can be assumed to be a stable and bounded unit as proposed in economic theory. The research conducted in South Africa, particularly during the last 40 years, and influenced by

similar debate about households in the West suggests that rural black households in the South African context are neither stable nor have impermeable boundaries.

While the focus here is on the conceptualisation and definition of the household in the South African context the complexities and characteristics described here, although the causes may be, are not necessarily unique to South Africa. It is possible that given South Africa's complex political, social and economic history and upheaval that this has led to an increase in the focus on the household, a concept that has been studied less outside of South Africa.

4.3.1 Complex family households

Historically the nuclear household was conceptualised as a relatively stable unit, and despite an acknowledgement of its inherent complexities, it was the unit of analysis in South African anthropological and sociological research. The concept of there being a nuclear household was taken for granted and influenced by Western sociological and anthropological theory. The myth was reinforced particularly by the work of Schapera (1935) and Wilson (1992), who among others used this definition as their contextual framework for analysis. The prevalent theory of the household being a nuclear unit is still generally considered by some proponents of the nuclearisation theory such as Ziehl (2002) and Steyn (1995). These theorists propose that there is a transition from an extended to a nuclear family, living together in one place. Such theorists hypothesise that this demographic change occurred because of modernisation and migration.

Some academics such as Gluckman (1967), recognised the greater complexity of the household and focussed on a wider residence-based conceptualisation of the household, and not purely on a nuclear household. He described the Zulu household as an *umdeni* or resident family group, in his comparison of kinship and marriage between the Lozi and the Zulu tribes. Few other researchers historically recognised the complexity of the residential family structure. In this study, I reject the assumption that all household types are based on variations of the nuclear family with any other forms being discounted. Both Murray (1980) and Spiegel (1986) argue that rather than it being either a nuclear or extended unit the membership of a household varies and the earlier definitions of the family and household respectively were limited in their use of the nuclear resident family unit as the basis of the contextual framework for their studies.

Recent studies that have collected both qualitative and quantitative data to determine the composition and organisation of black households in South Africa have shown that a broader, complex conceptualisation of the household is appropriate despite changes that may have affected the composition of the household. Analysis of the 1996 and 2001 South African Census

data suggests that, despite arguments to the contrary by Steyn (1995) and Ziehl (2002), urban black households predominantly comprise extended families (Amoateng, 2004). Russell (2004a) concurs with this conclusion. Some of the key findings that corroborate the claims made by Russell and others, arise from the analysis of South African Census data by Amoateng (2004), who showed that some aspects commonly associated with the structure of black households in South Africa had indeed changed. Household composition is shifting and adopting certain characteristics in order to adapt to very low levels of marriage, delayed marriage and high levels of premarital birth in these households. Despite observable transformation in black South African households to address these demographic changes, these families and households are still large, relative to other race groups in South Africa. He concludes that the family in South Africa is not becoming nuclear in its organisation but rather reflects a range of different household formations and specifically the extended family household (Amoateng, 2004).

Wittenberg and Collinson (2007) in their analysis of the longitudinal DSS data from the rural Agincourt study site identified a number of different household typologies. The trends observed in Agincourt indicate that there has not been an increase in smaller single person or nuclear households. Their results actually indicate a reduction in the number of smaller one person or nuclear households over time. These authors propose that the findings from other nationally representative studies which suggested an increase in these types of households reflect a selection bias due to changes in the sampling frame or information bias due to a change in the definition of a household used and do not actually indicate an increase in small one person or nuclear households. They speculatively conclude that their findings may predict future growth in the number of even larger three-generation linear households.

The generally accepted characterisation of black South African households as either a nuclear or extended formation has been questioned by Russell (2003a; 2003b, 2004a), whose work builds on that of Murray (1980), Spiegel (1986) and Spiegel *et al.* (1996). A consequence of these theoretical debates and the publication of a number of studies that aimed to understand what defines a household in South Africa, is that it is now accepted that the definition of the household as a nuclear unit dominant until the early eighties is not appropriate or applicable for black South African households (Siqwana-Ndulo, 1998). The conceptualisation of the family proposed by Siqwana-Ndulo (1998) who suggests that unlike the Western family based on individualism and independence the African family is a collective based on notions of interdependence. This conceptualisation of the family has implications for the conceptualisation of the household as complex, fluid and permeable. I will further discuss the implications of family interdependence in the discussion of social capital in Chapter 7. My thesis therefore

suggests that, rather than reflecting one household typology, black households in rural South Africa are complex and during the lifecycle reflect a range of different stereotypical descriptions.

4.3.2 Fluid households

Circular migration from rural to farming, urban, industrial or mining areas in South Africa has been happening for well over a century (Hobart Houghton, 1974). The physical and geographical divisions between race groups created by the Nationalist and Apartheid governments after 1913 fuelled the movement of people between areas designated as white and often urban to black homelands that were mostly in rural areas (Hobart Houghton, 1974; Russell, 2004a). The forced geographical separation of people instigated by the Apartheid government split whites from blacks physically and divided out the land. The separation led to shortages of labour in the white urban areas resulting in the internal migration of cheap male labour from the black rural homelands. Rural-urban migrants were forced to return to their rural homes after their employment contracts ended and their families were not entitled to migrate with them. These migrations were initially mostly of men, who moved without their families. The practice of circular migration has continued since the ending of Apartheid. This migration generally, and in particular the migration of women, increased considerably in the 1990s. Moreover, many migrants still maintain strong links to their rural households even if they move with their families or develop new families in areas closer to cities (Posel, 2003). Migrants linked to households in rural areas are therefore often considered non-resident members of these households (Hosegood *et al.*, 2006).

Anthropological studies by Spiegel (1986), Spiegel *et al* (1996) and Ross (1996; 2003) of social relationships in households and communities conducted in the Eastern and Western Cape respectively found that there was marked short-term domestic fluidity between and within households. They criticised the research of those who considered the household to be a static unit. Spiegel (1986) and Spiegel *et al* (1996) and Murray (1980) observed and reported a high turnover of household membership, including movement in and out of the households in rural South Africa and Lesotho.

An acknowledgement of the influence migration and other social, political and economic factors had on households in rural South African led to the adoption of the concept of a 'stretched' household by Murray (1980), a household with people who share membership but who are situated geographically separate from one another. This concept was later adopted by Spiegel *et al.* (1996) and others. The concept of a stretched household does not however, distinguish

between household types, which in the Southern Africa context, can be complex due to migration and marriage patterns. Spiegel *et al.* (1996) argue that, the idea of a stretched household goes some way to correctly conceptualising the household but does not apply to all forms of household. The concept of a stretched household can be used to define a relatively stable unit and does not account for the changeability of the household. Therefore, it is suggested that the household should be conceptualised as fluid.

Ross (1996) observed that the household dynamics in an informal settlement outside of Cape Town were very fluid and that the process of livelihood production and reproduction in the household influenced these movements. The studies by Ross and Spiegel *et al.* (1996) described the situation in an urban area and urban households. Spiegel *et al.* (1996) recommended that, in order to capture the diversity and fluidity observed in these households that further research would need to include a longitudinal component to the study design. In addition, an in-depth element that included biographies and histories of individuals was proposed to document movements of household members.

Although the qualitative research by Spiegel *et al.* (1996) and Ross (1996) was conducted in an urban context, the quantitative data from the study in Umkhanyakude by Hosegood *et al.* (2006) involved the analysis of the ACDIS dataset, which represented this rural population. Information about household residency was collected at regular intervals from all the households within the DSS. Self-reporting of household membership was a good way to collect household information accurately and ascertain the nuances not reflected in standard quantitative household data collection methods. The study found that intra-household memberships were not static by demonstrating frequent movements of people into and out of these households. The respondents identified both resident and non-resident household members to be integral parts of the household. In addition to those who were usually considered members of the household, the authors identified other resident individuals identified as 'affiliated' members. Examples of affiliated members included unrelated tenants and domestic helpers resident in the household.

A better understanding of the household and its relationships to kinship in the South African context has led to a definition of the household in the literature that more accurately reflects the reality in black South African households. As a consequence of reviewing this literature, I have adopted, like Russell (2004a: 63), a *de jure* definition of the household as "the flexible, stretched, divided group, not necessarily co-resident, not necessarily kin, who pool income over a life time." Like, Russell (2004a) I recognise that the concept of pooling of income over a life-time is complex and potentially problematic because it is not necessarily true for every

household or individual household member. Nevertheless, this notion yields a useful and meaningful definition of the household. An in-depth analysis of demographic changes that occur over time in one household, tracking the movements of individuals and the flows of expenditure, income and resources of membership, is an appropriate research method to capture the fluid, complex and diverse nature of black South African households more accurately.

4.4 Social support within the household and family in the South African context

Although contested and complicated, familial and broader community social networks nonetheless contribute to mitigating the impacts of illness and death (see Section 3.3.4). This conclusion based on international research may not be directly generalisable to the South African context, as argued in Section 4.3, due in part to the dynamic and fluid nature of the typical rural South African household. The fluid composition of households contributes to complexity in households affected by illness and death.

The changes to family and kin relationships in South Africa are relevant to the norms and values that govern access to the benefits associated with social capital. In order to adequately assess the important role social relationships play in the mitigation of the consequences of illness and death, the social relationships relevant to my conceptual framework need to be presented. In the case of kinship, this will include some history and analysis of the traditional system. The significance of changes to both the household and kinship networks as social institutions, because of modernisation, political factors and specifically the reality of HIV and AIDS are explored in the South African context in Chapter 7. In this section of the literature review I present some of the changes these institutions have undergone in the last 50 years and some of the resource support available that is not influenced by HIV and AIDS.

4.4.1 Kinship and the family network as a source of support and assistance historically in traditional Zulu society

Kinship has historically shaped many of the social norms by which individuals negotiate their relationships, interactions and responsibilities to other people in black South African households and society (Preston-Whyte, 1974; Russell, 2003b, 2004a). It is therefore important to assess how these relationships between kin were organised traditionally and how this history influences current family obligations and reciprocal relationships. The traditional Zulu kinship

system possessed many commonalities with those of other *Nguni*⁶ groups within Southern Africa. The system is patrilineal, meaning that descent occurs through the male line. Preston-Whyte (1974) argued in her analysis of the kinship and marriage systems in Southern Africa, that the system had important implications for the residential organisation of Nguni groups such as the Zulu. This system dictates that a woman moves to the homestead of her husband's father after the payment of bridewealth (*lobola*), thus making her a member of their extended family household. The latter, after the birth of children, may span three generations and include a number of siblings. The patrifocal system of kinship has implications for household formation, which was often made up of more than one family nuclear unit, especially because of the tradition of polygamous marriage for men. The payment of bridewealth also ensured that any children produced from the union were affiliated to the household of their father and their father's father. This patrifocal lineage system is important in determining not only norms of residency but also domestic responsibilities and obligations within the family and amongst close kin.

According to the traditional division of labour, as discussed by Sansom (1974), a wife is responsible for a range of domestic and agricultural responsibilities for her own nuclear family. Furthermore, the woman plays these roles in her father-in-law's household where she acquires an obligation to care for her in-laws, and specifically her mother-in-law. The rules of kinship, therefore, affect the obligations and responsibilities people have to other members of the kinship network and, in the case of women who are married, these domestic obligations move to the family of her husband. Men, on the other hand, remain responsible for, and traditionally often resident, in their father's household until the older man dies and thereafter the man and his siblings move on to establish their own homesteads (Preston-Whyte, 1974). Despite the patrifocal organisation of Zulu households, the maternal family remains important and special relationships exist, such as the relationship children have with their mother's sister or her brother called '*umalume*' (Krige, 1988). Krige (1988) in her analysis of the social system of the Zulu argues for the strong obligations for the *umalume* to help, as far as he possibly can, the children of his sister. The *umalume* is the representative of the maternal family. Therefore, despite patrifocal lineage being the traditional norm a married woman and her children maintain close ties with her household and family of origin. Vilakazi (1962) argues that the lineage is the basis of all reciprocities underpinning a moral and ceremonial unity amongst those who share the same *isibongo* (kin name).

⁶ The Nguni tribes of Southern Africa originate from a single group of nomadic pastoralists who migrated south and have since split to form a number of different clans and groups all linked through common heritage, linguistic and cultural similarities.

The strong feelings of concern for one's family and one's neighbours and the obligation to help them can be related to the concept of '*ubuntu*' (Carter *et al.*, 1999). The direct translation of the *isiZulu* term is personhood or humanness and there are similar words in a number of other African languages (Kamwangamalu, 1999). While the interpretations of the term are wide-ranging, there are two primary values of the concept, which have relevance to this discussion. These primary concepts are communalism and interdependence. Communalism is defined by Mthembu as quoted in Kamwangamalu (1999: 220), "in Africa, communalism is a strong and binding network of relationships". The paper goes on to cite examples of kinship terms within community and neighbourhood relationships suggesting the closeness inherent in these relationships. Interdependence in terms of *ubuntu* is often described as the reliance of an individual on the help, assistance and interaction with other people. These concepts therefore have relevance for traditional values and may influence behaviour, obligations and responsibilities. The family is of particular relevance in this section but the concept of *ubuntu* also has importance for relationships and social capital outside of family and kin (Nkosi *et al.*, 2007).

Historically, ties within wider kinship networks were cemented through the integration of individual household or homestead production into that of the wider kinship network (Sansom, 1974). The livelihoods of traditional Zulu households involved a range of mixed activities, which allowed the household to diversify its risk. These activities were shared within the household in a highly gendered division of labour. Women were responsible primarily for domestic activities, caring, cooking, tending poultry and lighter agricultural labour such as weeding and harvesting crops. Men, on the other hand, were responsible for the care of the livestock and heavy agricultural and domestic labour, such as house building (Sansom, 1974). The clustering of Zulu homesteads (although not in a village or tightly knit settlement as occurs in other traditional groups) meant that kin lived relatively near to one another (Preston-Whyte, 1974). This meant that it was possible for certain activities to be shared among kin. For example, those related by kinship were expected to act jointly for the communal good. Members of the family therefore enjoyed reciprocal relationships. Specifically, the provision of labour required for agricultural activity was shared to save time and energy and there was an expectation of assistance from relatives (Sansom, 1974; Shaw, 1974). Therefore, reciprocation, sharing and co-operation in productive activities, explicitly and implicitly meant that the demand for food and labour were evened out across kin. In the traditional Southern African context, generalised reciprocity or mutual aid was practiced as a form of social insurance (Buthelezi, 1984; Sansom, 1974). The sentiment behind generalised reciprocity is explained in this quote: "We give because someday we too will suffer the same need" (Sansom, 1974: 156).

These reciprocal patterns are not only relevant to the family and kin but also have relevance for relationships in other social networks that may provide some sort of insurance.

Members of family or kinship networks are, therefore, reliant on a fund of goodwill from other people within these networks and construct or maintain this fund by providing for or helping other members in their time of need. Therefore, strong familial ties are rooted in the geographic and economic organisation of the African kinship network (Siqwana-Ndulo, 1998).

Even historically, though, the evidence suggests that in times of disaster, generalised reciprocity practices between kin fell away (Sansom, 1974). Therefore, the threats faced by households dealing with illness and death in a contemporary South African context, along with a complex history involving changes in household composition and kin relationships and networks, have the potential to undermine these norms of family obligation and generalised reciprocity.

4.4.2 Contemporary households and kinship networks in rural South Africa

The traditional family relationships that comprise the Zulu kinship system, have been challenged by the modernisation of family life, and the political, social and economic implications of the Apartheid system, which often divided the family geographically (Steyn, 1995; Ziehl, 2002).

These changes in turn affected the formation and composition of the household and, therefore, the accepted norms of kinship, which influence household members' obligations and expectations. The norms of household composition no longer only reflect the structural formation based on patrifocal lineage. Household typologies vary because of a range of factors including high levels of circular migration and fertile extra-marital sexual unions, and fewer marriages (Amoateng, 2004; Hosegood *et al.*, 2006). The different types of household structure are complex and vary depending on the life cycle of the household and a range of other contextual influences. The roles and responsibilities of members in the household may also shift because of changes in household formation. The consequence of frequent extra-marital fertility and low levels of marriage is that many unmarried women and their children remain linked to their maternal households. Already Dubb (1974), in a very early review of how city and town impacted on the African family, suggested that the increase in female headed households as a result of internal migration and fewer marriages lead to the growing importance of matrifocal⁷ kin and stronger ties within these kinship networks. Given the traditional importance of

⁷ Defined as kinship groups related through mother's rather than father's kin.

matrifocal kin even in a patrifocal society, this may suggest an adaptability or resilience within the kinship network.

The assumption that the household is becoming increasingly nuclear, as suggested by some South African research and literature, implies that individuals also, no longer feel these strong kinship ties and obligations towards members of the household or kin (Russell, 2004a). The debate presented in the Section 4.3 about the dominance and changing profile of black households comprised of extended and nuclear families households in South Africa is relevant to this discussion. It seems possible that low levels of marriage and infrequent payment of *lobola* have decreased the extent of kinship networks because families no longer retain close ties with in-laws, cemented through these ceremonial activities.

Although the household and kinship network are undergoing major changes, the research suggests that many of the traditional norms of obligation, social networks and relationships, continue to function in South Africa (Nkosi *et al.*, 2007; Siqwana-Ndulo, 1998). Qualitative research conducted between 1988 and 1990 in order to assess the quality and characteristics of family life amongst black South Africans explored the norms and values surrounding marriage and family life (Viljoen, 1994). Many respondents in the study, particularly those who were older, expressed concerns about the erosion of family norms and traditional family-related institutions such as the payment of *lobola* and polygamous marriage, an increasing focus on the individual; and frequent divorce. All these factors have the potential to weaken the entrenched social network created by the family and kin and the existence of norms of respect and mutual support. Despite this, Viljoen (1994) found that the black extended family was still functioning, viable and strongly supportive, even with changes in family life and weakening family ties.

The obligations and expectations inherent in kin relationships still have an important role in private transfers, or 'giving' in South Africa, as suggested by the findings of the 'Giving in South Africa' national sample (Everatt *et al.*, 2005). The importance of the moral obligation of giving to family in South Africa has been described by Bozalek (1999) in her study of expectations and experience of caring amongst social work students in the Western Cape. She reported a lifelong obligation to provide care for family that underpinned the various forms of support and care provided within the household and family. The research did not differentiate between obligations within the household and those within the kinship network, as the report refers to family more generally. Sagner and Mtati's (2000) qualitative research explored and demonstrated the motivation for pooling or sharing of old age pension income in the Khayelitsha township of the Western Cape. The motivation for this practice was governed by culturally and socially constructed norms and obligations. Many of the examples presented in

their study showed that older people were also motivated to spend their old age pension on other household members in order to strengthen relationships with possible future beneficial consequences or to secure support and care.

Adato *et al.* (2006) assessed the role of social capital in the economic mobility of the poor in KwaZulu-Natal, using KwaZulu-Natal Income Dynamics (KIDS) quantitative panel data and a qualitative study based on a sample of 50 households. They found that social capital initially facilitates access to employment arising from within the family or household or from sources and social networks external to the household. Family remittances were the second most important source of support. Remittances had specific relevance for households and families in the South African context because of the fluidity of households that include many non-resident members. Posel (2001) has shown the financial importance that regular remittances sent to the rural home by urban migrants make for rural households.

Despite the fluidity of household composition and its dynamic demographic structure, the continuous changes to family, kinship relationships and organisation reported in the literature, I conclude that reciprocity and family obligations among family and kin remain hugely important in rural black South African households (Nkosi *et al.*, 2007; Siqwana-Ndulo, 1998).

4.5 Neighbours, community and groups: the role of non-kin in rural South African households.

In addition to social networks based on household and kinship relationships, households and individuals may benefit from membership in other formal and informal social networks or groups. Non-familial networks may be linked to friends or neighbours. Groups can be either formally or informally organised, and they include savings co-operatives, small prayer groups, *stokvels* (informal group savings schemes), church groups or burial societies.

Among black South Africans, and specifically the poor, support and assistance from community-based sources external to the household and the kin network is mostly beneficial. Adato *et al.* (2006) assessed the function of social capital in general in South African households using the KIDS panel study data. The findings suggest that given high levels of inequality, poverty and social exclusion, social capital was most useful for facilitating access to employment for poor households. Cross (2001) reached a similar conclusion in her qualitative assessment of the shock of death in households in KwaZulu-Natal. She found that, in terms of resources being available external to the household, access to casual labour and work within the

community was one of the most important responses for affected households (Cross, 2001). In descending order of importance, the authors found that, after remittances, which probably involve a familial or fluid household relationship, support from burial societies, cash loans or gifts, *stokvels* and savings, or borrowing groups were the most common sources of support or assistance (Adato *et al.*, 2006). However, the authors did not differentiate between the provision of cash loans and gifts from family and household or those from neighbours or community members with the result that it is difficult to assess who actually provided certain types of support to the households they studied.

Adato *et al.* (2006) in their research on social capital in KwaZulu-Natal also identified a number of sources of negative social capital in the community. Although barriers to social capital have been assessed in some of the international literature, the concept of negative social capital is seldom addressed in the literature. The three greatest sources of negative social capital that were identified were the issuing of credit; jealousy and competition between beneficiaries; and conflict and distrust within the networks. All of these may lead to increased levels of poverty in the household. These authors also reported that social capital was not equally available for everyone and that the profoundly poor or marginalised found it hardest to secure assistance. They also argued that although the assistance provided from social capital was important, it was not in itself a “pathway out of poverty” (Adato *et al.*, 2006: 244).

The growth in rotating savings and credit schemes amongst African women in South Africa dates to the early 1930's (Verhoef, 2001). More recent analysis of the KIDS data, shows that membership in these financial groups in KwaZulu-Natal is heavily reliant on high levels of trust in the extended family and with close neighbours, which then facilitated membership in these groups (Haddad *et al.*, 2003). Membership in these informal credit and savings institutions furnishes households with access to credit and income in times of need.

Analysis of the KIDS data found that of the groups that are not-financially orientated, 70% were religious groups (Haddad *et al.*, 2003). Groups based on religion could also provide important sources of support to their members through prayer and emotional support as well as financial or in-kind assistance. The importance of religion in charitable giving both directly to fellow members or to those identified as less fortunate was also identified by findings of the ‘Giving in South Africa’ study (Everatt *et al.*, 2005). Those who identified themselves as members of faith-based organisation were more likely to give than those with no religious affiliation. Most felt that giving was something required of them by their religion.

The South African research literature suggests that in addition to the important role that family and kin play in sustaining one another membership in other social networks such as among neighbours or other groups may also provide individuals or households with resource support at times of need.

4.6 The social security system in South Africa

Despite flaws in the social security system, the provision of social grants in South Africa is remarkably well developed relative to other countries within the region and almost on a par with social security systems in middle-and high-income countries elsewhere (Booyesen, 2004b; Booyesen *et al.*, 2005; Guthrie, 2002). South Africa has a history of social security provision that dates from 1928 when old age social pensions were made available (Sagner, 2000; Triegaardt, 2005). These pensions were initially only for white South Africans and, although access to old age pensions was extended to all race groups in 1944, the system remained discriminatory until the Apartheid system was completely abolished in 1994 (Lund, 1993). Pensions for black African, coloured and Indian South Africans were provided on a racially based sliding scale and the level of payment was substantially lower than that for whites (Sagner, 2000; Triegaardt, 2005).

Although other cash transfers, or social grants, including disability grants, foster care grants and state maintenance grants were introduced later than old age pensions, the allocation followed a similar pattern of gradually spreading but unequal access for different race groups in South Africa (Lund, 1993). Racial inequalities were only abandoned with the promulgation of the Social Assistance Act of 1992. The Act provided access to social security for all race groups equally and since then all social grants have been administered by one umbrella organisation the South African Social Security Agency (SASSA) (Lund, 1993, 2007; Triegaardt, 2005). This was a huge improvement from the previous administration of social security which had been divided up into 17 different parts dealing with various race groups, homelands and other 'independent states'.

Sagner (2000) described the history of the old age pension system in South Africa from its beginnings in 1928 to its expansion to all race groups in 1944, explaining the motivation for the implementation of social grants for whites and for all other race groups. Lund (1993, 2007) also provided a history of the changing social policy preceding and following the change to a democratically elected government in 1994.

During the period of political transition around 1994, South Africa witnessed a shift in the social security model to one based increasingly on social development principles (Lund, 1999; Lund, 2007; Triegaardt, 2005). The developmental social welfare approach followed during this period focussed on overcoming racial inequality and attempting to bridge the gap between rich and poor by providing individuals with opportunities for income generation and development (Lund, 2007). This approach to social security, which was aligned to the national economic policy, was not sustained and with the advent of the Growth, Employment and Redistribution (GEAR) economic policy, the focus shifted to that of a policy of general economic growth (Triegaardt, 2005).

The old age pension, disability grant, care-dependency and foster care grants were relatively well established by the time the policy changed in 1992. In particular, access to the old age pension, had been improved and achieved relatively good coverage for social pensioners in the country. The child support grant was only introduced after 1994 following a recommendation by the Lund Committee. This committee was tasked with exploring alternative social policy options for children and families (Lund, 2007). It was designed to reach out to and alleviate poverty in families and households with young and vulnerable children. The new social grant also replaced the state maintenance grant that had originally been designed to benefit white single parent families (Lund, 2002b; Lund, 2007; Triegaardt, 2005). Due to fiscal constraints the eligibility criteria to access the child support grant was constrained. Initially only children between the ages of zero and six years were able to pass the means test. This age limit was extended to 11 years in 2004, and subsequently to children up to 14 years of age in 2005.

The child support grant is currently paid to the principal carer of a child under the age of 15 years where the income and value of the parent or caregivers assets falls below the means test level laid out in the policy guidelines. The monetary value of the child support grant was R240 (£21) per month in 2010. According to the 2008 Department of Social Development Annual Report 8.2 million children received the child support grant in South Africa in the 2007/2008 financial year (Department of Social Development, 2008a).

The old age social pension is paid to poor men and women over the ages of 65 and 60 years respectively, who, along with their spouse, have assets and income with a total value below that of the local means test. The old age pension in 2010 was valued at R1010 (£80) per month. In 2007/2008 about 1.2 million elderly pensioners were receiving a state old age pension in South Africa. The qualifying age for men will be lowered to 60 years at the end of 2010 (Department of Social Development, 2008a).

The foster care grant can be claimed for children who are orphans and in need of care, and it was valued at R680 (£60) in 2010. In South Africa generally, and in rural KwaZulu-Natal specifically, this social grant is of great importance as it supports among others those orphaned by HIV and AIDS. Fostering for a variety of reasons is widespread in Southern Africa (Ansell *et al.*, 2004; Madhavan, 2004; Monasch *et al.*, 2004; Young *et al.*, 2003). This social grant was paid for 447 000 children in South Africa in 2007/2008 (Department of Social Development, 2008a).

The disability and care-dependency grants were valued at R1010 (£89) a month in 2010. The disability grant is available to women aged 18 to 59 years and men 18 to 64 years. The qualifying individual and their spouse must meet the means test and they must not be in receipt of another social grant for themselves. Both the disability grant and care-dependency grant require a medical assessment to confirm disability. Care-dependency grants target children aged one to 18 years and, except in the case of foster parents, the family of the child must comply with the means test requirements (Department of Social Development, 2008c). In 2007/2008 1.2 million people were collecting a disability grant while only 110 000 children were issued a care-dependency social grant (Department of Social Development, 2008a).

4.7 Impact of social grants: evidence from South Africa

Research conducted on how social grants benefit households has largely focussed on the old age pension, it has been available for longer than any other social grant and is the most widely accessed. The old age pension has been shown to have a substantial economic benefit for households. Case and Deaton (1998), analysed the South African Labour and Development Research Unit (SALDRU) dataset collected in 1993 and found that old age pensions were accessed appropriately by the elderly in many poor households and that their households benefit as a whole from the extra income the pension provides. Both children and other household members in poor households benefited from the redistribution of the income obtained from the old age pension (Case *et al.*, 1998).

In their analysis of household income and expenditure in KwaZulu-Natal, Ardington and Lund (1995) note how the old age pension income was redistributed to benefit all household members. The redistributive benefit of the old age pension to other members of the household has been validated in qualitative research (Lund, 1999). A review by Lund (2002a) includes findings from the South African Integrated Family Survey, which showed that 84% of black and coloured households pooled their old age pension income. These households showed better

adult health outcomes and growth of children than other households, demonstrating the benefit of having and sharing pension income in the household. Further analysis of the SALDRU data confirmed beneficial nutritional and anthropometric outcomes for female grandchildren living in a household with a female old age pensioner (Duflo, 2003).

Having an old age pension can also change the composition and demography of the household. Both SALDRU data and data from the 1996 South African Census showed that having a female old age pensioner in a household was associated with an increased number of children living in the household (Edmonds *et al.*, 2001; Posel *et al.*, 2006). Other evidence suggests that at least a part of the income from an old age pension is shared with prime-age adults living in the household, specifically males and that this may alter the labour supply for the household (Bertrand *et al.*, 2003).

The motivation for the pooling or sharing of old age pension income was explored and reported in qualitative research conducted by Sagner and Mtati (2000), in the Khayelitsha township of the Western Cape. They found that pooling and sharing of pensions was governed by culturally and socially constructed norms and obligations practiced by the elderly in the household. Older people were also motivated to spend their old age pension on other household members in order to strengthen intra-household relationships with the potential for possible beneficial consequences for the pensioner, including future support or care from other household members (Sagner *et al.*, 2000). This research confirms the importance of the old age pension and the implication of reciprocity and family obligation.

The presence of an old age pension in a household has also been linked to the 'crowding-in' of a number of positive household and individual outcomes in addition to the beneficial health outcomes outlined above. These benefits include improved access to care for vulnerable household members, the development of local economic markets, and the creation of micro-enterprises (Lund, 2002a). Research presented in this review shows that receipt of an old age pension enabled the aged and their households to secure credit. A pension also improved the agricultural productivity of the household. Observational data suggests that old age pensions stimulated local trade and markets.

Comparative analysis of the child support grant in South Africa and other cash transfers to families or children in Latin America and other countries in similar economic transition show that all of these grants assisted in the alleviation of childhood poverty (Barrientos *et al.*, 2006). The South African component of this comparative analysis was based on the quantitative analysis of the Africa Centre Demographic Information System (ACDIS) data collected in the

Umkhanyakude district of KwaZulu-Natal. Not surprisingly poorer families accessed the child support grant. Those parents who accessed the grant were more likely to be unemployed and their households possessed fewer assets than households that did not claim for this assistance. Households that accessed the grant benefited from a general reduction of poverty (Case *et al.*, 2005a).

Further analysis of the ACDIS longitudinal dataset showed that, in 2002, 87% of the primary caregivers receiving the child support grant were resident mothers and only 10% were grandmothers. Despite this finding, it still does not give a clear indication of who, in practice, cares for the children. Children who did not live with their biological mother were significantly less likely to receive the child support grant than those who did (Case *et al.*, 2003). The authors suggest that primary carers who were not the mother of the child may not have known that they were eligible to be awarded the social grant. Another reason for not having the grant could be that registration of births and access to birth certificates for children not cared for by their mother were more difficult. Evidence from a qualitative study conducted in the same research area has highlighted the difficulties such carers face in accessing social grants for children (Moitse *et al.*, 2003; Zungu *et al.*, 2003).

In summary, the literature shows the importance of social grants in poor South African households. It also suggests that there are both individual but especially communal benefits of access to social grants.

4.8 Rural economy in South Africa

The Apartheid government policies had implications for both the formation of the household and social networks and relationships that persist to this day and similar political, economic and historical factors have shaped the livelihoods of rural South African households. The consequence of this is that the livelihoods of households in rural South Africa are remarkably diverse, complex and flexible.

Geographical limitations on the movement of people and mass relocations enforced by the state led to an increasing reliance on migrant labour. This placed pressure on the already weakening rural agricultural resources and availability of labour in rural areas (Murray, 2002; Sansom, 1974). Mass relocations were designed to systematically destroy the African family and these forced removals were often to rural areas poorly suited to subsistence agriculture because of infertile soil, lack of water or very high population densities. Policies to prevent share-cropping and agriculture on what had become 'white' land negatively affected agricultural activities. In

addition restrictions were placed on both formal and informal economic activities in the homeland areas (Klasen *et al.*, 2008).

Along with these structural changes, an increasing desire for manufactured goods meant that waged labour and the opportunities presented in urban, industrial or mining areas became increasingly sought after aspects of the rural South African livelihood (MacKinnon, 2008; Sansom, 1974). The increase in access to waged labour was fostered by the Apartheid government that required a large unskilled workforce to improve production which was increasingly labour intensive (Klasen *et al.*, 2008). Availability of employment in urban industrial centres encouraged a corresponding reduction in agricultural production in rural areas, even just for subsistence purposes (MacKinnon, 2008; Sansom, 1974). Discriminatory laws favoured whites in training, access to education and certain jobs. In particular, skilled work was not available for blacks (Klasen *et al.*, 2008).

The Apartheid policies and practices still have an important effect on the contemporary rural livelihoods of black South African households. South Africa has an unemployment level around 30% (Klasen *et al.*, 2008). Analysis of the KIDS panel dataset between 1993 and 1998 showed that South Africa has one of the highest levels of inequality in the world (May *et al.*, 2001). Poverty is widespread and further analysis of the three waves of the KIDS data until 2004 indicated that poverty had increased progressively since 1993 (Agüero *et al.*, 2005). Levels of poverty and unemployment have both been reported to be higher in rural areas of KwaZulu-Natal where the bulk of the poor population are black and live in areas previously demarcated as homelands. Information obtained from the KIDS data by May and Carter (1999) provided evidence for the noteworthy contribution of informal economic activities to the livelihoods of rural South African households.

The role of the social security system in contemporary South Africa and the benefit it has for poor rural households are discussed in Section 4.7. The old age pension has been available to the elderly for many years and in the 1993 PSLSD the receipt of and prevalence of elderly grant recipients was already high, 77% for men and 80% for women. Outward migration of the economically active group, means that the dependency ratio is already high, for example in the Agincourt DSS 44% of the population are under 15 and 4 % are over 65 (Case *et al.*, 1998; Wittenberg *et al.*, 2007). Other social grants have been introduced at intervals during the last half century and these too have increased access to monetary resources. May and Roberts (2001) have reported that, despite the increasing levels of poverty over time observed in their analysis of the KIDS dataset, an observed improvement in well-being in new households formed

within the study period may be partially explained by access to the child support and other welfare grants.

Unlike the livelihoods of households in nearly all the rest of Africa, livelihoods in South Africa and in the study area are currently dominated by paid employment and social grants from the state (Carter *et al.*, 1999; Marcus, 1998; May, 2000). Less than half of the households in the nationally representative Project for Statistics on Living Standards and Development data were engaged in subsistence farming and the authors argue that agriculture seldom provides for all of the households needs and is of limited importance when compared with other economic contributions to households' livelihoods (Carter *et al.*, 1999; May, 2000).

4.9 Households, livelihoods and vulnerability within the study population

This section reflects on the household composition, livelihoods and vulnerability within the study population. The fieldwork for this study was conducted in the rural district of Umkhanyakude in northern KwaZulu-Natal, Southern Africa. The eastern coastal province of KwaZulu-Natal is one of the poorest and is the most populous, with fewer than 10 million inhabitants reported in 2003. Almost 80% of the South African population is black African, and they comprise 85% of the population in KwaZulu-Natal (Statistics South Africa, 2003a, b). The most commonly spoken language in KwaZulu-Natal is *isiZulu*.

The fieldwork for this study was conducted out of the Africa Centre for Health and Population Studies (Africa Centre), which is a Wellcome Trust funded Research Centre, affiliated to the University of KwaZulu-Natal. The focus of the research at the Centre, is the DSS that has been visiting households to collect household and individual level demographic, socio-economic and health data every six months since 2000. ACDIS covers approximately 11 000 households and 90 000 individuals including all of the households enrolled in my study (Muhwava *et al.*, 2007).

The households enrolled in this study were all situated within a fifteen-minute drive from the Africa Centre for Health and Population Studies offices, which are located at Somkhele. The study area includes households situated in rural areas, which during Apartheid would have been part of the state created homeland, designed to contain race groups while providing a false sense of self-governance. Nowadays the homeland is integrated into the rest of the province but local government is still controlled by the Tribal Authority. The study area includes a range of different communities including some that are rural communities. Other communities have fairly easy access to urban centres, some are considered peri-urban areas and there is an urban township called KwaMsane (Hosegood *et al.*, 2006). The town closest to the study area is

Mtubatuba, which is situated just off the N2 National highway, which gives the quickest access route to the closest port and industrial hub, Richard's Bay. The major city in the province, Durban, is 250 km south and is the second biggest city in the country and a major port.

Hosegood and Timæus (2006) suggest that like other rural South African households, households in Umkhanyakude are also characterised by both complexity and fluidness. 19% of all male household members are not resident, the large number of non-resident household members identified within the study provide evidence for this fluidity (Hosegood *et al.*, 2006).

Employment is most often found outside the area in neighbouring towns, such as Richard's Bay and St. Lucia, the city of Durban or as far a-field as Johannesburg in Gauteng province. In 2006, only 26% of the rural population within the study area were employed but almost 53% of those who lived in the urban parts of the Umkhanyakude district were employed (Muhwava, 2007). The results of the 1996 Census suggest that unemployment within the Hlabisa district was twice the already very high national average (Curtis *et al.*, 2001).

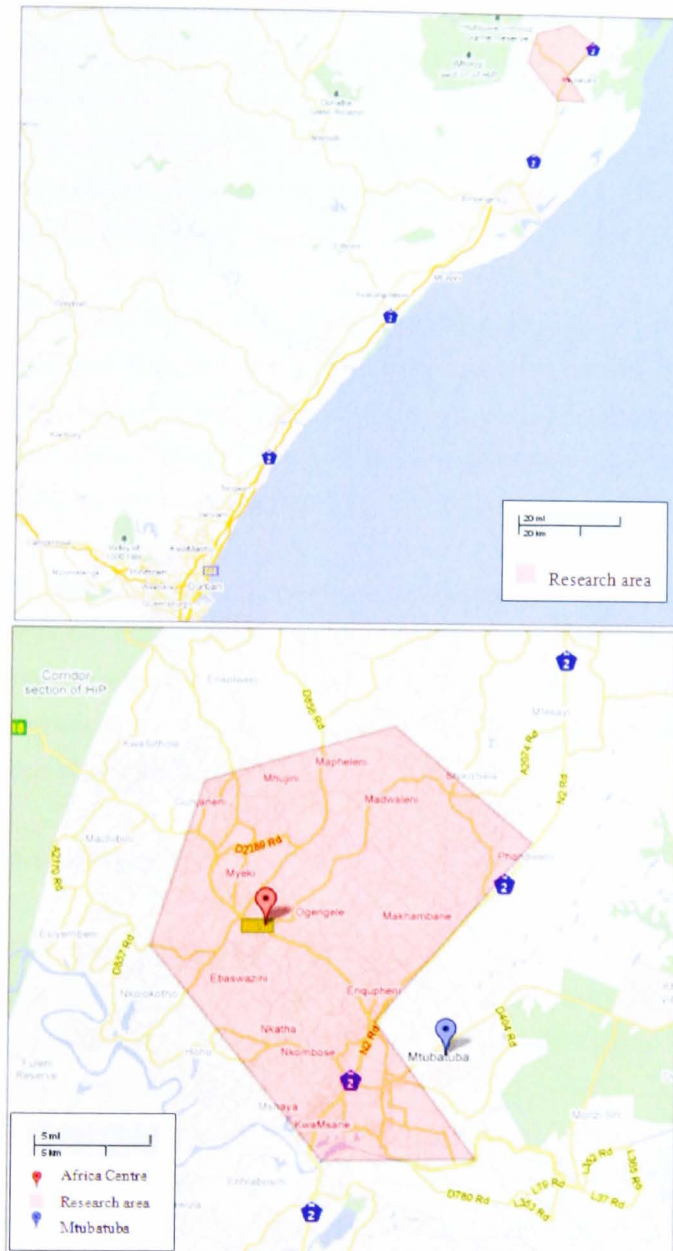
Very few households in the study area are primarily involved in subsistence farming, although about half of all households are involved in some sort of small-scale farming or livestock husbandry but very few of these were engaged in agriculture or husbandry for profit or to a level sufficient to supply the bulk of the household's consumption needs. About 44% of households within the study area produce crops for their own consumption, while a further 2.5% produce cash crops for profit only and approximately 9% produce crops for both their own consumption and profit (Muhwava, 2007). The findings suggest that few of the households are involved in subsistence farming as their primary economic activity. Analysis of the DSS data showed that in 2002 over half of the households enrolled in the study were receiving some sort of social grant. Of these 94% were getting at least one child support grant (Case *et al.*, 2005a).

In 2006, 42% of rural households enrolled in ACDIS in the Umkhanyakude district identified themselves as poor or extremely poor, whereas in urban areas, where employment was higher, this proportion classifying themselves as poor was only 18% (Muhwava, 2007). Analysis of the 1996 Census data suggested that poverty within the Hlabisa district was higher than both the national and provincial average levels (Curtis *et al.*, 2001).

Access to services and amenities, which is another indicator of socio-economic status, was also very low in the rural areas, with only 15% of households having access to private or public piped water and about half of households having a toilet or pit latrine. The urban and peri-urban areas are much better serviced. Another indicator of socio-economic well-being in the study

area is that in 2006 15% of households in the study area had adults who had missed a meal in the last year because the household could not afford to buy sufficient food (Muhwava, 2007).

Figure 5: Map of the area covered by the Africa Centre Demographic Surveillance Site, Hlabisa District, KwaZulu-Natal



Antenatal prevalence of HIV as calculated by the Department of Health (2009) for 2008, was 40 % in the study district of Umkhanyakude, which was the fourth highest prevalence reported

from all 11 districts in KwaZulu-Natal. Hosegood *et al.* (2004) reported a dramatic rise in mortality in the Umkhanyakude district from 1990 to 2000. Cause-specific mortality data collected from verbal autopsies in 2000 showed that 50% of adult deaths in this area were from AIDS.

ART has been available in the Umkhanyakude district since 2004 and an estimated 1800 people in the district were receiving treatment by 2006 (Nyirenda *et al.*, 2007). Analysis of verbal autopsy data from the Africa Centre Demographic Surveillance Survey (DSS) in the Umkhanyakude district showed that more widespread access to ART in the district had resulted in a substantial reduction in mortality – approximately a 22% reduction for women and 29% for men by 2006 (Herbst *et al.*, 2009).

Analysis of the Africa Centre DSS data in Umkhanyakude showed the complexity of household residency status and the relatively high proportion of household members that are non-resident. In the context of the extremely high prevalence of HIV in KwaZulu-Natal, the higher prevalence of infection in these non-resident household members may be counterproductive for rural households and their livelihoods (Hosegood *et al.*, 2006).

In the Umkhanyakude district in 2003/2004, both non-resident women and men household members had higher HIV prevalence when compared with resident household members. Among non-resident adult women, aged 15 to 49 years the HIV prevalence was 41%, while in resident women it was 27%. HIV prevalence was 34% in non-resident adult men and 14% in resident men aged 15 to 54 years (Welz *et al.*, 2007).

4.10 Summary

This chapter contains a background to the livelihoods of the households under study. It shows that the formation of the household, the social support a household relies on, the social security system and the rural economy all influence the livelihoods of rural South African households. These factors may also contribute to the household's vulnerability to various shocks and stressors or may even in some case act themselves as shocks and stressors. The analysis of literature and history in Chapters 3 and 4 helps to show the significance of the context and the components of the livelihood for the effects of illness and death on households and, therefore, will help to shape their response to HIV and AIDS.

This chapter also shows the factors that in combination with one another demonstrate the complexity and distinctiveness of the household and livelihood in the South African context.

While the fluidity of the household, access to social welfare and a reliance on waged labour are not individually unique to South Africa these factors together and along with South Africa's political, social and economic history contribute to the household and livelihood being quite unlike those found elsewhere.

Chapter 5: Methodology



5.1 Introduction

This study employs a number of different qualitative research methods. In-depth, retrospective and contemporary information about the experience of illness and death in households were collected in the Umkhanyakude district of Northern KwaZulu-Natal. Using different methods helped in building up and developing the household case studies, which were the major focus in analysis.

This chapter describes the way in which the case studies were developed and shows how this guided the collection of the data and led to the integration of the data collection and process of analysis. The selection process involved in the sampling of the ten households enrolled in this study is described, and some preliminary household characteristics are presented. The methods used in data collection are outlined and some of the practical and ethical problems confronted in the data collection are discussed. The case study development and methods used in cross-sectional analysis of the data are explored. Finally, limitations and strengths of the study design are examined.

5.2 Selecting cases

In this study, I enrolled a sample of ten households that were selected to reflect, the types of households in the area. The main criteria for household selection was that they had either

experienced the death of an adult from AIDS or they currently had an adult household member who was living with symptomatic or treated AIDS.

The key aim of this study was to interview households reflecting a range of AIDS illness experience, including death. It was considered important to include households where the PLHIV were currently receiving ART. In addition, the aim was to include those households where the sick household members failed to adhere, remained untreated or the therapy was ineffective. The study also included households where the sick household members were recipients of a disability and other social grant so that its effects on the livelihood choices of households could be studied.

In preparation for the research, I identified a number of possible sources for the identification of potential households for enrolment in the study. These sources included the local Catholic Church home-based care program, the verbal autopsy team at the Africa Centre and the existing data from the 'Household dynamics study'. These three sources were identified because they would provide households with a range of different experiences of AIDS illness. In addition, these sources were well-known to and had good knowledge of the households, thereby providing me with opportunities to be personally introduced to households. This knowledge also provided me with some background information about the households' experiences of illness and or death and their situation.

The home-based care programme (*Unkulunkulu Nathi*), operated out of the local Catholic Church. Although associated with the Catholic Church, the programme did not include church membership as a criterion for enrolment. Households in need are identified by the local voluntary staff working with the organisation through word of mouth. Households with members who are sick and are identified by themselves or other members of the community as in need of support are visited by the home based care workers. There are no clear eligibility criteria and the amount of support received and number of visits made depended largely on the availability of funds, resources and the home based carer. This programme helped me to identify households with a member who had AIDS. The inclusion of households with a person or people living with HIV (PLHIV) was important because it afforded an insight into the experiences of illness and the period preceding death in these households. The households affiliated to the home-based care programme were identified and introduced to me by staff working in that programme.

The verbal autopsy programme at the Africa Centre was identified as an important source of households that had experienced an AIDS death. The programme visits all households included

in the DSS to assess the cause of death. This team were therefore able to help me identify households that had experienced a death about 6 months before the start of data collection. This period was identified to ensure that the death was not very recent but not so long before that recall would have been difficult for the respondents. The verbal autopsy staff were asked to identify a number of households that fitted this criteria as well as being relatively easy to find and what they perceived as open to being interviewed about illness and death events.

