Living and Care Arrangements of Non-urban Households in KwaZulu-Natal, South Africa, in the Context of HIV and AIDS

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AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Clinic
ART	Antiretroviral Therapy
ARV	Antiretroviral
AWLAE	African Women Leaders in Agriculture and Environment
CBO	Community-based Organisation
CHW	Community Health Worker
DFID	Department for International Development
DOH	Department of Health
DSD	Department of Social Development
FAO	Food and Agriculture Organisation
FBO	Faith-based Organisation
FGD	Focus Group Discussion
GHS	General Household Survey
HBC	Home Based Caregiver
HDI	Human Development Index
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
ICD	International Classification of Diseases
KZN	KwaZulu-Natal
KZNDH	KwaZulu-Natal Department of Health
NACOSA	National AIDS Convention of South Africa
NGO	Non-Government Organization
NHI	National Health Insurance
OVC	Orphans and Vulnerable Children
PLWA	People Living With AIDS
PLWHA	People Living With HIV and AIDS
PMTCT	Prevention of Mother-to-Child Transmission
QLS	Quality of Life Survey
SA	South Africa
SADC	South African Development Community
SPSS	Statistical Package for Social Sciences
STATSSA	Statistics South Africa
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infections
TAC	Treatment Action Campaign
TB	Tuberculosis
UNAIDS	United Nations Program on HIV and AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organization
ZCBF	Zululand Chamber of Business Foundation

Chapter 1

Introduction

"AIDS is not curable, but it is careable"
Richard Thumi (UNAIDS, 2001)

This introductory chapter discusses the background to the study. The first section sketches the evolvement of HIV and AIDS in South Africa. The second section discusses the motivation for undertaking the study. In the third section the problem statement and the research questions which guided the research are presented. The chapter is concluded with an outline of the remainder of the thesis.

1.1 The evolvement of HIV and AIDS in South Africa

Just less than 30 years ago, in 1982, the first case of AIDS was recorded in South Africa. A few years later, in 1985, the South African government set up the first AIDS Advisory Group. In 1990, the first national antenatal survey in South Africa indicated that 0.8 percent of pregnant women tested, were found to be HIV positive. In the same year the total number of South Africans living with HIV was estimated to be between 74,000 and 120,000 people. A year later it was confirmed that, in South Africa, HIV was essentially heterosexually transmitted and the first AIDS training, information and counselling centres were established. In 1992, the newly formed National AIDS Convention of South Africa (NACOSA) was mandated with the task to develop a national strategy to cope with AIDS. By 1993, 4.3 percent of pregnant women tested were found to be HIV positive. In 1994, the then South African Minister of Health accepted NACOSA's strategy as the foundation of the government AIDS plan. A multi-media project was established to develop media productions to educate people about HIV and AIDS and other health issues. By 1995, the total number of people worldwide living with HIV was estimated to be 19.5 million, 850,000 of them living in South Africa, and the seriousness of AIDS was acknowledged by the then Deputy President of South Africa. By 1997, the percentage of pregnant women who tested positive for HIV escalated to 17 percent and the total number of people living with HIV in South Africa was estimated to be 2.4 million. In the same year a national survey of South Africa's response to AIDS revealed a lack of political leadership. The Treatment Action Campaign (TAC) was founded with the aim of being an advocate for rights of people living with HIV and AIDS and to campaign for a national treatment plan. It was also in this year that the AIDS activist, Gugu Dlamini, was beaten to death by her neighbours after disclosing on World AIDS Day, that she was HIV positive. In 1999, a HIV and AIDS youth education organisation was launched with the aim of reducing teenage pregnancy, HIV and sexually transmitted infections (STIs). In the same year, the total number of people in South Africa living with HIV was estimated to be 4.2 million and a total number of 420,000 children were estimated to be orphaned by AIDS.

In 2000, the South African Department of Health outlined its five-year plan to combat HIV and AIDS and STIs and it set up a National AIDS Council. In 2001 the World Health Organisation (WHO) and United Nations Program on HIV and AIDS (UNAIDS)

launched the *3-By-5 Initiative* with the aim of reaching 3 million people in the developing world with antiretroviral therapy (ART) by 2005. In the same year 24.8 percent of pregnant women tested were found to be HIV positive and the South African government launched another media campaign to educate people about the dangers of HIV. In 2002, the South African High Court ordered the government to make Nevirapine available to pregnant women to prevent the transmission of HIV from mother to child. By 2003, the number of people worldwide living with HIV increased to 37.8 million, with more than two thirds of them living in sub-Saharan Africa. It was in this year that the South African government finally approved the plan to make antiretroviral drugs publicly available. In 2004, the total number of people living in South Africa with HIV was estimated to be 5.3 million and the rollout of ART in the country commenced. Feedback from the *3-By-5 Initiative* in 2005 indicated that 1.3 million people in developing countries were