The 'Household Dynamics Study' was conducted at the Africa Centre for Health and Population Studies between 2002 and 2004 to explore the impacts of illness and death on households (Hosegood *et al.*, 2007b; Montgomery *et al.*, 2006). My study was designed to build on some of the findings of this older study and further develop the analysis of the impact of AIDS on households. Households from this study were chosen because they fulfilled similar criteria for inclusion in my study. Access to the archived and translated ethnographic fieldnotes from these households provided historical information about their experiences of illness and death in the past. This allowed the development of case studies based not only on data collected as part of this study but also on ethnographic data collected between 2002 and 2004. The findings from the interviews did not contradict the data provided by the study. In addition the interpretations made about this data in papers written by the principal investigator and colleagues mirror many of the findings made in our study although they do as expected reflect an earlier period and context (Hosegood *et al.*, 2007b; Montgomery *et al.*, 2006).

The 'Household Dynamics Study' enrolled 20 households in 2002 based on having at least one household member who had recently died or was ill with characteristic symptoms of tuberculosis (TB) or AIDS (Hosegood *et al.*, 2007b; Montgomery *et al.*, 2006). Households in the original study were recruited by volunteer home-based care workers, nurses working for the Africa Centre Verbal Autopsy Project and also through other opportunistic contacts (Hosegood *et al.*, 2007b). Analysis of fieldnotes and genograms from the 'Household Dynamics Study' assisted in my choice of households for possible inclusion in the study.

The purposive sample selection of households from a variety of sources was particularly useful because their inclusion afforded us access to a greater range of households with household members experiencing different stages of living with HIV and AIDS. An introductory visit to a number of potential study households suggested to me by the home-based care workers, verbal autopsy nurses and that I had selected from the 'Household dynamics' sample was undertaken, after which the final study sample of ten households was confirmed. No limit was placed on the number of households visited and if more households were required, the plan was to add them.

In addition to the criteria of covering and as far as possible representing a range of AIDS experience, the household selection was based on a set of suitability criteria. I decided that I wanted to try to represent as far as possible households that varied in their size, structure, who the sick person was and their primary livelihood activity. Most importantly, due to the longitudinal nature of the study and the planned need for repeated visits to the sample households, it was imperative that households were willing to participate for the full duration of the study. The principal investigator and the research assistant (both female), who was a fieldworker, interviewer and translator, needed to feel comfortable about making repeated visits to the household to conduct at least five formal interviews, therefore, safety was a consideration. The safety infrastructure (radio security support) and use of four-wheel drive vehicles provided by the Africa Centre was only available during conventional working hours and I therefore made a decision to limit interviews to weekdays. Some areas within the local community had been identified as at high-risk of carjackings and so, to reduce risk to both my assistant and myself, I decided to exclude households situated along these routes. In addition to ensuring safety, while travelling too and from the household it was also necessary to ensure that both Zandile and I felt comfortable and safe within the households.

In total 15 households were visited for an introductory visit. In two of the 15 households identified for possible inclusion in the study the sick person was both elderly and suffering from chronic disease, diabetes in one case, they were therefore excluded because the focus of the study was on adults living with HIV or AIDS. One household was discarded because some young men in the household made overt and sexually inappropriate comments to us that made us feel uneasy about returning. Another household was situated along a road where several carjackings had occurred recently and was therefore excluded. One other household was excluded after two preliminary visits, as we were unable to find anyone at home during the day. All these household members were either away working or attending school. The remaining 10 households were included in the sample and no further households were visited or considered for possible inclusion in the study because it was felt that the 10 chosen fitted the eligibility criteria of the study and reflected as many of the required characteristics as possible.

The first five households, with at least one member sick or on treatment, were recruited with the assistance of the home-based care programme. One household from the Hlabisa sub-district that had experienced an adult death due to AIDS before June 2007 (six months before the commencement of data collection) was included in the sample. The nurses affiliated to the Africa Centre Verbal Autopsy Project identified three households, but only one of the three households identified from this source was included based on the study eligibility criteria.

Including households that had experienced an AIDS death allowed a comparison to be made with households dealing with the implications of illness or a member on treatment. All three of the households I identified as possible options for inclusion from the 'Household dynamics' study were enrolled in the study. These three households are of particular importance in exploring how contemporary responses and situations are influenced by the historical experiences of households.

A further household was selected after an opportunistic contact with a respondent who had been a participant in an earlier study conducted by a PhD student who had explored stigma in PLHIV. When she heard we were working in this community, she asked to be part of my study. She was included in the study as she was openly living with HIV successfully on ART and employed. This respondent was the only household member undergoing treatment enrolled in the study who had a job at the beginning of fieldwork.

5.2.1 Summary of sample

In summary, a purposive sample of ten households with members affected by HIV and AIDS was selected. All households were situated within the Africa Centre study area, in the Umkhanyakude district of KwaZulu-Natal. The sample consisted of: five households identified from the local Catholic Church home-based care programme, one household that had recently experienced a death identified by staff of the Africa Centre and one household who had a member volunteered to participate in our study. The sample also included three households originally part of the 'Household Dynamics Study' (Hosegood *et al.*, 2007b; Montgomery *et al.*, 2006).

Some key household characteristics of the enrolled households are summarised in Table 1. As argued in Chapter 4 households in South Africa are complex and characterised by a number of different forms such as those proposed by Wittenberg and Collinson (2007) in the Agincourt DSS and by various other national datasets. The patterns suggested by them proved particularly useful for categorising the Mabena and Shabalala⁸ households, where the relationships that existed between household members were complex. All households in the sample included some non-resident members. The households had a range of income sources and livelihood activities. All the households had members who received a social grant at some point during the

⁸ The names and surnames of all households and household members used throughout this thesis are pseudonyms.

six-month study period. The sample also included households with members working in the formal sector and others with nobody fully employed. Households were included from areas located in rural areas some with relatively quick and easy access to services such as clinics, hospitals and social welfare offices and others where travel to such facilities is complicated and takes a while due to distance or inaccessibility. Two households were situated on the outskirts of a peri-urban area, which although within walking distance of some services is still a 10 to fifteen minute taxi-trip to the town centre.

Table 1: Basic household characteristics

Household (fictitious name)	Household Sampling	Head of Household* (HoH) (age)	Type of Household**	HIV/AIDS Event (Relationship to HoH)	Situation	Main Income	Other Income
Ntuli	Home-based care worker	Female (63)	Three generations	Death (daughter, daughter and son-in-law) and Illness (grandchild)	Rural	OAP/ FCG	Sugar cane sales/ Casual Work
Nkosi	Home-based care worker	Male (52)	Nuclear	Illness (HoH and partner)	Rural	DG (new)/ CSG	Casual Work
Mabena	Home-based care worker	Female (60)	Three generations	Death (brother) and Illness (daughter and brother)	Rural	OAP	None
Sibaya	Home-based care worker	Male (65)	Nuclear (adult children)	Illness (son)	Rural	Self-employed/ CSG/DG	Selling vegetables/ Sugarcane
Bhengu	Home-based care worker	Female (56)	Three generations	Illness (daughter)	Rural	CSG	None
Zondi	Ethnographic study	Male*** (21)	Sibling household	Death (parents)	Rural	FCG/ Life insurance	None
Dube	Opportunistic contact	Female (90)	Three generations	Illness (daughter-in-law) and death (son)	Rural	Salary/ OAP	Selling beer
Dlamini	Verbal autopsy nurse	Female (70)	Multi-generational	Death (children) and illness (daughter and grandchild)	Rural	DG/ OAP / CSG	Selling snacks at school
Shabalala	Ethnographic study	Male (unknown)	Complex related	Death ()	Peri-urban	FCG	None
Gumede	Ethnographic study	Male (64)	Three generations	Illness (grandchild) and Death (son)	Peri-urban	OAP / FCG	None

* Household headship (HoH) was self-reported by respondents

** (Wittenberg *et al.*, 2007)

*** Female non-resident head.

The study sample thus represent a range of possible situations, contexts and backgrounds which increases the possibility of being able to generalise the findings and interpretations formulated by the study to other similar areas and contexts and, therefore, promotes the wider resonance of the research (Schofield, 2002). Although extreme compared with the average within this community, in terms of the poverty, the study households have endured or of the severity of the disease they have experienced, these households are broadly representative of other households in the Africa Centre study area.

As I began to read and collate the findings from the household interviews, the importance of intra-household relationships and the way in which these affected household dynamics, quickly became apparent. Initially I had not considered the importance of intra-household relationships as much as that of inter-household relationships and dynamics. Similarly, increasing familiarity with the households and their unique contexts revealed that the formal separation between directly and indirectly affected households, as initially conceptualised, presented difficulties. While developing the research protocol for this research, I had assumed that the distinctions between directly and indirectly affected households would be easy to make and that I would need to further sample indirectly affected households in order to understand their experiences. The fluid nature of household membership meant that the death or illness of a non-resident household member in another household directly affected the rural household. At least five of the recruited households were directly affected by the illness or death of a resident member but were also affected by the illness or death of a current or previously non-resident household member. All of the households selected in some way or another exhibited signs of being affected directly by both the sickness and death of its own members or by non-residents and other affected households.

5.3 Data collection and initial interpretation

My intention in this research was to collect retrospective information from respondents in five formal semi-structured interviews, each of which covered a different topic (see Section 5.3.2 and 5.3.5). The research questions and a predetermined topic guide (see Appendix A for an example of an interview guide) were used to direct the anticipated subject matter of the interview. The aim was to utilise participatory methods in the first two household interviews in order to collect data about the experience of households during the previous five years. The anticipated outcomes of these first two interviews in each household were to be a household genogram and household event map. The third, fourth and fifth in-depth interviews with the household were designed to continue to elicit relevant retrospective data but also to observe their contemporary experiences of illness and death. I had also planned to conduct interviews

three to five with two separate respondents in every household in order to increase the sample size. All adult household members were considered potential respondents, including those living with HIV and AIDS, who are often difficult to interview. These PLHIV are particularly important because they may actively participate in decisions within their households and their perspectives and understanding of the disease, as well as of how the disease affects families, need to be considered. The data collection process was designed intentionally to increase the variation in types of data collected and to construct a multi-layered story about the household members and their experiences.

Data were collected using a number of different qualitative methods with the aim of developing in-depth case studies of each household, recording their context, situation and experiences.

Using a range of qualitative research methods permitted data to be collected about the experiences of the household as a whole but also about the individual experiences of household members. Using data from multiple sources and using different interviewing methods to collect the data is identified by Stake (2000) as facilitating the triangulation of research findings, therefore maximising the validity of the data being collected. Having valid data allowed for detailed household-level analysis of household dynamics and enabled individual-level perspectives to be disaggregated from the data. The information obtained provided an understanding of processes and responses to events and episodes that are observed (Mason, 1996).

In practice, the process of data collection was not static and evolved from the original plan. The change in plan was due, in part, to problems and obstacles confronted in the field. It also changed as we adapted successfully to the practicalities of data collection.

5.3.1 Informal household visits, non-participant observation and reflexivity

All the households were recruited in the first two months of fieldwork. Although there were five and, in one household, six visits at which formal interviews were conducted, the households were visited on many more occasions during the study period. Appointments to see people often did not take place because participants were not present for visits or were not available to be interviewed for a variety of reasons. People were encouraged to inform us if they were too busy or not keen to talk to ensure people did not feel coerced into being interviewed. There was ongoing emphasis that their participation in the study was valued. As a result, appointments often needed to be rescheduled. The outcome of this was that the respondents seemed to value our flexibility.

Although visits where interviews could not be conducted were frustrating, these visits provided an unintended useful research opportunity. They were a means to retain contact with the household and to be kept up to date with their current and ever-changing household dynamics and living circumstances. These informal visits were an important source of information about crises and events that occurred in these households in between formal visits, and provided the respondents with the opportunity to talk freely and share their immediate experiences with us. The fact that we did not rush our visits and were interested in all aspects of their lives was also important. It created a space for the development of trust between the researchers and the respondents. It also allowed people to feel comfortable enough to share private, sensitive or personal information openly. The informal information obtained was particularly important in further developing the household event maps and providing a background and context for each household and the case studies.

The observation of the physical state of the built environment, both subjectively in terms of personal expectation and in comparison to other households for example in cleanliness and apparent care taken and in terms of objective observation such as incomplete building works, in the different types of homesteads visited was also possible in these visits. Things like the state of the animals present on the property and the use of available land helped to inform questions about the household's livelihood.

I observed where possible the physical well-being of the HIV and AIDS infected and affected adults and their children. On-going and repeated observation afforded some indirect insight into the socio-economic status and dynamics of households, without the need to ask these sometimes-invasive questions directly. This indirect information enabled and prompted the inclusion of occasional probing questions in the process of validating our observations. I was also able to compare and validate the responses given by household members to assess whether they matched the observations. For example, I could observe whether, where and what various household members were eating, whether the severity of their illness impaired their ability to perform household tasks, and how other household members responded to the illness or death.

Non-participant observation provided insight into the physical situation of respondents but also allowed observation of their emotional response to questions in context. It also facilitated the observation of interactions and the dynamics of relationships, within the household, between households and with people from outside the household. Roles and activities with which respondents had not identified being involved, such as gardening and farming were observed and then consequently explored in greater depth in the interviews. This informal process enabled us to observe people engaging in the activities, which they had spoken about in the

interviews. We were able to observe routine everyday household activities, including the tasks or chores people undertook when not being interviewed.

Issues that emerged, problems and different and unexpected interpretations of questions during the interviews and visits were recorded in fieldnotes and memos. These additional responses are noted as important benefits by the proponents of using mixed methods of data collection (Ezzy, 2002; Seale *et al.*, 1997; Silverman, 1998). The additional informal information obtained included recording personal notes about my perceptions of the interview space and context. My emotional reactions to interview situations or interactions with respondents and reflections of these perceptions and my preconceived ideas were carefully considered and after reflection were recorded. Detailed fieldnotes were recorded after each household visit and interview. This process, along with non-participant observation, made the process of data collection and analysis reflexive.

Sensitivity in approaching qualitative data collection, collation, analysis and reporting has been identified as a very important process in qualitative research. Awareness encompasses sensitivity to, and knowledge of, the literature, but also an awareness and acceptance of the experience the researcher brings to the subject (Murphy *et al.*, 1998). For the researcher to be reflexive requires an understanding and acknowledgement of the social reality of the respondents, specifically in relation to that of the researcher's own reality (Mason, 1996). Personal reflection by the researcher and critique of the research method contributes to an increased validity and transparency of the processes, by acknowledging weaknesses in the interviewer or researcher (Seale *et al.*, 1997; Silverman, 1998, 2005).

5.3.2 Open-ended structured interviews (Interview 1 and 2)

The first two interview visits to each household were intended to be participatory household exercises with as many household members as possible. Participatory exercises were planned to include a range of household members in order to pool information from them and produce a genogram as well as preparing a household event map for each household.

The participatory data collection process proved to be very difficult for a number of reasons. My research assistant, who was conducting the interviews in *isiZulu* under my guidance found the concept of data collection in a participatory way difficult to understand and implement. Despite numerous role-playing exercises and discussions in a practice setting, she struggled to fulfil the demands required for the participatory research. An attempt to conduct these participatory exercises using the research assistant as an interpreter proved very time consuming and the

delays between the English and the *isiZulu* translations often meant that the meaning was lost in translation. As a result the respondents lost interest very quickly, interrupting the flow of the interview.

I also discovered that participatory exercises were limited by the literacy levels of the respondents. Those respondents with large complex family genograms found it difficult to understand which relationships would interest me. Ultimately, it was decided that it was easier in terms of time to construct the genograms from information collected from the households and then to verify the information with the households at follow-up visits. The collection and collation of the household information was also used to create the household event map. These maps proved a very useful tool to conceptualise a timeline of events and experiences for each household.

In addition, the respondents themselves and their own prior experiences of research influenced the interview process. All the households are part of ACDIS study area and had specific experiences and expectations based on the ongoing routine data collection visits undertaken by the Africa Centre surveillance teams. This proved both beneficial and a hindrance in this study. On the positive side, the respondents were open to answering questions about, illness and economic issues of the household. They were also receptive to receiving visits from researchers that had a link with the Africa Centre in their households. However, households were accustomed to responding to the structured questionnaires used in the quantitative research and it required time and effort to elicit detailed responses to our qualitative and in-depth research questions.

In retrospect, not enough prior consideration was given to the complexity involved with conducting these interviews using participatory methodologies. Participatory research techniques have been used successfully in a similar context and reported by Adato *et al.* (2004). These were one-off sessions, undertaken by an *isiZulu*-speaking researcher who conducted the participatory interviews over a long time. In my study the participatory component of the research was expected to be completed during the first of at least five household visits without wasting unnecessary time for the households. These sessions all took less than an hour.

5.3.3 Genograms (Interview 1)

Detailed information about the household, its members and their characteristics were collected systematically from each household during the introductory interview using a standardised semi-structured topic guide. The interview in each household was recorded using a tape

recorder. During the interview, I made extensive notes and a household genogram was drawn freehand. This hand-drawn genogram was later digitised and continuously updated after obtaining more household information from the translated transcripts of each household interview. The genogram provides a visual record of important details about how individuals within the household are related to one another. Initially, information about currently resident household members, including their name, age, marital status, role within the family, employment status, genealogic relationship to other household members, and whether the individual received a social grant was recorded on the genogram. The same personal socio-demographic data, including their relationship to resident household members, their current normal place of residence and with whom they normally resided was collected for non-resident household members. Information concerning both resident and non-residents who had died within the five years preceding the study period, their relationship to other household members, marital status, age and when they had died was also collected.

The genogram served as a means of recording family data and helped in the process of collation, reorganisation and interpretation of family relationship data. It provided a base on which the household case study was subsequently constructed.

The genogram was particularly useful in establishing relationships between household members, inter-household relationships and sorting out where non-resident and residents who have multiple household memberships fitted into the household. Collecting background information about the situation and experiences that exist within households without asking too many personal and involved questions assisted in creating a more relaxed environment for further interviews. The type of data needed for the genogram was not too unfamiliar or threatening for household members to provide during the introductory ice-breaking interview.

The genogram was also a useful tool to depict changes in the household during the six-month study period. Figure 6 shows the genogram of the Bhengu household at the time of the first household visit as an example. The Bhengu household was selected with the assistance of the home-based care programme. Nomsa, the head of the household, was permanently resident on the property where we visited her. She lived with five of her six children and five of her grandchildren. Until his death in 2007, she had lived on the property with her husband, John, who was also the father of her two youngest children.

Nomsa had lived with two previous partners with whom she had conceived her other four children and in whose households she had belonged as a non-resident member during her relationships with these men. Nomsa's oldest child, a daughter, Lungile, was a non-resident

household member and, at the time of the first interview, was living in Richard's Bay where she was training to be a nurse.

Figure 6: Genogram of the Bhengu household, January 2008

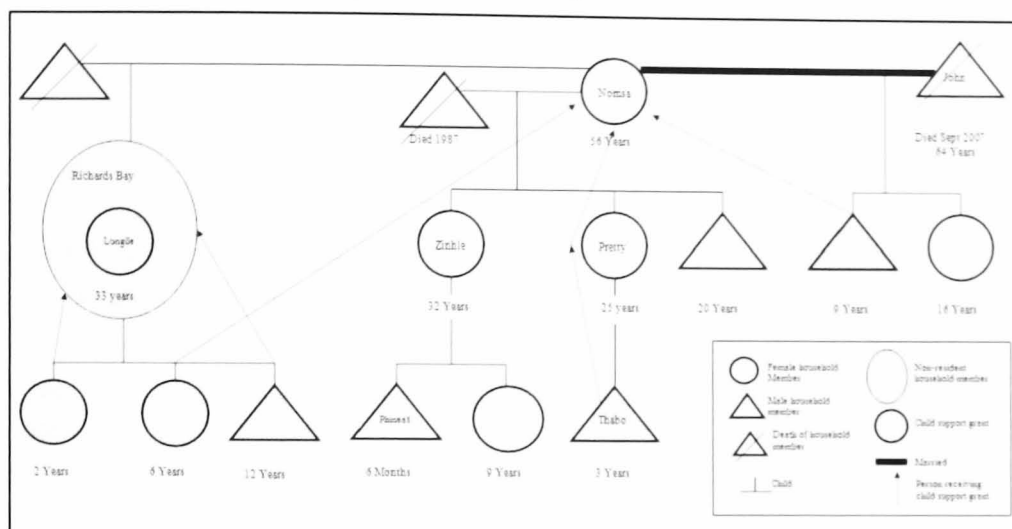
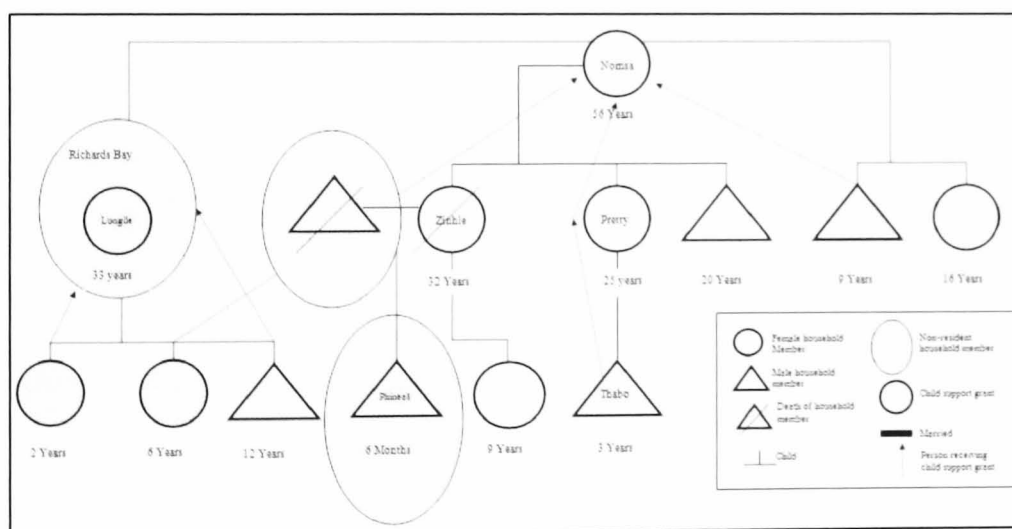


Figure 7: Genogram of Bhengu household, July 2008



No resident member of the household was formally employed at the time of our first visit and the household managed financially on three child support grants collected by Nomsa - one for her youngest child and two for her grandchildren. Nomsa's second daughter, Zinhle, was HIV-infected and had advanced stage AIDS. She had returned home from Richard's Bay only a week before our first household visit in January 2008 because of the severity of her illness.

During the subsequent four formal visits to the household, new household members and respondents not represented on the initial genogram, who may not have received any mention by the household members, were added. Changes in household composition or information relating to household members that occurred during the study period were also recorded. At the conclusion of the data collection period, there were two household genograms for the Bhengu household, one constructed following the first household visit (Figure 6) and the second genogram constructed using updated household information after the final household visit (Figure 7).

Figure 7 excludes Nomsa's deceased partners and focuses directly on changes that have occurred since the first household visit in January 2008. Zinhle, who had been very sick on our first visit to the household, subsequently died a month prior to our final visit. The father of Zinhle's baby (Phineas) was not a member of the Bhengu household. He too died, within two weeks of Zinhle. At the time of our final visit, Phineas was therefore temporarily living at the home of his father in order to attend his father's funeral, in accordance with Zulu custom.

This example is an illustration of the usefulness of household genograms in tracking the dynamic demographic changes in family structure observed in this study. The non-demographic changes in the household are much harder to document and track longitudinally. The household event map was necessary to assist with filling these gaps of information needed to eventually construct the household case studies.

5.3.4 Household event map (Interview 2)

In the second scheduled interview, the household was asked to identify events and episodes, occurring during the five years preceding the interview that were considered by the interviewees to have exerted an important impact on the household. If the household failed to mention illness or death events as was the case in two of the households then I prompted asking specifically about episodes and events relating to the illness or death of household members or the household's livelihood. The households that required prompting may have been less likely to talk about illness in an impromptu way reflecting either the fact that they felt it was less important than other events or episodes or they may have been reluctant to talk about these issues. This information assisted in the creation of a household event map, which is a time-lined recent history of the household and its members. The households were encouraged and guided to identify both positive and negative events and episodes that they perceived as significant.

The household event map shown in Figure 8 details specific life events and episodes mostly relating to illness and deaths experienced by the Bhengu household within the last five years as well as during the period of the study. Thus, for example, it shows Zinhle's progression into illness and records her employment history during this time, showing how her illness affected her employment status. The information becomes more detailed in the last six months of the map because it is based on not only the household and individual reporting their history, but also direct observation of household experiences obtained during the course of the fieldwork. The household event map also aids in identifying events linked to people outside of the household, both those that are not members (inter-household relationships) and those that are categorised as non-resident household members (intra-household relationships). In the map, the inter-household relationships are depicted in the blocks surrounded by double lines.

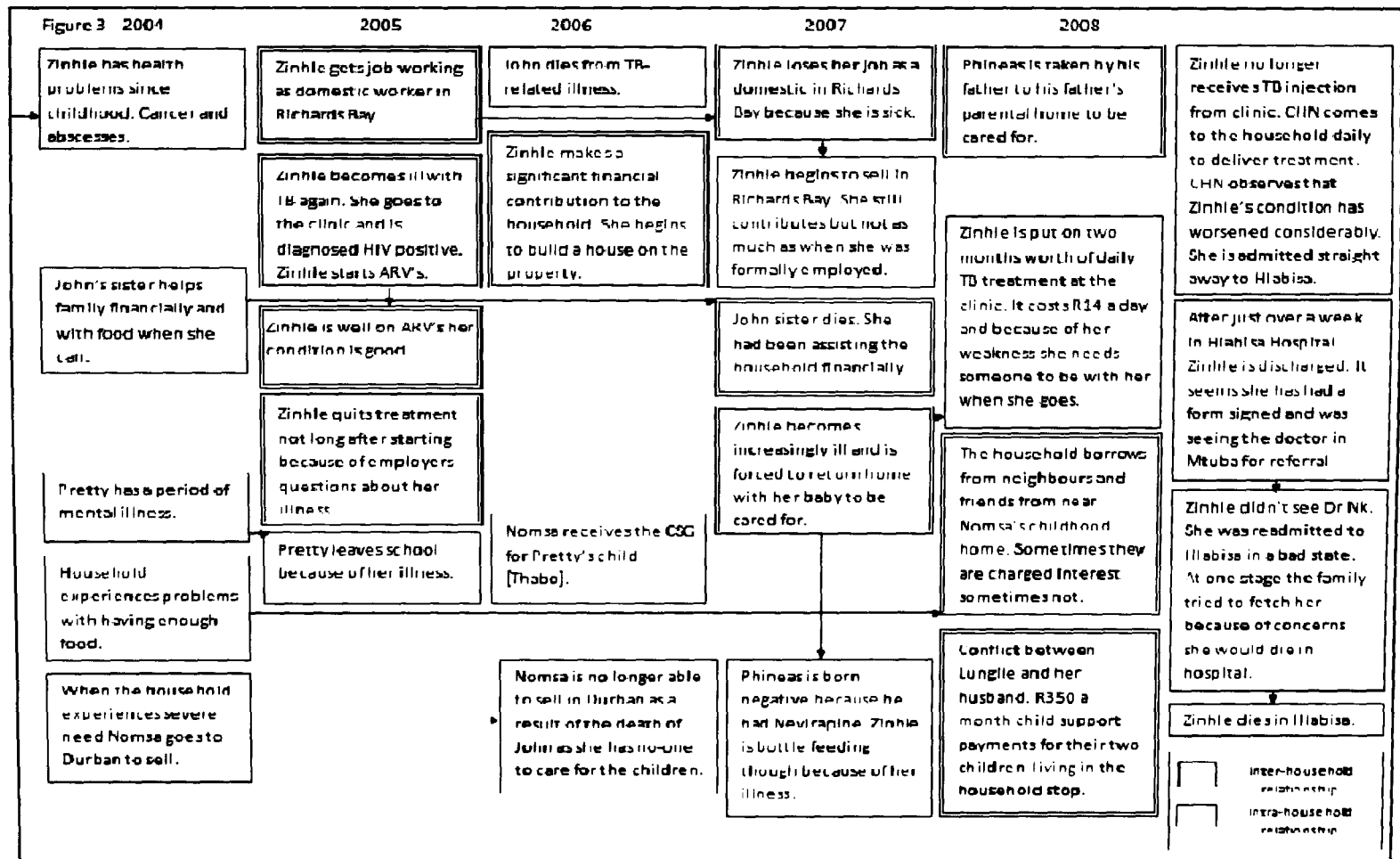
The household event map was developed by Adato et al. (2004) and used successfully to capture changes to and significant events affecting the household within a specified period. Their focus was on poverty dynamics but the methodology is applicable to other topics and is particularly useful to track changes within a household. The household event maps in this study were helpful in conceptualising the way in which periods of illness or deaths interact with and influence other episodes and events within the household. The visual nature of the household event map allows for changes within the household to be plotted and the relationships between the events surrounding the illness and death of an adult household member to be shown.

5.3.5 In-depth interviews (Interviews 3-5)

As suggested by Mason (1996) using in-depth interviews enabled the collection of complex data in relation to specific actions and behaviours. Interviews not only facilitated access to information concerning the livelihood of each household but also information about intra- and inter-household dynamics and, importantly, how each household and its members experienced HIV and AIDS (Murphy *et al.*, 1998).

In conceptualising the study, I anticipated that the in-depth interviews, (3 to 5) were to be used to collect retrospective data about the household and its prior experiences and history relating to illness and death. Through general discussion and contact with the household, it became apparent that almost unintentionally, prospective data about the household and their current experiences was also being elicited from the interviews. Therefore, in each interview I collected not only the planned retrospective data but also information relating to the current experiences of the households.

Figure 8: Bhengu household event map, 2004 to 2008



The main purpose of the third interview was to interrogate the responses that the households had provided in the first and second interviews and to explore the events and episodes they had identified as being important. This third interview included information on the impact of HIV and AIDS on the household generally, and on its livelihood more specifically. The topic guide (see example in Appendix A) was used as a guide but the actual questions were determined by the experiences that the households themselves had identified as important. The aim of this interview was to understand how people dealt with these episodes and events, why they thought they had happened, what the households' or individuals' response had been, and why they had responded in a particular manner. Other issues associated with illness and death such as treatment, healthcare, funerals, social grants and livelihoods were explored.

In two of the households who came from the 'Household Dynamics Study', the first two interviews were combined into one because I already had a comprehensive idea about the history of the household and as, therefore able to construct a genogram and household event map using that information. Every subsequent interview was modified after reflecting on the translated transcript of previous interviews. The information provided by the respondents themselves in preceding interviews was used to help inform the questions.

The fourth interview was used to explore ideas about intra- and inter-household relationships and social capital, particularly in relation to the events and episodes surrounding death and illness in the household. Issues such as whether households received help, from whom, and who they expected to receive help from were investigated. Other issues were explored including finding out the nature of the relationship they had with different households, individuals and who they themselves had helped. I was also interested in understanding the nature of the assistance that households received from various sources and what made people, other households or organisations decide to help each other.

The final interview was an opportunity to clarify any missing information needed to answer the research questions and to check any conflicting or confusing information collected from the households. A few other households were interviewed six times because new themes emerged as being of importance during the initial analysis of the data or missing information or points of clarification emerged during more in-depth reading, analysis of the transcripts and reflection on fieldnotes.

5.4 Practical and ethical issues in data collection

The close relationships we developed with individuals and households made it hard, on occasion, to remain an objective observer of their experiences. The nature of the data collected

changed from purely retrospective as planned to prospective data collection in practice about the illness and death that the household was experiencing at the time of fieldwork. This change in focus although subtle posed additional challenges. Instead of just asking historical questions about illness and death and the impacts, we were asking about things that the household was currently dealing with. Households were very vulnerable, had very high levels of unemployment, poverty, and therefore were already vulnerable to the harsh realities of illness and death.

The experiences of severe illness and death in the study households had the potential for devastating socio-economic outcomes and emotional implications. The amount of time invested in and personal engagement with the households meant that maintaining the objectivity and distance required by researchers, within households facing such harsh realities was difficult. People were very sick and two household members died during the study period. This created a tension for me between the scientific aims of the research and the human aspects of the respondent's lives. My engagement with the study participants was often a very difficult and emotional experience.

In dealing with households, I was confronted not only with my own desire to help but also with a certain level of expectation of providing material assistance from the households themselves. I therefore tried to help the households in practical ways that did not involve financial compensation, which was understandable for financial reasons and project longevity discouraged by Africa Centre policies. In three of the households, assistance was provided by transporting the sick person to the clinic or hospital because they were, too sick to travel or could not afford transport costs. I helped one of the sick household members to secure a disability grant by telephoning the Department of Social Development to follow up on the status of her grant application. I gave households that experienced a death a monetary donation in line with Africa Centre Longitudinal Study policy on funeral contributions. We also tried to provide useful information to households by answering questions about important matters, such as ART and social grants. Household members were also referred to the correct service when appropriate. At the end of the study, two of the households that were really struggling were referred to and enrolled in the Africa Centre home-based care programme, linked to the PEPFAR-funded ART provision programme, which operated from the state-funded local primary health care clinics.

The practical support provided to households was a way of reciprocating them for their time and effort in the study. This support enabled us to help relieve, in some small way, the harsh realities being dealt with by the households. It also relieved, to some extent, the pressure on us to be

impartial observers and some of the personal tension between the scientific aims of the research and human lives under study. The practical support, along with the continuous involvement in the study households, helped to develop the trust of the respondents and their wider households. Our involvement with respondents and household members, while providing practical support, was an opportunity to observe an important part of people's day-to-day lives, for example, by accompanying them on a trip to the clinic and presented very useful opportunities for informal conversation.

5.4.1 Ethical issues

The University of KwaZulu-Natal, Humanities and Social Sciences Research Ethics committee and the London School of Hygiene and Tropical Medicine, Research Ethics Committee, granted ethical approval for the study. The proposed research, including a preliminary research topic guide, was presented to the Africa Centre Community Advisory Board (CAB) for their comments and advice before fieldwork and data collection commenced.

Receiving informed consent from respondents has been highlighted as an important ethical issue in the collection of data, especially sensitive data, in both previous research activities and also by those involved in the development of qualitative research theory (Mason, 1996; Wilson, 1992). Respondents were informed about the nature of the research in general; its aims and how the information they provided would be used. Respondents were also informed about their rights to refuse to participate at any time, not to answer specific questions if they so wished and to ask questions concerning the research at any time. All household members being interviewed were required to sign a form consenting to being interviewed and showing that they had been briefed about and understood what the research involved. The information contained in the form was also discussed and explained in detail in *isiZulu* in the initial interview with each respondent (see Appendix B)(Wilson, 1992).

Every effort has been made to ensure the privacy and anonymity of all respondents (Wilson, 1992). All personal information, that would have enabled identification of the respondent and their households, have been removed from questionnaires and the transcripts of interviews; each household and the respondents within each were provided with a unique identifier for the study. In constructing the genograms, names were collected so that, during future interviews, we could use the genograms in order to assist us see how various household members fitted into the household organisation as a whole. All the respondents and their real family names have since been removed from the diagrams, transcripts and translations and replaced with pseudonyms. All demographic data and any details that would assist in the immediate identification of a

household were also removed. One master list of all households exists, with the names of participants and their unique identifiers. The list is retained in a separate electronic password protected file. All transcripts and audio files have been electronically password protected and only those working directly with the data have access to them. Informed consent forms and other paper records have been stored in the data archive at the Africa Centre.

Photographs were taken to provide context and a sense of the setting, households' physical circumstances and the individuals being interviewed. Permission for photographs was sought in the informed consent process and then again verbally if photographs were actually taken. The inclusion of photographs of people was considered carefully and it was decided that no individuals pictured would be linked to any sort of personal information. The decision was also made to include the pictures of individuals in the thesis and in no other disseminated versions of this work. The copy of the thesis has limited circulation and is available to quite a specific academic and scholarly community in the United Kingdom where it is very unlikely that the participants would be recognised. The only risk is that these people might be recognised by other research staff involved in the collection of data from these households but these people would be bound by similar ethical restrictions about the disclosure of personal information to myself.

5.4.2 Disclosure

Prior disclosure of the respondents' HIV status was necessary in order for us to discuss the implications of the illness and treatment of the index household member and to ensure I sampled only households affected by HIV and AIDS. Prior disclosure was partly addressed by the inclusion of households linked to the home-based care programme. In order to be part of the programme it was necessary that at least one household member was acknowledged to be ill due to AIDS, which involved some level of prior disclosure to outsiders. At no point did we ever ask household members directly to disclose their HIV status or the cause-of-death of other household members to us. We talked generally about illness and death and respondents often voluntarily disclosed their HIV status or that of other family members to us either directly or indirectly. The HIV status of respondents was disclosed to us in seven of the ten households.

In one household, the home-based care worker reported the HIV-status of a respondent to us but we did not discuss their reported status with the sick person or their family in order to prevent disclosure to other household members. In the other two households, we knew that people in the household had died from AIDS causes from the ethnographic data previously collected from the household. In these households, we were unable to discuss the precise causes of illness and

death, because although we knew the respondents' HIV status, this was not disclosed to us with the knowledge of the household. This reality did not seem to limit the willingness of people to talk about the consequences of these illness episodes, death and other events that were of importance to the study. In fact, many of the respondents were surprisingly open about their HIV-status, and were not constrained when the subject of illness, treatment and death was raised.

With the respondents who had disclosed their HIV-status to us, their HIV-status or issues, for example, treatment, were only discussed with them directly or with other household members that they had informed us they felt comfortable being part of such a discussion. Sensitivity about respondents' HIV status was important because, even if the person living with HIV and AIDS had disclosed his/her status to us, other household members may not have been aware of their being HIV infected and the issue of stigma in KwaZulu-Natal is still a major attitudinal problem.

5.4.3 Sensitivity in data collection

The need for sensitivity in the collection of data is highlighted by the stigma and marginalization that is still associated with HIV infection in South Africa. Research experience reveals that the development of trust is an essential element in facilitating the collection of sensitive information (Christensen, 1992). Visiting the households regularly, including for non-interview visits, helped to make the respondents and their families feel trusted and valued. Strong relationships were established with the households and their members and these facilitated the collection of sensitive data. People sometimes contacted us to relate events that had happened in their lives and in many instances seemed genuinely happy to see us when we conducted home visits. Some respondents became quite emotional when we told them that we would be leaving and not visiting them again at the end of the study period.

Researchers also highlight the importance of the environment in which data is collected (Christensen, 1992). Having a safe and private environment in which to conduct interviews was a difficult issue to address in this study. It was constrained by the way in which the homesteads were organised and by the areas in the household that people felt comfortable for us to access. On occasions, when other people were present in the household, respondents clearly did not feel comfortable talking to us. In these cases the visit was simply abandoned and the household returned to at a later stage. We also found that it was necessary to be flexible about where we conducted the interview. Although almost all the respondents were happy to be interviewed at their homesteads, we did visit one respondent in town because she was working and could not

see us at home during the week. We visited her three times during her lunch break in the town where she worked and once in her household while she was on leave from work.

Power relations between interviewer and respondents pose a potential ethical problem that was considered when planning the study. Research has highlighted the impact of inter-personal relationships on access to information, specifically the benefit of being introduced by and attached to a family within the local community, thereby reducing the differences and separation between the interviewer and the respondents (Francis, 1992). Someone known to them introduced all the households to us. In the households sampled by the Verbal Autopsy nurses at the Africa Centre and the 'Household Dynamics Study', an ACDIS fieldworker who had previously visited the household accompanied us on the introductory visit. The home-based care worker and area co-ordinator introduced us to the homes suggested by the home-based care project. Having somebody to facilitate household entry proved particularly important in the South African setting where divisions of class and race, relevant to all social research, are compounded by the political history of the country (Francis, 1992).

Respondents must have been acutely aware of the racial, class and geographical divisions between them (black rural) and me (white urban) that are unique to the South African context. In order to try to break down these class and social role conventions to ensure that they did not affect interactions with the household, I researched customs within households and possible household expectations. For example during all household visits I wore a skirt, which some people, especially older more traditional women, deemed acceptable behaviour. I felt that it was necessary to make people feel comfortable and respected by my presence in their home.

Multiple visits to the household were planned in order to establish rapport between the interviewer and the respondents. Previous qualitative research and theory has indicated that repeated contacts between interviewer and interviewee can be of assistance in bypassing the public version of accounts and accessing a more private version of household events and experiences (Murphy *et al.*, 1998). The public version of the story is what a person feels comfortable sharing with everybody. The private version of their story is that which they may not want everyone to know, sometimes relating to personal issues.

The original research plan was to individually interview at least two different people within the household for the three further interviews (interviews number 3 to 5). In practice, this was not feasible, as it would have required separating two or more people from each other within the home in order to conduct separate interviews. This was practically difficult to achieve, as in most cases there was not a separate space to conduct private interviews in the household.

Separating members for this purpose could have introduced an element of suspicion around these data gathering home visits. It was more appropriate to work with people in a way in which they felt most comfortable. In almost all the households, more than one person was interviewed. People however were not necessarily interviewed together at the same time, more than one person was interviewed in the household at different times or one respondent was interviewed repeatedly in subsequent interviews. It was easiest to get on with whatever worked for the household and difficult to direct who was involved in the interview.

I actively tried to speak to more than one person in each household though this was not always possible. The reason for wanting to repeat the same questions to more than one person per household was to increase the sample size and thus vary the acquired perspectives and reported experiences of different individuals in the household. The perspectives of different household members may vary significantly depending on their individual role, position and experiences. Montgomery *et al.* (2006) analysed the 2002/2004 ethnographic data from the 'Household Dynamics' study done at the Africa Centre. The results suggest that a bias existed in the roles that men were reported to have in the household. The role of men in caring and household activities relating to HIV and AIDS was underemphasised by both respondents and fieldworkers who were for the most part women. Although, in practice, I was unable to conduct each planned interview with two separate individuals, each being of a different gender, we did attempt to interview people of different genders and ages within the household. I also interviewed more than one person, either together or at different times in all but one of the households, where there was only one adult available to be interviewed.

The flexibility and informality of the interview process and the topic guide allowed us to ask similar questions at each meeting either of the same person or of different people. Having this flexibility helped to obtain insights into the varying and changing perspectives and stories of household members. In this manner, I was able to verify facts, to assess whether the stories people told had changed, and to elicit more and better information. Each genogram and household event map was constantly updated as new data were collected from the households. Constant and formative analysis of data allowed me to check for consistency and to test theories with respondents as I reflected and interpreted what I was learning from the interviews and observations (Ezzy, 2002; Green *et al.*, 2004). Adapting and contextualising interview questions has been identified as being useful in the collection of sensitive data and can be achieved by repeating interviews, either after the formative analysis or once all the household data has been collected (Christensen, 1992; Ezzy, 2002). The process I followed further highlights the value of multiple visits to the household.

5.5 Data management

All interviews were recorded using a tape recorder and then transcribed in *isiZulu*. I then reviewed all the transcriptions along with audio. The interview transcripts were then translated. Again all translations were reviewed by me and potentially difficult passages were discussed. Although I grew up in Northern KwaZulu-Natal and have a basic understanding of *isiZulu*, I am not fluent in the language. In order to conduct the in-depth interviews, I required the assistance of an interviewer and a translator, who conducted the interviews in *isiZulu*. I had initially planned to conduct the interviews myself using an interpreter. After some role-plays and pilot interviews I changed this approach. Given the prior experience my research assistant had as an interviewer and translator in similar qualitative study settings, she was able to conduct the interviews herself. Interpretation obscures and interrupts the flow of the interview and would have meant that the interview took twice as long compared with them being conducted directly by the research assistant. Although it was possible for me to follow the conversation, ask questions and guide the conversation, it was difficult to control how the questions were asked. The development of a question guide in *isiZulu* before each interview allowed questions to be formulated with the specific household and their experience in mind and further helped me to give specific direction to the interview content. The topic guide was used as a guide to formulate the questions and topics covered in each interview. Key prospective and explanatory questions were added.

Translation of transcripts from one language to another is not an objective process (Temple, 1997). Translators not only make literal translations of the words but also afford insight into the nuanced meanings of words and phrases. The desired outcome of translation in this research is for a comparable rather than a literal meaning, therefore the process relies on the knowledge and understanding of the cultural context of the translator and the concepts specific to it in order to provide meaningful translations (Birbili, 2000; Temple, 1997). Hence, it was important that the interpreter engaged in the study was a first language Zulu speaker, born in the study area and who spoke good English. This enabled her to contribute insight and context-specific knowledge and interpretation. The potential difficulty with using a local translator is that this person acquires personal and privileged knowledge of people in her community. There was a risk that household members or individuals important to the household were known to the fieldworker. This was discussed before commencing fieldwork as was the importance of absolute confidentiality. When the fieldworker did know someone who one of the household respondents talked about, we were able to assure them of the confidentiality of the information as agreed in the informed consent.

Training of the interviewer was an important preparatory component of the research process. It involved the familiarisation of the research assistant with the objectives of the research, the topic guides, the research questions and detailed discussion about any possible ethical issues or problems that could arise during the interviews. As part of her preparation, we discussed a number of research projects reported in journal articles related to my research methods and the study topics. The flow of conversation, ease of interviewing and interviewing style were also essential elements that were covered in preparatory discussions with the research assistant. I conducted some role-plays with the research assistant prior to beginning household interviews. Practical issues surrounding the interviewing process were also revisited and changes were made after the initial interviews were conducted. Adaptations were made to all subsequent interviews once I had conducted the first round of interviews, as this gave me a better idea of how the interviews worked in practice.

5.6 Data analysis

Using more than one method of data collection allowed the use of different methods of data analysis and interpretation. The data were initially summarised into household case studies, which were first analysed both separately and then compared with each other. The household genograms and household event maps constructed from the data collected were also used to process and organise the data and these assisted greatly with the analysis and interpretation of the interview data. The transcripts, fieldnotes and thematic and reflective memos that provide the written record of interviews and my observations during fieldwork were also summarised and analysed cross-sectionally.

5.6.1 Case study analysis

The process involved in developing a case study required collection not only of data on a specific topic but also observing the household in context and interrogating their experiences more deeply. The case study functions to describe the household experience but also to reflect on how the context and background of the household is impacted on by social processes, responses, episodes and events. In this regard, the focus on context and background has been widely identified within the literature as a way to facilitate comparisons between this research context and the experiences of other households but within similar contexts (Green *et al.*, 2004; Lincoln *et al.*, 2002; Mason, 1996; Schofield, 2002).

It has been argued that case studies can provide insight into “context-specific processes operating at household level that influence peoples paths in and out of poverty as a result of

illness” (Russell, 2005: 277). Research based on case studies facilitates the analysis of processes at a household level but also at an individual level, which was in line with the aims of this research. Examples of HIV impact research utilising case studies includes research reported by Goudge (2007) and Russell (2005). Writing within qualitative research theory, literature such as Mason (1996) and Yin (2003) have also proposed using case studies as a particularly useful analytical tool in documenting social processes, practices or change in communities. Analysis of the whole case study, its changes and experience over time also allows for cross-sectional analysis of case studies, which can then be divided up thematically and compared to one another (Mason, 1996).

Section 5.3 outlined how I used household genograms and household event maps as data collection techniques. The collation and organisation of the data into these schematic diagrams, was not only a data management tool but also facilitated the process of data analysis. The process involved selecting certain aspects in the diagrams to focus on and interpret how the household member responded to this situation by the stories that they told. These diagrams were dynamic and were updated following each round of interview and observation as events and issues were highlighted and clarified in relation to the aspects of the livelihoods framework. In this way, the data on these diagrams have been coded in a cross-sectional way according to the different themes identified in the interviews.

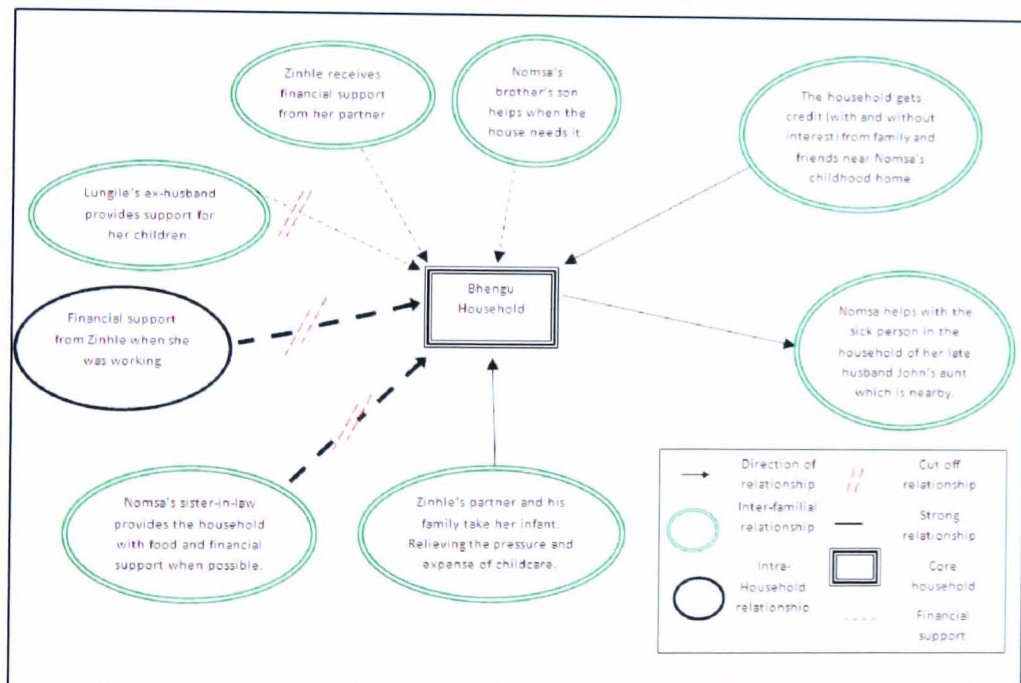
The household genogram is a record of reported facts about the household but also a summary of information specifically relevant to the study. For example, the genogram of the Bhengu household (Figures 6 and 7), highlights issues relevant to the study including information on deaths, illness, intra- or inter-household relationships, the receipt of social grants, and how these factors changed with time. The genogram excludes other information, which may have been collected but is not considered key to the study. In the example of the household event map (Figure 8), links between certain events, which were implicit in the stories told by respondents, have been made explicit within the diagram and intra- and inter-household relationships have also been highlighted. In some instances, inferences were made about the links in these diagrams based on additional information obtained from later household interviews. The process of deciding whether to eliminate and include data involved a process of reflection, analysis and interpretation on my part. Using these tools was very important and helped in the development of case studies that were used as the basis for further analysis.

The visual summaries of data obtained from the household genograms and household event maps were so useful that I decided during fieldwork, to construct similar diagrammatic maps of inter- and intra- household social networks, especially as the importance to the research of

mapping and understanding social networks became apparent. The social network map in Figure 9 depicts the movement of people and resources within and between related households. The social network map also shows the support that the household receives from external sources and organisations.

The social network map (Figure 9) for the Bhengu household shows the relationships of the core study household to both its non-resident household members (intra-household relationships) and other households (inter-household relationships). The example highlights the relationship of Zinhle, who was for a time a non-resident member with the household. It also shows the relationship the household has with the ex-husband of Lungile, who was now a member of another household. The diagram also depicts how support and assistance moved both into and out of the household. It illustrates the way in which relationships changed or disintegrated, in this case because of the breakdown in the relationship or a death in the household. The bold lines indicate a strong relationship defined here as being determined by familial obligations and underpinned by a close personal relationship or affective ties.

Figure 9: Bhengu household social network map, January to July 2008



Social network maps proved a very useful visual way to analyse relationships within the household, their strength and how they were maintained over time. It was also possible to see

how these relationships changed because of illness or death in the household. The maps also showed the type and direction of flows of resource support.

The visual analysis of the three schematic diagrams, assisted me to develop a case study that provided a holistic picture of the experience of the household over time. The core element of a case study involved assembling all the household information for each household into a narrative in chronological order. This involved writing a detailed description of the household and how it dealt with and experienced episodes and events relating to illness and death. It was then possible to compare the stories and experiences of the households that had different circumstances or contexts. The case studies described the events, episodes and experiences of illness and death in each household but also provided a historical and contemporary context to these events that enabled analysis of their impacts on the households within a specific context.

The case study enables the story of the household to be narrated largely from the perspective of individual household members. It therefore affords insight into the social reality of households and into factors that are not observable or available through merely one method of data collection. The comprehensive and validated data enabled me to describe and assess the impact, context and background of each household. In addition, it allowed for the analysis of social processes, responses, episodes and events. The particular focus on context and background has been widely identified from the literature as facilitating comparisons between different research contexts and to compare the inter-household experiences (Green *et al.*, 2004; Lincoln *et al.*, 2002; Mason, 1996; Schofield, 2002).

5.6.2 Coding the cross-sectional data

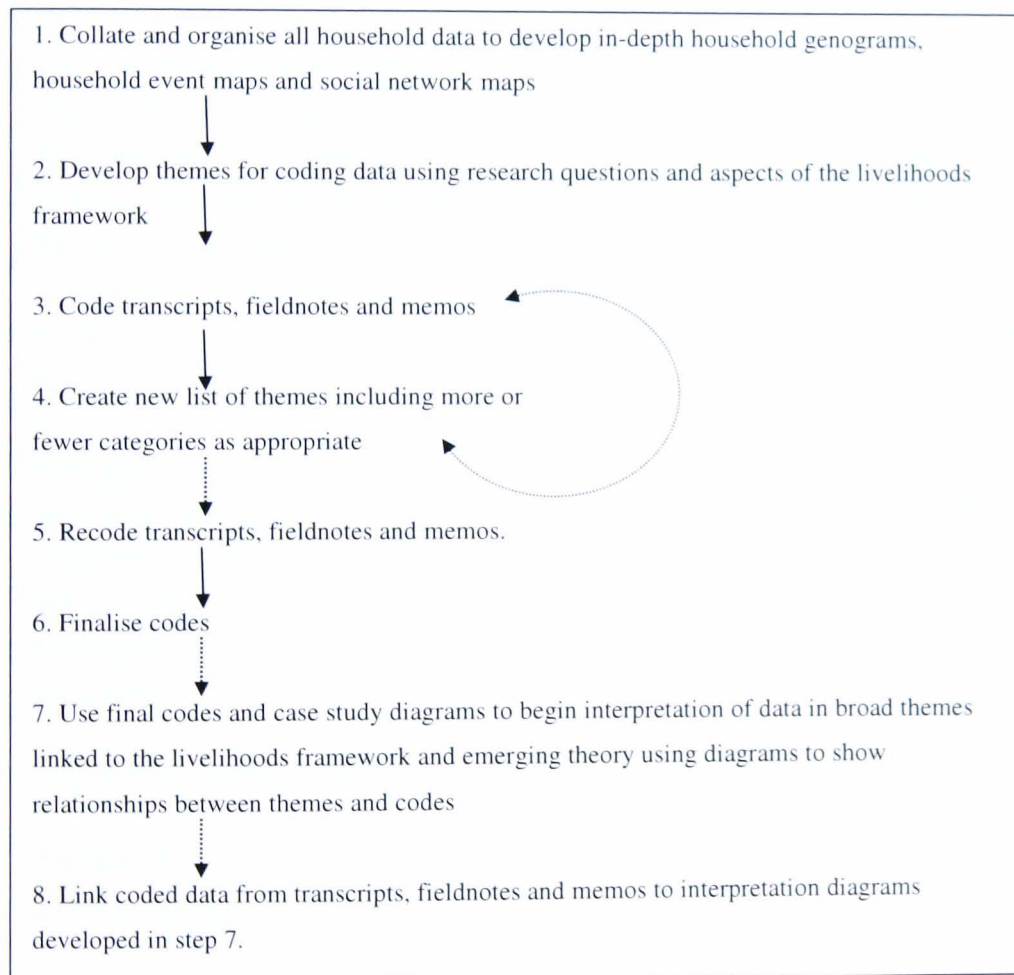
The development of case studies using the techniques mentioned above allow for the analysis and interpretation of the experiences of individuals either on their own or in comparison to the experiences of other households and members. In order to report the findings thematically the data from interview transcripts and other data collected from the households was analysed cross-sectionally. The process is graphically depicted in Figure 10.

The first stage of the cross-sectional process involved the collation and organisation of the data. The second stage involved creating an initial coding framework. The primary aspects of the livelihoods framework and the research questions were used to identify thematic codes that were applicable to code this data. In the third stage of the process the interview transcripts fieldnotes and memos, defined as notes written about specific experiences or themes during fieldwork, were coded according to the customised coding framework using *NVivo* software

(Green *et al.*, 2004; Ritchie *et al.*, 1994). The fourth stage involved the development of a refined framework for coding with fewer categories.

The revised coding framework included more appropriate subcategories and incorporated additional themes and codes that had emerged during the initial process of coding the data. In the fifth stage of the process, coding was repeated. Recoding allowed for the development of new theories through an evolving and iterative process. In this respect, the analysis process has been influenced by framework analysis, which was developed out of a combination of thematic analysis and grounded theory with the aim of ensuring policy-related findings from the research (Green *et al.*, 2004; Ritchie *et al.*, 1994).

Figure 10: Cross-sectional data analysis diagram



Codes were refined and finalised in the sixth stage of the coding process. The coding process employed was dynamic and the list of codes was constantly being refined and developed in an

iterative process. The coding of data allowed for comparisons and associations to be investigated within and between cases (Green *et al.*, 2004; Ritchie *et al.*, 1994). Stage seven involved a final round of closed coding according the final thematic framework in an attempt to answer some of the research questions and begin interpreting the results.

The final stage of the cross-sectional analysis process involved the interpretation of results according to the broad themes and objectives of the study. Mind mapping software was then used to interpret the way in which codes interact with one another and with concepts, issues, events, episodes, people and households within the study, in order to begin to draw some conclusions and allow theories to be developed.

5.6.3 Quality

Except for the first interview with each household, all interviews were developed using information collected from the households in preceding interviews. Preparing the questions for the subsequent interviews involved in-depth reading of the translated transcripts. This process of reading enabled familiarisation with their content. The importance of continuous reading and familiarisation is highlighted within the literature (Green *et al.*, 2004; Ritchie *et al.*, 1994). Reading and reflecting on the data collected highlighted issues to explore in future interviews but also confirmed recurrent themes and issues, which influenced the coding and analysis of the data.

Familiarity with the transcripts also helped to identify problems or areas of confusion in the translations and transcriptions. Returning to respondents to validate the information already collected permitted the respondents to clarify and explain problems or areas of confusion. This process enhanced the reliability and repeatability and as a result the credibility of the research. Credible and representative research is more likely to be generalisable (Bryman, 2004; Lincoln *et al.*, 2002).

5.7 Strengths and limitations in research design and implementation

The methodology and the design of the study have implications for the research in terms of limitations and strengths. These are reviewed starting first with the limitations.

5.7.1 Limitations

One of the major limitations of the study design used in this research is that I did not include a comparison group. It is, therefore, not possible to conclude whether the social networks observed in households affected by illness and death were different from those in households not affected. Including a non-affected group would have been very challenging to do. The focus of the research was on describing the way in which the household dealt with illness and death. In this area, the high prevalence of HIV and AIDS made it difficult to locate households that were completely unaffected by this illness and related deaths. Almost all households in the area are in some way affected or infected by HIV and AIDS. The time that was required to conduct a comparative analysis and the location and collection of data from completely unaffected households would have meant that there was insufficient time for as holistic an analysis as was possible for the household case studies.

In conceptualising the research I was trying to assess the wider impact of the HIV and AIDS epidemic, including what Barnett and Blaikie (1992) call "indirectly-affected households". In reality, this proved very difficult. In addition to practical implications, ethically I felt it was difficult to include indirectly-affected households identified by the directly-affected households. In many instances these households did not necessarily realise how much of a difference their help and support were making in the households enrolled in the study. In order to document this synergistic relationship it may have been necessary to disclose the HIV status of the household that was HIV infected and affected. This would also have required close analysis of a functioning relationship by the donor household with potentially negative consequences, if the motivations for doing this were analysed or called into question. It was therefore decided that to prevent potential conflict, accidental disclosure and negative consequences only the directly affected households enrolled in the first phase of the study would be included.

The selection of households was limited to those who had an adult informant present during the day and during the week who had consented to be interviewed. The convenience sample selected is not necessarily representative of all households. Having the capacity to talk to household members at home during the day, at the time of household visits, made the research feasible to conduct. These selection criteria do have potential implications for the data. They mean that the data were collected from those who were either too old to be working and present in the household or those who were unemployed therefore potentially missing different data that could have been provided by the employed household members missing during interviews. The selection of these respondents also potentially biases the data in terms of gender and age. Despite my best efforts those available and willing to talk were still mostly women and those

who were older. Therefore, the data were biased towards older resident women. These perspectives varied though because these women played different roles in their households. Some were merely resident but others were the head of the household or assumed the responsibilities associated with being head of the household including receipt of social grants.

Those perspectives most noticeably missing were those of younger men, many of whom were either non-resident, away working or elsewhere looking for work. To deal with this I tried to ensure as far as possible that the sample reflected a range of household types and contexts. The method of selecting the sample limits the internal validity of the study to the whole study area and population.

Other factors that could introduce some bias into the sample are the fact that households that were very small, recently dissolved or newly formed may have been excluded from the sample, as they would not have been known to any of the sources. In addition, the inclusion of a household through opportunistic contact may suggest that there is something unique about this household or the individual household members that influenced their inclusion in the sample. It is possible that in addition to these biases that certain information provided by the respondents is selectively provided and missing from the data because of social desirability. Therefore, respondents may exaggerate the negative impacts of illness or death or current circumstances in the hope of being provided with support or assistance by me. In addition, the social unacceptability of certain relationships or exchanges such as extra-marital affairs may not be reported by respondents desiring to provide social desirable information.

Another limitation of the research is the small sample size, a factor that limits precision of the results. Using case studies especially those limited to a single study site may have limited generalisability. Case studies however, provide valuable in-depth insight into the experiences of households and are an important method of analysing data in qualitative research (Mikkelsen, 1995). The aim in this research is not so much to generalise but rather to demonstrate the wider resonance that the findings in this context imply for households and individuals experiencing similar situations and contexts. The concept of transferability, rather than generalisability, is therefore particularly relevant to the development of an analysis of case studies.

The very small sample collected in this study also provided limited evidence for actually measuring demographic changes in the household. The measurement of demographic changes was not an aim of the study though and the review of the demographic impact literature in South Africa in Chapter 6 shows that this literature is extensive. Therefore, this thesis explores the

responses to illness events and household-level demographic changes observed within the household.

5.7.2 Strengths

Using case study methodology is one of the strengths of this research as it allows for the collection and analysis of both retrospective and prospective data. The stories obtained from each household can be developed to provide good contextual information but also provide a longitudinal perspective on household dynamics. Key information such as documenting the vulnerability of the household was possible as using these methods ensures that there is sufficient context and household history, which is a vital factor in fully understanding the impact of illness and death on households and livelihoods.

The other major strength of the methodology is the open-ended nature of the data collection, which facilitated telling the story of the household by members themselves and from their perspective.

The first two interviews were initially conceptualised use participatory exercises to obtain the baseline data. I have already explained why this was practically not feasible to do. I would argue that, despite this limitation of not obtaining the data by a participating free process, the interviews and observations proved to be extremely useful and provided the basis for the case studies. The baseline data were further developed and built on repeated home visits and ongoing collection, analysis and reinterpretation of new data.

5.8 Summary

The study employed a range of qualitative data collection and analysis methods in order to build up a holistic and in-depth picture of the experiences of households affected by illness and death. Almost all those we interviewed had not only dealt with the repercussions of HIV and AIDS related illness or death in the past but were in fact currently experiencing the impacts. Therefore, it was possible to collect information about previous and contemporary events and episodes. The retrospective data provided background to both the household and its experiences. In addition, the prospective data provided real-time insight into current realities being experienced by the household members.

Case studies enabled findings to be analysed, interpreted and conclusions drawn at the household level. Comparisons between different case studies were made possible by the cross-

sectional analysis of themes running through the various household case studies. It is difficult to generalise the findings outside of the South African context. The results should however provide a depth of knowledge and understanding of the KwaZulu-Natal context and experience currently missing in the scientific literature in relation to the impact of HIV and AIDS at a household level.

Chapter 6: Background to the household case studies



6.1 Introduction

This chapter provides some background information on the households enrolled in the study (for a summary of household characteristics please see Table 1). These households and the individuals that are either resident or non-resident members of the household will be referred to repeatedly in the following three results chapters and this chapter should therefore be treated as a reference section. It provides information about the case study households' composition in the form of household genograms and some background on their social and economic situation. The Bhengu household's genogram, household event map and social network map are presented in Section 5.3 and the household is discussed at length in Section 7.5, so the household has been excluded from this chapter to prevent repetition.

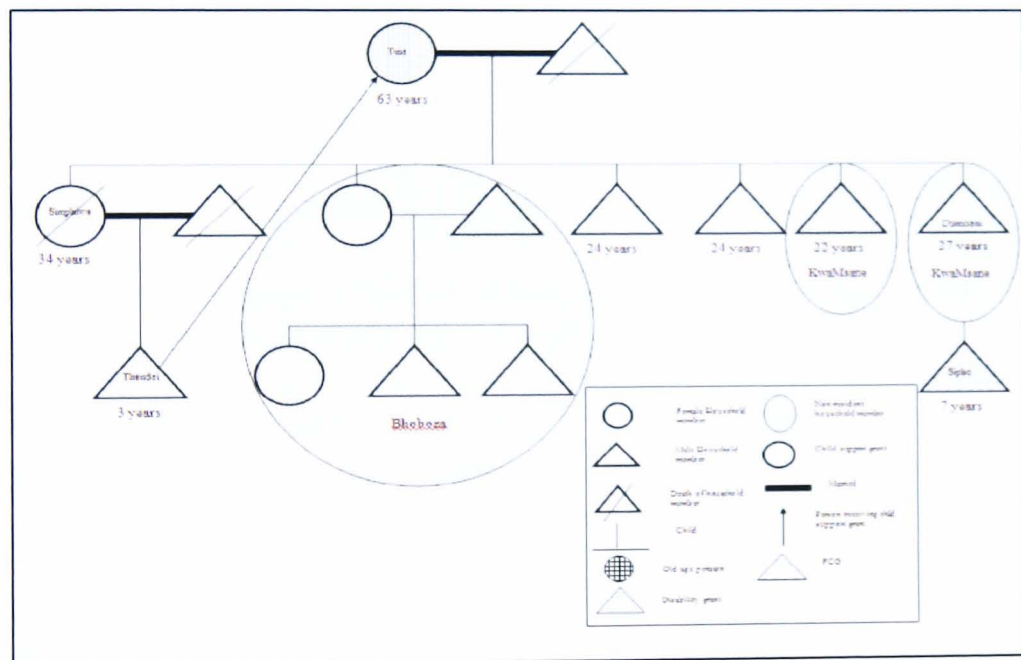
6.2 Ntuli household

Tina Ntuli was the 63-year old female head of her household when I first met the household. Her husband died many years before this. When I met her she was living with two of her grandchildren and twin 24-year old sons. Tina had four other children. Her daughter Simphiwe died in 2005 along with her husband. Two other sons, aged 22 and 27, are non-resident household members and live in KwaMsane and she has another daughter who lives with her husband and children in Bhuboza.

Simphiwe became ill and found out, while pregnant with her son Thendai, that she was HIV positive. Tina moved to live with her daughter at her husband's home and took care of her there. Following some conflict with her husband and his family about the person to blame for the couple's infection and when Simphiwe's condition worsened, she returned to her maternal home with both Tina and Thendai with the permission of her husband's family. Simphiwe died within months of returning to her maternal home. After her death Tina continued to care for Thendai.

Funeral expenses were paid for by Tina, who received her first old age pension payment in early 2006. In addition, she was provided with financial support by the congregation of the church where Simphiwe's husband was a preacher. Her own church community also provided assistance and some financial support for the funeral.

Figure 11: Genogram of the Ntuli household, January 2008



At the time of the first interview Tina's oldest son Dumisani's son, Sipo, also lived with her. Tina provides for the material needs of both Sipo and Thendai from her own old age pension, a foster care grant she gets for Thendai and intermittent financial assistance from Dumisani. She ensures the children are clothed, fed and in school. She also provides physical care for Thendai, who is HIV-positive and is on ART and, therefore, needs to take treatment and have regular check-ups. While Thendai only became Tina's responsibility after his mother died, Sipo was living with her and her responsibility well before his mother's death.

The twins assist their mother in the form of weeding and watching the younger children but do not contribute financially to the household. Their employment status is unstable and they had both moved in and out of work in the two years preceding the first interview. When they are not employed, they rely on their mother for support. Tina has a productive vegetable garden and a small sugarcane field that provide the household members with produce and income when they have enough money and manpower to maintain them, but they are expensive to run and when the household is short of money it struggles to pay for the inputs to keep the sugarcane field productive.

6.3 Nkosi household

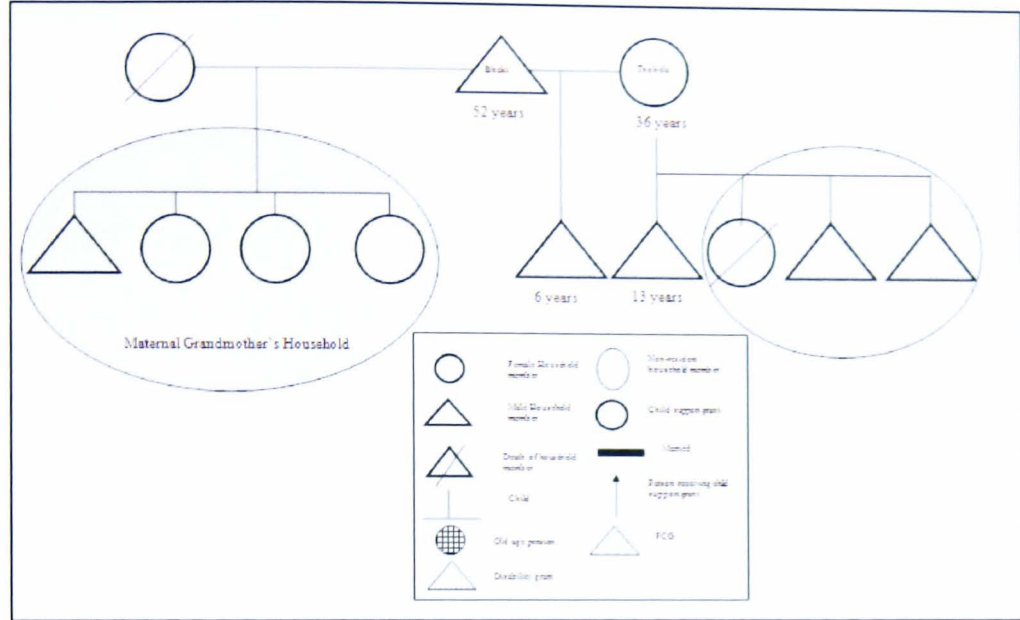
The Nkosi household comprised four key resident members when I first met the household. Bheki and Thobela were co-habiting and lived with their young son of six and one of Thobela's sons from a previous relationship who was 13 years old. Both Bheki and Thobela were HIV-infected and sick, although Thobela's illness was much more advanced than Bheki's. She was completely bedridden with swelling and infections on her feet and legs. She was unable to work or contribute to the household chores and was very reliant on Bheki to care for her. Bheki and the two children shared all of the jobs and chores around the house.

Thobela and Bheki both have children from previous relationships who are resident with and cared for by their paternal and maternal grandmothers respectively.

Thobela had been trading informally in Mtubatuba until her illness became so severe that she was forced to give up working in 2004 and had to return home. Bheki had not had formal work since he lost his job working at a hardware store in Mtubatuba, which closed down in 2002. Since Thobela's return home, her condition had deteriorated and it had become progressively harder for Bheki to leave home either to seek work or work, because he was needed to physically care for and stay with Thobela.

When I first encountered the household, they were surviving on one child support grant of R200 (£18) a month that Thobela received for their youngest child. Bheki sometimes obtained work keeping livestock away from his cousin's sugarcane or helping weed his field, but was seldom able to get work for more than two or three days a month. The labouring that Bheki undertook contributed approximately R100 (£9) to the household's monthly income. The household had no other livelihood activities or investments and no other income or products. Despite having a small garden, which had previously been used, when we met them the household was no longer producing any of their own food and the small plot lay fallow.

Figure 12: Genogram of the Nkosi household, January 2008



6.4 Mabena household

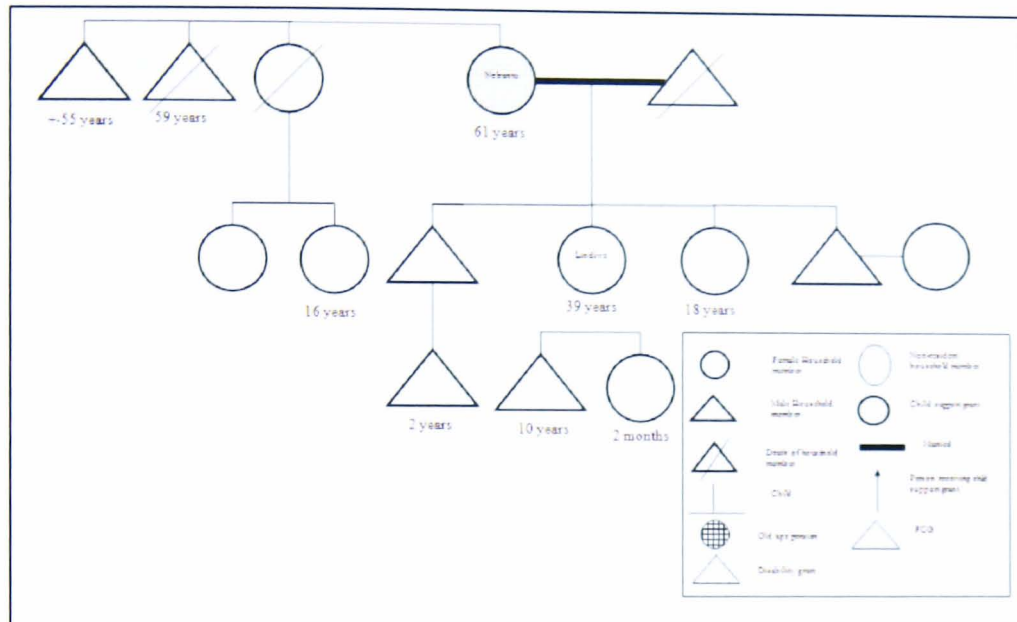
Nobantu Mabena was a 61-year old woman who was the head of her household. She was not working when I met her but was caring for three sick household members. These included Lindiwe, her HIV-positive adult daughter, who had recently been discharged from the local hospital after being admitted because of birthing complications related to her illness. Lindiwe had moved back to the household about 2 months before the start of fieldwork because she was unwell. Nobantu was also caring for two of her sick and HIV-positive older brothers, who had been resident at the homestead inhabiting an independent structure for a long time before they both became so ill that they needed physical care.

In addition to these three sick household members and a baby, Nobantu lives with two of her sister's children who have lived with her since her sister died, two adult sons and one of the son's pregnant girlfriend, another adult daughter and three grandchildren.

When I met the household Nobantu was supporting all the members of the household with the old age pension that she had begun earning the previous year. Prior to this she had supported the household doing piecemeal labouring for neighbours and others in the community. Prior to the worsening of her condition in 2007, Lindiwe had lived in Durban and worked as a domestic worker. During this time she was sending money home to the household to support the

household but also to build a single room addition to her mother's house. When Lindiwe became ill, she was forced to leave her job and return home to live with her mother.

Figure 13: Genogram of the Mabena household, January 2008



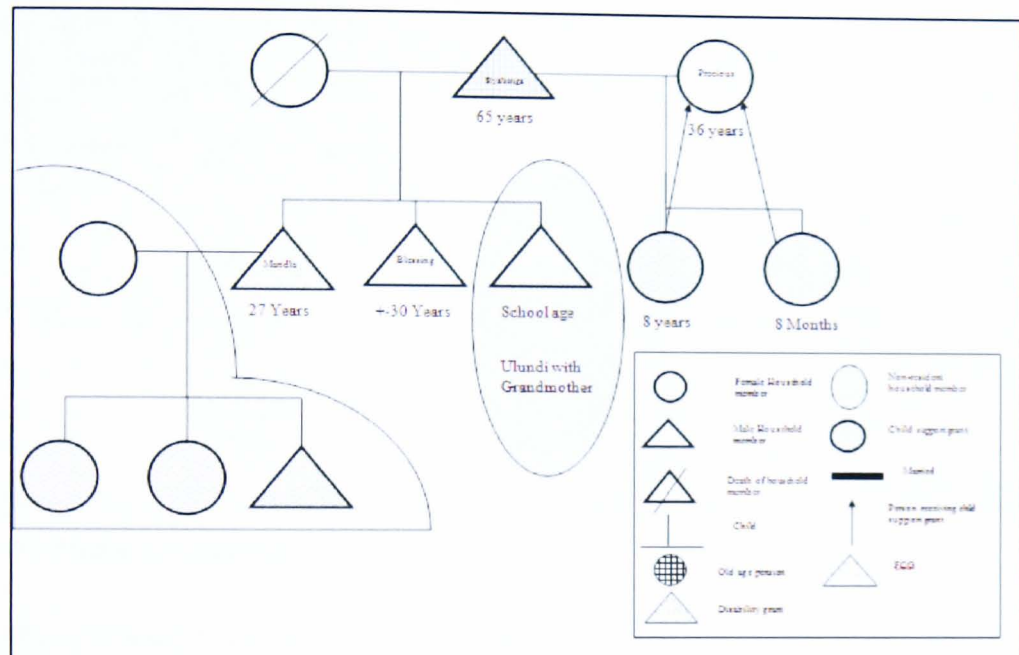
6.5 Sibaya household

Siyabonga Sibaya was the 65-year old male household head of the Sibaya household when I first met the family in January 2008. He was living with his 36-year old second wife, Precious, and their two young daughters, who were 8 years and 8 months old respectively. Also resident, were three of Siyabonga's sons, who were the children of his late wife. The youngest son was in his late teens and still at school, while the older two were in their late twenties. Neither of the older sons was working when we first met the household. The second son, 27-year old Mandla, had moved home to live in his father's household during the six months preceding the first interview because he was sick with Tuberculosis (TB). He was the only person sick at the time of the interviews in the household.

The Sibaya household relied on income from social grants accessed by various household members, from informal work and other informal economic activities. Siyabonga was receiving a monthly old age pension (R1010 (£80)) and Precious was accessing a child support grant (R240 (£21)) for one of their young children. When I first met the household, these were the primary sources of household income.

Soon after I first met Siyabonga, he started to earn money, to supplement his pension, by driving at night for people who were going into the timber plantations situated between Richard's Bay and Empangeni to forage for honey. Siyabonga was able to undertake this work because he owned a vehicle, which he used to do the driving.

Figure 14: Genogram of the Sibaya household, January 2008

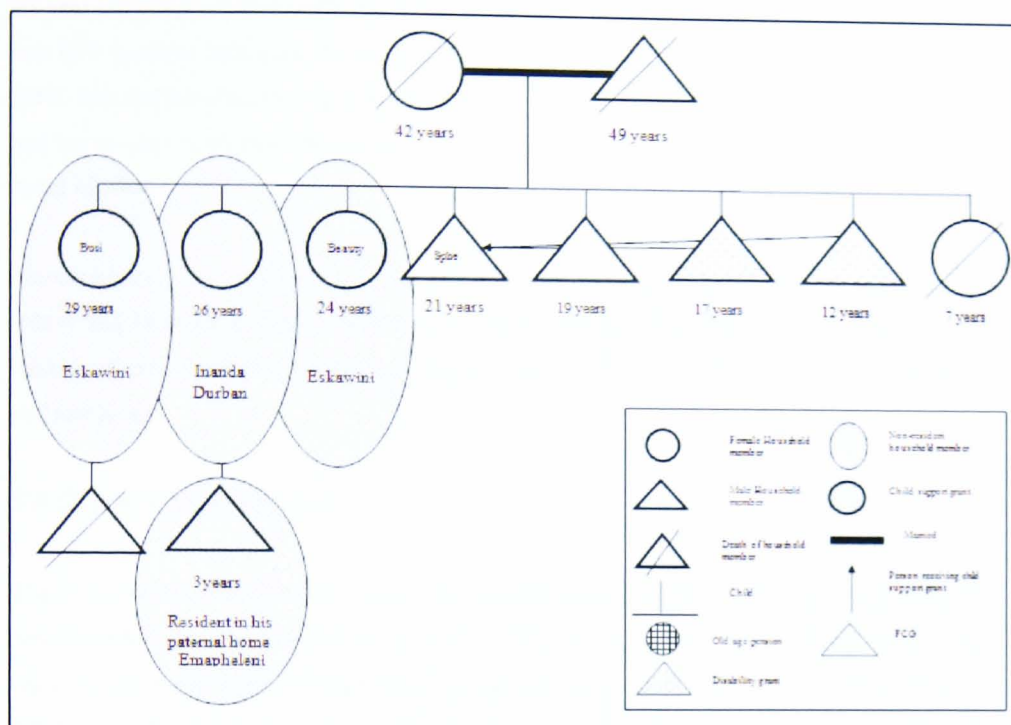


6.6 Zondi household

The Zondi household was a sibling household. Both parents died within months of one another in 2003. After their death, their eldest daughter assumed headship of the household but by the time I met the household all three of the older sisters, who were 29, 26 and 24 years of age had left it to go in search of work. The eldest and youngest of these sisters lived in Eskawini (a peri-urban township outside the town of Empangeni) and the middle sister lived in Durban. The eldest brother Sphe was the head of the household when I first visited.

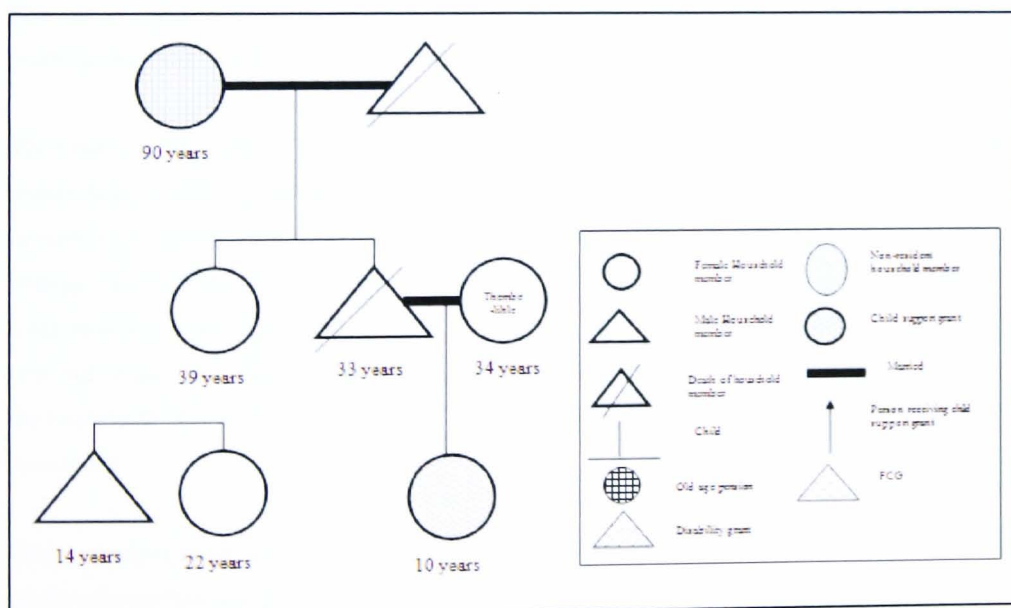
Along with a brother who was slightly younger than he was, he was caring for his younger siblings. Sphe was supporting the household with the income received from the foster care grant that the younger siblings qualified for because of the death of their parents.

Figure 15: Genogram of the Zondi household, January 2008



6.7 Dube household

Figure 16: Genogram of the Dube household, January 2008



The Dube household is headed by a 90-year old woman. Also resident in the household are her 34-year old daughter-in-law Thembilihle, her daughter and three grandchildren. Thembilihle was HIV-positive, had been on treatment since 2004, and was well when I met her in January 2008. She and her daughter became resident members of the Dube household in 2007 when she and her in-laws completed the traditional marriage process – started by her partner before his death in 2004.

Thembilihle is very well on treatment and has been working at a shop in Mtubatuba since recovering fully and losing her disability grant in 2007. Her mother-in-law also contributed to the household's livelihood by using the income she receives from her old age pension to buy and resell beer.

6.8 Dlamini household

The Dlamini household is a very large and complex household. The household is headed by Ntombizodwa who is a 70-year old woman. She was the first wife of a polygamous man who has a second wife slightly younger than Ntombizodwa. These relationships produced nine offspring, only five of whom were still surviving and only two of whom were still resident in the household when I first visited. Gugu was Ntombizodwa's eldest living daughter and was largely responsible for the decision-making in terms of livelihood activities and economics in the household. She was HIV-positive but has been on treatment since late 2006 and was well. She has two children that live with her in the household. The younger of them was also HIV-positive and on treatment.

The household has experienced a number of deaths especially amongst Gugu's siblings and this means that a number of Ntombizodwa's grandchildren who were previously non-resident household members returned to the household after the death of their parents. Gugu had one younger male sibling who was also resident in the household but he spends much of his time away from home looking for work and is not involved in decision-making. In addition to his two and Gugu's two children, there are seven other of Ntombizodwa's grandchildren resident in the household. Two of these grandchildren have children of their own who also lived in the household.

Gugu managed the household finances and when I first met the household they were surviving on the income from a range of grants. Seven of the younger children in the household received child support grants, Ntombizodwa received an old age pension and Gugu received a disability grant.

In addition to grant income, the household also had a business selling food both bought and prepared at the local primary school, which is next door to the household.

Figure 17: Genogram of the Dlamini household, January 2008, Part 1

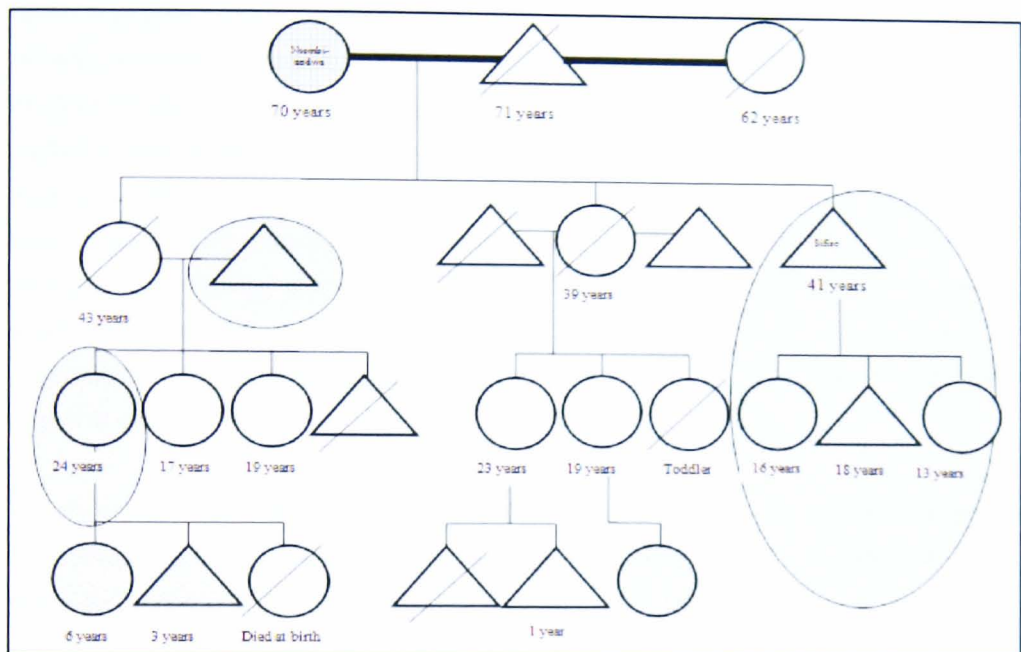
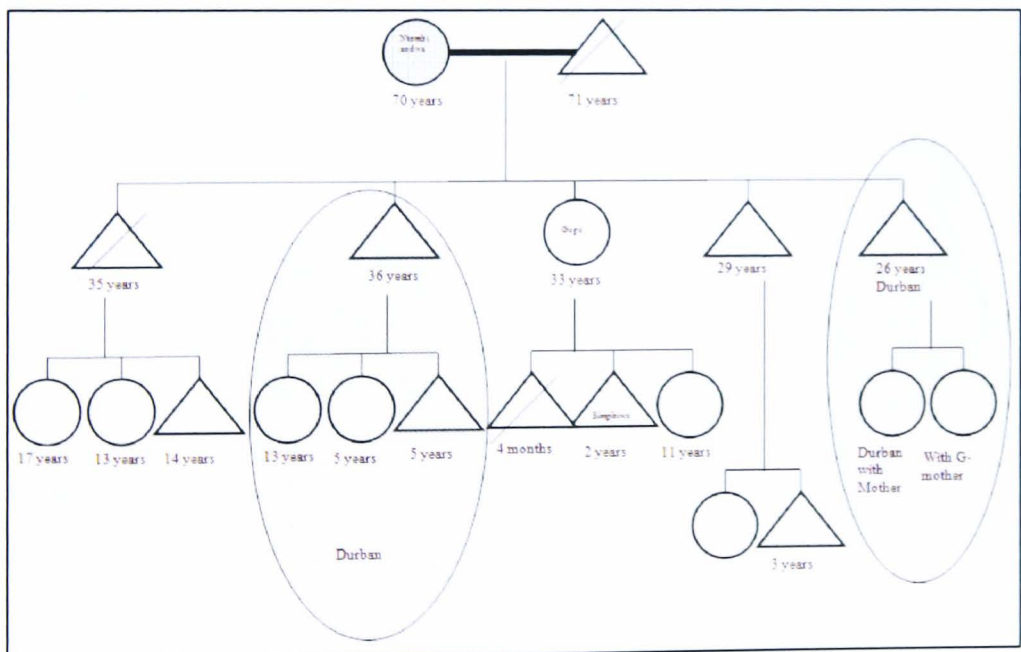


Figure 18: Genogram of the Dlamini household, January 2008, Part 2

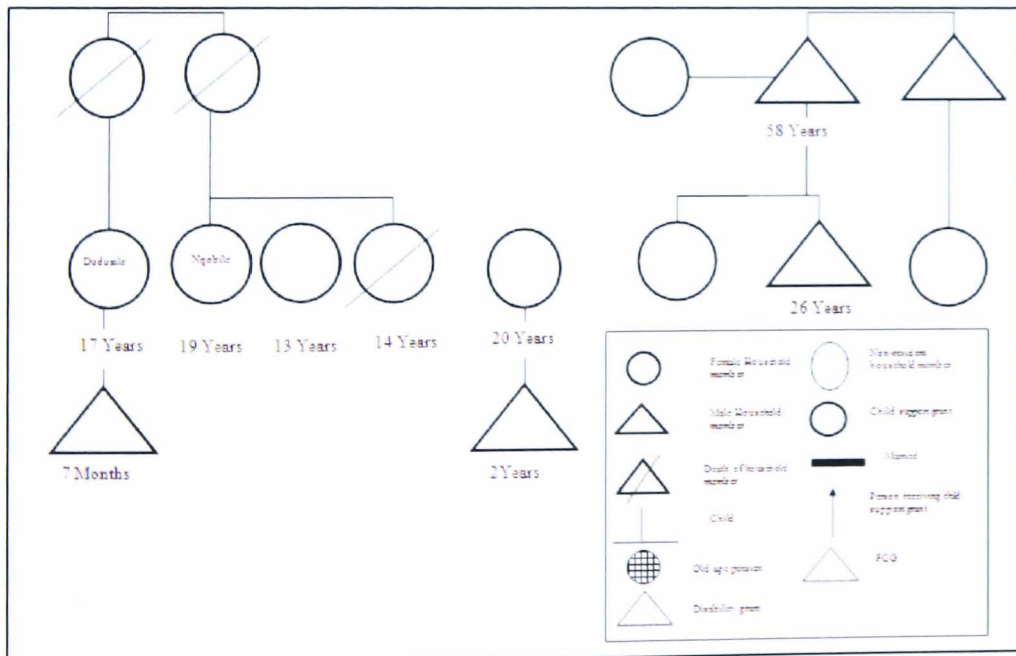


6.9 Shabalala household

The Shabalala household was another complex household. This household was originally enrolled in the 'Household Dynamics' study. At that time the household was headed by an elderly matriarch. At the time of the original study she had lost one daughter to AIDS already and she lost another one in 2003. She herself was ill and also died in 2003, leaving an adult daughter, Nokuthula, to use the children's foster care grants to care for her siblings' four orphaned children. When I met the household in January 2008, the remaining three living orphaned children were living by themselves in their grandmother's house. Two of the girls were 17 and 19 and the youngest living child was 13-years old. The girls took care of themselves, their siblings and, in the case of Duduzile, her young son. They lived in very close proximity to other relatives, namely two of their grandmother's nephews whom they called uncle and their families, along with a cousin and her young son, and considered these people to be part of their household.

When I met the household Nokuthula had met a man and moved to another section of the peri-urban area but she still collected grants for the children and gave them a proportion of the money to cover their costs. Despite the presence of adults in their lives, family and household the girls were largely responsible for themselves and controlled their lives and personal financial situations.

Figure 19: Genogram of the Shabalala household, January 2008



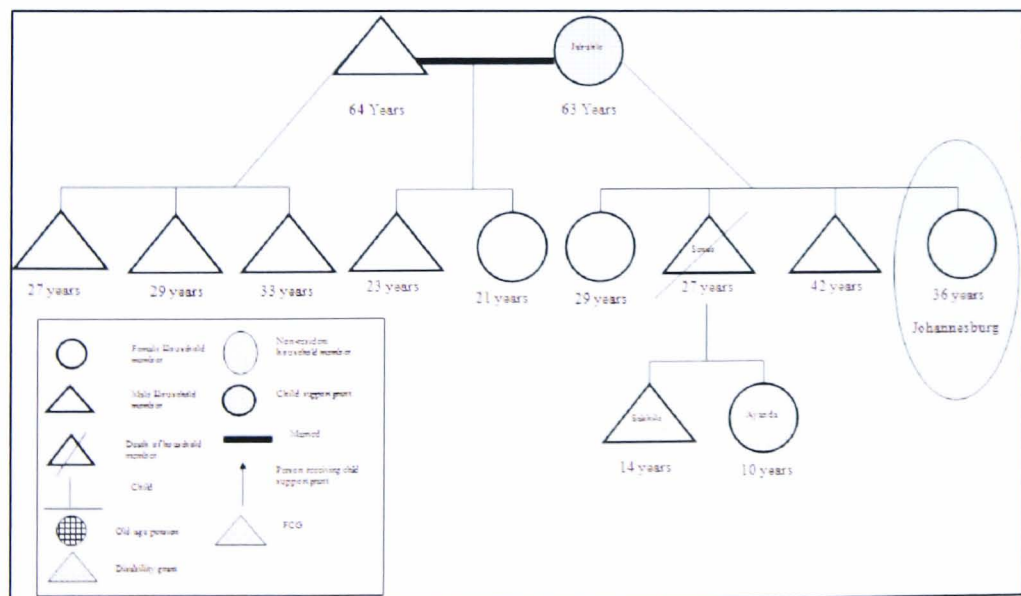
6.10 Gumede household

The Gumede household is headed by a 64-year old man and his wife Jabulile. When I met the couple they lived with seven of their adult children, five of which were from previous relationships, and two orphaned grandchildren.

Their son, Senzo Gumede, had been a non-resident member of their household but moved back to his parents' household when he became ill. Senzo's mother, Jabulile, was responsible for both of his children who were resident in the rural household before he fell ill. She carried on ensuring that the children were fed, clothed and attended school during Senzo's illness, and continues to ensure this along with managing the foster care grants she receives for the children since his death. The younger girl of ten is HIV-positive and has been sick, Jabulile ensures she takes her treatment and has been in charge of her physical and medical care since she has lived with her.

None of the adult children in the Gumede household had permanent work, although some did piecemeal work such as labouring or buying and selling in town when they could find it. One of Jabulile's daughters lived in Johannesburg and sent money and groceries home when she could afford to and was working. The Gumedes receive an old age pension for Jabulile and two foster care grants for Senzo's children. In addition, the old man receives a small monthly pension from the local government as he used to be employed at the St. Lucia Wetland Park.

Figure 20: Genogram of the Gumede household, January 2008



6.11 Summary

This chapter provides some background to the original socio-economic situation and composition and structure of the case study households enrolled in this study in January 2008. The following three chapters use the data collected from these households to expand on the household case studies presented above or using quotes that are selected to support the arguments presented by the chapters.

Chapter 7: Exploring the livelihoods in affected households



7.1 Introduction

This chapter turns to the findings from my research. The livelihoods framework is used to provide a holistic overview of the impacts of illness and death on the affected households in the study. I have selected three household case studies to discuss in-depth because the three reflect the broad themes about the impacts of illness and death on the livelihood and facilitate the most succinct discussion of these. These three household case studies are provided as detailed examples but examples from some of the other seven study households are also included in the discussion. This chapter provides an analysis of the evidence for how households respond in order to sustain their livelihoods. To begin with the literature and existing research into the impacts of illness and death on households in South Africa are reviewed. The findings demonstrate the differences between the average rural livelihood in South Africa and elsewhere in Africa.

In the following three chapters quotes have been selected to support the arguments or to build on the case studies being presented. Where it is deemed necessary the interviewer's questions are included but in the interests of space these are not always included.

7.2 Demographic impact of HIV and AIDS in South Africa at household level

The consequences of having high prevalence and incidence of HIV and AIDS is that there are correspondingly high levels of mortality and morbidity and an increasing number of infected but well PLHIV on ART. As discussed in Chapter 1, 3 and 4, these factors have direct implications for households' livelihoods. The burden of disease also affects the demographic composition of the household that in turn affects its existing vulnerability and therefore the capabilities of household members. The demographic impact of HIV and AIDS is therefore closely linked to the overall ability of the household to make a living.

Booyesen *et al.* (2002) reported on the differences between affected and unaffected households in their cohort study in the Free State province. They showed that affected households had a greater dependency ratio, children under the age of 15 and adults over the age of 65, than non-affected households. It remained difficult however to determine whether this was a result of a death in the household or due to other socio-economic factors existing at the time of illness. The study employed a definition of the household requiring members to be resident in the household for a minimum of 4 days in a week therefore ignoring non-resident household members in their calculations.

Madhavan and Schatz (2007) analysed the Agincourt DSS data to track changes in household composition and demography between 1992 and 2003, the period during which the AIDS epidemic expanded rapidly. They found that the average household size decreased over this period, more women headed households, fewer households contained foster children and more children were maternal orphans, although the increase was relatively small. Contrary to findings in the Free State, households in the Agincourt study area observed a decreasing dependency ratio. This study however summarised in a descriptive way the whole cohort and the purpose of the study was not to look for an association between having an AIDS death and demographic changes occurring. By contrast, in the Free State study, the situations of affected and non-affected households were compared.

Changes in the dependency ratio such as that found in the Free State study and, especially, an increase in the child dependency in South African households as a result of adult AIDS death means that a decreased number of economically active household members are supporting a greater number of child dependents (Booyesen, 2002). This may present an economic burden for the household and affect other components of the household's livelihood indirectly. Receipt of a

social old age pension has been shown to contribute significantly to the household income in a number of studies (Booyesen *et al.*, 2005; Reddy *et al.*, 2005; Schatz *et al.*, 2005). It is thus possible that the increased number of elderly people in the household will not influence the household as much, because of their receiving these social grants.

Some early research into the impact of AIDS deaths suggests that this would lead to more orphaned children that could lead to a large number of child-headed or skip-generation households (Adato *et al.*, 2006). The hypothesis of the emergence of child-headed households has not been corroborated by the South African evidence, where very few such households were found in both the Agincourt and Umkhanyakude DSS areas (Hosegood *et al.*, 2007a; Hosegood *et al.*, 2005; Madhavan *et al.*, 2005). Hosegood *et al.* (2007a) suggest that as half of all non-orphans are being cared for by at least one grandparent, that child rearing by grandparents and high levels of fostering observed before the HIV and AIDS epidemic occurred continues when children are orphaned by AIDS.

These findings suggest that these children live in skip-generation households without adults. In fact, Wittenberg and Collinson (2007) established that this did not occur. Despite, an observed increase in the number of skip-generation households detected in the Agincourt DSS between 1996 and 2003, this increase was no longer found to be significant when non-resident household members were included in the analysis, suggesting that the increase was observed because of adult migration rather than AIDS death. Results like this suggest that DSS studies such as Agincourt and the Africa Centre may reflect a more nuanced and accurate reflection of the household typology and composition than other statistical and quantitative research both in South African and elsewhere that does not consider both resident and non-resident household members.

Crisis-led fostering is not a new practice and, as Hosegood *et al.* (2007a) have demonstrated, children live with other family members and fostering is commonly practised regardless of a crisis or orphanhood occurring. Another analysis of the changes in orphan residence in the ACDIS data suggests that 7% of maternal and double orphans and 2% of paternal orphans live in skip-generation households (Hill *et al.*, 2008). In South Africa, this is particularly evident because, as Hosegood *et al.* (2007a) reported, demographic factors such as labour migration, low levels of co-habitation, union instability and high rates of extra-marital pregnancy mean that, even amongst non-orphaned children, only 27% lived with both of their biological parents. This is not due to the death of a parent, but it may be that the parents are non-resident household members such as those described by Wittenberg and Collinson (2007). Fostering has historically been shown to happen both voluntarily and because of crises (McDaniel *et al.*, 1996).

The return migration of sick family members or, in the case of rural South African households, of non-resident household members to the rural household is common. The implications of this circular migration have not been sufficiently researched in terms of the impact on livelihoods of illness and death. Analysis of the Agincourt DSS data provides evidence that short-term circular migrants returning to rural areas have a higher risk of death than either resident household members or long-term migrants (Clark *et al.*, 2007). Similar findings were made by Welaga *et al.* (2009) in the analysis of ACDIS DSS data, where migrants were found to be at higher risk of dying from AIDS than other residents. Clark *et al.* (2007) and Welaga *et al.* (2009) both conclude that migrants who get sick because of HIV and AIDS, return to be cared for or to die in their rural home.

The most direct demographic impact of AIDS is therefore a death. The death of an adult can have a number of knock on demographic effects for the household. An adult death may change the balance of people in the household and thus increase the dependency ratio. For example, orphaning of children may result from a death. In turn, patterns of household fostering may change or adapt to incorporate orphaned children. Illness may cause changes in patterns of migration as is observed in some studies of the return migration of sick household members to their rural homes. In addition to changing dependency ratios, households affected by HIV and AIDS death may dissolve completely. This dissolution may be as a result of livelihood failure or as the only way for remaining members to survive and this may indeed prove be a relevant outcome in some instances (Hosegood *et al.*, 2007b; Hosegood *et al.*, 2005).

7.3 Situating the analysis of the impact of illness and death within the existing literature

The household's livelihood is composed of a number of components, many of which may be affected by illness and death that may affect its ability to earn an income from being employed. This is especially in the South African context where there is high unemployment. Oni *et al.* (2002) conducted a cross-sectional study of rural households in the Limpopo province of South Africa and found that sick household members who became too ill to work lost their jobs and therefore their households lost the financial support of an income. Affected households had a monthly per capita income 32% lower than in households not affected by HIV and AIDS. The study defined a household as an economic unit of people who live and eat together for 3 out of the 12 months preceding the study and therefore excluding those non-resident household members who may not have been resident in the household for shorter period than this from their analysis. Another finding was that affected households were more likely than non-affected

households to diversify their income sources and participate in alternative economic activities in order to supplement the monthly household income. In addition to the loss of income from a household member who became sick, carers were also deprived of earning or lost employment due to illness in the household.

The counter argument is made by Bachmann and Booyesen (2003), whose Free State study population was generally very poor and was already affected by high unemployment. They argue that a causal association between changes in employment status due to illness and death was very difficult to detect. I would argue that the very high levels of unemployment and poverty in both the rural and peri-urban areas in which this study was conducted and nationally in South Africa, mean that the reduction of household income from job loss might not be as significant as expected.

The analysis of KIDS data by May and Carter (1999) provides evidence for the significant contribution of informal economic activities to the livelihoods of rural South African households. Oni *et al.* (2002) also show that economic activities in South African households had undergone substantial diversification. There is however very little research into how illness and death in the household influences informal economic activities that households engage in as alternatives to employment in South Africa. There is some evidence from a Zambian study cited in Booyesen and van der Berg (2005) that those who fell ill tried to change their employment. If they were informal workers, they tended to shift from doing productive work to more service orientated work, a switch that better accommodated their diminished physical capabilities. Given the role that informal work and activities play in the economic life of the household it is an important research question to answer. In the study in the Free State it was shown that affected households decreased their expenditure more than unaffected households (Bachmann *et al.*, 2003; Booyesen *et al.*, 2002). The costs associated with illness and death also affect whether the household is able to continue with or maintain their involvement in informal activities.

In South Africa, public-funded healthcare is either free or available for a limited cost based on the financial means of the patient. In the Free State, direct costs of health care for HIV and AIDS-affected households were slightly higher than for unaffected households because of the need for repeat visits to health facilities by PLHIV. The direct costs did not seem to affect households severely and these costs were much less than in other developing countries (Bachmann *et al.*, 2003; Booyesen *et al.*, 2002). An investigation of health-seeking behaviour using the ACDIS data showed that 90% of ill adults who sought public-funded health care also obtained private-funded health care. Furthermore, 50% consulted and paid out-of-pocket for services from traditional healers, regardless of how poor they were and despite ready access to

free health care (Case *et al.*, 2005b). In KwaZulu-Natal, private and traditional health care is very expensive, which suggests that the direct costs of health care contribute a large economic burden on the household especially where the PLHIV believes that they require more than the care offered by the public-funded health care system.

Coetzee and Natrass (2004a) reported on the analysis of patients receiving ART from a *Medicins Sans Frontieres* clinic in Khayelitsha in the Western Cape over a long follow-up period. They observed that the direct cost of health care was very low. However, the indirect costs of treatment and health care such as expenditure on over-the-counter medicine, transport to visit the clinic and the opportunity cost of long time-delays waiting at the clinic were considerable. These costs may increase greatly once the PLHIV is on ART because of required monthly visits for check-ups and medicine collection. However, indirect health care expenditure should eventually decrease if ART is successful. Evidence as to whether health care costs associated with being on treatment, but relatively well, would be smaller is not yet available. The costs and expenses associated with a treated chronic, but life-long, disease for affected households in South Africa still need to be ascertained.

Booyesen and Bachmann (2003) in the Free State study found that although the direct costs of illness were less than expected because of the availability of free health care, the likelihood of lost employment was low due to high levels of unemployment. This did not compensate for the huge financial burden that South African households, particularly in rural areas, faced when confronted with an illness or death. The household would cover the bulk of the funeral costs from its current income, savings or from the sale of assets, although assistance is at times received from friends or extended family, community organisations and formal or informal funeral insurance schemes (Bachmann *et al.*, 2003; Booyesen *et al.*, 2002; Lundberg *et al.*, 2000).

Hosegood *et al.* (2007b) have shown that in Umkhanyakude the reality is that households are faced with both complex and multiple shocks. Their 'Household Dynamics' ethnographic study of the impacts of illness and death in that district found that many affected households experienced more than one case of illness and or death as a result of HIV and AIDS, but also had deaths from other causes that were detrimental to the household's livelihood.

In this chapter, using a livelihoods framework, I will provide a holistic analysis of how the household's livelihood is affected at different stages of AIDS illness and death in this specific context of extreme vulnerability occurring in my study area. The South African literature does not include much holistic qualitative analysis of the impacts of illness and death on the

livelihood in South Africa. This chapter aims to start to fill this gap through analysing the impacts of AIDS at a number of key stages of illness using a livelihoods framework. The current literature raises some important questions. The first is the impact of access to ART for the household's livelihood. While there is some evidence for the impact of access to treatment on formal employment, there is limited evidence for the impact of treatment on informal activities and work that the household is able to rely on (Coetzee *et al.*, 2004a). The impact of access to treatment for the livelihood is also explored more generally within this chapter.

It is very difficult to analyse the impact of illness and death in isolation and the demographic impacts are closely interlinked with other factors such as policy, the rural economy and the costs related to illness and death and the implications these have for the household. In addition, the components of the livelihood are intricately linked to each other but also to the parts of the vulnerability context. Therefore, each case study begins by providing some context and history of the household's livelihood. The household case studies are used to explore how the components of the household's livelihood are affected by and mobilised in response to the experience of illness and or death for households. The second part of the case study explores the impact of the illness and or death on the household livelihood and the household's response. The final section summarises the primary findings.

Each case study represents a different household situation, experience and response to illness or death. Case study 1 explores the impact of the illness of a non-resident adult household member in a household with a relatively well-developed and diverse livelihood and with limited existing vulnerability. Case study 2 also investigates the situation in a household with a sick non-resident household member. The household had a relatively limited livelihood though and some existing vulnerability. Case study 3 had very limited livelihood activities and illness had a severe impact on the livelihood, which was already very vulnerable due to a number of pre-existing problems in the household.

7.4 Case study 1: diverse livelihood and little significant impact of illness

The Sibaya experiences provide a good example of the contribution that informal work and economic activities make to the livelihoods of poor, rural, South African households. Siyabonga's work was informal, insecure and marginalised. His ability to work was dependent on other individuals requiring his service but he was also highly dependent on his vehicle functioning. His was the only study household that owned a functioning vehicle and this proved to be a definite advantage in terms of enabling Siyabonga to work and earn an income.

Consequently, he lived away from the household for much of the week and, although he tried to return home most weekends, this was not always possible.

Siyabonga was unable to afford the costs for extreme repairs if required as these exceeded his income and required him to spend savings. This meant that his income was more fragile than if it had just been dependent on his own ability to work. Precious expressed her and her husband's concerns about the security of his job.

[Now] his truck is stuck so the whole of last week he [couldn't] work. He came [home] on Wednesday and left yesterday, he said that truck has no brakes. He phoned yesterday to tell me they are not fixed yet. So he has no work...His job is fragile.

Precious Sibaya, Wife of household head, 36 years

Despite the insecurity of Siyabonga's work, the Sibaya household had both this informal work and the social grant as sources of income. It was not easy to determine the value of Siyabonga's contribution to the household because, after Siyabonga started driving, Precious became our primary respondent on household issues. Siyabonga did not reveal the full amount of his earnings to Precious. He gave her only small portions of his income for household expenses.

About 4 months into fieldwork, Siyabonga decided to work at KwaMbonambi instead, also as a driver. He preferred it as he was working in the day rather than at night, a change that made very little difference to the rest of the household. Other than Siyabonga and Precious, no other household members, either resident or non-resident, contributed to the household income. However, access to two different income sources facilitated the further development and diversification of the household's livelihood.

Unlike any of the other households in the study the Sibaya family owned a productive sugarcane field and a vegetable garden. The produce from the garden added to the household food pot and they sold any excess production to neighbours and community members for a small profit. During harvest season, the household sometimes had extra produce and managed to sell buckets of onions or potatoes for R20 (£1.76) or R30 (£2.65) each. The sugarcane field also produced seasonal benefits but, like the garden, required intensive inputs such as labour, the purchase of seeds and production costs. The income the household secured through access to both social grants and Siyabonga's informal employment provided important capital for the purchase of seeds, helped to pay labour to weed and harvest the sugarcane and ensured that both the agricultural activities remained viable ventures. The fact that Precious was resident at home, had no formal employment, well and other than caring for her young children and housework, had

no additional responsibilities meant that she was able to dedicate much of her time to working and managing the land that ensured the productivity of the field and garden. The productivity of these was another example of the importance of informal economic activity.

7.4.1 Households' experience of illness

When Mandla, Siyabonga's son from another mother, returned to the rural household from Johannesburg, where he had been seeking employment, six months before our first meeting with him, he was very sick. At the time he was unemployed and had no income. Soon after his return home, he was diagnosed with TB and HIV and he applied for a disability grant. Between moving home and receiving the grant, he was completely reliant on financial and material support from his father's family. Although he was not sick enough at this time to require intensive physical care, his stepmother, Precious, cooked for him and his brother Blessing and, when Mandla required some intermittent nursing care, this was also usually provided by Precious too. The access that his father and stepmother had to income from work and social grants enabled them to respond to the financial needs imposed by Mandla's presence and illness, with few direct negative implications for the household's livelihood. In the long-term however these responses may have negatively influenced the livelihood.

A little over two months after moving back home Mandla secured a disability grant, which coincided with an improvement in his health, due to his TB treatment. Despite still being weak and looking unwell, Mandla felt better and was more independent and able to travel outside of the immediate household. He was out visiting friends during our visits and Precious explained that Mandla was better and much less reliant on her. This change in his physical and financial circumstances also brought about a change in his relationship with the other members of his father's household.

His increasing physical and financial means gave him some independence. Despite this, Mandla, along with his brother, were provided with food by his father and Precious. In all other respects, he operated independently from the household and chose not to contribute either time or money to the household's livelihood.

After completing 6 months of TB medication Mandla was started on ART and, his condition continued to improve. Later however, he defaulted on his ART and was admitted to hospital, only to refuse further hospital care and discharge himself. He went to stay with his mother's family. However, his cousin, who was employed at the Africa Centre, located him there and encouraged him to return to the hospital. His cousin and mother's family were an important

source of support for Mandla and helped to ease the burden of caring for a sick person, which would, under other circumstances, have fallen on other resident members, of the Sibaya household.

In addition, to support for Mandla from his mother's family, the Sibaya household had a very close relationship with the family of Siyabonga's sister. Their homestead was situated on the hill close to the Sibaya homestead. The members of both households visited each other regularly and Precious explained how the households were always willing to help each other and share when either had leftovers or too much of something. Mandla's female cousins from this household checked on him during his period of most severe illness, if he required physical care they provided this, again relieving some of the responsibility for providing physical care that would without their support have been shouldered solely by Precious.

Mandla had three children, who were living with their mother in her mother's home in another province. Although Mandla contributed money from his disability grant to help support his children, their mother was responsible for their day-to-day care. Therefore, neither Mandla nor any of the other members of his father's household were providing physical care for his children. This situation was not the same in other study households, five of which were caring for the children of household members, both resident and non-resident, who were currently sick or who had died.

Although caring for Mandla had limited economic impact on the household, his illness had other implications for other people in the household. Precious spoke about how caring for her stepson had changed her life since Mandla moved into the rural homestead and when he was most sick.

It has changed a lot because you can't do whatever you want to do, [Mandla] will [call for you] now and then... if you prepare [food] he doesn't like [he shouts]...he wants what is not even around.

Precious Sibaya

Precious felt that Mandla was demanding of her time and wanted special treatment and this affected her freedom to do what she wanted. She was also unhappy with Mandla's choice to distance himself from the household and be independent, after his condition improved and he received the disability grant. Despite this independence Mandla was still living at home and relying on Precious for both food and physical care when required. Precious felt that, in return for the support and care she had provided when he was more ill and had yet to access the grant,

there ought to have been some reciprocity. She considered that his failure to assist in the household once he was able to, indicated disrespect for her and the household itself. Inter-personal tensions arising between those who are sick and their carers are explored in more detail in Chapter 7.

7.4.2 Summary of findings and comparison to other study households

The economic and livelihood impacts that were felt by the other household members when Mandla was dependent on their support, were mitigated because of the Sibaya household's diversified livelihood. If one aspect of the livelihood suffered or was difficult to secure, then there remained another source of support for the household. The diversity of the livelihood was also well entrenched and although Siyabonga's informal work was relatively new and insecure, the household's other informal economic activities and receipt of social grants, meant that the household was not particularly vulnerable. The vehicle, field and garden were tangible assets that facilitated participation in alternative economic activities and therefore income for the household. The role of farming and gardening was very unusual. While five of the other household enrolled in the study had gardens and one also had a sugarcane field, no other households reported producing sufficient to sell. In addition to these tangible assets and the advantage they provided for the Sibaya household, they also had access to and claims on social grants. While no-one in the household was formally employed, the diversity of income sources and activities maintained the livelihood of the household. The role of informal economic activities and the reliance of the household on these are also demonstrated by other households enrolled in the study.

Financial assistance and material support for the household from neighbouring family and even physical care from kin for Mandla assisted the household to respond to and recover relatively quickly from the impact of his illness and return to the family. These networks would have also helped the household had it experienced a further shock or crisis, such as if Mandla had lost the disability grant or even died.

The other reason the household was successfully able to respond to the presence of a sick member, without too many negative consequences, was that Mandla was able to access treatment, TB drugs initially and thereafter ART. Although Mandla was experiencing some difficulty adhering to therapy and still looked ill the last time I saw him, his condition had improved. Thus, he was able to leave the house and had wider economic and social interests than those he had had at our first meeting with him and his household. The consequent health and financial independence he gained meant that, despite not contributing anything to the

household, the only demand he made of the household was for food and occasional physical care. While he did cause an annoyance in the household by being drunk or bringing friends to the household and the relationship with his stepmother was complicated, he had a limited disruption to the household's livelihood.

7.5 Case study 2: significant changes to the household's livelihood because of illness

Nomsa was the female head of the Bhengu household. She was widowed and, when I first met the household in January 2008, she was living at the homestead with five of her children and six of her grandchildren. Nomsa had an adult daughter, Zinhle, who had become sick while she was living and working in Richard's Bay. As a result of this illness, Zinhle returned to her mother's rural home in the month preceding our first encounter.

7.5.1 Household context

Prior to Zinhle's illness and her return home, the household's livelihood had been comprised largely of income from child support grants, received for the children living in the household. In addition, the household relied on financial assistance and material support from Zinhle and maintenance payments by her sister Lungile's ex-husband for their children who were living in the household. When Zinhle was first diagnosed with HIV in 2005 she was started on therapy. At this time, she was working as a domestic worker in Richard's Bay and was regularly sending money home to her mother in order to provide financial assistance for her young daughter, who was resident in her mother's household, but also to help to build another structure on the property. Zinhle's support for the household continued for the next two years.

During this time, Nomsa was claiming child support grants for one of her own children and two of her grandchildren. The grandchildren were Zinhle's older sister, Lungile's child and Nomsa's other younger resident daughter, Pretty's child. Lungile had lived in Richard's Bay since separating from her husband. In the intervening period, two of their children had moved into the rural household and were being cared for by Nomsa. When I first met the household, Lungile's husband was paying about R350 (£30.86) a month to Nomsa towards the care of the children, a contribution that added to the household's income.

Before Zinhle's illness worsened and began to have consequences for the household, the household's livelihood had already undergone a change because of the death of Nomsa's husband, John. Before his death, the household had been able to rely on the income from his

disability grant. Nomsa had also been able to use the money both from his grant and from the other social grants to go to Durban or Richard's Bay to sell clothes that she sewed. John cared for the children in her absence. John's sister, Lillian was another source of support both before and after John's death. She was close to the household and used her old age pension to help buy the household extra groceries when they experienced extreme need or crisis in this period. Lillian died within a year of her brother. The loss of these two older people, their financial assistance, material support and, in the case of John, his physical presence had a detrimental effect on the household. At this point there was no-one other than Zinhle who was employed in the household.

7.5.2 Household's experience of illness and death

Zinhle discontinued therapy soon after starting it in 2005 because of difficulties her employer had with her taking time off work to go collect treatment from the clinic. Zinhle's health deteriorated to such an extent after stopping ART that she was no longer able to continue working as a domestic worker and she was forced to quit her job. This may have also been because of the stigma associated with AIDS. Although she was too ill to work in formal employment, Zinhle remained in Richard's Bay and began trading goods in the marketplace, which was more flexible, and she was still able to make relatively regular financial contributions to the rural household's livelihood.

The household was, therefore, reliant on financial support from the child support grants, remittances and material support sent by Zinhle. Although this was sufficient to maintain the household financially, it left no additional money after John's death to allow Nomsa to continue her sewing and trading business. The lack of additional income also meant that Nomsa was unable to buy seeds to plant in her garden to produce extra food for the family to eat. This was exacerbated by water shortages that Nomsa claimed were drought-related.

We were planting down there but we are running short of water because of the drought. I used to try planting some small things here. Just now, we also don't have seeds we should already have planted.

Nomsa Bhengu, female household head, 56 years

Towards the end of 2007 and after the birth of her second child, Zinhle became much more ill and was eventually forced to stop working all together and move back to the rural household. These two events had very important implications for the livelihood of the rural household.

In particular, the loss of the financial assistance and material support for the rural household, resulting from Zinhle's inability to work had a repercussion. The other problem for the household was the burden of having Zinhle, a sick, previously non-resident household member now resident and requiring care. Zinhle brought her baby with her and when her illness was at its worst was unable to care for him alone. In addition to nursing care Zinhle had no income and due to administrative difficulties and barriers was unable to access a disability grant. She also required financial assistance in order to access healthcare and obtain treatment for her advanced illness. The barriers and difficulties encountered by the household in accessing a disability grant for Zinhle are discussed in Chapter 7. Nomsa provided the majority of the care, for both Zinhle and her children, with some help from Pretty. Nomsa described the way in which the presence of a sick person affected the household's ability to participate in informal economic activities.

We don't have the material [to make mats] we buy it for R25 each, where should I get the money?...One mat needs one and a half [bundles of reed] these things are very small they are [overpricing the bundles]. It was better when I was with [my husband] because I went to Durban to sell and he stayed with the children and also I was sewing, I got a small amount [of money for that] so it was not the same... we survived like that for quite a long time but now there is no-one to give me money to start that business again.

Nomsa Bhengu

Zinhle's deteriorating health and poor record of adherence to therapy resulted in the clinic staff being reluctant to start her on ART until she had completed her course of TB treatment. Although she was eventually started on ART it was started relatively late and this, coupled with her physical disability and the household's financial difficulties getting her to the clinic, affected her recovery. In fact, in the final two months of fieldwork her condition deteriorated dramatically. This, combined with her inability to access the disability grant, had important implications for the household's livelihood as the limited income on which it was reliant was consumed by Zinhle's care. Towards the end of the study period, when Zinhle was re-admitted to the hospital for the second time, the household was in such a dire financial situation that Nomsa could not afford to visit her daughter in hospital.

During Zinhle's illness, the household obtained income from social grants and financial support from Lungile's ex-husband. The household sometimes found it hard to provide for Zinhle's needs, owing to shortages of money and the other resource needs of the household.

We don't have bread. [Zinhle] was going to the clinic. She was crying that she was hungry while she was at the bus stop.

Nomsa Bhengu

Like, many of the households in the study who took on an additional sick member the Bhengu's were just getting by and were therefore very vulnerable to the negative socio-economic consequences of having to care for a sick adult member.

The situation in the Bhengu household was complicated by additional problems and stresses that influenced the ability of the household to maintain or expand their livelihood. Neither Nomsa nor Pretty was healthy. Nomsa suffered from hypertension and was easily tired, Pretty had a history of mental health problems that meant that Nomsa was reluctant to leave her to care for Zinhle or the young children in the household. Nomsa felt responsible to be around and felt that as her young adult sons were still at school they were not old enough to be solely responsible for caring for either Zinhle or the children. During the study period, the payments Nomsa had been receiving from Lungile's ex-husband for the maintenance of his children stopped, because of an argument he and Lungile had had about a new woman who had moved into his homestead. This was an added blow to the household's already depleted access to income and support.

The household was able to access some other limited resources. Zinhle was in a relationship with the father of her young son, Phineas when she fell ill. Petrus and Zinhle were still in a relationship, but were not living together. Petrus was part of his parents' household. He sent some money to cover some of the costs associated with Zinhle's health care needs such as for transport to the clinic and hospital. Petrus's family also contributed to caring for Phineas and shared some of the responsibility. When Zinhle was admitted to the hospital initially, the baby was sent for care to his father's family for about a month. It was not clear who initiated this arrangement but the close relationships between Zinhle and Petrus suggested that this was a way to help the Bhengu family respond to Zinhle's illness.

Zinhle did not recover sufficiently to be discharged from the hospital a second time and she died soon after her mother tried to visit her. The household was completely financially unprepared for Zinhle's death and could not even raise sufficient money to pay for the transport of her body from the hospital in Hlabisa, where she died, to the homestead in Somkhele. Nomsa was emotionally distraught about Zinhle's death, particularly because she had been unable to visit her during her hospitalisation. Zinhle's sister Lungile was phoned as soon as the household found out about the death and she was able to return home in the following week to be there for her mother and family. The household relied on material support from neighbours and friends.

borrowing money and using money from social grants to cover the funeral expenses. At the time, this was devastating financially: it took the household two weeks to collect enough money to pay for the transport of the body back home from the hospital.

Despite the immediate costs, the household seemed to recover its financial stability relatively well after the death. This may have been because the costs associated with Zinhle's death were one-off expenses. Once the household had absorbed these expenses their situation was slightly better than it had been during the period of Zinhle's severe illness with all the inherent costs in time, energy and finance. In addition, Petrus died soon after Zinhle. With the death of both parents, Nomsa continued to be the primary care giver to Phineas and his older half sister. She applied for foster care grants for both children. The income from these two social grants was more than double the household's monthly income being received at the time of Zinhle's death.

7.5.3 Summary of findings and comparison to other study households

The Bhengu household is average relative to the other 9 households in the study in terms of its livelihood, with an income limited to social grants and some financial support from non-resident or other kin. The support provided by non-resident members in the household demonstrates that the livelihood of households is not limited to activities in the geographical proximity of the rural homestead. More examples of this were found from other case studies. Siyabonga Sibaya was away from home during the week in order to earn a living. These examples emphasize the importance of the resource contributions of non-resident household members to the rural household's livelihood despite the geographic dispersal of the household's members.

After John died, the Bhengu household was not involved in alternative livelihood activities that could have provided the household with an additional source of income or necessary produce such as food. This was in contrast to the households who more successfully responded to illness and death such as the Dube and Sibaya households whose members were involved in a variety of activities that diversified their livelihood. In addition to existing vulnerability because of the deaths of other supportive adults in the Bhengu household, this was aggravated by the additional financial pressures and difficulties. These households had limited access to alternative sources of income because of high levels of unemployment of other members, loss of income from child support because of conflict, all of which compounded the expenses associated with illness and limited the options available to the household members. In other circumstances, access to these things would have enabled the household to diversify their income or maximise the livelihood capabilities and increase informal livelihood activities.

Moreover, Zinhle was unable to access a disability grant and her ART initiation was too late to improve her physical condition. Despite the emotional shock caused by her death, the financial implications were mitigated by Nomsa's access to two new foster care grants for her newly orphaned grandchildren. These social grants were a major source of new income and the additional support from other kin ensured that the household managed to survive and continue to function.

The Bhengu household shows that despite access to treatment (although it was very late and Zinhle's health was very poor), improved health, well being and consequently being able to contribute in some way to the functioning or livelihood of the household is not guaranteed. The household may continue to bear the burden of a sick or dead household member over a very long period.

7.6 Case study 3: limited livelihood activities and existing vulnerability

In the Nkosi household the situation had not changed much in the preceding 3 years except that Thobela's condition varied. Therefore, prior to my meeting them, the household had already experienced three years of vulnerability.

7.6.1 Household's experience of illness

Thobela had been on ART for four months at our first meeting but had experienced difficulties accessing a disability grant. Without receipt of a disability grant, she struggled to find the money required to transport herself to the clinic to collect her treatment and to attend for her check-up appointments. Bheki's illness was not far enough advanced for him to qualify for ART or to receive a disability grant; his illness nevertheless left him tired. Bheki was also needed at home to care for Thobela who was seriously ill so was unable to find and commit to permanent or even part-time formal employment.

Thobela explained that, because of her illness, she was unable to work in the garden and this coupled with the lack of recent rain meant that the garden was unproductive. The situation in the household was such that the children were occasionally required to beg from neighbours for food and scraps, especially towards the end of the month, but the family seldom received much assistance.

During the study period, the household was increasingly reliant on donations from their neighbours as Thobela's health deteriorated and she required progressively more nursing care and the household's expenses, associated with trying to access health care services, social grants and particularly travel costs, increased. Other than charity, the household had limited access to support from outside of the household possibly linked to their inability, because of their inability to reciprocate or illness and poverty, to participate effectively in any sort of social network, a factor that rendered the household increasingly excluded.

7.6.2 Summary of findings and comparison to other study households

The Nkosi household was in a very insecure and vulnerable situation and, had they experienced any further shocks or stresses, it is unlikely that the household would have been able to survive. Fortunately, Thobela's physical condition began to improve because of the treatment and she eventually received a disability grant. The disability grant helped to improve her health and the health and welfare of the rest of the family. The importance of access to grants as a source of household income was also observed in two case studies presented in this chapter and in all the other households enrolled in the study where at least one social grant was being received.

Despite access to social grants, the Bhengu household's livelihood remained fragile. If Thobela had been forced to forfeit the disability grant for any reason or the household experienced a further livelihood shock, such as Bheki's condition deteriorating or one of the children becoming ill, the household's economic situation would have returned to being very precarious. The household would have been at risk of becoming destitute or collapsing. The household and its livelihood was therefore still vulnerable to the impacts of shocks and stresses, despite access to social grants, as they were merely surviving on a day-to-day basis and had no opportunity to further diversify their livelihood as they were both still unable to work. The livelihood of both the Nkosi and Bhengu households had been particularly vulnerable because those who had been making the most significant contribution to the livelihood were those who became sick.

7.7 Discussion

In this chapter I analyse the impact of illness on the livelihoods of three of the households in this study. The livelihood's of households in rural South Africa are distinct from those that have been studied elsewhere and reported in the international literature, the review of which provides some insight into the livelihoods of rural households elsewhere in Africa. The distinctiveness of these rural households and their livelihoods is a primary consideration in this thesis. The context

of rural South African households is explored in both Chapter 4 and in the case studies in this chapter.

Three primary factors contribute to the distinctiveness of the households observed in these case studies. The first contextual factor is the very high HIV prevalence that has arisen in the generalised epidemic in South Africa. The scale and nature of the epidemic has important consequences for how it affects individuals and households in the community. South Africa is also unique in that it has one of the few fully functioning national AIDS treatment programmes in Africa. Together with a public health system that provides affordable health care to the majority and free health care to specifically vulnerable groups, this means that those sick with AIDS requiring treatment in South Africa, within close proximity to or able to access health facilities, can access treatment. Very few other places in Africa have a similarly widespread epidemic or have a national health system that provides affordable access to ART for those HIV-infected.

The other two contextual factors making rural South African households distinct are inter-linked and reflect the country's complicated and turbulent social, economic and political history. This history has contributed to the organisation of the South African rural black household into a complex and fluid structure with varying membership and residency that is still characterised by the internal or circular migration of its members. The third factor is that livelihoods of South African rural households are reliant on waged labour, informal economic activities or work and social grants, unlike most other parts of Africa that remain largely dominated by agriculture. These three factors are observed in the livelihoods described in the case studies presented within this chapter.

7.7.1 Dispersed livelihoods

The fluidity and stretched nature of households detailed in Chapter 4, means that some aspects of the demographic impact in this rural South African context are distinctive. Analysis of the Agincourt and ACDIS DSS data documented the return migration of sick non-resident adult household members (Clark *et al.*, 2007; Welaga *et al.*, 2009). In these case studies, the burden placed on rural household livelihood by non-resident household members is observed. The stretched household livelihood is described by Murray (2000, 2002), who studied the livelihoods of farmers and ex-farm workers in the Free State, as a 'dispersed livelihood'. These findings were confirmed by our case studies. They indicate how dispersal of both the household and the livelihood spatially help the household cope with disease and death. Both the household

and their livelihood are porous units not bounded by residential membership or a local economy.

In analysing households' livelihoods, one needs to consider how widely it has to be dispersed and to ensure that all those who participate in or contribute to it are considered. This finding does not imply that the livelihoods framework should be abandoned, but it may mean that the livelihood capabilities of the household extend further than the physical boundaries of the household. The concept of dispersed livelihoods was not envisaged in the current livelihoods framework. In addition to extending the notion of the livelihood, reconceptualising livelihoods in this way emphasises that some household vulnerability arises from the non-resident household members.

7.7.2 Household-level analysis at the expense of the individual

The standard household-level conceptualisation and analysis of the livelihood and how it is affected by illness and death in other research does not necessarily account for the independent role of the individual as a contributor to the household livelihood. The inadequate consideration of the role individuals have on livelihoods stems from the household or community-level bias of the livelihoods framework (Chambers, 1995; Murray, 2000, 2002). The role of individuals demonstrated in these case studies is particularly important in the South African context, where non-resident individuals and sometimes their close nuclear families often contribute to or burden the rural household's livelihood. Household members have different roles to play in the household. Some have primary responsibility for livelihood activities, decision-making and ultimately the functioning of the household, whereas, others are occupied with their own work and have limited contribution to the livelihood. The dynamics of these interactions, what motivates them and determines obligations for the maintenance of these close relationships and livelihood contributions are described in Chapter 7.

7.7.3 Livelihood diversity and existing vulnerability

In a review of the literature and analysis of the Project for Statistics on Living Standards and Development (PSLSD), May (2000) and, Carter and May (1999) demonstrate the diverse nature and complexity of the livelihood in South African households. Our case studies suggest that households with diverse portfolios of claims and access to intangible assets, stores and resources of tangible assets, as well as livelihood capabilities, are better able to spread the risk and impacts associated with illness and death, which corroborates the findings by May (2000), Ellis (1998) and Ellis and Freeman (2004). This diversity of livelihood activities in the case study

households reduced the existing vulnerability of the household. Similar findings on vulnerability and livelihoods were reported by Moser (1998) and Bebbington (1999). In the study area, households were able to cope with the presence and needs of a sick person, particularly the direct and indirect costs imposed by illness or a funeral. In addition, they effectively absorbed the burden imposed by the ill residents and were better able to sustain their existing portfolio of livelihood activities.

7.7.4 Livelihood capabilities, intangible resources and claims

The livelihood capabilities, access to intangible claims and resources households are able to make were important components of their livelihood for households enrolled in the study. In particular, I demonstrate the very significant role that the opportunities household members had to undertake informal work, economic activities and paid work play in the livelihood of households within the study. Important relationships exist between informal activities, formal employment and the role of treatment that shape household's experiences of illness. In addition, to informal and formal work, the claims on the state for social grants, their access to individual and household social capital as well as their ability to tap into social networks make substantial contributions to the livelihoods of affected households that help them respond to illness and death better.

7.7.4.1 Livelihood capabilities, access to employment and economic activities

Illness reduced the ability of household members to engage in formal work or employment, informal economic activities or paid work. Similar findings were reported from other studies in South Africa by Oni (2002), Booysen (2004a; 2002) and Bachmann and Booysen (2003). The importance of waged labour, and particularly informal work or labour, in this rural context is very different to the situation elsewhere in rural Africa. A consequence of the contribution that agriculture, and particularly the continued importance of subsistence agriculture, is that illness and death are felt disproportionately on human capital so integral for such economic activities (Wiegiers *et al.*, 2006; Yamano *et al.*, 2004).

The case studies provided examples of the importance, of the changing formal employment status of those who are sick. The loss of or changes in employment status caused by illness were observed in both the Bhengu and Nkosi households amongst others. There were also examples within the households of those who lost formal employment moving into informal work in order to supplement the household income, as has been observed in Zambia and argued to be a response (Bachmann *et al.*, 2003; Rugalema, 2000). The case studies also illustrate how loss of

the income of non-resident household members threatens the livelihood of the household as a whole.

The findings also suggest that illness reduces the ability of the household to participate in informal economic activities. The direct and indirect costs of illness and death reduced the income available to the household. Therefore affecting the household's ability to secure the capital necessary to begin or continue involvement in informal activities such as trading, small-scale gardening and artisanal production. In addition to reduced capital, households were also influenced by the reduced capabilities of household members either directly because of illness or death or indirectly through household members need to provide care. Therefore, when the household or the individuals doing the work experienced a crisis which affected their health and ability to work, an occurrence which was frequent for those who were sick, they were unable to continue with the informal work in which they were involved. Thus, informal activity was not a reliable source of income and, although it was very important for all of the case study households at some point in time, it remained dependent on a number of factors. In addition, unlike formal work, it is unregulated and irregular, it may be highly seasonal and depend on the availability of the work in the case of labour. In this sense, the findings of the effects of labour on small-scale or subsistence agriculture in the international literature are broadly applicable to informal work, employment or activities in South Africa.

The evidence in the case studies suggests that, although agricultural activities are not large-scale or commercial and are not dominant, some households do cultivate a garden, field or keep small animals as part of a diversified livelihood. This, like other informal economic activities, is dependent on labour and the financial resources available to the household. Where households were able to maintain these as productive and viable enterprises, they helped to support the household in terms of the provision of food and extra income, as in the example provided by the Sibaya household.

Those who were sick or HIV-positive in the study had either lost a job or forfeited participation in the informal economy because of severe illness. Although the participation of these people in the formal labour market was already limited, as argued by Booysen (2004a; 2002), many of those who became sick had been involved in the informal market. Despite access to ART, many of these people were limited in their ability to reintegrate into the labour market, formal or informal. This was because of widespread existing unemployment and the limited availability of money-generating informal work both locally and further afield. Respondents within the case studies suggested that the lack of opportunities for work was the major factor preventing them from working and therefore limiting their access to income.

Illness not only affected the ability of those who were sick to undertake or participate in economic activities but also indirectly affected other household members. These effects were felt either as a result of financial restraints, because of costs associated with illness and/or death, or as a result of caring responsibilities as has also been observed by Russell (2004b), Oni *et al.* (2002) and Rajaraman *et al.* (2006).

7.7.4.2 Social grants

The importance of social grants for the livelihood of households affected by illness and or death is clear in all three of the case studies. These social grants played a different role in the livelihood of each of the case study households. In one household, the disability grant ensured that the sick person was able to be self-sufficient and operate independently from the rest of his household, therefore limiting the impact of his illness on their livelihood. In another, the grants that the household received helped to sustain its livelihood and ensured that the household was able to eat and survive despite the negative impacts of illness and eventual death. In the long-run, the grants enabled the households to diversify and develop the livelihood. The disability grant in particular provided households with a lifeline and meant that those that were struggling to respond to the negative impacts of illness were able to survive from day-to-day. Therefore, social grants were not just another source of income and played an important role in helping the households respond to the impacts associated with illness. Social grants are discussed in-depth in Chapter 8.

7.7.4.3 Social capital

Another livelihood component, which had specific significance for the case study households, was the access to support that households were able to secure because of claims on their social network. The notion of the dispersed livelihood is applicable particularly to the examples of the financial assistance or material support the household was able to secure from non-resident members on an ongoing basis. The fact that non-resident household members maintain ties that often include financial assistance and material support for the rural household means that their illness and subsequent job loss or inability to continue participating in income generating activities or work had major financial implications for the rural household being supported. Examples within the results also suggest the significance of other kin and in some examples even those from outside of the household. This support was particularly important in this time of extreme crisis within the household. The potential that non-resident members and members of other networks have to further impact on the rural household is therefore, important for livelihoods in the rural South African context. The dynamics and social interactions,

implications and motivation for support and care are discussed and explored further in Chapter 7 of this thesis.

7.7.5 Tangible assets

I have argued already that the livelihood capabilities, intangible claims on and access to resources that rural South Africa households have are comparatively worse affected by illness and death than tangible assets. Nevertheless, the tangible assets that the household has access to and is able to make claims on are also significant for mitigating the impacts of illness and death. As argued within Chapter 3, the financial resources available to the household are affected by the costs and expenses the household has and are a consequence of the access the household members have to income-generating activities, which have been discussed under intangible resources.

7.7.5.1 Financial resources

The literature review identifies two specific financial costs associated with illness and death. The first is the costs of illness, which includes the costs of health care. In contrast to the findings suggested by Booysen (2004a; 2002), the households enrolled in the study found indirect health care costs burdensome, in particular the transport costs associated with getting to the local clinics for treatment and obtaining specialised hospital-based treatment and care. Sick household members who were not earning a social grant and unable to work or earn an income were a financial burden on their households. As hypothesised in the review, because ART requires regular visits to the clinic, it has the potential to increase the burden of health-related expenses on households. This was particularly the case for households that were already vulnerable and unable to diversify and sustain their existing livelihood activities because of illness.

In addition to the costs associated with obtaining health care, there were other major costs associated with a death and a funeral. The relevant case study shows that these extend beyond the costs directly associated with the funeral which are acknowledged within the existing South African and international literature to be relatively large (Booyesen, 2004a; Case *et al.*, 2008; Lundberg *et al.*, 2000). Other costs associated with death, such as the movement of a body if the person dies elsewhere and the transport for family members who need to be at the rural household to observe the traditions associated with the death, also place a burden on the household.

7.7.5.2 Physical resources and asset sales

Stores and resources of tangible assets are relatively much more important within the literature from the rest of Africa than they were found to be in this study. Sale of assets was found to be a response to illness in studies in Kenya, Chad, Zimbabwe and Mozambique, specifically those where the majority of the livelihood is dedicated to agriculture or subsistence farming (Mather *et al.*, 2004; Wyss *et al.*, 2004; Yamano *et al.*, 2004). Sale of assets was not mentioned as a response to the impacts of illness or death by any of the households enrolled in this study. In other contexts, the ownership of land was found to be significant and it was worked for produce and income or sold for support (Rugalema, 2000; Seeley *et al.*, 2008; Wiegers *et al.*, 2006). Land ownership was not common in the study context, where the land is seldom owned directly by the person living on it but is rather owned by traditional authorities who grant the household or family tenancy. Vehicle ownership in one of the households was very important and enabled a household member to undertake informal work, helping to diversify the income.

The examples in the study of access to land did show that, despite the relative unimportance of agriculture and land for the livelihood within the community as a whole, those with capital, labour and water were able to work the land. They produced small outputs for the household in order to help to diversify the livelihood thereby facilitating better responses.

7.8 Summary

The findings of these case studies indicate that the livelihoods of households in rural South Africa should be conceptualised as dispersed because of the fluidity of membership of and residence in rural black households and the role that non-resident household members play in the household. Analyses of the household's livelihood consider the household contribution but also the role of the individual.

Having access to tangible assets facilitated the diversification of a household's livelihood and helped such households respond better to illness and death of members. Access to social capital and social grants, mitigated the repercussions of crises or stress and enabled affected households to respond effectively.

Access to ART can improve the health of sick household members substantially, thus mitigating the impact of HIV and AIDS on the livelihood of households. The overall improved health of the household members benefits the household in terms of both their resource and a reduction in the time spent caring for the sick member and other illness-related expenses. Despite this, the

lack of employment opportunities and limited possibilities for economic reintegration of the previously sick person means that an additional unemployed adult household member may continue to be a burden on the livelihood. Even with access to ART, the health of PLHIV does not always improve and recurrent bouts of ill-health can be nearly as disruptive to a household's livelihood as continuous ill-health, requiring variable levels of support with resource implications for the household and its ongoing livelihood.

Chapter 8: Social capital as a means to mitigate the impacts of HIV and AIDS



8.1 Introduction

This chapter further expands on the support that the households enrolled in the study were able to secure from other people, this was something that emerged in the analysis of the households' livelihoods. This support came from a range of sources and there were a number of complexities and factors involved in its provision. The chapter reviews the existing literature for the support that households and individuals affected by illness and death are able to rely on in South Africa. It also presents an assessment of the type of support, the motivations for the provision of this support and the limitations of and barriers to the support that is available from close family members who are also members of the rural household. The support that affected households receive from kin in other households is considered, as are the different types of support provided and the factors that influence this support. In addition to the household and kin, the support, assistance and care secured from individuals, households and groups that are external to both the household and the kin network are examined. The support and assistance that affected households are able to provide to other households or individuals are also investigated.

8.2 Social support in South African households affected by HIV and AIDS

Chapter 4 provides background to the different kinds of support that South African households are able to rely on from other members of their social networks regardless of the impact of HIV. This research suggests that, despite arguments to the contrary by some, family and kinship networks in South Africa are resilient and, despite changes to the household and the impacts of social, economic and political policy and history, remain important sources of support. This section reviews the research into the support that households and individuals affected by illness and death are able to rely on. Preston-Whyte (2006) conducted an analysis of the structural conditions under which HIV has spread in South Africa. As part of this, she analysed the increased vulnerability to infection associated with the general weakening of social capital available to people over time. She also refers to concerns about the way in which illness and death are eroding social safety nets, therefore reducing the resilience of social capital. However, this review provides little empirical evidence as to whether the often assumed erosion of social capital because of the impacts of illness and death actually plays out in reality.

A qualitative study of households that had experienced a death in KwaZulu-Natal, which in the context of the study were assumed to be caused by AIDS, provided some evidence concerning what support affected households were able to rely on from within the kinship network (Cross, 2001). The research in KwaZulu-Natal found that the movement of children between households required strong bonds, through either blood or marriage. The study suggests that relatives and especially parents were an important source of support for households affected by death (Cross, 2001). Evidence from Botswana provided by Heymann and Kidman (2009), also suggests that the fostering of family members was important and, in the case of the households in the study, was viewed as an obligation. In research into the dual impacts of AIDS and tuberculosis undertaken in both Zambia and South Africa, close kin and particularly parents in South African were found to be the most important source of support. Caregiving of the sick was most often undertaken by mothers but fathers and brothers were identified as an important source of financial support during illness and for funerals. The relationships within the family were not uncomplicated though and there were examples within the research of conflict and tensions between the sick person, their caregiver and the family. In South Africa this was intensified if the sick person got a disability grant (Bond *et al.*, 2009).

Another qualitative study, this time of the general impact of adult deaths in an urban community in the Western Cape, explores the role played by the complexities and conflict inherent in social relations in the aftermath of a death (Bahre, 2007). The author notes the importance of the

support that kin provide for family members affected by illness and death. He also raises the issue of the difference observed between urban and rural networks. Ross (1996; 2003), Spiegel (1986) and Spiegel *et al.* (1996) conducted research into social relations within and between households in informal settlements in the urban Western Cape. The results from both authors show the greater importance of the kinship network as a source of a range of support types in rural as opposed to urban networks (Ross, 1996; Ross, 2003; Spiegel, 1986, 1996). The Cape Town study of repercussions of death also suggests the significance of social sanctions that threaten those who are not able or willing to support the members of their family with a loss of respect. Family members were found to need to demonstrate publically that they were providing support (Bahre, 2007).

Another assessment of the repercussions of death, and particularly the funeral, was conducted using a module on deaths attached to the DSS data from the Africa Centre. The results from this study confirm that in the rural South African context the funeral is an elaborate and expensive affair because of the large number of mourners who attend. They are often very expensive and are important for not only the family, but also other members of the community and neighbourhood. Much expectation is placed on the family of the deceased, specifically those who were closely related to the deceased or household members, to provide both finances and time (Case *et al.*, 2008). The costs associated with an AIDS death have been explored in a number of other studies in South Africa. As in most African societies, funerals are an important rite of passage. People from the wider community are also often expected to contribute (Bahre, 2007). Booysen *et al.* (2002) found that 60% of funeral costs were paid for by friends or family, but does not differentiate between the two, making it hard to determine who it is that provides the most support or what the differences were. Cross (2001) suggests that what limited support households were able to rely on from neighbours and friends after a death, was provided at the time of the funeral.

The impact of stigma because of AIDS and the effect this has on relationships and the support affected households were able to rely on were raised in the ethnographic research conducted amongst affected households within the Umkhanyakude district (Hosegood *et al.*, 2007b). The respondents in this study felt that the fact that members of their household were sick, along with their poverty, limited the support the household was able to claim from sources external to the household. The study also provided examples of conflict between family members because of stigma, which changed a household's ability to access support from both the family and wider afield. The dynamic and fluid nature of the household meant that some households were affected by multiple cases of illness and death amongst both resident and non-resident members.

The results also suggest that support from family members and neighbours reduced with the number of deaths that a household experienced, because they became either reluctant or increasingly unable to help.

As already discussed in Chapter 4, the role of groups, either formal or informal, is particularly important in the provision of social support. Some research focussed on the impacts of HIV and AIDS provides evidence for the role played by informal and formal groups in the support of households during times of difficulty. For example Cross's study of the impacts of death in KwaZulu-Natal, found that *stokvels* were an important source of credit for households that had experienced a death (Cross, 2001). In his analysis of death within a township in urban Cape Town, Bahre (2007), also found evidence for the importance of neighbourhood burial associations. These had been formed in response to an increase in deaths locally in order to provide burial insurance. The evidence he provides suggests that, in the study's urban context, support from neighbours and community members and membership in groups is complex and affected by the quality of the relationships between members.

It has been argued within some of the policy literature, sometimes based on anecdotal evidence and assumptions and not backed up by empirical evidence, that social support from within the social network can support adherence to ART. The evidence to link social support and ART adherence is limited (Nachega *et al.*, 2006). Research in KwaZulu-Natal exploring this relationship suggests that while social support appears to be important for adherence there is no direct link between the two and may reflect disclosure or reduced stigma as a result of increased communication and closer relationships (Ncama *et al.*, 2008).

The South African literature suggests the importance of familial obligations and reciprocity for the provision of support for HIV and AIDS affected households. Despite changes in the structure and organisation of the family and its living arrangements, the obligations, duties, rights and expectations inherent in these kin relationships still influence the livelihoods of rural South African households. The literature, both international and South African, suggests though that the burden that illness and death places on the household may lead to diminishing support from within normally reliable social networks. However, while the literature provides some examples of the help affected households are able to rely on, there is little analysis of the complex and supportive relationships, which exist within fluid South African households. This chapter aims to analyse the different types and sources of help affected households, including those with members on long-term treatment, are able to secure from the various social networks of which they are members.

The research conducted so far also largely fails to assess the norms, values and therefore expectations and motivations that underpin the support that both affected households and the individuals within them have access to from within the household, within the familial or kinship network and from within other social networks situated outside of kinship ties.

The distinction between the household and the wider kin or familial network is particularly important in the South African context where members of the household can be resident elsewhere. Non-resident members potentially have stronger links and ties to the household than other kin. This distinction may distinguish South African rural households from other developing country contexts. It is also particularly important that, as argued in Chapter 6, the livelihoods of households in South Africa are in many ways different to those in the rest of Africa. This means that at times the types of support households can rely on may be quite different. For example, Seeley *et al* (2008) find that the role of land, its cultivation and access to the rural household has to it are particularly significant for households and that access to land is facilitated or hindered by members of the kinship network. In the South African context, where land on the scale observed elsewhere in Africa is comparatively less important and because of the smaller scale it is less complicated in terms of inheritance, assistance with the provision of work, as in the example described in Adato *et al.* (2006) may be comparatively more important.

8.3 Rural household as a source of material support, financial assistance and physical care for affected individuals

Relationships between household members are influenced by the dynamic and fluid nature of the household because membership is extended beyond the boundaries of the rural homestead. This is very important in the context of AIDS, where the illness of adult non-resident members, has been shown in Chapter 6 to have implications for the household. These non-resident household members play different roles in households affected by HIV and AIDS, depending on their own circumstances and, in particular, on their own health. The material support, financial assistance and physical care of sick household members and their children, whether resident or previously non-resident, provided by resident household members also matter, as do the motivations and social relations that underlie this provision. These concepts have been introduced in the preceding chapter in terms of the dispersed livelihood and the importance of the individuals within the livelihood.

This section investigates whether the changing structure and formation of the rural household has altered prevailing norms of family obligation and the norms of reciprocity that operate

among kin. Some South African academics studying the functioning of the family suggest that, despite undergoing changes, the black South African family and the obligations and norms that operate in it are still very powerful social factors (Sagner *et al.*, 2000; Siqwana-Ndulo, 1998; Viljoen, 1994).

8.3.1 Non-resident returnees to the homestead

In five of the households studied, non-resident household members had returned home because they were sick and needed care and support. Four of the households had one previously non-resident sick household member and one of the households contained multiple members who had migrated into the household with differing degrees of illness. The rural household was an important source of support for the migrant in times of crisis, specifically in the context of HIV and AIDS when the non-resident member became ill.

Non-resident household members who became ill while living in urban and peri-urban areas, found it hard to manage their social and economic situations there because of loss of employment and their need for physical care. This meant that, in many cases, the non-resident members were forced to return home. Zinhle Bhengu and her family situation were introduced in Chapter 5 and expanded upon within Case Study 2, Chapter 6. An example of a migration home was provided in this household. The pastor from Zinhle Bhengu's church in town brought her back to her mother's household when she became ill. Zinhle's mother, Nomsa, explained that the reason for this was that there was no-one to physically care for her in the town.

Senzo Gumede was another example of a non-resident household member who moved back home when he became ill. Even though both Zinhle and Senzo had friends and were members of social networks based on common worship or shared living quarters in the urban areas, these relationships did not stretch to physical care and material support, and financial assistance remained limited.

8.3.2 Financial assistance and material support

Zinhle, unlike Senzo, was in a relationship at the time she became ill. However, she was neither married to, nor lived with Petrus. Although he provided some financial assistance for her treatment, Zinhle's lack of a formal relationship with Petrus's household meant that her mother's household was the location to which she returned when she became ill. Had this relationship been formalised, through the payment of *lobola* or some other sort of marriage rite,

the situation would have been different. Zinhle and Petrus would have continued to live together, and his family may have supported Zinhle.

The rural households therefore confronted difficulties in providing sick, resident and previously non-resident household members with physical care, financial assistance and material support. This reality was particularly marked in the cases where these individuals were unable to or had difficulty accessing the disability grant. All of the sick resident and previously non-resident household members, enrolled in the study, had lost their job or ability to earn an income, because of their illness, and were therefore unable to support themselves financially. Financial assistance for the sick from other household members enabled the ill members to pay for the transport they needed to visit the clinic for regular checkups, treatment and visit the Department of Social Development offices or pay points to access social grants. Zinhle Bhengu was an example of this. Financial assistance from her partner and from money pooled from child support grants and borrowed by her mother, enabled Zinhle to attend her daily appointments at the clinic to receive her TB medication.

Seeking healthcare and treatment was not only expensive but also difficult. Nomsa reported the difficulties that she and her household confronted while trying to help her sick daughter Zinhle access treatment and healthcare at the clinic.

[Zinhle] can't walk, I don't have money. Where can I get the money to go to the clinic everyday? [Zinhle] can't walk she falls down and [there are times] I have failed to take her to the clinic... [Zinhle] went together with my youngest daughter. They had to take a taxi, there is nothing else they can do. I borrowed the money [for it]. I don't know what we will do tomorrow. [Zinhle] will have to go alone.

Nomsa Bhengu, female household head, 56 years

In addition to the costs associated with access to health care and treatment, the household confronted the physical barriers to transport directly caused by illness. Zinhle required either special transport or someone to accompany her in order to ensure that she was able to complete this journey.

Despite the difficulties and potential impacts of providing financial assistance and material support to a new sick household member, households mobilised the few resources that they had access to in order to do so. One of the ways in which the household accomplished this was to pool income. In the Mabena and Bhengu households, the household matriarchs and heads, Nobantu and Nomsa, were the people responsible for the care of the sick household members.

were also the only people earning social grants within the household and, therefore, employed their social grant income in order to provide for the needs of the household.

The pooling of individual income with that of others in the household, therefore, acts as a source of financial support for all household members. Along with the example of the income pooling in the Bhengu and Mabena households, discussed already, there is the example of the Dlamini household. Gugu Dlamini used both her own income from the disability grant she was receiving and the income from her mother's old age pension in order to provide for the other members of the household, many of whom were the partially or fully orphaned children of Gugu's siblings, who themselves had died as a result of an illness. Schooling, clothing and transport needs of the children resident in the household were paid for using pooled income, particularly for those children who were orphaned or who had a sick parent. In the Mabena, Bhengu and Dlamini households, a portion of this pooled income was used to provide for the material needs, particularly the food for all the household members including the sick person or orphaned children.

8.3.3 Physical care and responsibility for children

Physical care was provided by the rural household, and specifically by a primary caregiver, to both sick adults who were resident and those who had previously been non-resident. In four of the five households that had a return migrant because of illness, the return migrant was provided with intensive physical care while resident in the household. In all the households with a previously non-resident sick member the primary caregiver was a woman and in three, the Ntuli, Mabena and Bhengu households, the caregiver was the mother of the sick person, while in the Dlamini household the primary caregiver had been Gugu, who had cared for her siblings. Those who were very ill, such as Zinhle Bhengu, required help with dressing, washing and getting to and from the toilet regularly. Zinhle also needed physical support in order to get to the clinic and her treatment, as discussed above.

Another example of physical care for a sick household member was observed in the Nkosi household, where Bheki and at times the children in the household, took care of his wife, Thobela, who was very ill and required help from her sons and husband in order to move around the house and property, including frequent trips outside to toilet. As a result of her immobility, Thobela also needed help washing and dressing herself. She needed help washing, dressing and applying medication to the sores on her feet and legs. Thobela also required physical care and help with what used to be her domestic responsibilities. Therefore, the washing, cooking and cleaning were now shared between her sons and husband who supervised these activities. The

situation in the Nkosi household shows that the physical care of sick household members is not always provided by a women and not always by a mother.

Another very important source of help that the rural household and family provided was the physical and emotional responsibility for the children of the sick household members. Four of the five households that cared for a non-resident sick household member also cared for the children of these people. These children were absorbed into the household in all the cases in the study, the primary caregiver of the children being in every case the mother of the sick person.

In the Dlamini household, the deaths of three of the previously non-resident children of the household matriarch meant that during the study period there were seven orphaned grandchildren resident and being looked after in the household, ranging in age from 13 to 23 years. All these dependents had been resident in the household since the deaths of their respective parents. Of these resident grandchildren, two had children of their own and in addition, the household, continued to care for two resident children of a grandchild who was now also a non-resident member of the household. This household was a good example of the extended and complicated nature of the familial relationships within the study households.

Other examples of fostering and care for orphaned children were provided in the Gumede and Ntuli households where Jabulile and Tina each cared for two of their grandchildren. In each case one of the children was sick and on ART. Both started caring for these children either before or during their parents' illness.

The care and fostering of children, therefore, largely commenced before people became ill and was an established practice that continued after the children's parents became ill or died. These earlier exchanges of financial assistance and material support, in return for the care of the children, helped to secure future physical care. However, illness and death and the financial and socio-economic implications they have for the household in both the short and the long-term have contributed to the intensification of the fostering of children.

8.3.4 Building social capital by investing in relationships with other household members

The preceding section has provided examples of the way in which the rural household was an important source of material support, financial assistance and physical care for those who became ill and their children. A number of factors influenced and motivated the support that

these non-resident and resident individuals received. Many involved the type and quality of the relationship they had with other household members.

8.3.4.1 Family obligation

The significance of affective ties or love between resident and non-resident household members are demonstrated in the Ntuli household. Despite being married and living in a nearby township with her husband and young son, Simphiwe Ntuli maintained a close relationship with her mother, Tina, and siblings at her maternal home, she saw them regularly and her mother described their relationship as good and close. She attended church with Tina and visited often so that, when she fell ill, Tina initially moved to her household to care for her and thereafter both Simphiwe and Thendai returned home to be physically cared for by her mother. The relationship shared by mother and daughter, reinforced Tina's desire to help her daughter, a factor that is linked to her ongoing care of her grandson. Tina Ntuli related her feelings about caring for her grandchild.

I don't have any problem with [caring for her grandson] because I know that he is my child's, so he is mine too.

Tina Ntuli, female household head, 63 years

The close personal relationships between members of the same household were important. The development of these relationships increased the ability of those involved in the relationship to obtain help from within the household network.

Tina Ntuli, also spoke about the responsibility she felt to care for her non-resident daughter.

[Simphiwe] was sick, I went to stay with her [at her husband's house]. When I decided to come back, she asked the church elders whether she could come back to my house, because she was sick and had no-one to take care of her, even though she was supposed to stay because she was a minister's wife. They allowed her to come home....

Tina Ntuli

As in the case of Tina and Simphiwe, the closest and most important relationship was most often that existing between children and their mothers, who felt the greatest obligation to care for their children. The statement above by Tina also shows that the obligation to one's biological children may also stretch to an obligation to their children who as Tina states are also viewed as children. The bonds and obligations of parents to children are therefore not only of

biological parents to their own children but may extend to social parents, in this case grandparents who are socially expected to take responsibility for their grandchildren.

Three of the non-resident members provided further examples of the ties that exist between the non-resident household members and the rural household. Zinhle Bhengu and Senzo Gumede both had children living in their respective rural homes and were being cared for by the children's grandmothers. Zinhle and Senzo were living and working in St. Lucia and Durban respectively, but retained close contact with their rural households, their children and their mothers, who were their children's primary caregivers.

Within the literature, it is proposed that parenting amongst the Zulu and other sub-Saharan African groups is a communal exercise (Mkhize, 2006). The suggestion that the family is becoming nuclear, Westernised and insular would assume then that parenting too would become more focused around the biological parent-child dyad. The statements above by Tina and the evidence below from the Bhengu household do suggest the importance of affective ties between parent and child. However, the statement below, made by Sifiso the non-resident brother of Gugu suggests that there is a wider family obligation to support young children in need of assistance if members of the family are able.

Here at home we are just those people who believe in customs. So there are those people who pass away and there are children who are orphans who don't have support but they get support from my mother's grant because here at home my mother is the one who supports them and also my sister [Gugu] who earns the grant for her child.

Sifiso Dlamini, non-resident household member, 41 years

Despite the understanding that the material support of rearing of children may be a communal activity within the household shared by adults or older teenagers who help with day-to-day domestic tasks in all the households enrolled in the study there is one person who is ultimately responsible for assuming the primary role of caregiver. In all the households this person is also primarily responsible for ensuring that the needs of the majority of the household members are met and that the required domestic tasks are completed.

The bonds and strong obligations of parents to their biological children versus other household members are demonstrated in the Mabena household.

The extent of Nobantu's motivation and dedication to caring and support was visibly different between her daughter and her brothers. Although Nobantu described the help, physical care and

material support she provided for her brothers; lunch every day, help with washing and giving them their medication, this was different assistance to the physical care and material support she was observed providing for her daughter, Lindiwe. She attended hospital and made clinic visits much more regularly than her uncles, paid for by her mother. Nobantu also cared for Lindiwe's newborn baby. She lived within her mother's house, while her uncle's slept in a structure separate to the main house on the same property. This structure was visibly ill-equipped and unfinished. One room was used for sleeping and was only half covered and remained one third open to the elements. Moreover, Nobantu was visibly more distressed about Lindiwe's condition and was actively concerned with her care.

Nobantu's decision to support her brothers seemed to be dominated, in part, by their extreme need but also possibly by a strong obligation to kin, as indicated in her response when asked why she cared for them: "They are my brothers, they have no-one else". Despite this, the level of support and desire to provide she felt for her own daughter was observed to be more than that for her brothers, whether she consciously made this decision or not.

The decisions Nobantu made about the way in which the money was spent were strongly guided by her obligation to provide for the needs of the members of her household, but also a need to support close family members. Nobantu's income was the only source of revenue available to fulfil all the needs of the household. In this household, the most urgent needs were food for the household members. Anything remaining from the old age pension money was spent on transport or other necessities, first for her daughter Lindiwe and thereafter for her brothers.

Gugu Dlamini was the resident and eldest living daughter of Ntombizodwa who was the female household figurehead. Gugu was HIV-positive and when I first met the household, she had recently started treatment. She was responsible for all of the decision-making in the household, including both the continued operation and functioning of the household and the economic activities the household undertook. Gugu had physically cared and ensured material support for two of her sisters who moved into the household when they were very ill. This is how she responded when asked why she did so.

I just help my family, I think it is right to help other people...

Gugu Dlamini, daughter of household head, 33 years

The people who remain or return to the household to provide financial assistance, material support and physical care to the household members in need are often either unmarried or separated women like Gugu and Thembilihle. For example, in the Dlamini household Gugu

lived at home and was responsible for the decision-making within the household and for the care of her siblings' children and livelihood activities. Here, Gugu's mother Ntombizodwa reflected on the matter of Gugu's responsibilities to the household.

It is [Gugu's] job now [to take care of things and people within the household]. I don't know what to say, but it's because she is a girl and also because she was born here.

Ntombizodwa Dlamini, household head, 70 years

Gugu had three living brothers and yet the greatest responsibility for the other resident household members and domestic activities falls to Gugu. Ntombizodwa's statement suggests that the reasons for this are her gender and the fact that she is linked by birth to the household. I would suggest that the responsibility of unmarried women to their parental household is perpetuated by the expectations of both the family and the community. Resident and non-resident male members of the household were expected to contribute material support or financial assistance to the household in times of need and, in many cases, maintain ties to the household.

However, the bulk of responsibility for day-to-day domestic activities, decision-making and domestic activities, for example the provision of physical care for other household members falls to a greater extent firstly to those members who are resident and therefore there to help. The female members of the household shoulder more of a responsibility for care, as well as general domestic responsibilities within the household. This I would argue is influenced not only by their residency within the rural household that enables them to provide care and undertake domestic responsibilities but is also an example of the female obligation to do certain kinds of work. Resident sons in the Sibaya, Ntuli and Bhengu households although assisting others where necessary in care and domestic responsibilities were considered unsuitable, often by the female household heads, to undertake this sort of work and unable to do this on their own. The obligations of women do change over their life-course though, depending on their social situation. Prior to marriage, they are obligated traditionally to their father's household and this obligation is still felt for single women like Gugu (Preston-Whyte, 1974). However, once they are married, their responsibilities are to the family of their husband. For example, this is clearly seen in the Dube household, where Thembilihle continues to live with the household of her late husband and supports members of his family, despite maintaining close relations with her own family.

The family and rural household were an important source of support in other times of crisis or stress, unrelated to illness. This was observed in Tina Ntuli's household. Her non-resident son

lost his job in town. Thereafter, he returned to the home of his mother where he relied upon her for food and financial assistance until he was able to obtain fixed employment. Similarly, one of Nomsa Bhengu's daughters also returned to her mother's home for a short period after she separated from her husband, until she managed to gain admittance into a course in a nearby town to study nursing. Therefore, for those non-resident members of rural households who have migrated to urban or peri-urban areas, the rural household and family remains an important safety net during periods of difficulty in their lives.

8.3.4.2 Generalised reciprocity

The rural household and the members, with whom the non-residents in the study maintained close relationships, as identified as good or particularly close by the respondents, could be relied upon to help the non-residents in times of need. The rural household is therefore a very important source of financial assistance, material support and physical care for those who had previously been non-resident members. The continued maintenance of close social or economic relationships with their rural household had allowed for the return to the household at the onset of serious illness. This is because of the close personal ties as described above, fostered through joint household membership, and generalised reciprocal relationships that have in many cases been secured through various forms of investment that can act as social insurance.

Non-resident household members visited their rural households when they could, remitted some of their earnings to the household and brought groceries to the homestead when they visited. These reciprocal relationships helped to build on and maintain relationships within the household, and with certain family members, in particular, through the provision of goods and money. For example, Zinhle and Senzo provided financial assistance for their children. Zinhle had been sending money home to her rural household and, during one interview, her mother, Nomsa, spoke about the change in the household's financial situation since Zinhle had become ill and could no longer contribute materially and financially to the household.

[Zinhle] was the man [of the house], there were deliveries to the house before she was sick but now there is nothing. Look at that building, [Zinhle] was the one who was building that house.

Nomsa Bhengu

The description of Zinhle as a man is an interesting indication of the gendered norms still operating within these rural households. Whether actually happening or not the role of provider, in this case sending money home to build and develop structures and materially support the

household is still viewed as the role of a man. This is in contrast to the statement above by Ntombizodwa Dlamini about her daughter Gugu and her responsibility to the domestic realm as a woman. Therefore, despite the household reality being different and no longer organised according to traditional principles, there is still a gendered division of roles within the rural household.

Nomsa felt that the situation in the household had changed considerably since Zinhle had become ill, and that the household was substantially worse off now that Zinhle was no longer contributing to it. The Mabena and Gumede households had similar experiences, the change in work and life situation of the non-resident household members had exerted a substantial influence on the household, mostly through the loss of remittances and the discontinuation of material support and financial assistance for the household provided by the non-resident household member. Where there is migration home involved, the household also acquired the added responsibility of providing for the new sick resident household members.

Zinhle had also been sending money home for building a dwelling at the homestead. The family would have been able to use it when it was complete, as was the situation in other households within the study. Zinhle would also have been able to use the dwelling when she returned to the household but had fallen ill in the middle of construction and, therefore, the building was not completed. Lindiwe had helped to pay for an extension to her mother's home and for the repair of the roof. These repairs made a significant difference to the quality-of-life for the Mabena household and meant that Lindiwe retained a room in the house when she became ill. The contribution of buildings and structures as well as remittances to the rural household ensured that according to norms of reciprocity the non-resident member was able to make claims on support, care and assistance on the rural household.

Part of Nobantu's motivation to help her children is demonstrated in a statement she made while discussing her efforts both to pay school fees and buy clothes for her other children who were not sick and, therefore, not in need of urgent help, but nevertheless resident in the household at the time.

There is nothing else for me to do [other than help] or my children will grow up and kill me if they think that I was not helping them.

Nobantu Mabena, female household head, 61 years

The above statement is very telling. Although Nobantu does not mean that her children will literally kill her, she is referring, in this instance, to the fact that they will not look after her later

on when she no longer possesses the capacity to take responsibility for the household and its members, and when she herself needs to be cared for. She is therefore motivated to care for and support her children in part by the hope that they will care for her in the future. This provides an example of how generalised reciprocity, giving what you can in the knowledge that someone will provide for your needs in the future, operates alongside a sense of family obligation within the household and family network.

8.3.5 Complex and conflicted circumstances

The situation in the Sibaya household is different from that in the other households where someone returned home because of the onset of serious illness. Mandla was ill when he returned home, his stepmother cooked for and fed him, his father paid for his food and he was resident on the property. However, in most other aspects as argued in Chapter 6 he operated quite independently from the household and family. Mandla had not maintained a very close relationship with this household and, although his stepmother, Precious, cooked for him, she undertook this task grudgingly and expressed her dissatisfaction with the situation on more than one occasion.

Mandla doesn't give us anything. He keeps his money [from disability grant] in his pocket.....We don't know how he spends his money, he doesn't even help us to buy food.....Mandla and Blessing are just supported, here at home, by their father. Neither of them buy food. Their father buys the food.....and me I also buy [food] with the money from the child support social grant.

Precious Sibaya, wife of household head, 36 years

Precious was particularly unhappy because of Mandla's lack of financial contribution to the household, both before his return to his father's home and since becoming ill, despite now accessing a disability grant. Precious was highly critical of what she perceived as Mandla's spending on wasteful extravagances instead of contributing to the household. This suggests that, notwithstanding the existence of a family or moral obligation to support and care for family members, a degree of reciprocity is expected if one is able to provide something in return for the support that other household members are providing.

Some of the difficulties in accessing support from members of the household or the extended family arose because of the development of new relationships. There were two examples of this given within the study. Tina Ntuli felt that her son's new partner had affected the household's relationship with him and the support upon which the household could rely on from him.

These days I'm missing [my son], because he is the one [child] who helps me. He often has different girlfriends, but at the moment, he has the worst girlfriend. She doesn't want him to share his money with his family. He even failed to support his child when his mother passed away.

He fell in love with someone older than him, I think that's the problem. Even when he was at school and staying in town he made sure that he knew that we are eating. Now I think this new girlfriend is telling him not to help or be involved.

Tina Ntuli

The obligations that family and non-resident household members felt for family resident in the rural household were complicated and this example provided by Tina suggests that there is a potential conflict between the obligations that, adults who live elsewhere, have to their natal family and household and to new households or relationships. This shifting of obligation towards a new family seemed to be particularly strong for men who moved away from the household, married and started new families and were torn between the obligation to their natal home and their new homes. Tina also experienced a problem with another son who had been in trouble with the law and had subsequently severed ties with the family because of the risk his associating with the family had for them and for himself.

8.3.6 Summary

In summary, although complex and with exceptions, the type of relationship that household members maintain with one another influence the motivation of and obligation felt by members of the rural household to support and care for the sick person. This obligation to support and care for other household members often had positive consequences for the sick person and for their children. The results also show the significance of reciprocal relationships and of willingness to participate actively in these relationships as a form of social insurance and to foster feelings of obligation to family who are also household members. The results suggest that those who are unable or unwilling to follow the norms of generalised reciprocity and obligation to close family may eventually not be able to secure support or may find that the support that they receive is more limited than that to which they feel entitled. The results also provide evidence for the potential negative impact that these norms of reciprocity and family obligation may have on the household's livelihood because of the obligation to support household members who are sick or dealing with the effects of an illness.

8.4 Non-resident household members as a source of material support, financial assistance and physical care for affected households

In addition to presenting a potential burden for the household, as was the case for sick resident household members, non-resident household members were also a source of support for the rural household in times of crisis or stress. In this way, they were able to maintain close ties with the rural household and invest in relationships that they could potentially draw on for help in the future.

8.4.1 Financial assistance and material support for funerals

Within the Dlamini household, material support and financial assistance from non-resident household members was particularly important when members or non-resident members of the household died. The expectation to contribute in some way to the household for funerals was particularly strong. It was not always easy for people to contribute as they were expected to, especially when the family was dealing with extreme burdens such as the multiple deaths in the Dlamini household. Nevertheless, when they could, they often did. Gugu spoke about the contribution her brother Philani made to the household.

Philani should give us more money, unfortunately there are all these deaths, things that need money. He is going to buy a cow to slaughter at his father's ceremony in June.

Gugu Dlamini

In this quote it is clear that despite the fact that Philani was expected to buy a cow for their fathers' ceremony, the household and Gugu did not consider his other contributions as being sufficient for their needs.

The Dlamini household held many funerals and were particularly reliant on both non-resident members and resident household members to assist as far as possible with the funeral expenses. This expectation and desire to help at the time of funerals could be linked to the notion of displaying family support, as these are public occasions, with many expectations attached (Finch, 2007).

My elder brothers helped with the funeral preparation because there were some problems with his funeral cover. My brothers tried to sort out everything.

Gugu Dlamini

In terms of expectation and motivation to provide material support and financial assistance Tina related an incident where one of her non-resident sons had bought her and her household some food.

He came by at the last minute. We returned from our journey with no food, I was starving. I was going to be mocked by the other women for not having supportive sons. He said he didn't have time but that he would try. After that, he phoned my phone but [my phone] was not very good. I saw a child coming with the phone saying that my uncle will phone now. He said he would try to come and give me provisions that I need. I said I need juice, meat and buns without sugar.

Tina Ntuli

Tina's statement demonstrates the high levels of community expectation placed on support from this son. Despite acknowledging the difficulties he may experience in providing her with the groceries she needs, she remains conscious of what will happen to her if he fails to fulfil his promise. Tina is afraid of being mocked by the other women in the community for not having a supportive son. This family resource is clearly a much-prized asset and expected amongst her peers. Some of the sociological literature argues that people want to be seen 'doing family' and presenting a public display of cohesion and quality of family life, these public occasions offer a perfect opportunity to fulfil these roles sanctioned by society (Finch, 2007).

Examples of fostering of orphans or children as members of an alternative household were relatively common within the study. In the Nkosi household, Thobela moved her eldest two children from a previous partner around repeatedly. Initially she placed them with their paternal grandmother, who cared for them by drawing on her old age pension. Then, when she and Bheki became ill and needed help in the household, they moved the younger child back in to the residence with them so he could undertake some of the household chores and care for Thobela and Bheki's young child when Thobela had to seek treatment at Hlabisa Hospital and at Addington Hospital in Durban.

My other children stay with their [paternal] grandmother. Their grandmother gets a grant and she supports them....I was selling in town. I was not together with the father of these children, he took his children and went with them to his mother's home, because I was failing to support them. I asked them to give me one child when [Bheki] became sick and he couldn't even go to the river.

Thobela Nkosi, wife of household head, 36 years

Therefore, children were moved between households within the family network to help support the members of the affected households. This is yet another way in which non-resident household members, in this case young children with multiple household memberships, could help domestically, within the household. The results here show that non-resident household members are a valuable source of support for both affected households and individuals. Even those households and individuals, who are excluded from wider social and kinship networks, as demonstrated in the next section, are able to rely on fellow members of their household for support. Despite this, support from within the household may not be sufficient to ensure that the livelihoods of households that are socially excluded or marginalised survive the consequences of illness and or death.

8.4.2 Complexity and conflict in the support provided by non-resident household members

Sifiso Dlamini, Ntombizodwa's non-resident eldest living son, had moved away from his parental household to live with his partner and start a family many years before we met the household. In the statements below Sifiso illustrates some of the difficulties and conflicts in obligation he experienced in supporting and financially assisting his family. The first statement describes his ambivalence to taking in one of his orphaned nieces again after he tried to foster her for a while and found the child difficult to handle.

When I came here for the funeral I didn't find [my niece] here. I think that if I take [my niece] back she will spoil my children because I have a girl that will learn [from her]. I took [in] another child of my sister.... She also chased boys...I ended up thinking that I can't [look after these children] so I decided to be a Christian with my family and forget about [the children of his siblings].

Sifiso Dlamini

Sifiso's choice to describe the focus on his nuclear family as 'being Christian' is interesting. Vilakazi (1962) who explored the Zulu family and household in the late 50's and early 60's observed a difference between those household's and families who were converted to Christianity and those who still observed traditional customs. He observed that Christians limited their support and assistance of others to those who shared their beliefs and were part of a close-knit religious community compared to the others where the obligation to support and provide physical care as in his example fell within the remit of both close family and wider kin. Sifiso's statement may be reminiscent of this and a choice to limit his support to those within a

close network with similar beliefs and values to his own thereby limiting what he views as the negative influence of his nieces on his own children.

Sifiso was a very interesting case because he was one of the few household members that was non-resident at the time of the study whom we were able to interview and therefore provided some of the perspective of these household members. Sifiso describes the difficulties he had in providing the expected material support and financial assistance at the time of two of the funerals the household had in the 5 years preceding the study. The first funeral Sifiso referred to was that of his father. This old man did not die of AIDS but rather in contested circumstances. He was ill and old but the family believe that he was murdered; the medical examiner disagreed and argues that there is a lack of evidence and therefore the police refuse to investigate. Sifiso describes here the difficulty he experienced helping to contribute financially because of his other commitments.

We buried him using the money from [a loan] but my younger brothers did try to make contributions I was still paying back [the loan] from my wedding and it was at the beginning of 2007⁹ [expensive time of year].

Sifiso Dlamini

Sifiso also had trouble contributing financially to the burial of his sister because of his own illness.

It was in April that my sister passed away. I was very sick so I couldn't help bury her like a member of the family but I was there.

Sifiso Dlamini

This example suggests that non-resident household members experience conflict between their obligations and their own circumstances. These affect their ability to contribute financially to the rural household in a way that is deemed fit, 'like a member of the family'.

⁹ January is anecdotally understood to be an expensive time of year in rural South Africa. Many people get paid bonuses just before Christmas and many *stokvels* are designed to pay out in December allowing people to make large bulk purchases around this period. It is a time when many working people have to take compulsory leave and the rural household numbers are swelled with the addition of visiting non-resident members increasing the demands for food and resources within the household. This has knock-on effects for January in which people may be paying back loans taken to fulfill the January needs of the household. January is also the start of the school year and although largely non-fee paying this month is associated with extra costs because children require uniforms, school shoes, supplies and transport needs to be paid up front.

8.5 Material support and financial assistance from kin external to the household

This section explores how other members of the kin network, external to the household, act to mitigate the impacts of illness and death on directly-affected households within the study area. The financial assistance, material support and physical care an individual or household can rely on are affected by the types of relationships they enjoy with other members of the kinship network. The factors influencing the exclusion of individuals or households from social networks are explored as are the expectations that people have of kin, whether fulfilled or not. The exclusion of households from familial networks influences the household and household members' vulnerability and has implications for the household's ability to respond to the impacts of illness.

Traditionally marriage determines responsibilities for children. Once a woman is married her children become part of their father's side of the family and therefore also their responsibility (Preston-Whyte, 1974). As family formation and organisation have changed, this is no longer always the case and there were examples within the study where the child was fostered by either their paternal or maternal families. This may partly be because few of the parents were in long-term relationships or married to their partners. The fostering of children into the rural households was an example of the support provided within the rural household because of familial obligation or generalised rules of reciprocity. Once this had happened though there were examples of the relationships between the households in which the child was resident and their other kin living elsewhere. Again, this did not seem to follow tradition, seemed to be flexible, and based on the relationship of the kin with the children and the parent related to them.

Below, Jabulile talks about the difficulty confronting the household because of the discrepancies between the two children's different maternal families.

During school holidays, I send [Sakhile] to visit his granny. It is good because he likes to visit them. The problem is [Ayanda], we don't even know who her grandmother is; we only know that she is an orphan. It is difficult because the children talk and the elder one talks about visiting and about how his uncle gave him this and his granny did that so it is difficult for me because the younger grandchild has no-one else.

Jabulile Gumede, wife of household head, 63 years

The relationship with Sakhile's maternal family was important. They, and particularly the grandmother and uncle, maintained an interest in his life and helped materially support him when he spent time in the household. This may have been because the members of the Sakhile's maternal grandmother and uncle maintained good relations with the child's paternal family or because the maternal family felt some sense of family or kin-based obligation. The relationship with Ayanda's mother was difficult, however, and the Gumede's did not know very much about her family. Her mother had abandoned Ayanda at a very young age at which point Jabulile had assumed responsibility for the child.

The evidence from the Gumede family suggests that, although traditionally there may have been a fixed rule about the responsibilities of the maternal family's kin in Ayanda's life these customs are not always adhered to. In affected households, there may be greater reliance on strong inter-personal relationships, than norms associated with traditions of kinship, reciprocity and obligation. These complexities may stem from the relationship the family had with the child's mother.

In the Bhengu household, Zinhle's youngest child, Phineas, was the product of a relationship, which remained ongoing at the time of her death. Unfortunately, his father, Petrus, was also sick but his family undertook joint responsibility for Phineas and he was moved between the rural households of his grandparents, both before and after Zinhle's death. Petrus died within a month of Zinhle. At our final follow-up visit to the household, Phineas was resident primarily in his maternal home, but the Bhengu household maintained a close relationship with the father's family. This relationship was still good and he was spending time at both of the households, both of whom were concerned with Phineas's physical care and wellbeing.

In some other households the example of joint caring provided in the Bhengu household for children who had lost both or one biological parent, was not the situation. For example, in the Ntuli household, Tina was caring for the young child of one of her sons, whose mother had died. Despite the traditional obligation to care for the child of an unwed mother falling to the family of the biological mother, in the case of the Ntuli household, the family of the mother exhibited very little interest in the child and his wellbeing or in having any relationship with him.

The uncle ... said that his father should support the child. The child used to visit [his mother's family] but they say they won't take him anymore because the aunt said he is very naughty. Children are just naughty. I just support him now with the child support grant and his father also contributes.

Tina Ntuli

This situation is complicated slightly because the child still has one living parent and the family of the mother therefore argue that the father should be responsible for the child. The father has chosen to have his mother take care of his son and has signed over the paperwork so that his mother is able to collect the child support grant and financially assisting her in providing for the material support and financial assistance of the child. Tina is, despite this financial help, still ultimately responsible for the day-to-day care and needs of the child and his education. In both the Ntuli and Gumede households children were cared for in their paternal homes despite, in terms of tradition and in cases where there is no marriage between the parents the children would traditionally be the responsibility of the mother and her family.

The situation is similar with Tina's other grandchild whom she cares for, is sick and an orphan.

The relatives of [Thendai] don't even know how old he is. I don't really care about them though because they were not the blood relatives [of the father]. I don't put any pressure on them. I don't have a problem with them because I have Thendai's money [from the social grant] I can buy other things and also save for him.

Tina Ntuli

Tina was fortunate because she was able to receive a social grant for the child and was therefore able to provide for Thendai without needing other help. Had she not been able to secure the grant she may, in her words, have had a 'problem' with the family of Thendai's father. It is also interesting to note that one of the reasons Tina gives for the other family's lack of interest is that Thendai's father himself was adopted by these people and was not a blood relative. This may suggest that despite caring for his father they feel no obligation to support the child. In this situation the marriage of Thendai's parents would suggest that his father's family should have ultimate responsibility for the child but this is not the case. His maternal grandmother was very close to Thendai's mother and chose to take care of both her daughter and grandson.

The results suggest that while in many cases traditional norms may not be followed children do seem to be being provided and taken responsibility for within their wider family networks. While the sample was in no way representative and we sampled households rather than individuals, there was never any mention of the abandonment of children or examples where all sides had relinquished responsibilities for children.

The support of kin who were not members of the household helped affected households within the study in a number of other ways. For example, Nomsa spoke about help she received from her sister while Zinhle was at her most ill.

I had no money so my sister went to Hlabisa and she said she will visit [Zinhle].

Nomsa Bhengu

Here, Nomsa is referring to a time when her daughter Zinhle was in the hospital and she was not able to afford to visit her and see how she was doing.

Nomsa provided two more examples of two different members of her and her late husband's family who provided for the household's material and financial needs when they were able. The first was a nephew.

[My brother's son] was giving me money. When he went to visit his aunt in Dukuduku he would call me and say that I should go there and he would buy food for me.

Nomsa Bhengu

The second person who helped the household was Nomsa's late husband John's sister, who helped the household to buy food with her pension money before she died.

When [my husband's sister] bought herself groceries she always gave us something, maybe a quarter of what she bought because she was staying alone, something small like maybe a basin of maize or potatoes. At other times she gave us R50 (£4) to buy our own. Then I would give the money to whoever was going to town and get them to buy something for me, because you can't go into town with R50 (£4) [it is not enough]. Now there is no-one in the family left to help, they all passed away, she was the last person.

Nomsa Bhengu

This support from within the kin network seemed to be in response to a perceived need within the household. The material support and financial assistance made a difference to the household situation and the members missed it when this person died.

Respondents within the study spoke about the close relationships that their households maintained with households of other family members. Tina spoke about the close relationship her household has with the household of her husbands' late father, which was at the time of the study his brother's household, and the degree of material support and financial assistance this household provided.

The last home of my late husband's family is over there [indicating across the valley]. We are a family, there is nothing that they do without us. It is the home of my husband's

father, his brother lived there, but they have all passed away. It is the only the son of my husband's brother there now, he lives in Empangeni but his daughters and their children stay there. Since my husband passed away, they have helped me a lot. The children go to school because of the son [at the original family homestead].

Tina Ntuli

In a similar way, Precious Sibaya spoke about the close relationship her household maintained with the household of her husband's sister. The latter was located on a property next door to the Sibaya household and was an important source of support for the Sibaya family in times of need. The close proximity of the two households, in homesteads adjacent to each other, may also have explained the strength of this relationship.

In many of these situations, households were able to rely on the individuals or households within the family network to provide them with help. Such aid was usually in the form of financial assistance, material support and even physical care in the knowledge that, at some point in the future, they will themselves require and be able to negotiate benefits from being in a relationship with the household. Such a social arrangement highlights the generalised reciprocal relationships existing within the family network and their particular importance not only to both affected households but also to the other households within the family network.

Family members were not always available or able to help and there were examples within the study of households that had expected help from kin but whose expectations remained unfulfilled. The respondents gave a number of reasons to explain such a failure. The first showed an understanding of the difficulties that other households were also experiencing leaving them unable to provide the expected support.

There are people who should help if there is no food, but because of the living conditions in their homes they can't.

Nomsa Bhengu

Other people, who are expected to help, do not help, despite the weight of expectation arising from the affected households. These households felt that they were excluded from certain traditional kinship networks. They also felt that family members, who they expected to serve as a possible source of support, were not willing either to associate with them anymore or to provide them with the expected assistance. This reality was particularly observable in the case of the Nkosi household who, although they received help and assistance with the care of their children from the children's other families, were unhappily recipients of little other direct

assistance for themselves. Thobela felt that they were purposefully being excluded from the family networks that should have been able to help. In particular, she identified her brother who lived in Durban as someone who should have offered support but who, in her opinion, had severed ties with the household and with his sister's family.

I have nobody, there is my brother in Durban but he doesn't care about me...He is the person who should help me. I don't know how many times my husband and I have phoned him but he doesn't come to help us....Since I became sick in 2005 with TB.... he hasn't come to see me.

Like a brother, he is supposed to be helpful, you always help your siblings, but he doesn't do that. I can't force him to do that, I think he is happy where he is. I don't even wish to visit him.

He can [help], he is working for the government at a Hospital. He has money. He is supposed to help.

Thobela Nkosi

It was not clear why Thobela's brother had chosen to isolate himself from the Nkosi family but the reason could be that their needs would have drained his own resources and income.

Thobela's argument that her brother has the means to financially assist her is also not necessarily true. The Nkosi household was already socially isolated, they had no family who lived nearby or had any regular contact with them. They talked about the fact that except for charity they did not have any contact with neighbours or other community members who were considered friends. They were also particularly vulnerable because they were not able to rely on the support of anyone else and were therefore socially excluded.

Thobela was not the only person who mentioned her brother as a source of material support and financial assistance. Nomsa Bhengu also mentioned that if she had any living brothers that she would possibly have been able to rely on them for some form of help, as dictated by tradition.

There is no-one I think should help. I don't have brothers they all passed away.

Nomsa Bhengu

The relationships between family members were not always straightforward and did not always follow the rules dictated by tradition and the rules of family obligation. Relationships were complex. There seems to be a point at which the one-sided nature of the relationship leads to the breakdown of generalised reciprocity despite the normative obligation to help family. Therefore,

reciprocal relations with others where balanced reciprocity could be assured, for example a wider neighbourhood network, become more important than family obligation where the return of support or assistance was no longer guaranteed. This was especially the case where those on the receiving end were significantly worse off and potentially just a drain on one's resources. The lack of close family links, for example the fact that Thobela and her brother's parents had died, seemed to make it easier for members of the kinship network to distance themselves in a way which was significantly harder in the household where livelihoods and social lives were intricately linked.

There are also examples of conflict within families, which limited or changed the support that individuals or households could rely on, from kin who wanted or were expected to help.

[My brother's son] can't help me now. His mother doesn't want him to help. The child likes to help but she doesn't want him to anymore.

Nomsa Bhengu

In this quote, Nomsa is discussing a nephew who had been helping her household in times of need. According to Nomsa, this man reduced the assistance he had provided to her household and, had to resort to secrecy because of pressure from his mother, whom she had been told, was opposed to him helping the family of her late husband.

Similarly, the Dlamini family spoke about the household's relationship with the husband of one of the daughters who had moved back to the household with her children on becoming ill and who had subsequently died within the household. Gugu stated:

[Her husband] didn't help with anything, he came on Thursday and we planned to bury her at home,her husband was not there because he was working. We talked to his family about what they thought and they agreed. We had everything for the funeral here. He came on the Thursday and [her husband] wanted to take her away because she was his wife, but he didn't do anything to help with the planning. I did everything, although I did use her insurance money. I knew about the insurance because I used to pay for her if she didn't have money.

[Her husband] is not supporting his children. [Their eldest child] was using the child grant to support them, she is also paying for their funeral policy. We excluded their father because he went to Johannesburg, he was not helping.

Gugu Dlamini

The Dlamini family argued that the physical care, during her illness, they had provided for the daughter and the fact that they currently took responsibility for her children, along with the consultation with the husband's family, implied that they were entitled to decide about the funeral and burial plans. They also felt that, as the husband was not contributing financially for his children on an ongoing basis, did not contribute towards the funeral of his wife and didn't come until the day of the funeral, they were obligated to make the decisions about how it would happen. The fact that Gugu had helped pay and was given control of this sister's burial insurance made it possible for the Dlamini's to actively exclude the husband. The disagreement between the two families, over the funeral and lack of financial assistance from the husband meant that despite marriage to their daughter and a traditional obligation to provide for his wife and children, the household was not able to rely on him for support. Therefore, it was strongly believed, he had effectively denied his obligation.

The results suggest that relationships between kin were more complex and the traditions of obligation and reciprocity less stringently adhered to than within the household. This may be due to the proximity and close linkages between members of the same household who would have found it harder to ignore the demands of other household members than other kin would. Although kin provided an important source of support for individuals, and particularly affected households, this was more reliant on rules of generalised reciprocity and there were examples of social exclusion. The affected households were able to secure material support and financial assistance from within the kinship network, the examples of physical care though were limited and the amount and extent of support and assistance seemed to be on a smaller scale than support from within the household.

8.6 Relationships with non-kin

The respondents in the case study households discussed a range of ways in which other households, individuals, informal groups or institutions helped them at various times in their experience of stress and crisis as a result of HIV and AIDS. In this chapter, I do not consider the direct implications of state support in the form of cash transfers, rather the indirect influence of social grants in enabling support has been considered. The influence of social grants on affected households is analysed in-depth in Chapter 8 dealing with social grants. Instead, to continue exploring the themes of social capital, family obligations and reciprocity, this section explores financial assistance and material support that the household receives, from other individuals and households who are not kin.

Unlike help and assistance from within the household or kin, which is strongly governed by norms of family obligation and generalised reciprocity as demonstrated in the preceding section, the degree and type of assistance obtained from people external to the family is less stringently sanctioned by family and community expectation. Again, the quality of the relationship between individuals, families or households is important and may be tied to reciprocal understandings or some sort of obligation. However, these relationships are not always supportive in character and certain factors act to limit the support households are able to both secure and provide. Thus, households can be excluded from external support and become particularly marginalised or vulnerable to the impacts of illness and death.

Some households were linked through close personal relationships that seemed to foster a sense of trust and enabled reciprocal and supportive relationships. In the Shabalala household, there was an example of a close neighbourly relationship, which was cemented by previously intimate relations between family members.

My child stays up there with my aunt. She is our aunt because she was in love with my uncle. [The child] is no longer staying here... [The child's father] lives [in housing in the township] ... [His family] do nothing for the child...What I have I take it to [the aunt caring for her child].

Duduzile Shabalala, sibling household member, 17 years

Dudu was trying to attend school in the absence of support from her own family and the family of her child's father. Therefore, she was assisted by a neighbour, who cared for her young son. Although Dudu refers to the neighbour as her aunt, she is no blood or kin relation and is no longer in a relationship with the girls' uncle. The relationship between Dudu and the woman is still supportive though. Dudu does pay the woman a proportion of the foster care grant income she receives from her real aunt every month.

The woman in that [neighbouring household] is very good, if I'm hungry, she calls me and gives me food also when I get home from school.

Duduzile Shabalala

These examples of close supportive relationships with neighbouring individuals or households were important to the households affected by illness and death and those, such as the Shabalala household, who were dealing with their after effects.

The Zondi household was another example of a household with close relationships, in this case with the Mbuzi family who lived nearby. The original link between the two households was a relationship between one of the Zondi daughters and one of Mrs Mbuzi's sons. Despite this relationship ending, the two households continued to have a good relationship and Mrs Mbuzi clearly felt some obligation to help the children remaining in the household after their parents' death.

[Mrs Mbuzi's] home is just up there, Busi was in love with her son but they broke up. I don't know why they broke up, but there wasn't that link anymore. I heard that there was conflict between them. [The Mbuzi family] don't have any problems [with us] because even if we meet on the street we do talk, it's like it was before. If they have a problem, we will go and help them and they will come and help us. Even if there is someone who is sick [Mrs Mbuzi] would give us money for him/her to go to the hospital. If there is something we don't have, we ask... We have a boy here who is studying at Nomathiya so they take him to school every day with staff transport because they have a car.

Beauty Zondi, non-resident sibling, 24 years

The Zondi children did not experience any change in the household's relationship with other people or households after the death of their mother. Other than the Mbuzi family, the children had experienced little contact with the other households in the neighbourhood and they had provided them with little support both before and after the death of the children's parents.

Other households maintained good relationships with neighbours and through this were able to access support that could be considered charitable handouts. For example, the Dube household received support in the form of groceries from their neighbours, the Cebisa family, who lived opposite them at the time of the funeral of Thembilihle's partner. The Dube family had maintained a very good relationship with the Cebisa family.

We got help from the Cebisa family [when her partner died] they bought us rice. We have a good relationship with these neighbours. They give us groceries.

Thembilihle Dube, daughter-in-law of household head, 34 years old

The Cebisa family were observed and reported to be well off, compared to the Dube family, and because the two households enjoyed a good relationship, they were able to provide them with small amounts of groceries to assist with the needs of the household at the time of the death.

In both of these specific situations, the household providing the material support for the affected households were of a higher socio-economic standing, with better access to resources. Their ability to help the affected household, combined with the good relationship between the household members, may have been factors that influenced the support that they had provided. The generation gap between the Mbuzi and Zondi households may have added to the obligation felt by the older supportive household member, who may have felt some sort of parental responsibility to help these young people, who had lost not only their parents but also the majority of supportive adult figures in their life.

In some of the particularly vulnerable households, specifically those marginalised or with limited access to support from the extended family network because the latter no longer existed, because of conflict or conscious marginalisation, the support of neighbours and members of the community was particularly important. Examples of support for these socially excluded households were most common during times of extreme need. For example, the Mabena household received support from neighbours at the time of the death of one of the brothers whom Nobantu was caring.

I don't have a family to help me, I don't have. It was my brother there Mr Thokoza who helped me and this woman who is the neighbour working as a home-based carer...[Mr Thokoza] is the one who helped me with the tent [for the funeral]...and only that woman who help me with the mats...I think they saw that [the help] was necessary, because people were standing in the sun [they required the shade of a tent].

Nobantu Mabena

This is another example of where the respondent refers to the neighbour as a member of the family. Mr Thokoza neither is a member of the Mabena family nor is he related directly to Nobantu in anyway, but because Nobantu's maiden name was Thokoza, the neighbour is considered a member of the same family and she further refers to him as her brother. Despite this seemingly close relationship, the obligation to provide financial and resource support to the Mabena family does not appear to be as strong as it would be if the Thokoza family formed part of their extended family. In fact, the tent was rented from the Thokoza family and the household was in extreme debt after the funeral trying to pay for it.

The relationship that Nobantu has with her neighbour is an example of a balanced reciprocal relationship, one where there is an equal exchange of goods or services that requires some level of trust and membership within a common network. Geographical proximity also plays a role in the relationship between Dudu Shabalala and her neighbour and the relationship between the

Mbuzi and Zondi households, a factor fostering a closeness which may not have existed had the households been situated elsewhere.

Access to credit from neighbours and other members of the community was an important source of financial assistance for households struggling under the burden of illness and death. Access to credit helped enable the households deal with and manage crises and times of extreme need such as death. For example, the Bhengu household borrowed money to pay for the expenses associated with Zinhle's illness. Loans required a certain level of trust on both sides and, therefore, as in the example provided by Nomsa below, those that she could rely on for credit were members of her home community who knew her well and were, in addition, somewhat lenient on the amount of interest they charged. This was important, because borrowing from people with whom one did not enjoy a close or good relationship often meant that interest was charged at extremely high rates.

I'm still borrowing money to take [Zinhle] to the clinic, nothing has changed. The neighbours make no difference. The people I was close to when I was living at my parents' home [are the ones who I borrow from]. It was at the Mapheleni area, my family is now at Dukuduku. I borrowed from those people and I pay them back when I get [the money]. [Some charge interest] but others say I don't have to pay interest, they have mercy on me. There is no-one near here, because all their children [relatives of her husband] have passed away and my sister [who does live nearby] has no-one who can help.

Nomsa Bhengu

Nomsa highlights the importance of these good relationships, particularly in the absence of support from the family or kin. The quality of this relationship and the relatively high level of trust meant that Nomsa was able to negotiate a relatively equal and balanced arrangement, based broadly on the principles of balanced reciprocity.

However, such favourable circumstance were not always the case, and in some of the households in the study, the respondents described the difficulty they were experiencing in repaying money borrowed at very high interest rates. Sometimes causing people to become stuck in a cycle of debt because of borrowing from moneylenders, also known as *mashonisa*.

Tina Ntuli needed to borrow money for various reasons not necessarily related directly to illness or death, but her comments about moneylenders and the impacts of debt are both very telling.

Interviewer: There is no-one who just gives you money?

Tina: There is nothing like that, you can be beaten by the snake [money lender] on the tar road [if you don't pay the money owed back]

In response to a question about people giving money to help the household financially sustain itself in difficult times, Tina spoke about the potentially negative repercussion one could face if unable to pay back loans from moneylenders.

In another interview, Tina discussed the implications of the high interest rates on money she had borrowed to buy a door for the front of her house.

On [social] grant day, I didn't have money for food because I borrowed money last time to buy a door [for the house] [R1000 (£88)], so now I have to pay R2000 (£176). I realised too late that I should have done it on lay bye¹⁰ and paid the instalments.

Tina Ntuli

Tina owes double the amount she initially borrowed to purchase the door because of the interest and is no longer able to use her old age pension to pay for necessities, such as food for herself and her household, because she now has to repay the money.

Others were able to secure credit from further afield. For example, Jabulile managed to borrow money from her employers in St. Lucia after Senzo's death, in an attempt to help pay for some of the expenses associated with the funeral.

I was still working so I got credit from my bosses, because [Senzo] was over 21 years old, he was out of my insurance policy. So [my bosses] helped with the funeral [expenses].

Jabulile Gumede

Access to credit either from members of one's own social network or from other sources such as employers, who possibly were able to calculate more fairly, amounts earned and owed and could be less risky than credit from independently-operating moneylenders. The relationships with moneylenders were examples of negative reciprocity where the creditors were lending money at the expense of their clients because the focus of such an operation is profit.

¹⁰ A lay bye is another description of a hire purchase. This is used for larger products which are purchased with a deposit and paid off in installments over a set period with interest calculated depending on the payment period.

Another negative interaction with the wider community was reported by Beauty Zondi.

Interviewer: Is there anyone among the neighbours who you have a good relationship with? Who for example look after the children if you are away.

Beauty: There is no-one, because instead of finding things [as we left them]. We find them very bad. [the neighbours] come and take whatever they like. The children thought that if they went nearby nothing could happen [so left the doors unlocked] but [the neighbours] came in anyway because [the children] are staying alone.

Other households in the study were also fearful of people breaking in and stealing things and were worried about their things and safety, suggesting that the neighbours and community members may actually contribute to pushing affected households further down.

In households that were socially excluded or marginalised from extended family support networks, neighbours and the community could be a source of support. In the case of the Nkosi family, where the situation was dire and the household had almost no income and where both adults were sick, the financial assistance and material support that others provided was charity because the household was in most of these cases not able to reciprocate at all.

The household attributed the lack of help, to the presence of illness in the household, a situation perhaps associated with stigma. Here Thobela refers to the change in the relationship with the neighbours since the onset of her own illness.

We visited each other, but now [the neighbours] don't [visit me] because I'm sick. People like you when you look good but when you are sick they all stay back, they are running away.

Thobela Nkosi

In this quote, the way in which Thobela refers to her illness and the fact that the neighbours are “running away” suggest that this may be related to stigma either of the illness afflicting her family or of their extreme poverty. In later interviews, Thobela also discussed the fact that the neighbours have decided to distance themselves from the household and no longer provide support. Another factor she associates with this is burn out of the neighbours, whom she says are now tired of them and their regular requests for ongoing help.

The neighbours are far, very far away. They can see that I'm needy, even if I send a child for something [to beg] he will come back empty handed. They are tired of me.

I treat people badly. I continue [to send the children to beg] because I don't know what I should do. [The children] are sometimes afraid to go to neighbours for food. I said they should go because there is nothing I can do. They go and sometimes they come back with something small and we go to sleep having eaten, but sometimes we get nothing if they don't have. You get help for that day if you send the child [to beg].

Thobela Nkosi

In most other affected households, assistance was reciprocal and based on a good social or sharing relationship, or at least a certain minimum level of trust. The Nkosi household, who lack familial support and are unable to reciprocate in any way, are reduced to begging. When they were able to secure support, it was charitable and consisted of leftovers, hand-me-downs and material things that others were discarding, in any event.

The situation as described existing above in the Nkosi household also serves as an example of the limitations of help from in the neighbourhood or community. Another limit to the ability of other households to help people lies in their own financial and economic situation. Tina Ntuli here talks about households with whom they are close and who would help them if they were able but who are limited by their own situation.

I'm not used to asking other people [for help] because even the people [I know well] don't have the things I need. There are those who are very open.

Tina Ntuli

Jabulile goes on to provide another example and explanation. She refers specifically to the frequent deaths within the community that the other households in the neighbourhood and community are dealing with currently that make it difficult for people to help one another.

We have a good relationship [with the neighbours]. Shortly... there will be no one who can help us because everyone had a problem. We go to doctors and also to the clinics everybody has a problem. In the [se] households [near us] there were deaths and [those households] also need help. All around here there were deaths.

Jabulile Gumede

The respondents also gave examples of other relationships, which were decidedly unsupportive. Nomsa recounted Zinhle's experience in her formal employment as a domestic worker.

[Zinhle] was using them while she was working. She had to fetch them from Hlabisa, so her boss complained about her missing work, [Zinhle and her boss] ended up not having a good relationship, so she decided to quit [taking the drugs] and continue working. Whites have that attitude about sickness. You have to hide it because they need to know the reasons why you go [to the clinic] so often.

Nomsa Bhengu

This relationship was very negative and may have fuelled Zinhle's illness because she started and then interrupted treatment and ultimately lost her job because she got sick again. This may be an example of the stigma and discrimination those directly affected by illness may experience. Nomsa spoke about a similar negative relationship her daughter Lindiwe had experienced with her employer in Durban. She attributed Lindiwe's choice to leave her job to her employers' unsympathetic attitude towards her illness. Such unhelpful relationships had potentially serious implications for the impact of their illness on the household and livelihood as discussed in Chapter 6.

8.6.1.1 Contradictions

Some of the respondents contradicted themselves during the interviews, claiming that no-one helped them and that no-one cared in one interview, only to subsequently provide examples of support they had received or remained recipients of in other interviews. Such inconsistencies could have occurred because the support that they did receive was below a threshold of expectation that they maintained and because this help was simply taken for granted. Despite, the clearly stated purpose of the study and the informed consent process there may have also been changes in reporting as respondents became familiar with the purpose of the study and it became clear that there were no additional benefits to be had.

Nobantu Mabena was an example of this. In both the first and second interviews with the household she answered that no-one helped or supported the household. The second time we asked specifically about relatively small needs and help the household would be able to access for these.

Interviewer: Is there anyone who helps you with something if you are running short of something?

Nobantu: There is no-one who I can ask, my child.

In fact, when one of her brothers died Nobantu provided examples of a neighbour and a community member who helped her out, one lending her a tent and another providing help to prepare food. In addition, the Mabena household was one in which the support and care provided by the home-based care workers for all three of the sick household members was much more active than in other households.

8.7 Support in return

Households affected by illness and death were not only recipients of and providers of support to fellow household members. They were also providers of help to other households. Gugu Dlamini spoke about the way in which she helped her neighbours whose daughter was sick and eventually died. These people had enjoyed a good relationship with the household already.

We have helped other people a lot. There was someone sick at the neighbour, I took her to the clinic because she didn't have money, up until she passed away. We helped with the funeral arrangements, because she didn't have a funeral policy, with her children who were grown up. To pay the credit. I also used to help the neighbours like the one at Machibini. They are people who we have a good relationship with because of my mother's prayer.

Gugu Dlamini

Gugu and her family also had good relationships with some of their neighbours and helped support another household dealing with a death.

I help people a lot. There was a family up here where people passed away straight after each other. They couldn't afford to fetch his body from Hlabisa. So we just tried to collect money for the car. I sold [vetkoek and mats] to make the money. We didn't manage to pay for the car that time but we contributed R360 (£30) and also blankets.

Gugu Dlamini

Another example of support and help provided by the affected households enrolled in the study, was given by the Gumede family. Jabulile explained the impact and difference experienced by the household when they had a car that worked. This meant that the neighbours would regularly come to them for help with transport.

[The neighbours] come here as if it was their home. I help them with what I have... [even though] they didn't ask for [help]. I do things I never expected that I would do. I just do it because it is a neighbour...we helped [the neighbours] a lot when we had the car. [Its difficult] because [the neighbours] had no money, he couldn't pay us back and you can't ask for [the money], you know you will never get it.

Jabulile Gumedde

Jabulile went on to describe the difficulties inherent in asking neighbours for payment for the use of the vehicle. The reality for them was that when one owns a car people request help and support and cannot always be expected to reciprocate.

8.8 Groups, organisations or institutions as a source of external help and support

Social capital, as is acknowledged by the theory, is not just based on the relationship between individuals or households formed into networks, but also membership in collectives and groups. This often requires sharing of trust and ability to contribute depending what the groups are based on. This section assesses access to home-based care services but excludes social support provided by the state that is addressed in the following chapter. Members of affected households who were members of groups and had invested time and energy into them could rely to a certain extent on help from these groups.

8.8.1 Church

The church was particularly helpful when the household experienced a death and often provided some assistance either in the form of physical help, such as helping to prepare refreshments or of financial assistance. Almost all the respondents within the households, specifically the women, were members of churches and church communities. Some attended organised prayer groups that met weekly. Gugu Dlamini and Nomsa Bhengu were active members of such prayer groups. Tina Ntuli also had close links with church. Her late daughter was very involved in the church community because of her late husband's role as a pastor. All three women gave examples of support from the wider church community or from their own prayer groups. Gugu spoke about the financial support the household received from her family's church community for some of the expenses associated with her father's funeral.

I can say there is help because [the people from church] came the day before the funeral with money to buy food for my father's funeral.

Another example of this support, although it was of a more substantial nature and scope, was the financial support that the Ntuli family received when Simphiwe died. The amount involved was relatively large because Simphiwe's late husband had previously served as minister in the church and the collection included not only the elders and friends of the family, but also a further collection from the entire church congregation.

The church elders from her husband's church gave me the sum of R2600 (£229) [when Simphiwe died]. So I used that money together with the little that I had left, because the diseased person is more costly than the well one ... A short time after we reported her death, three ministers came and they contributed R300 (£26), after a few days the congregation gave me the sum of R2600 (£229) and they attended the funeral.

Tina Ntuli

The church was also a source of other kinds of help. Thus, for example, the priest from the church was the person who personally paid for and physically helped to enable Zinhle to return home to her mother's household. Another example of the church's assistance was the emotional support for the members of prayer groups. These were of a similar nature to that upon which Nomsa was able to rely.

When I go to church, I go there to ask god to comfort me from all the problems I have and [my church friends] also come to pray for me if I have problem. I just say and they come to pray.

Nomsa Bhengu

This emotional support and friendship was important but seldom acknowledged by the respondents in the household when we asked about support. Throughout the study, the focus from respondents was on the physical manifestations of support, with which they clearly were more concerned than emotional or social support. This could be because of the way in which support, assistance and care was able to maintain the livelihoods of the household.

8.8.2 Stokvel

Membership in an informal savings scheme, although it involves making payments, is considered in this context a form of social capital for the household and functions and exists as a balanced reciprocal relationship based on membership of a social network. *Stokvels* are

commonly organised amongst groups of friends and neighbours, and a certain level of trust and social interaction is required to maintain the good organisation of a *stokvel*.

If households or members were able to maintain their payments to the *stokvel*, the support received from the *stokvel* for one month of the year- either at random or at Christmas, depending on the groups organisation, was very important for the household. Furthermore, money from the *stokvel* often helped contribute to household for longer than just the month in which they were paid.

I do pay into a stokvel with others from the clinic. We pay R300 (£26) for the whole year. Then we lend it until the end of the month [to make money out of it]. [We get] 25kg of maize and 3 kg rice, two packets of sugar, flour, cooking oil, 2 kg of washing powder, 5 juice and soup. It's not enough; we also get samp and beans. I see the difference because I always have food now. It lasts maybe it lasts 3 months.

Thembilihle Dube

The Dube family also considered the *stokvel* important because, at the time of her partner's death, Thembi's mother was able to obtain an advance payment from her *stokvel* in order to help pay for the funeral. This income was a significant contribution to the household at a difficult time and helped the household meet funeral expenses.

Limitations exist to membership in these groups and barriers that negate the potential advantages that membership may provide. Among the most difficult things that households face is maintaining the ongoing monthly payments. Here Gugu and Tina discuss the way in which deaths and the related expenses in their households affected their financial affordability.

This year we stopped paying for the stokvel. We have stopped because there will be the ceremony for the death of my father this year and my mother was sick so we had no money and it forced us to stop.

Gugu Dlamini

I am not a member of a stokvel or burial society now, I was in a stokvel but I couldn't afford it. I joined after my child passed away but I couldn't afford it, they gave me my half. I also joined the funeral society one year but I ran short of money so it collapsed.

Tina Ntuli

Burial society membership was afflicted by similar limitations to that of *stokvels*. The burial society members of the Dlamini household benefited from were more formal than societies and required signing up long-term. Thus, the arrangements were more about being able to afford membership than trust or friendship like the *stokvel*.

8.8.3 Treatment support groups

Membership of other groups was also important. For example, Gugu Dlamini was a member of an HIV-positive treatment support group that operates out of her local clinic. Gugu related her experiences of membership and the groups' plans and potential benefits to other HIV-positive people and generally, for the community.

[The treatment support group] are helpful but we have not yet started to do much, we are planning to help people and also help ourselves. We are going tomorrow. We have found a place to plant [a garden] and I have also told them that I know how to sew. We have found a place near the clinic. We will be planting spinach and other stuff. We will see whether we can sell it or just help people in our community. We will be visiting people in their homes because there are those who are just afraid to ask for help.

Gugu Dlamini

In contrast, Thembi who had been a member of a treatment support group for quite a lot longer than Gugu talked about the role that illness and death have played in depleting the group and possibly rendering it less effective in providing support.

[They treatment support groups] sometimes don't work out because people from the group die or they don't come to the clinic because it is too far and they feel tired if they come.

Thembilihle Dube

Although the examples here do not identify these groups as a source of financial assistance or material support, they remain important in terms of emotional and moral support and Gugu acknowledged this. They may also become a source of other types of support in future, in terms of the development of co-operative schemes that Gugu describes. Treatment support groups have the potential to provide very important support for members who are positive and on treatment and their families but this role did not seem to have been fulfilled in the study households where very few infected members were actually members of groups.

8.8.4 Home-based care

Another form of external support that some of the households were able to access was assistance from a home-based care worker. Many of the households in the study were identified through contact with the home-based care project linked to the Catholic Church. Very few of the households who were identified this way could count on regular visits or support from these workers and during our time with the households we saw very little evidence of consistency regarding access to the service. Very few of the households mentioned the home-based care team as a source of support or assistance when asked. Even the households who had been introduced to us by the home-based care team and therefore had had some contact with them in the past in many cases dismissed the contribution of the home-based care workers.

[The home-based carer] hasn't come here since the last time, with you. We met on the street and she asked about Mandla but she didn't come here. No-one came here.

Really I haven't seen anyone besides that boy I told you about.

Precious Sibaya

Thobela discussed the difficulties she felt in asking for help from the home-based carers, as it amounted to admitting one's needs. Her quote also points to the unreliability of the home-based carers, who made promises they were unable to fulfil.

Telling [the home-based carers] that you have nothing, so please could they help, you have to expose yourself to people...They promised to give us some porridge but we haven't got it yet. If you can get porridge then you take [ART], you can't take [ART] without eating anything.

Thobela Nkosi

The Nkosi's were one of the households who did receive some support from the home-based carers.

[The home-based carers] help because sometimes they come and they give you that small thing. We are then able to buy something to eat because they give us that R100 (£9), before they gave us R300 (£26) it was better because we bought maize and beans, they help us. They found out about us from the home-based care visitors who go to other people's homes.

Thobela Nkosi

The reason for the reduction in the amount was not explained to us by either the household or the home-based carer, but it may reflect perceived needs of the household or the resources available to the home-based carers.

The home-based carers and the physical help that they gave the household was particularly important in households such as the Mabena and Nkosi families, with little outside support from either other members of the community or kin. Below, Nobantu talks about the physical support that the home-based carers provided to her.

[The home-based carers] help you with bathing the sick person... [The home-based carers] are the only ones who come and help me, I don't have a family... [The neighbours] don't care about other people.

Nobantu Mabena

This support was particularly important because Nobantu was caring for three people who were sick and had little support in fulfilling this role from any of the other members of the household.

There was other home-based care support available, linked to the PEPFAR-funded ART programme at the Africa Centre that was operating out of the clinics within the area. Nomsa found their support for both her and her sick daughter Zinhle particularly helpful.

She is being given injections here at home, there is a nurse ... she comes here every day to give Zinhle injections. Zinhle can't walk she falls and I have failed to take her to the clinic.

Nomsa Bhengu

Prior to receiving a daily visit from the nurse to administer her TB treatment, Zinhle had been required to attend the clinic daily. This had inflicted a huge burden on Zinhle, herself, whose illness made reaching the clinic very difficult. In addition, her mother and household also suffered under the demands of ensuring that the household had access to sufficient money on a daily basis to transport both Zinhle and a carer to the clinic in order to access her treatment.

This was a very important service for this household and, in the context of wider access to treatment within the area, would have been as valuable in other affected households as it was in this household. It was difficult to assess the availability of this service but it did not seem to be very widely spread.

8.9 Discussion

Households and individuals affected by illness and death receive different types of help from a range of sources. In the study, these fell into three broad categories of help also identified in the existing literature. The types of help were material support, financial assistance and physical care. Individuals or households from four distinct categories of social network provided this help: those people who were members of the household, those who were kin, individuals or households within the community not related through kinship ties and social groups or organisations. As discussed in Chapter 2, Bourdieu defines social capital as the potential people have to benefit from the trust developed through participation in social structures and networks (Bourdieu, 1985 456). Within this conceptual framework, the building blocks of social capital are identified as reciprocal relations, familial obligations and a sense of obligation or charity to those less fortunate. The results presented here show that membership and participation in a range of social networks plays a vital role in helping affected individuals and their households negotiate support, assistance and care, and therefore, developing their social capital.

8.9.1 Family obligation and generalised reciprocity within the household

The fluid and stretched nature of the rural household and the traditional ties that bind members of not only the household but also the kinship network are very important for members affected by HIV and AIDS. The evidence from this and other studies exploring remittance behaviour and strong social ties within the rural household in KwaZulu-Natal suggests that non-resident members maintain strong ties to their rural household and the family (Posel, 2001; Russell, 2004a). The relationships between household members, whether resident or non-resident, are particularly important given the large number of non-resident household members and their apparent reliance on the rural household as a source of support. The importance of return migration to the rural household in this study is corroborated by quantitative evidence from DSS data in two rural areas in South Africa (Clark *et al.*, 2007; Welaga *et al.*, 2009).

The bonds that resident and non-resident members of rural households manage to preserve despite distance and, in some cases, long periods of separation act to support and facilitate the familial obligations that the household members have to one another. It is important to note that, rather than the nuclear family, I am referring here to all family members making up the household. In many cases this is an extended family group. The obligation to support other members of the household and possibly members of the wider kinship network is governed by culturally and socially constructed norms, as suggested by other South African studies of intra-

household support and care and argued within the theory of familial obligation (Bozalek, 1999; Finch *et al.*, 1991, 2005; Sagner *et al.*, 2000). These moral obligations are also often linked to familial relationships, such as filial or sibling relationships, therefore affecting the quality of the help provided. This suggests that those individuals and households with stronger, more personal ties are better able to secure more consistent, long-term and personal help owing to the sense of obligation inherent in belonging to the family. Social expectations govern much of the sense of obligation family members feel to support each other. The case studies emphasise that it is socially unacceptable not to help a member of one's household, or to provide some level of care or support for one's kin. Therefore, despite changes to the household that have been observed by the likes of Viljoen (1994) and Amoateng (2004) and the disappearance of certain aspects of tradition, the norms which govern obligation, social ties and familial relationships in the households enrolled in the study have largely managed to remain intact.

In addition to the social expectation to provide support there is the potential for this to affect the reporting of the provision of this support because it is socially sanctioned. There is a chance that some of the reported support is inflated or falsified in order to present a socially acceptable level of support. I developed trust with the households and multiple visits provided opportunities to observe the actual provision of care, assistance and support. I would argue that these allowed me to get beyond potentially false representations to a more accurate and real representation of what households and individuals were experiencing.

Within the household, a gendered element exists to the obligations household members feel to provide assistance and support, which reflects traditional social roles. Unmarried women have a greater responsibility for their household than men who, although they are expected to support the household financially in times of crisis, seem to have less of a responsibility for the day-to-day running and functioning of the household (Preston-Whyte, 2006). Women were the predominant providers of care to children and those who were sick in the households enrolled in the study. Furthermore, they appeared to maintain closer ties than men to the household, if they were non-resident. This gender divergence may be associated with a traditional expectation that women contribute to the domestic life of a household (Sansom, 1974). Unmarried women may also feel a stronger obligation than their brothers may, to provide support and care within their paternal household in a reciprocal sense, because of physical and emotional care that other members of the household may have provided or provide for their children. The case studies suggest that men who leave to establish new households or relationships may be faced with conflicting obligations to their natal and newly-formed homes or relationships.

It is interesting to note that, as in other research that suggests that traditional practices are changing and adapting to a modern context, these gender norms are no longer completely rigid. I observed, for example, the provision of physical care by a husband for his wife. The important role of men within affected households and for providing care for sick household members was highlighted within the 'Household Dynamics Study' (Montgomery *et al.*, 2006).

As the historical evidence on fostering and remittance behaviour in South Africa suggests, the ties and bonds between household members were not only practical and social, but at times involve financial assistance or material support for the rural household or for the non-resident household member (Madhavan *et al.*, 2007; McDaniel *et al.*, 1996; Posel, 2001). This acted as a kind of social insurance and fostered generalised reciprocal relationships within the household, in addition to family obligation. For example, certain non-resident household members had children who were resident in the rural household and cared for there or were supporting building projects within the household as an investment for the future. These individuals were closely connected to the household, therefore, not only personally through familial ties, but also financially and materially.

The members of rural households, whether resident or not, were therefore also influenced by norms of reciprocity. Reciprocal relationships were fostered when one household member provided support or care to another, trusting in the knowledge that their contribution would be returned in some way by another member of the household if the first member was in need. This generalised reciprocity is not balanced and therefore requires a level of trust common within households or, though not necessarily, kinship networks. Members of households were likely to be linked by closer familial relationships than other kin so that livelihood outcomes aligned with social relations. These relationships were therefore characterised by trust, a familial obligation to support and potentially a desire to help those to whom one is related and have an emotional connection with. Members of the same household, whether resident or non-resident, invest in the household, in this physical sense, because they share a desire for the success of the household's livelihood and its ultimate survival but also have love for and closeness to other members.

These reciprocal relationships functioned in both directions. While their age and life circumstances seem to place non-resident members at a high risk of HIV-infection, at other times in the life cycle of the household, non-resident household members are an important source of financial assistance and material support for the rural households. Although non-resident household members do not necessarily contribute in any regular fashion, at times of crisis within the household such as the extreme illness or death of a household member financial

assistance and material support from non-resident household members is crucial. This means that the illness of a non-resident household member has the potential to be a double burden because the household loses their support and is burdened with their care. While the relationships within households were not straightforward and the case studies provide examples of conflict between members, particularly where the norms of reciprocity were not observed, the household and its members was still the first and most important source of support. This was particularly the case for sick individuals who were either resident or had been previously non-resident. Affected households utilised the resources of their own members, either resident or non-resident, first before calling on external support.

Despite changes in traditional practice, the evidence from within the households and the kinship network, as well as the examples of fostering and the support and care provided for children, suggest that the family is still the most important source of support for affected individuals and households. Although the informants may not follow hard and fast rules dictated by tradition, their actions are still largely governed by a sense of obligation to those to whom they are related. As argued by Finch (1987) in her family obligation theory, however, there is negotiation and I would argue flexibility involved in these obligations and the assistance provided.

The results also provide evidence for the continuing importance of the norms of generalised reciprocity expectations inherent in kin, and, especially in this case, household relationships. Family obligation and generalised reciprocity also plays an important role in the livelihoods of rural South African households not affected by HIV and AIDS, and are dictated by social norms (Everatt *et al.*, 2005; Haddad *et al.*, 2003; Russell, 2003b; Sagner *et al.*, 2000). The complex, dynamic and sometimes conflicted relationships within households are utilised to mitigate the impacts of illness and death for the affected individual household members or the household as a whole. The results suggest that family obligation and generalised reciprocity are fostered through maintaining close relationships or affective ties, with other household members and family members. These close relationships and norms of obligation and reciprocity help affected individuals and household respond to the impacts of illness and death. The importance of an obligation to family in South Africa has been acknowledged by Ross (1996), Sagner and Mtati (2000) and Bozalek (1999) as motivating various forms of support and care within the household and kinship networks. The benefits of family obligation and generalised reciprocity are felt by all affected household members both resident and non-resident and, in the same way, all household members, resident or not, are a potential source of support. Household members dispersed over space and time therefore can act as either a burden or a benefit for the household

as a whole or for certain individuals. This ties in to the argument as proposed by Murray (2000, 2002) for conceiving livelihoods as dispersed geographically.

8.9.2 Family obligation and generalised reciprocity within the kinship network

The roles other members of the kinship network play, have been discussed with respect to funerals in the South African context (Booyesen, 2004a; Booyesen, 2002; Case *et al.*, 2008). The results presented here also demonstrate the support and assistance that kin provide around the time of a death. The death and subsequent importance of the funeral of a household member often had large financial implications for the household. Funerals are socially important events and the traditions around them require the household to provide hospitality for the family, kin and members of the community, adding to their cost. The findings, therefore, suggest that there are specific expectations governing the provision of support in times of death and attendance at funerals. Even kin and household members with weak ties to the household, who had not contributed or supported the household in other times of crisis, were expected and observed to provide support at the time of a funeral. The public aspect and social sanctions associated with the funeral and the presence of kin and members of the community, already discussed with reference to the household, may act as an incentive for kin to contribute and be seen to provide support for the household. This display of kinship solidarity has been suggested as significant in the motivations for supporting households at a time of death by Bahre (2007) in his research in the Western Cape. This also serves as a reciprocal relationship and the norms associated with the event mean that contributions to affected households within the kin network secured reciprocal assistance from these households in the experience of a death in the contributing household.

Reciprocity and the expectation that when one possesses the capacity, one should return a favour are also shown to be important for members of the kin network. Generalised reciprocal relationships between kin were based on an understanding that each would help the other as far as possible, safe in the knowledge that such assistance would be returned in their own time of need. In this way, households were able to develop and build up their social capital to ensure assistance in times of extreme need. It would therefore appear that the norms of generalised and balanced reciprocity, as identified in Sahlins' (1972) analysis of what he refers to as a primitive society, are still relevant in contemporary rural family life in South Africa.

This research also shows that, unlike within the household where, despite conflict and complex relationships the obligation to family is observed in most cases, some households are excluded fully or partially from kinship networks. In the case studies here this arose because of the

household's extreme need, where households had exhausted the support available to them, and in some cases because of conflict. Some households were excluded despite having strong expectations of their kin, for example the brother of a woman, who would normally be an important source of support.

8.9.3 Reciprocity and trust: building support from the community

In this study three forms of reciprocity largely dominated transfers between unrelated households within communities or neighbourhoods. Those individuals who sustained close personal relationships with other members of their community or neighbourhood were able to rely on support that amounted to generalised reciprocity in times of stress, crisis or need. Many of the affected households who were able to access help and support in this way could provide examples of times when they themselves had actively helped other households within their network, thereby both investing in and constructing social capital. The examples within the results may also have been affected by generational differences in the household's make-up, an important factor that contributed to the help that younger affected households were able to secure. Despite these examples of generalised help and trust on the part of unrelated households, few of these relationships were unconditional in nature, highlighting the significance of balanced reciprocal exchange within these community or neighbourhood networks.

There appear to be definite limits to the generalised help households can rely on from sources external to the household or family. Transfers between affected and other households where there was limited trust and no really close or personal bond, tended to operate according to the principles of balanced reciprocity. Such transfers and support from households or individuals within the community included access to credit, involving a more reasonable rate of interest than those available from a *mashonisa* (moneylenders), and the borrowing of goods and services in direct return for something of equal value. Even these balanced reciprocal relationships required relatively high levels of trust and investment in social networks in order to claim support.

The levels of support and assistance provided by family and by neighbours and other members of the community differ greatly. The community and neighbours are much more likely to provide one-off assistance, especially in times of extreme need such as illness or for organising and financing a funeral. This was also found to be the case in Nombo's (2007) Tanzanian study. The help provided by family and those within the kinship network was more wide-ranging and included both relatively long-term small-scale material support and financial assistance and more intermittent larger contributions. This concurs with findings made by Hosegood *et al.*

(2007b) that describe the role of stigma in determining the support affected households can secure from other households and individuals within the community. This may also have been the case in the households in our study, although it was hard to disentangle whether it was actually illness or the severe poverty and need that hindered support affected households were able to reply on. In addition, members of the neighbourhood and community provided charitable support for households most vulnerable or in need.

The results presented in this chapter imply that, unlike the obligations and norms of reciprocity inherent in and governing the transfers between those in relationships within the household and kinship network, membership in a community or neighbourhood, in rural South Africa does not automatically entitle a household or individuals to their support. Rather, I would propose that the ability to obtain help from others within the community is reliant on the investment in and active construction of social relationships with other people and, therefore, trust, as advocated for as the basis for social capital by Bourdieu (1985). Social capital is fostered through maintaining and actively supporting close personal or familial relationships and participating where possible in the full range of possible reciprocal exchanges.

8.9.4 Group membership and external support

Bourdieu (1985) emphasizes the importance of group membership for social capital. Although much of his discussion concerns family and kinship networks, social capital is not exclusively related to the family and may relate to more organised whether formally or informally groups of people. In the rural South African context, membership of relatively well organised groups is common as suggested by the findings of Adato *et al* (2006) and Cross (2001) in KwaZulu-Natal and of Everatt *et al.*(2005) and Haddad and Mallucio (2003) who analysed nationally-representative data. Membership of church groups was particularly common in the study households, either of a wider less organised church community or of smaller, more formal and organised prayer groups. Those involved in the smaller prayer groups have close relationships with other members and were better able to secure support from them than from the wider church community where trust and ties were not as secure. This included prayer and emotional support something not discussed by the interviewees in the context of other sources of support.

The evidence provided in this study of support from the church or faith-based organisations is minimal in comparison to evidence from studies in other parts of Africa such as Seeley and Russell (2010) and Russell and Seeley (2010). While the respondents did mention where church members provided financial assistance or material support, for example around funerals, they seldom mentioned other types of emotional or spiritual support membership in these groups

may have provided. It is not clear why this is the case but could be due to the way in which the respondents, and possibly I, conceptualised support in a physical or material sense. Therefore, they felt that while membership was important to them in their personal capacity and lives that this was less important to the overall physical well-being of the household.

Unlike church groups, *stokvels* and burial societies function on the principle of the pooling and sharing of income or finances for the organised benefit of all members of the group. Therefore, membership of these more formally organised groups required participation in the form of contributions. The financial implications of the presence of a sick person meant that, as suggested by Nombo (2007), those not able to contribute and participate financially are therefore not able to join or are excluded. Another finding that parallels those of Nombo (2007) is that groups such as *stokvel* and burial societies only pay out once a year which limits the benefits households gain from membership within such groups.

Groups found to play a role in affected households within the study included treatment support groups such as those found to be important by Seeley and Russell (2010) and home-based care organisations. Treatment support groups were a source of support for those individuals who were sick and on treatment but the benefits they got from being a member of a well-organised group might also have had repercussions for the wider household. For example, if groups were organised and helped to provide financial assistance or material support for income generation, these benefits would also have been felt by other household members. Membership of treatment support groups could also help to prepare individuals for work by supporting the sharing of skills and knowledge. In addition, although there was limited evidence within the study, other literature would suggest that these groups might also support adherence to ART (Coetzee *et al.*, 2004a; Nachega *et al.*, 2006).

Access to help from home-based care services appeared to be dependent on personal contacts with the church members within the community who provided the service. Despite this, the type of service households received was variable and dependent on the provider of the service and their dedication. Another crucial factor concerns the level of training the workers had undergone, which may have affected the type of help that they were able to provide.

8.9.5 Social exclusion

The isolation of some households from their kinship network demonstrates the limitations to the support available. It also shows how vulnerability and poverty erode a household's ability to reciprocate and therefore may result in a cycle of social exclusion. Similar conclusions about the

exclusion of households from social networks as a result of poverty and an inability to reciprocate were drawn in Nombo's (2007) work in Tanzania and suggested by the likes of Baileys (2002) and Seeley *et al.* (2008) in their conclusions. In the examples in this study the exclusion of the household was made more severe because family members seemed to have actively chosen to distance themselves from the study household, despite the high level of expectation on its part. I would, therefore, argue that the social exclusion be considered as part of both the vulnerability context in the livelihoods framework and as part of the social relationships conceptual framework adopted for use in this chapter. In this case, the exclusion households experience can be either from within the kinship or external social networks.

8.9.6 Summary

The results presented here suggest that, as argued nearly two decades ago by Seeley *et al.* (1993), the household and kin networks remain a 'safety net with holes'. It is a safety net that, despite the inadequacies and the pressure placed on it, is resilient and functions to support the individuals and households who are affected. Depending on the family, and more specifically the household, as a source of support is not a new survival strategy. The historical evidence from South Africa and other parts of Africa suggests that the household and extended family have remained a constant source of support (Baileys, 2002; Cross, 2001; Hosegood *et al.*, 2007b; Seeley *et al.*, 2008). Political upheaval, widespread migration and high mortality have exerted pressure on these institutions and they have undergone changes, both in their composition and formation. In the present era, illness and death add further burdens to the pressures that households face. Kin networks, and specifically the relationships within the household, were generally the greatest source of support for households and individuals dealing with illness and death. Although it has been argued within the literature that HIV and AIDS would effectively destroy the household and family's ability to survive and continue to provide help and support, the evidence suggests otherwise. Thus, illness and death exert pressure on the household and do result in times of extreme vulnerability, but the household and kinship remains largely resilient and an important source of support and assistance.

The analysis in this chapter suggests that, despite arguments to the contrary, members of the social network within the wider community do also provide for affected individuals and households in times of need. However, such support was reliant on the type of relationship applying. Those who were better able to build and invest in both informal and formal social networks and groups and, therefore, social capital were in a far more advantageous position to receive such support.

Chapter 9: Social grants



9.1 Introduction

Government social grants in South Africa are administered in the form of direct cash transfers to categories of individuals who are considered vulnerable or in need (Lund, 1993). High formal sector unemployment, a high dependency ratio, low levels of subsistence and small-scale commercial agriculture and high adult rural-urban migration have combined to make these grants one of the most important sources of income for poor rural households in South Africa (Swartz *et al.*, 2006). The national social security system has come under criticism, especially in the light of the social and economic impacts of the HIV and AIDS epidemic. One of the primary criticisms levelled at the current South African system is that it is premised on what has been shown in Chapter 4 to be an unrealistic assumption of high levels of formal employment. The result is that there is no government provided financial safety net for unemployed adults (Hardy *et al.*, 2006; Lund, 1993; Simchowitz, 2004). In addition, criticisms have been voiced over the eligibility criteria required for receipt of a disability grant along with the criteria for the official termination of the disability grant for those sick with HIV and AIDS (Department of Social Development, 2008c; South African Social Security Agency, ND).

In this chapter, I investigate the way in which receipt of social grants changes the experience of households affected by HIV and AIDS. In addition, I assess the appropriateness of the current social security system for those suffering from the impacts of HIV and AIDS. Addressing these

issues is particularly relevant in light of mounting criticism of the South African system. Section 8.2 reviews the literature dealing with the socio-economic benefits that social grants have for South African households affected by HIV and AIDS. In the following section, the current critiques of the South African social security systems, focussing on the recent debate about the possible relationship between the disability grant and ART, are explored.

The chapter then investigates how household members affected by HIV and AIDS negotiate the use of social grants. The ways that the different social grants are spent are examined, as are the role that social grants play as part of the livelihood in affected households. Some of the barriers confronting households in their attempts to access social grants and specifically disability grants are then described. The consequences of these barriers to access for PLHIV and their households are explored. Finally, the chapter assesses the relationship between ART and the disability grant.

9.2 Social security in households affected by HIV and AIDS: evidence from South Africa

Research in South Africa has shown that access to social grants, especially old age pensions, is a key factor in the alleviation of poverty in rural households with eligible members in the Free State (Booyesen, 2004b; Booyesen *et al.*, 2005; Case *et al.*, 1998). Social grants have also been shown to provide a substantial contribution to household income in other studies involving households affected by illness and death in South Africa (Case *et al.*, 1998; Case *et al.*, 2003; Goudge *et al.*, 2009a).

Despite these findings, it is still unclear how different social grants are spent by households or what decision-making processes and negotiations underpin how these social grants are used in households dealing with HIV and AIDS.

Not all those who are eligible for social grants are able to negotiate the complex application process involved in having one awarded. There has been some research investigating the barriers faced by those trying to access social grants (Case *et al.*, 2003; Hardy *et al.*, 2006; Moitse *et al.*, 2003; Simchowitz, 2004; Zungu *et al.*, 2003). However, the consequences of an individual's failure to access a social grant, specifically a disability grant, have not been explored sufficiently. More investigation is also needed of what characteristics of households or individuals act as barriers to people obtaining social grants. This study attempts to begin to

answer these questions with specific reference to the experience of households affected by HIV and AIDS.

There are reports on how social grants have assisted households dealing with shocks or stresses associated with HIV and AIDS. Lund (2002b) reported on research conducted in Brazil, where a non-contributory old age pension and disability grant programme for the poor improved and increased the financial sustainability of livelihoods in illness affected households.

Booyesen and van der Berg (2005) and Booyesen (2003, 2004b) conducted a study in an urban and rural community in the Free State province of South Africa comparing households affected by HIV and AIDS (having either a person sick with AIDS or having experienced an AIDS death) with unaffected households. The purpose of the study was to assess how each of the five main social grants described in section 4.6 influenced levels of poverty and inequality between affected and non-affected households.

In affected households, social grants accounted for over 28% of household income. Households receiving an old age pension or child support grant were better off despite being affected by AIDS. Receipt of a social grant was instrumental in reducing household poverty for the beneficiaries. The income from social grants was spent mostly on food. Having money for food improved the health outcomes of PLHIV, especially those on ART. The study also found that the lowest uptake of social grants was amongst the poorest households (Booyesen *et al.*, 2005). These vulnerable households, often with the sickest people living in them, had the greatest difficulty in accessing social grants. This finding has implications not only for PLHIV but also for their households as a whole.

In the Free State study, the proportional contribution to household income of the disability and foster care grants were higher in affected than that in unaffected households. Despite relatively low numbers of people accessing foster care grants, it was associated with the third greatest reduction in poverty in affected households of all of the five social grants (Booyesen *et al.*, 2005). The effect of foster care grants on households' livelihoods has received less attention than that of any of the other social grants in the literature. The care-dependency grant, for sick or disabled children, has possible positive implications for households with children affected by AIDS because of the transmission from mother to child. The foster care grant, for children who are fostered possibly because of orphaning because of AIDS death also has the potential to have benefits for the affected child and their foster family.

Zungu *et al.* (2003) investigated how children in two households affected by HIV and AIDS in KwaZulu-Natal benefited from foster care and care-dependency grants. A follow-up study on one of these households was also conducted (Moitse *et al.*, 2003). The grant application process was found to be complex and a large number of stages and players are involved in making decisions about whether to award a grant or not. Foster parents encountered particular problems proving that a biological parent is not available to care for the child. The courts need to be involved in order to obtain the required affidavits. Care-dependency and disability grant applications, on the other hand, require a medical certificate from a medical doctor. The application process takes a long time and can be costly to the applicant (Moitse *et al.*, 2003; Zungu *et al.*, 2003).

The affect of chronic illness, including HIV and AIDS, on households was assessed in a study in part of Limpopo province using qualitative and quantitative data collection methods (Goudge *et al.*, 2009a). The study focused on the influence of social grants on the costs directly associated with illness rather than on the household's livelihood in a more general sense. Social grants helped prevent affected households from sliding into poverty and enabled them to afford the costs associated with the illness. The money had a general developmental effect, increasing the ability of the household to purchase resources. The grant money also facilitated households to maintain and draw on their wider social support networks because it enabled them to reciprocate support.

9.3 Critiques of the social security system

The current South African social security system presupposes that a large proportion of adults are employed and, therefore, the system does not provide for poor and unemployed adults. This is a false assumption and has been widely criticised (Hardy *et al.*, 2006; Nattrass, 2005; Simchowitz, 2004). Many countries in the developed world such as Canada, the United States of America and the United Kingdom provide a general safety net for the poor, vulnerable and unemployed and this is the most striking difference between their social security systems and that in South Africa (Whitworth *et al.*, 2006).

In South Africa the need for the social security system to support the unemployed has become increasingly important with the rise in unemployment but also the high prevalence of HIV that can itself lead to unemployment (Swartz *et al.*, 2006). Although those incapacitated by AIDS may qualify for a disability grant, this is the only option open to unemployed people in South Africa. High unemployment and HIV may exert further fiscal pressure on the social security

system through increasing the number of disability grants in payment (Hardy *et al.*, 2006; Nattrass, 2005; Simchowitz, 2004; Whitworth *et al.*, 2006).

9.3.1 Disability grant and ART

There is concern about the overlap in the criteria for eligibility to access a disability grant and to obtain ART (Nattrass, 2005; Simchowitz, 2004). The eligibility criteria that qualify PLHIV for a disability grant have until recently been almost identical to those that are used to decide whether that person should be initiated on ART. There is a particular concern that PLHIV may defer initiation of ART in order to be classified as disabled and benefit from a disability grant. The withdrawal of the disability grant from those whose health has improved because of ART is also an area of concern.

In South Africa free ART initiation has been available through the public health services to those with a CD4 count below 200 cells/mm³ or those who are assessed medically to have reached WHO stage 4 of the illness (Department of Health., 2006; Lawn *et al.*, 2005a). Using stage 4 as a criterion for eligibility to initiate ART may result in treatment being started relatively late. A number of South African studies have shown that those who commence therapy with CD4 counts below 200 cell/mm³ or who have stage 4 AIDS are at a higher risk of mortality than those who start ART when they are healthier (Lawn *et al.*, 2006; Lawn *et al.*, 2005a). Despite this, in a study in the Free State province of South Africa ART given even at this comparatively late stage of the disease was shown to decrease mortality and was associated with an increased CD4 count and body mass (Fairall *et al.*, 2008).

In 2008 protests by a group representing the rights of people living with HIV and AIDS drew attention to the inappropriate, and what they felt unfair, discontinuation of disability grants without proper medical assessment. The protests also highlighted the inappropriateness of the use of CD4 count or viral load as a criteria for access to the disability grant (Hardy *et al.*, 2006). The Minister for Social Development has clearly stated that the South African Social Security Agency (SASSA) cannot suspend disability grants based on PLHIV attaining a certain CD4 count or HIV viral load but on their medically assessed inability to work (Department of Social Development, 2008b). Use of a CD4 count or viral load as a tool to assess disability is therefore not Department of Social Development policy. Anecdotal evidence and discussion about the fact that these assessments are still being conducted abound in the media, among citizens and even amongst Department of Health employees.

These links between eligibility for the disability grant and ART have fuelled a debate around the inherent contradictions in the disability grant policy in South Africa (Nattrass, 2005; Simchowitz, 2004). Unemployed adults in South Africa are not eligible for social support. Thus, if they are also HIV-infected, there is an incentive for them to be classified as medically unfit so that they can obtain a disability grant. This may well encourage some PLHIV to want to appear sicker and even to default from treatment in order to benefit from a disability grant (Hardy *et al.*, 2006; Nattrass, 2005; Simchowitz, 2004). The literature highlights this anomaly created by the tendency of certain local or provincial-level departments to cancel short-term disability grants as the health status of PLHIV improves on ART. There is concern that this may create a perverse incentive for a PLHIV to discontinue medication. People may also be inclined to delay initiation of ART in order to access or retain a disability grant. Thus, it creates a cycle of sickness and health, because of increased stress, decreased access to good nutrition and possibly a consequent decline in health.

Vulnerable people find it difficult to access disability grants. Information about eligibility criteria is hard to obtain and this is compounded by complicated requirements and administrative procedures (Simchowitz, 2004). Simchowitz (2004) also identified problems with the delivery of grants to the recipients. In the Mashini case in the Eastern Cape failure to provide recipients with sufficient notification meant that 54 000 lapsed temporary disability grants were reinstated and not severed as planned. Simchowitz (2004) also highlights the issue of fraudulent claims for social grants. The Gauteng study confirmed the difficulties encountered by those trying to access social grants, including the prevalence of misinformation and the complexity of the social grant application process. The authors argue that the social security system fails those who are sick but who are not considered disabled despite the fact they are unemployed or living in poverty (Hardy *et al.*, 2006).

In the Free State province, Booysen and van der Berg (2005) found that the length of time a person is allocated a disability grant remains poorly monitored. There was a generalised failure to reassess those in receipt of disability grants, suggesting that fewer grant recipients had their grants terminated than is reported in the literature.

Research conducted by the AIDS Law Project in Gauteng province explored the relationship between receipt of a disability grant and adherence to ART in PLHIV (Hardy *et al.*, 2006). A similar research question was posed in the Eastern Cape province (Peltzer *et al.*, 2007). Qualitative and quantitative data was collected from community health workers and PLHIV accessing the disability grant. The findings from both studies suggest that those receiving ART would continue their medication despite losing the disability grant. The fact that a potential

trade-off between the treatment and the disability grant was raised by health care workers and caregivers in the Gauteng research though and it has been suggested within the literature that it is an issue that may require further research (Booyesen, 2004b; Hardy *et al.*, 2006).

A study conducted in the Western Cape showed that the health outcomes and quality-of-life of patients receiving ART continued to improve for those who survived through the first year of therapy (Coetzee *et al.*, 2004a). ART has also been shown to improve both physical health and quality-of-life in those patients who received treatment in a number of other studies in South Africa (Coetzee *et al.*, 2004a; Louwagie *et al.*, 2007; Wouters *et al.*, 2008). However, during the first year, and particularly during the first six months of therapy PLHIV are still at a higher risk of both morbidity and mortality (Bussmann *et al.*, 2008; Etard *et al.*, 2006; Lawn *et al.*, 2005b).

Although the literature investigating the link between individual or household socio-economic status and successful ART outcomes is limited, there is some evidence suggesting that this association is important. Two international studies, one conducted in Italy and another in the United States of America (USA) reported that PLHIV on ART who were poorer had worse health outcomes than those with a higher socio-economic status. The study conducted in the USA controlled for patients' access to health services, which the study in Italy did not (Cunningham *et al.*, 2005; Rapiti *et al.*, 2000). A study conducted in Malawi reported a clear link between mortality and malnutrition among those receiving ART. Malnourished patients were six times more likely to die within the first three months of commencing ART than those who were well nourished (Zachariah *et al.*, 2006).

These findings imply that there could be a positive relationship between ART and receiving a disability grant thereby improving the socio-economic status of the individual and household influences the health outcomes of those on treatment.

In South Africa there has been a strong call for more widespread access to social security in the form of a basic income grant that predates the debate about the disincentive effect of the disability grant (Nattrass, 2005). A basic income grant would benefit all the unemployed and poor in the population rather than just the sick. The basic income grant is proposed to be a universal grant with no assessment criteria attached. Samson (2002) suggested that a basic income grant system would be feasible to implement, affordable and it would reduce poverty, promote economic growth and job creation.

In the absence of adequate social provision for those who are unemployed in the general population or a generalised basic income grant, as proposed by Samson (2002) and others

(Nattrass, 2005), Simchowitz (2004) has suggested a revised disability assessment model. The process of assessment of disability has changed over time and varies between provinces. In some places an assessment panel is used and in others a state physician employed by SASSA assesses all the applications. There was very little standardisation of the medical criteria to assess the level of disability used in the decision to award a disability grant.

The model proposed would take into account medical as well as social and environmental factors that contribute to disability. A similar model was proposed by Swartz and Schneider (2006) in their critique of the disability grant system in South Africa. This model of assessment would be contextual and relational rather than based only on the state of physical wellbeing of individuals. Countries such as Canada, the United Kingdom and Australia have endeavoured to incorporate these relational factors into their assessment of a person's disability (Swartz *et al.*, 2006).

9.4 Social grants as a safety net for households dealing with HIV and AIDS

All of the households in our study were receiving at least one social grant. Social grants were not necessarily used for the sole benefit of the individual who was the registered recipient. The benefits depend on the existing socio-economic status of the household, the stresses and crises it is dealing with as well as its greatest needs. The experiences of the Mabena household illustrate the ways in which receipt of an old age pension can benefit a household affected by illness and death.

Nobantu described how things in the household had changed since Lindiwe became ill and returned to her mother's rural home.

[Lindiwe] became very sick and then she came back [to the rural household] from work [in Durban]. She had been living at her place of work, in the suburbs. [Before she stopped working] she helped me, she changed the roof, as you can see, over that room [indicating a bedroom next door] and this one [indicating the living room in which we were sitting], and she also bought us these mats.

Nobantu Mabena, female household head, 61 years

Lindiwe's illness and subsequent job loss meant that before the start of fieldwork Nobantu was the only household member earning an income. Before receiving the old age pension, Nobantu

was employed as a seasonal labourer, weeding the field of a neighbour. Nobantu elaborated on how the old age pension had changed her ability to provide financially for her household.

How can I not feel happy about getting the old age pension? Without it I wouldn't be able to buy anything. I can now take a rest from weeding the sugarcane...I am able to buy maize meal and a bag of beans at the end of every month.... Now I buy a big bag of maize meal and another of beans and maybe it will last us for the whole month.

Nobantu Mabena

The decisions Nobantu made about the way in which the pension money was spent were strongly guided by the most urgent needs and responsibilities of the household.

Nobantu Mabena: I buy a big bag of maize meal and beans. Maybe [they will last] for the whole month...[not enough food] causes hunger at home. I also buy a big bag of sugar. I also buy washing powder and pay for the transport for the children who are schooling, which is R60 [£5]. I am left without anything. I also have to pay back the money I borrowed from the neighbours for the funeral [of her brother] because I haven't finished paying the instalments.

Interviewer: How much do you pay the neighbours back per month?

Nobantu Mabena: R240 (£21)

Interviewer: How do you pay for the things that the sick people need?

Nobantu Mabena: I went out and borrowed money from other people when I had to fetch [Lindiwe] from the hospital because [the hospital] said that she couldn't wake up and walk.

Nobantu's response suggests that the most urgent household need was for food. Anything remaining of the pension money was spent on transport, for the special needs of the children and other basic household necessities. If the old age pension had not been shared with the rest of the household it is unlikely the family would have had enough food as they had no alternative income. Nobantu supplemented her pension in times of need, such as for the funeral of her brother or when Lindiwe needed to travel to the clinic, by borrowing money from neighbours.

Nomsa Bhengu related the concerns about her own health and that she did not feel strong enough to do manual work.

Nomsa Bhengu: I don't know where I will work.

Interviewer: Can you not do small jobs in other people's sugarcane?

Nomsa Bhengu: I can't work there I'm failing [not enough energy to weed]. I lose energy.

Maybe I have sugar diabetes. I sweat at night and drink a lot of water. I forget things and I pass urine the whole night, I can't sleep and feel warm.

Nomsa Bhengu, female household head, 56 years

The low socio-economic status of the household was affected by the unemployment of relatively well household members. Their unemployed status was compounded by the burden of caring and providing for sick household members.

Both Nomsa and Thobela spoke about how difficult it was to access a disability grant for the sick. The Nkosi and Bhengu households both relied initially on child support grants as the only source of household income. Household money was pooled in order to provide for the most urgent needs of all members in the household.

I try, with this R600 (£52), to buy groceries, pay the school fees and also for the school transport for R100 (£9). I am left with R500 (£44). I went and bought 25 kg [of maize meal], it doesn't last the month, I also buy a bag of beans and I pay for insurance [funeral insurance for herself and the young children]... As I have explained we are hungry. Last month I had to get R200 (£18) credit because I didn't even have any maize meal left.

Nomsa Bhengu

Circumstances in these households were such that none of the social grants the household received was used specifically for the recipient of the grant. The money was pooled and reported to benefit the sick household members and the rest of the household.

Receipt of a social grant was important because it facilitated self-reliance for the household. The households were, no longer dependent on the sympathy or contributions of others for work or basic household resources. Nobantu explained the implications of her old age pension for her and her household.

Before I got the smallest amount of money from weeding [other people's sugarcane] and bought what I could, but I had to also ask for help from the neighbours.

Nobantu's receipt of an old age pension meant that her household was essentially self-sufficient financially and provided enough money to purchase food for the household, for almost the whole month. Access to state support was very important particularly for those vulnerable and socially isolated households such as the Mabena and the Nkosi families who did not have kin networks for support or who were reliant on the charity of neighbours.

9.4.1 Social grants as a safety net for households dealing with death

Access to social grants was especially important when a death occurred in the household. Tina Ntuli talked about how her old age pension assisted her.

When I did get my grant.... I felt great, but I had expenses at that time. My daughter passed away. I was very much hurt but now I'm okay because I know what I did with [the money from the old age pension] I buried my daughter the way I wanted to..... with the little that I had left because the diseased person is more costly than the well one.

Tina Ntuli, female household head, 63 years

Tina qualified for an old age pension about the same time as her daughter died. Although her pension did not provide sufficient money to pay for the whole funeral, she was also able to get financial assistance from the church where the daughter of her late husband had been a preacher. This money, together with her old age pension meant that she was able to pay for a funeral to the standard she wanted.

Nobantu Mabena also reported that her old age pension had assisted with funeral costs after the death of her brother.

Because I had this bad luck [death of her brother] I borrowed money from neighbours. On my [old age] pension date I have to pay [them back]. I will not have [enough] money left and the people who were helping me at the funeral need food.

Nobantu Mabena

Receipt of a regular social grant such as the old age pension enabled recipients to borrow money based on being able to repay their debts and provide proof of a regular income. This provided them with a financial safety net that helped them to respond to the costs associated with crises in the household such as funding a funeral.

Receiving a social grant was not only an asset for the household in which the recipient was a resident member. In the Dube household, Thembilihle spoke about how she and her partner's family paid for his funeral.

My mother lent me money that she borrowed from the stokvel [informal savings group] and promised to pay back, monthly. [Her mother] paid for [Thembilihle's partner] to go to the [funeral home] because grandmother [his mother] was not yet getting her grant.

Thembilihle Dube, daughter-in-law of household head, 34 years old

Thembilihle's mother was not a member of the Dube household. She used the money from her old age pension to negotiate an advance from her *stokvel* in order to contribute to the direct and indirect costs of the funeral.

9.4.2 Social grants and the after effects of an AIDS death

Social grants assisted PLHIV in the household but also benefited other sick household members or orphaned children following the death of an adult due to AIDS. Jabulile Gumede used the foster care grant she collected for the two grandchildren in her care, the youngest of whom was HIV-infected and sick.

We decided to pay for [Ayanda] to go to school by staff car because she is suffering when she walks down to school. We don't want her to suffer. So we spend the money [from the foster care grant] on that.

Things became better after we got the foster care grant because [Ayanda] had one uniform but now I have managed to buy her another one. I used to wash the one she had every day when she came home from school. I use the social grant to buy this and that, things we need, but I make sure that I save R200 (£18) at iThala Bank, so that when she continues with school that money will help her.

Jabulile Gumede, wife of household head, 63 years

Jabulile used the social grants in order to improve the quality of the lives of her grandchildren, she was also saving some of the money for their future education. Some of the foster care grant was also pooled and contributed to paying for other general family needs. The situation was similar in the Ntuli household.

It helps [getting the foster care grant] because I use some to buy food [for the household] and the rest I save for him.

Tina Ntuli

Accessing a foster care and child support grant for her two grandchildren was particularly important for Tina.

I don't get to enjoy [my old age pension] because of my debts [which need to be repaid]. They are more than other people's [debts]. On grant day, I didn't have money for food because I borrowed the money last time..... so now I have to pay [them back]. I realised too late that if I should have paid in instalments [to avoid interest]. I also joined the stokvel so when I get this money [old age pension] I pay all to that person [who runs the stokvel]... So that's why I can't see what I'm doing with it [my grant]. You find out that there is something you have to do and that this thing needs money, only to find that you don't have any and you have nowhere to get it from.

Tina Ntuli

Tina had incurred large debts, despite having an old age pension. The child support and foster care grants enabled Tina to buy food for the whole household, and to provide for the needs of the young children especially her grandchild who was sick with AIDS and on ART.

Receipt of a range of social grants enabled these households, both of whom had at least one orphaned and HIV-infected sick child, who was being cared for by a grandparent, to survive financially. In both instances the grandmothers, felt that providing adequate care and support for their grandchildren would have been difficult without these grants. These social grants benefited the children as well as other household members, as a proportion of the money was pooled for basic household necessities such as food.

9.4.3 Social grants used to facilitate livelihood changes in households

Receipt of a social grant provided affected households with a safety net in times of illness or death, but also stimulated or facilitated changes in their livelihood activities. Nobantu Mabena's receipt of an old age pension allowed her to stop working for other people as a way to contribute to household finances. The intended purpose of an old age pension is to enable elderly people to retire from active working. Tina Ntuli supported this assumption about the old age pension.

It is better [since I got the old age pension], I can say, because before I was surviving by weeding [in other people's fields] but now I know that I can borrow money from someone else knowing that I will be able to pay them back when I get my grant, unlike before.

Tina Ntuli

For these older women, not having to work to earn money meant that they had more time to care for those in need in their household. In the case of Nobantu it was her grandchildren and her daughter who needed her care. When asked whether she had considered returning to work Nobantu replied:

I can't leave [Lindiwe] alone while she is sick and go to [work in] the sugarcane.

Nobantu Mabena

Having an old age pension ensured that these elderly women were rightfully able to stop working and repay their debts. Tina reported that she bought supplies on credit from the local shop in order to purchase sufficient groceries to last her household a month. She also bought a door to improve the security of her home. Access to credit in the Ntuli household improved the home and living conditions. Receipt of a social grant improved informal and formal work patterns in all the households in our study. In the Sibaya household, for example, despite receiving an old age pension, Siyabonga chose to continue to work informally as a driver.

Social grants therefore facilitated the diversification of livelihoods in other households. The Dlamini household received a pension for their eldest member: Ntombizodwa. Her daughter Gugu received a disability grant and the mothers of six of the young children resident in the household contributed some of their child support grant money towards the communal household finances. Gugu was responsible for financial decision-making, ensuring the household met its basic needs. These included paying for Ntombizodwa's health care for her diabetes. She used any money left over at the end of the month, to invest in a business selling *vetkoek* (deep fried dough served either savoury or sweet) and sweets at the nearby primary school. Any additional money was used to purchase the raw materials (reeds) to make *mcansi* (grass sleeping mats) that were then sold. Her nieces assisted with running the trading business. At other times however, spending on household stresses and crises associated with HIV and AIDS, took precedence over this and other business-related expenses.

Additional sources of income, such as social grants, in certain instances, enabled people to be independent of each other. This was the case in the Sibaya household and therefore Mandla's

disability grant income was not pooled by the household but was used by him as the grant recipient. In the Sibaya household, the old age pension was pooled to purchase food, however no other individual social grants were shared. This was similar in the Shabalala household where the various household members all possessed separate living quarters and operated in a financially independent way, despite identifying each other as resident members of the same household. This is an example of the dispersed livelihood of the household even though there is no geographical dispersal of the household members.

9.4.4 Barriers to and difficulties with accessing social grants

The barriers or difficulties that households or individuals face in applying for and becoming recipients of social grants affect the individual and households ability to use them. Delays in the receipt of social grants cause hardships for households especially where they rely on them to feed and care for sick household members, educate children or service debts.

The Gumede and Ntuli households confronted obstacles in trying to access social grants. In particular, the grandmothers in these households had difficulty accessing death certificates for the mothers of their grandchildren in order to obtain foster care or child support grants.

The staff at the clinic helped me to get the [foster care] grant for the child because I was failing. They told me to look for his mother but I didn't know where to find her. So they didn't want to help me. I told them that I didn't have money to help this child [her grandson] when he needs help. They told me to ask for an affidavit from the court and take it to [Department of Social Development].... They did it for me [that affidavit for the grandmother]. I already had his father's death certificate.

Jabulile Gumede

Jabulile was fortunate to get an affidavit proving that the mother of her grandchild died, thus allowing her to qualify for a foster care grant. She also received a foster care grant for her other grandchild. In this instance, the maternal grandmother of the child assisted by ceding responsibility for the child, therefore, facilitating the grant application process. The application however remained a lengthy process. Only when one of the children became ill did she ascertain that she could access the foster care grant for that child, even though the mother was still alive, because she had deserted her and the family had had no contact with her for a very long time.

In the Ntuli household, Sipho was a maternal orphan living with and being cared for by his grandmother, Tina. Tina was unable to provide documentary evidence of the death of the

mother of the child because the family refused to provide her with the death certificate. Her family felt that Dumisani, Siphos father should take responsibility for him and should not need a social grant. Dumisani however, remained unemployed and lived away from his son. Despite him sending both food and money home whenever possible, the amounts received were limited and Tina urgently required the social grant money to care for Siphos.

When their uncle didn't want to give me the death certificate [of Siphos mother] her sisters did a copy of it to give to me. I said no, I will go to jail, [Department of Social Development] need the original one. I didn't get the death certificate, I went to [Department of Social Development] and explained to them that the child was previously earning social grant, but for the last year he hasn't earned it and that his uncle refused to give me the death certificate. [Department of Social Development] told me to go and fetch [Siphos] father to go and get an affidavit to say that the child is his. The child earns the social grant now because I did just that.

Tina Ntuli

If documents were missing, an affidavit could serve as a replacement for the missing documents. An affidavit could be obtained from a court or tribal authority. Eventually Dumisani accompanied Tina to the Department of Social Development offices where he verified the death of Siphos mother.

In the Nkosi household, Thobelas mother, who cared for one of Thobelas sons, did not apply for a child support grant for the child. Thobela explained why this was the case.

He [her son] was staying with his grandmother and she was afraid to register him [for the CSG] because she said her grant [old age pension] would be cut off.

Thobela Nkosi, wife of household head, 36 years

The grandmother thought that she was not entitled to have more than one social grant. By applying for a child support grant she thought she would lose her old age pension. The child also did not have a birth certificate as it had been destroyed in a fire. In order to apply for the social grant, a duplicate birth certificate was needed.

The respondents also felt that there was inefficiency and needless bureaucracy from employees of the Department of Social Development and SASSA.

You hear that [the form] is not read by anyone at [Department of Social Development]. Sometimes people just leave them on the table. It is better if you can take the form to them yourself. Even then sometimes when you go and check to see if your social grant is there, they say it has not arrived yet.....maybe it is still on the table.

Thobela Nkosi

Many of the respondents also alluded to their experiences of criminal activity and corruption both within and outside the social security system. Sifiso Dlamini spoke about how unscrupulous people obtained other peoples social grants illegally. Tina Ntuli's immediate response on not obtaining her social grant was to assume that it had been stolen.

This month I didn't get my social grant...I think it may be because those criminals who are stealing government money took it. Other people have said it is because I didn't renew the foster care grant.

Tina Ntuli

When I presented the preliminary results of this study to the Community Advisory Board at the Africa Centre at the conclusion of my fieldwork, a ten-minute discussion about fraud and corruption of the grant system ensued. There is quite a lot of anecdotal evidence for fraud within the Department of Social Development and at the time of fieldwork there was quite a lot in the media about corrupt staff and members of the public claiming social grants fraudulently (Ensor, 2008; Govender, 2008).

The difficulties that households encountered in accessing social grants had substantial implications for the health and wellbeing of sick household members but also for the general socio-economic status of the household. Difficulties that people experience with this system are complex.

9.4.5 Disability grants

At the time of the first household visits, two households had members receiving a disability grant. In addition, one household member had received a disability grant that was withdrawn and another accessed a disability grant towards the end of the study period. It was, therefore, possible to observe the effects of receiving a disability grant at different points for both individuals and their households. It also proved possible to explore the relationship between receiving a disability grant and being on ART. This was possible because all but one of the household members who had a disability grant was also on ART at the same time.

The focus of much of the social policy literature and debate concentrates on the potential for a PLHIV to lose their disability grant as their health improves on ART (see section 8.3). In addition, there is the premise that it would act as a disincentive to their adherence to medication. Such arguments assume that those eligible actually receive the disability grant in the first place. In contrast, little available evidence exists about the relationship between a disability grant and the outcomes on ART. There are positive relationships reported between the socio-economic status of a household and the clinical outcomes during the first year of ART. These findings would suggest that access to the social grant should correlate with successful ART outcomes (Cunningham *et al.*, 2005; Rapiti *et al.*, 2000). As a foundation for the discussion that follows, I initially describe the disability grant application process and the potential barriers and difficulties those applying face.

9.4.5.1 Application process for the disability grant

The disability grant application is a complex and multistage process and varies somewhat across provinces in South Africa. In the study area, at the time of fieldwork, to begin the process of accessing a disability grant, a PLHIV had to collect application forms from the Department of Social Development offices in town (Mtubatuba). The forms were then taken to a doctor employed by the Department of Health whom they consulted at no charge in either a provincial clinic or hospital. A private doctor could complete the forms for a fee. The form to be completed by the doctor required detailed information about the patient, their medical condition and a medical assessment of their level of disability. The completed disability grant form was then submitted at the Department of Social Development offices. A compulsory appointment for the applicant to be re-assessed by the local district surgeon (another state employed medical practitioner) was arranged. The final decision about whether to award the disability grant was made by the district surgeon. The ill person was able to appoint someone to access the social grant on their behalf, but to arrange this required another visit to the Department of Social Development offices and they still needed to attend both medical assessments.

9.4.5.2 Inability to get a disability grant

In addition to the difficulties encountered by those applying for other social grants there were some further barriers and difficulties encountered in applying for the disability grant. Three of the households in this study had members who struggled at some stage to access a disability grant. Thobela Nkosi and Zinhle Bhengu had begun the application process and been informed that they should qualify for the disability grant. At the beginning of the study, both women were

bedridden and very reliant on the care from other household members, Thobela was unable to walk at all and Zinhle walked with great difficulty.

A clinic doctor had previously medically assessed Zinhle. Her completed disability grant application forms had been registered at the Department of Social Development offices. Officials however had informed her that she would only receive the grant when she had been medically assessed by the district surgeon.

Interviewer: Why have you not taken [Zinhle] to the [Department of Social Development] doctor [in Mtubatuba]?

Nomsa Bhengu: I haven't been able to take her because I don't have any money left. I have to hire a car [to get Zinhle to Mtubatuba].

Nomsa recounted in another interview the difficulty she experienced in getting Zinhle to town to fulfil the final step in the grant application process. Zinhle's weakness and difficulty walking made their usual mode of transport, either a minibus taxi or a bus caught on the main road very difficult to access by walking. Thobela has similar experiences, even though she was able to get the use of a wheel chair that helped her access the road the taxi drivers were not happy to transport her with the wheelchair because of its bulk and the amount of space it took up.

Zinhle and Thobela's physical disability prevented these PLHIV from accessing transport therefore obstructing the completion of the grant application process. The availability of appropriate transport affected their access to social security, health care and treatment services, despite the willingness of their households to assist. The financial limitations of households highlighted in Nomsa's quote also contributed to the difficulty to access services. It was just too costly to utilise alternative, more expensive transport options to get to services.

Nothing has changed since we got the [child support grants] grants. You can see these children still have to go to school. How am I going to buy school clothes and food for them?

Nomsa Bhengu

Due to Zinhle's illness and inability to obtain a disability grant, much of the household's limited income was spent on transporting Zinhle to health facilities and on food for the households' members. Zinhle was on Tuberculosis (TB) treatment and needed extra food for her increased

appetite because of the medication. The social grants the household were accessing were insufficient relative to the needs.

As I have explained we are hungry. Last month I had to borrow R200 (£18) because I didn't even have any maize meal left.

Nomsa Bhengu

At one point Zinhle needed to visit the clinic daily to receive her TB treatment at a daily transport cost of R14 (£1). This difficult situation continued for three weeks until she was allocated a home care nurse by the Africa Centre ART programme who visited daily to administer the treatment. Having home-based care reduced transport costs and meant that Zinhle was spared the trauma of daily travel to the clinic. It did mean a concomitant increase in gas costs because the drugs required refrigeration and, therefore, the family needed to keep their fridge operational.

Within a month of our first meeting with the household, Zinhle was started on ART at the nearest clinic. Despite being on ART, her condition deteriorated and within a month she was admitted to Hlabisa hospital. Her mother spoke about the family's concern for her health.

There is a girl at Empangeni [distant family member] I asked her to phone [the hospital] because I don't have money to call, then she called me back?...Yesterday when she called me she said that the situation [with Zinhle in the hospital] is bad. She [Zinhle] is not getting better. She is not even eating now...She is not drinking or eating anything.

Nomsa Bhengu

The fact that Zinhle was unable to obtain a disability grant was detrimental to her health, despite having completed a course of TB therapy and going on ART. The reason for this treatment failure is complex, it could partially be ascribed to Zinhle's generally poor standard of health and hygiene and the fact that she started ART once she was already severely ill. The Bhengu household battled to fulfil her basic needs because of its size and meeting the rest of the household's needs.

Within a few weeks of this last interview Zinhle died of complications from AIDS at Hlabisa hospital. After Zinhle's death no more formal and recorded interviews were conducted because all planned interviews had been completed. We visited the household immediately after hearing that Zinhle had died and a further three times leading up to the funeral. The impact of Zinhle's

death on her household was devastating. The household struggled to manage with Zinhle's death and the care of the two children she left behind. Below is an extract from my fieldnotes from after the household had gone into mourning following her death.

The biggest problem that the household currently faces is the expense of getting the body back to the homestead. Nomsa has already told us how concerned she was about this when Zinhle was in hospital, so much so that even before Zinhle died they tried to fetch her from the hospital and bring her home to ensure they would not have to pay for this expense.

Unfortunately Zinhle was not where she was supposed to be when they first went to the hospital to bring her home, so that she could die at home, and they couldn't pick her up.

Transporting the body home from Hlabisa will cost about R700 (£62). The longer the family waits for the body the more they have to delay the funeral, which will mean that the number of people who come will be greater, as will the cost.

Field notes

The household was crippled financially after Zinhle's death, due to their limited access to an alternative income. In order to survive, the household relied on both formal loans and loans from friends to meet their essential expenses.

9.4.5.3 Struggling to get a disability grant

Similar difficulties faced the Nkosi household. When I met the Nkosi household, Thobela, was bedridden because of swelling and infections on her lower limbs. Thobela's husband Bheki and Thobela both spoke about her illness.

Bheki Nkosi: As you see I am staying here [at home] now, I can't go anywhere, who can I leave her with? I have to give her everything, even water, everything she wants.

Interviewer: Who cooks for the children and does the washing?

Bheki Nkosi: It's me, there is no-one else.

Thobela Nkosi: Now I'm just like this [sitting on the floor] I can't walk.

Thobela had been on ART for four months when we first met the household. Thobela and Bheki both spoke about the poverty in the household and their feeling of desperation and mentioned the disability grant as a possible solution to their problems.

It's not enough [money] ...to go to the clinic I need money, it's all credits [the money to go to the clinic] if I get a [disability] grant it would be better.

Thobela Nkosi

Thobela's illness and resulting disability complicated her efforts to access a disability grant. Here she talks about two of the effects of her illness.

Being sick is very painful. Its better if you can walk for yourself because you can go [to Department of Social Development] easily and they sign [the form] and put it on the computer, but if someone is doing it for you, you will never know [whether the application has been made properly]. Taxis won't pick me up with the wheelchair.

Thobela Nkosi

Although Thobela knew she could send someone as a representative to the Department of Social Development offices she also highlighted her perceived difficulties with the system. Thobela, like Nomsa Bhengu, also raised the difficulty of transport clearly it was a barrier to accessing needed social services. The mandatory consultation and assessment of the physically disabled potential recipients by both a doctor and the district surgeon led to some of them being unable to access a disability grant.

Thobela experienced another problem. Her first application for the social grant had reportedly been unsuccessful. As a result she had re-applied for the social grant.

The government should have helped me to get a [disability] grant. Even though the disability grant is not enough for us [to survive]. To go to the clinic you need money. The money we have now is all from credit [borrowed], if I could get a social grant, things would be better.

Thobela Nkosi

Approximately four months after meeting the Nkosi family, Thobela had gone to the social grant pay-point to collect her child support grant and her disability grant that she thought would be available at this location. She was devastated when she found it was not available.

Out of concern for the family and their desperate socio-economic situation we approached the social worker at the Africa Centre to see if she could help Thobela to access her social grant. An enquiry at the local Department of Social Development office revealed that Thobela's grant had, according to their records, been available for the past 6 months at the Hlabisa social grant

collection point. This was not Thobela's closest pay-point. It was not clear why Thobela had not been receiving her money whether she was incorrectly informed, whether her money was being fraudulently collected or whether it was just a clerical error. Fortunately, though, when she went to the pay-point at Hlabisa she received her cash transfer and back payment.

The reaction of the household at receiving the disability grant was one of great joy. They telephoned us immediately on discovering this and were very grateful. The benefits for both the household and Thobela's health were clear during subsequent visits and interviews. The socio-economic status of the household improved dramatically and rapidly.

Having more money also affected the rest of the family. Bheki's health improved and he appeared less tired and stressed than in previous meetings with the family. He confirmed that he was under less pressure to provide resources for his family and felt generally better and more rested. The first disability grant payment allowed the family to purchase new school uniforms for the children. Having school uniforms removed the threat of expulsion from school, an action that had been threatened on previous occasions for not having complied with this local school rule.

It was possible to observe a dramatic improvement in Thobela's health that influenced the rest of her household.

It's not like it was before. We are not suffering now. You can see that now I can walk. A person can die, if they are not eating and taking pills [ART]. I will be fine now.

Thobela Nkosi

Thobela attributed the improvement in her health to her being able to afford food that is more nutritious. Thobela resumed tending her garden and had increased capacity to perform domestic chores. Towards the end of the study period, Thobela was walking, albeit slowly and with some pain. Spinach was growing in her garden. Furthermore, the homestead appeared both cleaner and tidier.

9.4.5.4 Disability grant and ART

A positive relationship appears to exist between access to disability grants and health outcomes of ART in PLHIV. This relationship was confirmed by comparing the experiences of different households.

In the Bhengu household, Zinhle did not have a disability grant. Both Thobela Nkosi and Gugu Dlamini were receiving ART when we first met them. Crucially, they were also both receiving the disability grant. Thobela accessed her disability grant about six months after commencing therapy. The improved socio-economic status of the household seemed to trigger important improvements in both her health and the situation of the other household members. Access to the disability grant seemed to contribute to Thobela making a relatively quick recovery, which she herself attributed to being able to feed both herself and her family.

Gugu Dlamini experienced a similar improvement in her physical condition after commencing ART, she was still receiving the disability grant when I met her.

When I started taking treatment I went to register for my disability grant. Everything went quickly and I got it in November [one month after starting ART]. I have seen a big difference. I can see that my body is much better.

Gugu Dlamini, sick daughter of Household Head, 33 years

Gugu was the key decision-maker within her household, deciding how both her disability grant and her mother's old age pension were spent. She controlled the purchase of food for the whole household and was responsible for the informal family business that had ceased to operate due to her illness.

Thembilihle Dube was another example of a household member whose health improved on the combined receipt of ART and the disability grant. Like Zinhle, Thobela and Gugu she had been very ill when she commenced with ART but had accessed a disability grant at about the same time. However, Thembilihle's disability grant had already been discontinued when we met her. Despite this she appeared to be coping well. She had requested the doctor at the clinic to continue the disability grant but he had informed her that her health had clearly improved and her CD4 count had normalised. She now had a formal job working full time at a grocery shop in town. She continued taking her medication and had negotiated working hours with her employer enabling her to attend the clinic or hospital without jeopardising her work.

Thembilihle, like Gugu, was the key decision-maker in her household. She contributed her income from her job to the household, which was combined with the pension from her mother-in-law. An extra income came from her mother-in-law who bought and sold beer locally. This income was used to support Thembilihle's child, her sister-in-law and her two adult children, who were unable to contribute financially to the household. Thembilihle also planted and tended the household garden and fruit trees that provided the household with seasonal produce. She

was also a member in a *stokvel* along with other women in the community. The *stokvel* was not merely a saving scheme but the money pooled was lent to others and the interest generated added to the income.

These examples suggest a positive relationship between improved health, social and economic reintegration into the household by recipients of disability grants. The generally improved health status of household members is dependent on access to ART, and on the ability of the household to provide sufficient care, nutrition and other necessities for those living with HIV.

In poor households, receipt of a disability grant is particularly important at the same time as commencing ART. If all PLHIVs in poor households received a disability grant when they commenced ART it would prevent any need to divert other social grants from other members of a household affected by HIV and AIDS

9.4.5.5 Loss of the disability grant

Limited data are available from my interviews about the possible disincentive that a social grant has on the need for PLHIVs to commence ART. This effect features prominently in the literature and in the everyday discourse of health and social development workers.

In this study respondents seldom spontaneously initiated reports of their concerns about the loss of a disability grant. It was only when asked that they mentioned these concerns. My impression was that PLHIV receiving a disability grant and ART were much more concerned about maintaining their own health and the personal positive associations that health improvements implied for themselves and their households than losing the actual income from a disability grant.

Members of households in this study would not have jeopardised their own health in favour of receiving a disability grant. All of the examples where sick people's health dramatically improved made concerted efforts to re-engage with work and informal livelihood activities. Thembilihle acquired new formal employment at a shop in town. Gugu took up an appointment at a local crèche. Gugu was also able to restart the informal trading business and Thobela recommenced work in her garden and reclaimed responsibility for domestic activities. If we had had enough time to see Thobela's health to improve, I suspect that she would once again have returned to the informal entrepreneurial activity that she had been doing in Mtubatuba prior to falling ill. She was already more able to help in the household and was starting to work in the garden thereby freeing Bheki's time up so that he was able to go in search of work.

Gugu did articulate her fear of losing the disability grant.

They told us that we could lose the [disability] grant. I don't know how I feel about that. That is [threat of losing the social grant] why I want to register this child [her sick son for a care dependency Grant], because when [my disability grant] gets cut off I will need help.....I went to look for a job before but I had a problem because this [young sick son] was not staying with me and he didn't take his treatment well. I am afraid to leave him again [to look for work] because maybe he won't take it again and will get sick.

Gugu Dlamini

Gugu was particularly concerned about losing the disability grant because she was caring for her sick child, and would probably have to leave home to seek employment if she lost her disability grant.

In fact, when we visited Gugu again to check on her household almost six months after the study, she had found work at a local crèche. Unfortunately, we could not speak to Gugu herself at this visit as she was working and it was unclear whether or not she was still receiving the disability grant. We did ascertain that both Gugu and her young sick son Simphiwe had improved their health on ART.

9.5 Discussion

The significant contribution that social grants made to the livelihoods of study households is described in this chapter. Every household in the study accessed at least one social grant and these contributed a substantial proportion of the income in the poor rural households in the study.

Three key themes have emerged that inform the overall suitability of the current South African social grants system. The first is the part social grants play as a financial safety net in households affected by HIV and AIDS. The second relates to the barriers and difficulties that household members faced when trying to access grants, specifically with the disability grant. The third theme is the synergistic relationship between receipt of ART treatment and of the disability grant in PLHIV.

9.5.1 Social grants as safety nets

Receipt of social grants acts as a safety net for poor households during times of stress or crisis associated with illness and death. It was shown to have positive economic benefits for the household generally but specifically for household members living with illness. These findings are consistent with those of Booysen and van den Berg (2005) who found that social grants, but specifically the old age pension, contributed to reducing the depth and severity of poverty in households affected by HIV and AIDS. My results have demonstrated the importance of access to all forms of social grants to the household.

Households with a diverse livelihood, including formal employment and a range of informal work or income-generating activities, were able to make use of social grant income to further diversify and consolidate their livelihoods. Those with access to a multiplicity of income sources faced fewer restrictions on spending for the most essential needs in their households. Households with diverse livelihoods were therefore better able to respond to with the effects of stresses and shocks associated with AIDS. In this study, households that experienced a death and had a diverse livelihood that included a regular income from an old age pension were able to secure credit in order to respond to the short-term financial demands of the death. The household was able to repay their debts and to continue caring appropriately for the most vulnerable and high-risk household members. Simultaneously, provision was made for the basic needs of the household as a whole.

Affected households experiencing need made use of social grants paid to other households. Affected households drew on relationships within their kin network to claim assistance from others who receive social grants. This enabled affected households to mitigate the effects of AIDS. Therefore, receipt of social grants outside of households linked to the affected household through family obligations or norms of generalised reciprocity had potential benefits for the affected household. This is described fully in the chapter on social capital.

Receipt of social grants also facilitated a change in, diversification or displacement of livelihood activities. Elderly household members receiving a pension were able to choose not to work any longer and retire from economic activity. Social grant income allowed households to invest in informal income-generating businesses or to maintain an already established informal business. Another example of how social grant money was spent was the purchase of raw materials for a garden. Investments in informal economic activities diversified the potential sources of income for the household and the livelihood activities. The ability to diversify the livelihood is shown in Chapter 6 to be an important way for affected households to respond to stresses and crises.

Receipt of social grants meant that certain individuals within the household were able to operate independently and were no longer reliant on other household members. In addition, to enabling retirement for pensioners, social grant income also enabled individuals to change or limit their participation in livelihood activities, instead undertaking necessary domestic activities and responsibilities, including care for the sick or children. Such changes in activity patterns were reported particularly with receipt of an old age pension but the results suggest that access to income from social grants may provide households with the economic resources to undertake these domestic activities.

The results demonstrate the significant benefit of the larger social grants, such as the old age pension and the disability grant, for affected households. Other research in South Africa also suggests that the larger social grants have a greater positive impact than the child support grant on households affected by illness and death (Booyesen *et al.*, 2005). Social grants not only facilitated diversification of the livelihood, but also enabled the household to cope with the economic and livelihood repercussions of illness and death such as the loss of an income or remittances because of illness of a member. Social grants also helped to ease the financial burden incurred by caring for a sick household member.

The preceding chapters have shown that certain households are particularly vulnerable to the impacts of AIDS and possibly of being socially excluded. The households where PLHIV experienced difficulty accessing disability grant were particularly vulnerable to the effects of illness. Limited or no access to other sources of income or material resources in these vulnerable or isolated households meant that household members seldom had any choice but to pool their social grant for communal use. Pooled income was used to satisfy the most pressing basic household needs. In this study the priority was consistently identified to be food for sick members. This pattern is consistent with findings from the Free State cohort study where the proportion of social grants spent on food was higher than any other household need (Booyesen *et al.*, 2005).

In those vulnerable households where the value of the social grants combined was small and access to other income was limited, the pooled use of the social grant often resulted in it being diverted from the intended recipient. The diversion and distortion of social grants resulting from frequent illness or death could have negative implications for the intended recipients. For example, households were at risk of having to withdraw children from school, for not having school uniforms or school fees, despite having receipt of a child support grant. Diversion of grants would also have affected access to food and adequate nutrition for grant recipients in the interests of meeting the needs of the whole household. Respondents sometimes reported missing

meals in households with pooled income. However, the relationship between pooling and negative outcomes is difficult to quantify.

High unemployment locally and limited opportunities for generating income increased the reliance of poor households on social grants as a financial safety net. In addition, one consequence of illness in the household or of acquiring responsibilities for caring for the sick or children was to limit livelihood capabilities and therefore economic activity, and increase reliance on social grants. As a result of decreased access to capital, reduced opportunities for employment and the burden of the direct or indirect expenses associated with adult HIV and AIDS related illness also forced households to rely on grant income. These are important findings because the existing research in South Africa, while suggesting the importance of social grants for illness-related expenses and as a general safety net, do not explore the implications of the receipt of a social grant for the livelihood of affected households (Goudge *et al.*, 2009a).

Social grants have been shown to have positive developmental outcomes for households in South Africa (Ardington *et al.*, 1995). Evidence from other research also suggests that social grants, specifically the old age pension, have redistributive benefits. Grant income shared with other household members, was found to result in reduced adult migration from poor households, improved child welfare and improved anthropometry outcomes (Ardington *et al.*, 2007; Case *et al.*, 1998; Duflo, 2003; Lund, 2002a; Posel *et al.*, 2006). The evidence here suggests that these wider beneficial impacts of the social grants observed in other studies such as Case *et al.* (2005a) may not apply in very vulnerable households with limited income sources. Respondents expressed concern about their ability to cover important household expenses such as school fees, transport to school and investment in other livelihood activities. Limiting this expenditure may ultimately have detrimental effects for the household members, such as for children, who would have benefited from access to these activities and services.

Dependence or reliance on social grants has been a topic of some heated debate in the literature. Some suggest that receipt of a disability grant may discourage reintegration of ill household members into the labour market (Booyesen *et al.*, 2005). In this study, some household members changed their economic activity in the household because of having a social grant. Those who changed activity were elderly household members who discontinued informal jobs because of having a pension. No other household members reported or were observed ceasing to seek employment or to leave a paying job because they were receiving a social grant. Rather, employment changes happened because of illness or the loss of formal employment. Household

members, especially those who had been sick, sought employment when their health improved because of ART, regardless of receiving a disability grant.

9.5.2 Barriers to social grant receipt

The second key theme arising from this study was the difficulty and barriers applicants encountered in accessing social grants and specifically the disability grant. The individuals who experienced the most difficulty accessing disability grants were from the most vulnerable, poor and marginalised households in the study. The common characteristics identified in these households included very limited access to employment, limited social grant income or potential to access social grant income, and weak social support networks. In combination, these characteristics result in increased poverty, vulnerability and ultimately isolation from social protection.

Households and individuals in my study experienced and spoke about a range of barriers or difficulties accessing social grants. People were misinformed about eligibility requirements and were particularly concerned about risking the loss of their existing social grants or those of other household members if they tried to access more than one social grant. Missing documentation and problems accessing correct documentation constituted another key barrier to social grant access for the families of deceased parents trying to access a foster care grant. The problem of missing documentation confirms the findings of another ethnographic investigation into foster care and care dependency grants access in the Umkhanyakude district (Moitse *et al.*, 2003; Zungu *et al.*, 2003). The respondents also raised concerns about fraud and corruption in the social grant system. The problem of fraud was believed to occur amongst applicants, within the Department of Social Development itself, and amongst SASSA staff. These difficulties confronting those applying for social grants appear to be common for all the social grants.

The process of accessing a disability grant is more complex than obtaining other social grants. The application involves many steps including repeat visits to health and social services. In poor households with more basic needs, money cannot be prioritised for accessing a grant. The findings therefore suggest that there was limited extra money available in order to pay for the expenses related to applying for a grant. Not having money restricted access to transport to SASSA offices, the clinic or the district surgeon. Households had particular problems with paying for transport. In addition, transport operators made it difficult for sick people to travel. The reality is that poor households require additional resources in order to access social grants. Sickness itself also made travel to the required facilities very difficult. The physical disability associated with advanced HIV and AIDS meant that these PLHIV had limited mobility and

sometimes needed another person to attend appointments with them or in their place. Sickness itself, as a barrier to social grant access, has not been identified elsewhere in the literature and, although it seems an obvious issue, does not seem to have been considered sufficiently by service providers.

These hindrances affected key steps in the application process, making it a challenge to complete all the necessary stages of the application process. Households often experienced a combination of these barriers including the additional difficulties to those encountered when accessing other social grants. For those who found these difficulties insurmountable and as a result were unable to access a disability grant, the repercussions could be very severe. Households in which a sick person struggled to access a disability grant and that lacked other household members in formal or informal employment or access to the social grants such as old age pensions, were particularly vulnerable to increased impoverishment. Therefore, the difficulties households face in accessing grants may further contribute to household poverty. And may lead to a recurring cycle of poverty and illness.

9.5.3 ART and the disability grant: a synergistic relationship

In the households where sick members were able to access a disability grant or where the socio-economic situation of the household was enabling, household respondents reported proper feeding and care of the sick person. Household members on ART and adequately meeting basic needs, spoke about and were observed making considerable progress toward good health. The observed relationship between treatment and socio-economic status and, specifically, access to the disability grant, was very important to the successful future return to health of sick household members.

The bio-medical literature suggests that there is an association between health and poverty or socio-economic status of the household (Adato *et al.*, 2007; Cunningham *et al.*, 2005; Rapiti *et al.*, 2000; Zachariah *et al.*, 2006). This study demonstrates that social grant income in very poor households, with limited access to additional or alternative income or sustainable livelihood activities, is used to meet the basic needs of household. In most instances this is food, first for the PLHIV and then for the other household members. The health care needs of ill household members are another priority need addressed by having social grants. The relationship between health and poverty probably develops because PLHIV require a quality nutritious diet. The relationship may also be evident because of the stress or pressure placed on the sick household member who is often not able to contribute financially to the household.

A comparison of households with PLHIV who received the disability grant and ART, and households where the sick member was on ART, but not receiving a disability grant or any other major income sources suggests that there is a synergistic relationship between early receipt of a disability grant or equivalent financial assistance and better observed and reported health and social outcomes on ART. Even where the sick household members were receiving ART, poverty within their households frequently led to inadequate nutrition. Reduced food intake and nutrition may be a reason for their slow recovery despite being on ART. This relationship between ART and the disability grant has important implications for the health and socio-economic reintegration of the sick household member and therefore for the livelihood of their household.

The relationship between ART and socio-economic status has implications for the future employment or economic activity of the sick person. In all of the households where household members received the disability grant and ART, the return to health meant that the individuals were able to make substantial contributions to their livelihoods. Previously sick household members were able to reintegrate and contribute to the livelihood through either formal or informal employment. They were also able to make investments of time and labour into diversifying the livelihood of their households. Additionally, the treated household members were able to fulfil their domestic responsibilities and household chores, relieving other household members to undertake other domestic and income generating activities.

Evidence from the literature suggests that the first six months or year of being on ART is the most important period to determine whether treatment is going to be successful and, the risk of both mortality and morbidity decreases (Bussmann *et al.*, 2008; Etard *et al.*, 2006; Lawn *et al.*, 2005b). Therefore, the greatest concern around the relationship between ART and the disability grant should be that those receiving treatment obtain access to the social grant as early as possible in their treatment regime. Such an observation is especially of importance given the health and emotional consequences associated with inadequate diet in the outcomes of treatment.

One of the primary concerns in the relationship between access to the benefit of receiving a disability grant and access to ART is the categorisation of the stage of illness that qualifies for the commencement of ART. Despite changes to the ART guidelines for those who are very vulnerable, the qualifying criteria have not changed for the average sick adult in South Africa (Department of Health, 2010). The criteria still require people to have a relatively low CD4 count or very advanced disease.

These guidelines, coupled with relatively late presentation of PLHIV for treatment and testing observed within South Africa, contribute to the relatively late commencement of ART for those who are ill. By this late stage, health has often deteriorated to such a degree that very few of those who start treatment are still employed or able to earn money by any means. For those commencing ART late the potential positive effect of the disability grant is increased in that it may be able to keep the household economically viable until the person is healthy enough to seek formal or informal economic activities. The link between the first year of treatment and household or individual socioeconomic status is crucial to the debate about access to the disability grant. The positive relationship between ART and the disability grant is ignored in much of the current literature, both that focused on social policy and that dealing with the clinical outcomes of ART.

Rather, the debate within the literature focuses on the implications of the threat of the loss of the disability grant for adherence to treatment, making an implicit assumption that those who are eligible are receiving the disability grant (Hardy *et al.*, 2006; Nattrass, 2005; Simchowitz, 2004). The difficulties faced by those applying for the disability grant within this study and other empirical research in South Africa, do not suggest that this is the case. Therefore, in order to make good policy decisions, a better understanding is needed of what impact the barriers to receipt of the disability grant have on the health of the individual and the consequent social and economic implications this has for their households.

The debate within the literature goes on to suggest that the similar eligibility criteria for receiving a disability grant and ART may represent a disincentive to the proper use of ART. It is argued that the disincentive may impair full recovery and may result in encouragement to default from treatment, in order to retain access to the disability grant (Hardy *et al.*, 2006; Nattrass, 2005). The results of this study did not suggest this. Rather, sick household member expressed concerns about losing the disability grant because of the implications for their households. When questioned, none of the household members on treatment and receiving a disability grant expressed particular worries about the loss of the disability grant for themselves. Their focus, rather, was their renewed health, which some of them attributed to the disability grant. The household members who recovered their health actively sought work, reintegrated into the formal or informal labour market and participated in their household's livelihood. The evidence of healthy participation in household and livelihood activities suggests an appreciation for the value of money earned from work.

9.6 Summary

Social grants provide affected households with an important safety net. They help households to respond to the effects of both illness and death. Social grants helped households provide for the basic needs of the household, pay for illness or death associated costs and in some cases allowed household members to undertake new roles within the household and livelihood. In addition, receipt of social grants helped some households to diversify their livelihoods and return to or begin involvement in informal economic activities.

While affected households that were able to receive social grants felt many benefits, certain households and members were faced with difficulties and barriers to social grant access. These barriers and their negative repercussions for the household and livelihood were particularly marked for those household members trying to get disability grants. One of the most severe barriers to access for those applying for disability grants was the illness and disability of the applicant that, coupled with the complexity of the application process and existing household poverty, made disability grants very hard to get. When sick household members were able to access a disability grant the outcomes were overwhelmingly positive. Vulnerable households that were not able to access a disability grant struggled to respond to the impacts of HIV and AIDS, thereby falling further into poverty. The barriers to accessing the social security system therefore put some of the households or individuals who need it most at risk and undermine many of the potential benefits of the social security system.

The results suggest that there is a synergistic relationship between ART and receipt of a disability grant. It is possible that this relationship is linked to the importance of nutrition for those on treatment. The findings suggest that this relationship is very important and also that the often assumed disincentive effect between ART and the disability grant discussed at length within the literature does not often exist in reality within affected households.

Chapter 10: Conclusions and recommendations



10.1 Introduction

This chapter summarises the main findings of this research. It starts by recapping the contextual issues that have been shown by this research to have particular relevance for the primary conclusions of the thesis. The primary conclusions are explored in relation to the primary aims of the thesis, as is their contribution to the South African livelihoods and HIV literature. The theoretical and methodological contributions made by the research are then examined. The conclusions have potential policy implications and lead to some recommendations.

10.2 South African issues of primary contextual importance

Three common contextual themes that influence the vulnerability of households within the study district run through this research. The first is the very high prevalence of HIV within South Africa in general and particularly in the district under study. Very large numbers of people in the district are living with illness and the mortality rate has increased dramatically (Hosegood *et al.*, 2004). The effects of the high prevalence of illness and death caused by HIV and AIDS are therefore widespread. In this study, it was difficult to distinguish between directly and indirectly affected households. Given the high prevalence of HIV, improved roll out of and access to ART and other related HIV-treatment services are shown by this research to have the potential to

change the experience of illness in affected households for the better, because of improvements in health.

The second contextual theme is the distinctive composition and structure of rural black households in South Africa. The combination of history, politics, industrialisation, tradition and socio-economic changes have produced households, like those observed in this research, that are identified within the literature as complex, multi-generational and fluid with both resident and non-resident memberships (Hosegood *et al.*, 2006; Wittenberg *et al.*, 2007). The fluid nature of the household and the importance of non-resident household members, have repercussions for the livelihoods of rural households affected by illness and death, as a potential burden or source of support, as shown in Chapter 4.

The livelihood is the third contextual theme. The livelihoods of black South African households, like the composition and structure of households, have been shown through an analysis of the literature to develop in a distinctive way from those elsewhere in Africa. Socially fluid households together with very high rates of circular migration of individual household members have caused the dispersal of household members who individually contribute to and make up the collective livelihood of the rural household. The dispersal through migration of individual household members means that the household is not involved in one joint rural livelihood activity as suggested in the original livelihoods framework, but rather is made up of individuals participating in a range of activities in various contexts. Formal employment in the labour market, although important if accessed, is hard for households to obtain and, because of this, is not a part of the livelihood of many of the rural households in the study. In comparison, informal work was important for all study households and made a large contribution to the household income. The lack of formal work in the surrounding area contributes to high circular migration as rural household members migrate to places in search of work. A history of relatively good access to social grants, the introduction of some new grants and changes to eligibility criteria since the end of Apartheid have meant that social grant income has been shown in this and other research to have become another important source of income for poor rural households.

The results of this study show that these three contextual factors are extremely important in affecting the pre-existing vulnerability of affected households. The following section summarises what this study has found about how households vary in their ability to respond to and mitigate the impacts of illness and death.

10.3 Summary of main findings

In the distinctive South African context described in the previous section, this study has sought to explore the social and economic implications that illness and death from AIDS have for rural households. The study has drawn on in-depth case studies representing a range of different stages of illness and a variety of household situations and allow for the analysis of the way in which these different stages of illness and death, including access to ART affect the experiences of households.

10.3.1 Diverse, dispersed and dependent livelihoods

The ability of households to respond to the impacts of illness and death was conditioned by the pre-existing vulnerability of their livelihood. Households with a diverse portfolio of livelihood activities were much better able to respond to the impacts of illness and death than those with limited livelihood diversity. The diversity of the livelihood was affected by a number of important factors. There was limited availability of formal employment, which meant that despite availability of labour households were unable to benefit from the potentially positive benefits that access to formal employment would have afforded to the household. In addition to the shortage of paid work, many of those that were fortunate enough to be employed in affected households were forced to forfeit this employment as a result of their own illness or caring responsibilities. These implications of AIDS illness on employment are shown to be a reality in other South African studies (Oni *et al.*, 2002).

The scarcity of formal employment meant that households' involvement in informal economic activities such as craft, trading of produced and purchased goods, small-scale farming, informal labour or subsistence gardening were comparatively much more important for affected households. This findings supports arguments by Bachmann and Booysen (2003) that suggest that high unemployment meant that loss of formal employment was not as significant as suggested by some researchers. Informal work and activities were very important for the livelihoods of affected households. Like formal employment, informal activities were also affected by the repercussions of illness and death, such as a reduction in the availability of labour due to illness or increased costs that limit capital for investment in these activities.

Affected households within the study were characterised by the extreme fluidity of their household membership, this was observed within the study and examples of it are also provided by the analysis of DSS data from the local community (Hosegood *et al.*, 2006; Welaga *et al.*, 2009). This fluidity of the household membership resulted in the fluidity and dispersal of the

individual household members and their livelihood activities that contributed to the household's livelihood. The dispersal of the livelihood and its implications for the livelihoods framework will be further explored in Section 10.4.

The results of the holistic analyses of the impact of illness or death on the household case studies show that affected households enrolled in this study were dependent on the receipt of social grants and support from members of the household and members of the kin network and community. In order to build on the results of the analysis of the household case studies, the importance of social support and social grants were further explored.

10.3.2 Social relationships: reliance on the household, family and community

The fluidity and dispersal of the household, along with a number of other observed changes in its formation because of social, economic and political influences, affect the ability of the household to respond to the impacts of AIDS. The findings show though that, as argued within a review by Nkosi and Daniels (2007) of the strength of the South African family, the household and family are remarkably resilient. Members of the household are motivated through a sense of obligation to family, affective ties and norms of generalised reciprocity to provide material support, financial assistance and physical care to both resident and non-resident members affected by illness. Similar examples of support by family in South Africa are provided by Cross (2001), Bond (2009) and Bahre (2007) but these studies do not differentiate by household membership or the motivating factors for providing this support. Non-resident household members in this research provide financial assistance and material support both in times of crisis for the household and individual members dealing with illness and death. Support is also provided at other times as an investment in norms of generalised reciprocity in order to secure support from the rural household in the future.

In addition to the support secured from other members of the household, this study shows that members of their kinship network outside of the household are very important for providing support to the household and the individual members. Family obligation, influenced by kinship bonds and affective ties, and norms of generalised reciprocity are also demonstrated by these findings to operate within these wider networks and ensure that affected households and individuals are supported by kin and therefore able to respond to the impact of illness and death.

Affected households were also able to draw on social capital invested in their communities or from formal and informal groups. Assistance and support from within these social networks, unlike family and kin networks, was dependent on the development of high levels of trust and

ties of friendship that helped to bind people together. Both balanced and generalised reciprocity was very important within these networks along with charity. Membership of more formal groups such as stokvels were also dependent on people's ability to contribute and this may have limited participation therein.

Despite important examples of the benefits associated with membership of social networks within the household, family and community, not all households in the study have social capital they could draw on in this way. These households were often particularly vulnerable. Due to their precarious situation and inability to respond to pre-existing poverty along with the repercussions of illness and or death the household members found it hard to participate in the reciprocal relationships required to foster social capital, and therefore trust. They were therefore socially excluded from the support they would have been able to rely on in other circumstances from these social networks. The particularly vulnerable and socially excluded households were very reliant on charity but also on government provided social welfare support.

10.3.3 Social grants

The members of affected households were also reliant on the financial assistance provided by social grants for the maintenance of the household's livelihood. The substantial financial contribution that social grants make to the income of affected households observed in this study has also been found in other South African studies conducted by Goudge et al(2009b) and Case et al.(2005a). It is shown here that these cash transfers support the incomes and livelihoods of affected households in much the same way as an income from a wage or informal activity would.

Support from the disability and foster care grants, particularly, are demonstrated by this study to assist the household financially at times of extreme illness and death. Receipt of a social grant, especially the disability grant, had positive implications for the economic situation of affected households in this study. Social grant income was a potential source of support for the small-scale informal income-generating activities and livelihoods of the affected households in the study.

The results of the study point particularly to the importance of the disability grant for households and individuals affected by severe illness. The current system of disability grants was designed before the severe repercussions of the HIV and AIDS pandemic were felt in South Africa and the system is therefore not designed to respond to these impacts. Affected households, especially those with members who were sick and applying for disability grants,

faced barriers in their application for grants, with negative repercussions for their households. However, those who were able to receive social grants benefitted from the extra income these contributed to the household and such grants had a number of positive consequences for affected households and their livelihoods. They enabled the household to provide for the needs of the sick person, pay for costs associated with illness or death and use extra income to help to diversify the livelihood in response to the impacts of AIDS.

The role of access to and successful treatment with ART and the implications this has for households and their livelihood have had limited study within the literature, where the focus has been on the physical health of the treated person (Coetzee *et al.*, 2004a; Louwagie *et al.*, 2007; Wouters *et al.*, 2008). My findings reveal the positive consequences of treatment, not just for the sick person themselves, but also for the well-being of their household and its ability to respond to and survive the impact of illness related to AIDS.

The findings of this study demonstrate that successful treatment is closely related to the household's general economic condition. Therefore, the PLHIVs receipt of a disability grant enabled the household to respond to the needs of the sick person, and facilitated a more rapid recovery on treatment. The receipt of the disability grant also enabled the other household members to adapt their livelihood in order to respond to the negative impacts of illness.

10.4 Theoretical contribution

The livelihoods framework has already been shown by Seeley (2002) to be a useful conceptual framework for the analysis of the impacts of AIDS. The importance of the addition of the vulnerability context of the household for the livelihood is highlighted by the findings of this study. It shows that this sort of research cannot be conducted in isolation from the household's context. The underlying vulnerability of the household is therefore very important and can be affected by things such as the diversity of activities in which the members of the household are involved. In this study the vulnerability context was affected by both illness and death but also other exogenous and endogenous factors such as access to social grants, the individuals' access to employment and the impact of South Africa's political and economic history on the composition of the household.

In addition to the consideration of the vulnerability context, which may differ from place to place, it is important that the conceptualisation of the livelihood be physically expanded. The community or household-level bias of the original livelihoods framework is a major limitation and I have therefore suggested the adoption of a framework that considers a physically

dispersed livelihood as proposed by Murray (2002). This expansion could be valid in all settings such as South African with similar household fluidity and composition. The framework should consider the role of individual household members as one person's contributions and experiences can dramatically change the livelihood of the entire household, either positively or negatively. In addition, despite the linkages between resident and non-resident individuals in the household, the geographical dispersal of these individuals and their livelihood activities, contributions and needs, is both important and changeable given the fluidity of the household and its composition. This reconceptualisation of the livelihood and the household members as dispersed has important implications for the study both of the impact of illness and death and of households' response to these impacts.

The framework of social capital and its building blocks was also a very useful theoretical basis for the analysis of the support that affected households and individuals were able to secure. The findings suggest that social capital in this context is still a valid and applicable concept at the individual and household-level despite the debates surrounding the theory. The results show that true to the definition of social capital adopted for this study that social capital is the benefits people can claim from the trust engendered through participation in social structures and networks. The theory facilitates the analysis of the different types of social network membership and the accompanying factors that influence individuals' ability to secure assistance, support or care or, in keeping with the framework, the benefits resulting from access to social capital. The results show that different individuals, within the household, get or give varying amounts of support from or to others, depending on their individual characteristics rather than on those of their household. Family obligation and generalised reciprocity dominate household and familial relationships while balanced reciprocity and *richesse oblige* largely determine relationships between community members or neighbours. Like the livelihoods framework, the use of the framework of social capital has highlighted the need not to treat the household as a bounded unit with no internal variation.

The results of this study show the importance of family obligation in the supportive relationships within co-resident families. These findings highlight the resilience of the South African household and the importance of non-resident household members, kinship bonds, affective ties and generalised reciprocity. The reliance on the family extends beyond the household to within wider kin networks to where generalised and balanced reciprocity have been shown by the findings to operate within these social networks. In the same way, obligations to those who are close (although not necessarily family) are shown to operate within the community or among neighbours regardless of reciprocal relationships. The results of this

study also show that despite many being able to secure support as a result of social capital the concept of social exclusion is still valid and it was an important reality for some affected households within the study.

10.5 Methodological contribution

Despite, the limitations inherent in this small-scale research study such as the restrictions imposed by some of the selection criteria and the potential bias towards the perspectives of available and willing respondents that these introduce, I would argue for the value, validity and reliability of the data collected for this study. The in-depth qualitative methodology employed in this research has highlighted the significant benefits of in-depth multi-methodology qualitative research to collect rich prospective ethnographic data about the day-to-day lives and experiences of households facing illness and death. This methodology is replicable in a number of other contexts.

Repeated visits to enrolled households helped to develop high levels of trust and confidence in the respondents allowing for the collection of sensitive personal data about people's lives. Over time, people revealed increasingly detailed information about their lives and I was able to explore, unpack and explain people's changing responses. Contradictions in responses suggest a level of comfort and a move from a public, guarded or socially desirable response possibly motivated by expectations of reimbursement, to a more honest and sincere response. Therefore, unlike cross-sectional survey data, which collects quantitative data at a single point in time, the methodologies employed in this research allowed me to interrogate people's responses, and observe household experiences and how they changed over time.

The methodological issues facing qualitative researchers collecting sensitive data in households dealing with the harsh realities of poverty, vulnerability, illness and death cannot be ignored. I would argue for further consideration of these experiences and their implications for not only the subjects of study but for researchers immersed in and facing the realities of their research subjects' harsh existence. The study shows the value of trust and the need to consider the issue of reimbursement of respondents very carefully, without the provision of support, in-kind advice and assistance in this case, the dire situation respondents were living in could have potentially acted as a barrier to multiple visits and interviews and to in-depth data collection. Therefore, these issues should be planned for before research to prevent barriers to or problems with data collection.

10.6 Recommendations for supporting rural livelihoods

The primary findings and conclusions of the research raise some important areas for possible interventions in order to support poor rural households and individuals affected by illness and death. These recommendations cover a wide range of possible interventions.

10.6.1 Existing household poverty and vulnerability

The high level of unemployment nationally and in the study area has negative socio-economic implications for all the households within the district. These are particularly severe for the households enrolled in the study as for them the impacts of unemployment on the livelihood are compounded by the repercussions of illness, death or caring responsibilities. The limited availability of formal employment in the area contributes to existing poverty and vulnerability. While making a relatively small contribution to the livelihoods of the households enrolled in the study, more widespread access to formal employment, would have had beneficial economic and, indirectly, social repercussions for the household and its livelihood.

In order to reduce the burden of illness on the state in the form of long-term disability grants and to try to reduce unemployment and poverty in affected households, the government could adopt policies to facilitate greater participation in the formal labour market. The South African Departments of Public Works and Labour have adopted an Expanded Public Works Programme (EPWP) the aim of which was the creation of one million jobs over a five-year period (Department of Labour, 2005; Human Sciences Research Council, 2007). It aims to create low-waged self-targeting employment provided through government funded public works (Human Sciences Research Council, 2007). Programmes like this have been used successfully elsewhere. But, while a well functioning and efficiently managed programme could be very beneficial in communities such as the one studied, there are some criticisms of the current programme (Human Sciences Research Council, 2007; Nattrass, 2006). An evaluation suggests that, along with reaching only small numbers of the poor, it is affected by corruption and inefficiency. It has trained fewer people than planned and manages to retain people in employment for short periods only. Therefore it is unfortunately limited in its impact on structural unemployment and on poverty alleviation (Human Sciences Research Council, 2007). It seems that it is the most vulnerable that are least able to reap the benefits and take advantage of these opportunities.

Despite these criticisms, effective public works still have the potential to improve access to employment (Nattrass, 2006). Public works also provide skills, training and have the potential for the reintegration of individuals previously excluded from the labour market and construction

of national assets (Human Sciences Research Council, 2007; McCord, 2005). The EPWP recognises the social service needs of South Africa and that a small proportion of the public works jobs currently provided are in education, social development and health care in the form of early child-care and development services (Human Sciences Research Council, 2007; McCord, 2005). A social service focus could promote primary health and social services required by those affected by AIDS.

10.6.2 Loss of employment for PLHIV

The loss of paid work because of illness has been found to be important in this study. The importance of ensuring the sick are retained in employment is brought sharply into focus by individuals who were once sick and lost their employment, but have since been able to access treatment and become healthy again, but are now unable to get work. The significance of a regular income for those on treatment and previously unwell has been clearly demonstrated in the observed relationship between ART and the disability grant.

Initiatives to help to keep sick people in employment, providing them with purpose and their households with an income, are therefore important. Ensuring those who are sick or receiving ART have time off for adequate access to health care or are accommodated by health services and therefore a greater opportunity for positive treatment outcomes is therefore valuable. This study describes two case studies where non-resident household members employed as domestic workers in private homes were forced out of work by their employers because of their illness and need for time off to obtain medical care. While their jobs were legally protected by the Labour Relations Act (Department of Labour, 1995) and the Basic Conditions of Employment Act (Department of Labour, 1997), neither individual was aware of her rights and, by the time they lost their jobs, both were unable to work.

Greater awareness of the existing legislation for both employers and workers would help to prevent the unnecessary loss of work. Improved awareness of the benefits of treatment by employers, as well as education in order to reduce discrimination and stigma, would enable more workers, particularly domestic workers, to retain their employment.

10.6.3 Informal sector activities supporting or diversifying livelihoods

This study highlights the importance of informal activities as a primary source of income for the livelihoods of affected households. One of the repercussions of illness, death, their related costs and the care responsibilities they may cause is the effect it has on the ability of household

members to do informal work. Informal economic activities, including gardening and small-scale farming, self-employment seasonal or short-term paid work, were all identified as enabling the diversification of the livelihood, as well as enabling the household to respond to economic crises caused by illness or death.

Therefore, interventions that enable the household to continue self-directed informal income-generating or small subsistence activities are important to consider. Although it is difficult to provide households with the labour required to maintain these activities, it is possible to provide financial or material support. One of the most successful examples of support for small-scale informal activities is the Grameen Bank model of affordable micro-finance (Hietalahti *et al.*, 2006). Micro-finance or micro-credit provides low-interest loans to support small-scale livelihood supporting business initiatives.

An intervention along Grameen principles in a rural South African community enables access to relatively small loans that members would struggle to access through other formal sources such as banks. Possible weakness exist such as the exclusion of those who are particularly poor and vulnerable, the risk of some group members free-riding, the threat of becoming trapped in debt and the high costs associated with running such programmes (Hietalahti *et al.*, 2006; Reinke, 1998; van der Ruit, 2002). Nonetheless, reviewers argue that such programmes have made important contributions and improved the pride and self-confidence of members, along with increasing their sense of empowerment and decreasing unemployment. This sort of intervention is valuable in that it removes the need to access credit from local providers charging very large rates of interest. They support the poor by providing increased social and economic security and they facilitate potential economic growth among the moderately poor (van der Ruit, 2002).

Another example along slightly different lines is the start-up fund operating in the Western Cape that provides micro business loans to individuals (Reinke, 1998). The loans are dependent on the attendance at a programme of business skills training, a deposit and the opening of a formal bank account for repayments avoiding the joint responsibility of solidarity group lending and instead using a framework of incentives to encourage borrowers to repay loans.

10.6.4 Strengthening families, households and kinship networks

The findings here show the importance of material support, financial assistance and physical care that households and individuals affected by illness and death secure through their membership of social networks. The household and family have been identified as one of the most important sources and beneficiaries of support from other household members, either

resident or non-resident, therefore suggesting that there is value in maintaining the integrity of the family and the household.

The care of sick household members is largely undertaken by other household and family members but places strain on them. An effective system of home-based care, such as that proposed in the National HIV and AIDS strategic plan, has the potential to support those providing care within the family by providing education, information, treatment support and counselling while supporting the care work that they do (Russel *et al.*, 2000). While some home-based care was available to study households, such support was patchy and programmes were affected by resource limitations, variable support, care, and the skills of the care workers. Existing programmes were both PEPFAR-funded and may now be affected by the reductions in funding as a result of the economic recession.

The importance of family strengthening is highlighted by the Joint Learning Initiative on Children and AIDS (JLICA), especially with regard to the families' ability to care and support children affected by illness and death (Chandan *et al.*, 2009; Wakhweya *et al.*, 2008). While the support and care for children is very important, this study's focus is on the ability of the family as a whole, including resident and non-resident household members and others within the kin network, to support and care generally for other household members, including the sick and children. It is therefore proposed that all interventions considered for affected households place general family support and strengthening as central to their aims. Belsey (2005) in his review of the impacts of AIDS on the family argues for capacity building within the family and policies that support the existing integrity, functioning and system of obligations and support, thereby ensuring the well-being of the family.

10.6.5 The important influence of social grants

Social grants have been shown to be very important for affected household and can be used to provide support as wide-ranging as that provided by indirect employment and income support mechanisms such as public works and micro-finance programs.

Households that fulfilled eligibility requirements experienced a number of barriers and difficulties in attempting to access social grants. Affected households could benefit from a simpler application system and an overhaul of some of the processes involved in accessing social grants to ensure that those who do qualify for social grants are able to access them. Possible changes to the current system include:

- Equipping home-based care workers, clinic staff and other potential sources of advice or support such as church elders or leaders with accurate information about social grants. Providing household members with the correct information about where to apply for documentation and their rights in terms of payment for this information.
- Greater accountability and transparency, a stronger stance against corruption and fraud and a facility for complaints and seeking recourse for problems.
- Limiting multiple appointments at dispersed offices would limit the need for travel and associated difficulties.
- Limit the number of visits that have to be made by the sick person and allow applications to be made on behalf of the sick. Alternatively, mobile teams could be used to assess and process social grant applications in people's homes. Provide compensation for costs associated with social grant applications and travel.

Another way to adapt the current system to address the impacts of illness would be to reduce the number of steps and visits to SASSA and health services involved in accessing a disability grant. A solution would be automatic certification for the disability grant by the Doctor prescribing ART or TB treatment. One of the simplest ways to achieve this goal would be to integrate the point of access for these services.

Another alternative, to go along with the integration of health and social development services, would be the introduction of voluntary counselling and testing (VCT) and ART as preconditions for access to the disability grant. This conditionality would enable the enforcement of adherence to ART and help to ensure successful treatment outcomes.

Based on evidence and research conducted here and elsewhere, the most urgent policy intervention that could be given serious consideration is the creation of a completely new grant targeted at those with chronic illness, especially those with HIV and AIDS as suggested in the National Strategic Plan 2007-2011 (Department of Health, 2007; Richter, 2009). Those with HIV could qualify for the grant at diagnosis, thereby acting as an incentive for early VCT. Early VCT would mean that people are known to the health service and are not presenting late for healthcare and treatment. A chronic disease grant would be specifically targeted towards illness costs and because of its specific design would be easier to control and implement than the disability grant (Silber, 2009). It would remove the threat of loss of the disability grant and any current temptation to stop treatment in favour of access to the disability grant (Booth *et al.*, 2008). It can also be argued that the chronic illness grant would reduce stigma and public

misunderstanding about the way in which people with chronic illness qualify for the current disability grant and highlight the fact that AIDS is an illness and not a disability (Silber, 2009).

10.7 Concluding remarks

This study has provided an in-depth analysis of the way in which households respond to different stages of the HIV and AIDS epidemic at both the individual and household-level within the distinctive South African rural context. This research demonstrates the importance of context in the study of household responses to various stages of AIDS, including illness, treatment and death. While the study is very small-scale, given the significant role played by context and the similarities between Umkhanyakude and other rural communities in South Africa with very high prevalence of HIV infection the results of my study are probably applicable to these other settings.

The livelihoods framework has been shown to be an effective tool in framing small-scale household and individual-level research into the social and economic impact of HIV and AIDS. Although, given the distinctiveness of the South African household and its dispersal, it required some adaption to be completely suitable and its use in other settings may require other adaptations depending on other contextual factors.

The observed synergistic relationship between access to ART and receipt of the disability grant has not been considered elsewhere in the literature. Instead of the importance of the positive relationship between these two interventions being recognised, as it is here, the bulk of both the research and policy attention has been on the fact that the fear of losing the grant may be a disincentive to adherence to treatment. I would argue that, as an alternative to focusing on this potentially negative relationship, policy-makers need to recognise the potential benefits of the two interventions for each other.

One of the most significant contributions made by this research is methodological and shows the significant value of small-scale, time intensive collection of retrospective and prospective data for the collection of rich ethnographic data about the day-to-day experiences of household dealings with harsh realities and pre-existing vulnerability. The methodological issues facing qualitative researchers collecting sensitive data in households dealing with the harsh realities of poverty, vulnerability, illness and death cannot be ignored. I would argue for further consideration of these experiences and their implications for not only the subjects of study but also for researchers immersed in and facing the realities of their research subjects' harsh existence.

While the findings of this study cannot be generalised completely to other contexts or situations because of the unique context within South Africa there are situations where certain findings may be applicable to contexts outside of rural South Africa. For example, the fluidity of the rural household in South Africa resembles that of the peri-urban or slum communities attached to urban centres elsewhere in Africa, many of which also have correspondingly higher rates of HIV infection than observed in rural communities. In addition, while more limited in their scope, some examples exist from other parts of Africa of social welfare interventions in settings where there is access to ART and these could be considered in light of the findings in this study.

This thesis demonstrates that despite improvements in access to treatment and an increasing number of well people on treatment that many of the social and economic problems faced by households with members who are sick or have died persist in rural South Africa. Treatment is not necessarily an immediate solution to people's problems and access is still limited. This study shows the courage with which the households enrolled in my study face their circumstances and are able to make use of the resources available to them to respond to the negative impacts of illness and or death. African families and communities despite the hardships they face are still remarkably resilient and still provide support and require consideration in future interventions. The social welfare system is also very important but was not designed to deal with the repercussions of the AIDS epidemic, administrative reform would benefit affected households. These factors if considered in future legislation and planning will further help these affected families to help themselves.

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Appendix A: Examples of interview guides

Household 1: Interview 3 to follow-up on data collected in household genogram and household event map.

The last time we met with your household you helped us to identify things that have happened in the last five years that you felt were either good or bad for the household. We want to find out a bit more about these and the way in which they were experienced by your household.

Please can you describe for us what happened when your daughter's husband fell ill in 2004?

Prompts

- What was your reaction?
- How did the illness affect you and your household?
- How did you help your daughter and her husband?

Please can you describe for us what happened when he passed away in 2005?

Prompts

- Can you please tell us about the funeral?
- How did you/they pay for the funeral?
- How much did it cost you?

If you received assistance for the funeral, can you describe what sort of assistance you received and from who?

What happened to your daughter and her baby when her husband died?

Please can you describe for us what happened when your daughter passed away in 2005?

Prompts

- Can you please tell us about the funeral?
- How did you/they pay for the funeral?
- How much did it cost you?

If you received assistance can you describe what sort of assistance you received and from who?

How has having [your grandchild] living here with you affected you and your household?

How has having a child in the household changed the things that you do?

Can you please tell us about how you found out that [your grandchild] was sick?

Prompts

- Was he sick?
- Did you take him to the clinic?
- What were the problems that you faced in trying to access treatment for him?
- What has the impact of him being on treatment had on the household?

Please can you describe how you went about getting access to the foster care grant for your grandchild?

Prompts

- How have things changed since you got the grant?

Can you describe how you use the grant every month?

Prompts

- How did you find out about the foster care grant?

- Did you have a hard time?
- Who helped you to access the foster care grant?

Household 8: Interview 4 investigating social capital in the household

We want to talk today about the assistance and support that you receive from other people and households. Here we are talking about all sort of help, not only money and things.

Can you tell me about any households or people that you/your household have a good relationship with?

Prompts

- Why do you think there is a good relationship?
- Neighbours
- Family/kin

How have your relationships with other households or people changed since you became sick?

Prompts

- Why do you think they have changed?

Are any members of the household members in community organisations? If so, what organisations are they members of?

Prompts

- Church
- *Stokvel*
- Burial insurance

What (do you think) are the reasons for their/your membership?

Can you please describe the support or assistance these have provided to you/your household? If money, how much did each source give?

If limited or no assistance has been provided, what assistance do you/your household expect them to provide?

Last time we were here, you told us that you sell at the school. Is anyone else in the household doing anything to make money, even very small amounts?

Does anyone in the household do temporary work?

Do you have a garden/sugarcane?

You have told us that you get grants for yourself and for the child. Can you please tell us about any other assistance money or other types of assistance that you/your household have received?

Prompts

- Non-governmental organisations such as charities
- home-based care programmes
- Community health workers

What sort of assistance was provided? If money, how much did each source give?

Was the assistance needed?

Did the assistance help the household?

Can you please tell us about the times in the last five years in which your household has received assistance/help from other households?

Prompts:

- Were they family?

- Neighbours?

What was the reason that the assistance was provided?

What sort of assistance was provided? If money, how much did each source give?

Did you/your household ask for the assistance /was the assistance needed?

How did the assistance help the household?

Can you think of times/situations where other households, people or groups did not help, who you feel should have helped you?

Prompts

- Family
- Neighbours

Why do you/your household think they didn't help?

Can you tell me about any times when you have helped another household and how you helped?

Why did you/your household help?

How did you assist them? If money, how much did you give?

Can you tell me about any times when you have been asked to help/feel you should have helped but you/your household have not?

What were you/your household's reasons for not helping?

Appendix B: Informed consent form

Information Sheet for Participants

Study Title: The impact of chronic illness and death on the livelihoods of rural households in KwaZulu-Natal, South Africa

Investigator's Name: Lucia Knight

Investigator's phone number:

Research Assistant's Name: Zandile Gumede

You are being invited to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what is involved. You are not obliged to take part in this study and you are free to stop the interview at any point. Please take your time to read/listen to the following information carefully. Please feel free to talk to your family and friends about the study if you wish.

We are Lucia Knight and this is Zandile Gumede. Lucia is a student from London. Zandile is a researcher working at the Africa Centre for Health and Population Studies.

This study is looking at some of the effects that illness and death have on this community.

Your household has been identified as one, which is experiencing illness through the Catholic Church home-based care programme.

Each interview will last about one hour. We will ask you questions about your own and your family's experiences. If you decide to participate in the study, we would like to visit your household four or five more times over the next few months to talk to you again. However, even if you agree to participate now, you can still change your mind at any time if you decide that you do not want to talk to us anymore.

You will not be paid for participating in the study.

Lucia's Zulu is not good enough to conduct this interview. To make sure that we understand each other properly, Zandile will be acting as an interpreter. With your permission, we would also like to make recordings of all the interviews. This is so that we can record what you say accurately and do not miss any important information. With your permission, we would also like to make written notes during the interviews.

What we want to do today is to collect some information about your household. Who lives here, how they are related to one another, whether they are male or female, their age, what activities they are involved in, whether they are sick or not. We also want to know whether anyone has moved into or out of the household recently or has died. This is all important information about your household and we are happy for everyone who is here today to join in this exercise.

During future visits, we will ask you about different aspects of your own and your household's experiences, specifically those which relate to illness and death. We also want to know any events in the last five years that you feel have had a very negative impact on your household.

Recordings, transcripts of the interviews and any notes of the interviews will only be heard or seen by staff employed by the research project. The results of the research will be part of my PhD document and will be published in academic journals as papers. When the results of the research are discussed with people outside the project team or published we will not include any information, which could allow people outside of the project to identify you. We may use your words within the reports or other published work we produce for the study but your name and personal information such as where you live will never be revealed to anyone outside the project team. Photographs will only be taken during the interviews with your permission and will not be associated with any specific information that you provide us, so that no-one will be able to see a picture of you and know what you said.

If you do not want to answer any question, you do not have to. If you feel uncomfortable or find things difficult to talk about, we can stop the interview at any point or skip to another question.

Ethical approval for this study has been granted both by the University of KwaZulu-Natal and by the London School of Hygiene and Tropical Medicine.

Please feel free to ask a question at any stage of the interview or to let me know if any of the questions we ask make you uncomfortable. We can give you contact details of the Africa Centre and the Ethics committee if you need them.

Informed consent

I have been asked to participate in a study about the impacts of illness and death on the household's livelihood. I have read the information sheet or have understood the verbal explanation of the study. I understand what will be required of me as a participant of this research.

Any immediate questions I have about this study have been answered and I am aware that I am able to contact the study staff if I have any further questions. I have been given the contact details for the Community Liaison Office at the Africa Centre and for the ethics committee of the University of KwaZulu-Natal in case I have further questions or wish to complain.

DECLARATION

I.....(full names of participant)
hereby confirm that I understand the contents of the participant information sheet and the nature of the research project, and I consent to participating in the research project. If I agree to participate, I will be given a copy of this document and the participant information sheet, which is a written summary of the research.

I understand that the interview will be tape recorded unless I specifically ask for it not to be.

I agree to my words being used in the write up or publishing of this research.

I understand that my participation in the study is voluntary and that I may withdraw from this study at any time without giving a reason, should I so desire.

Signed:
.....(Participant)

Name: Date:

Signed:
.....(Witness)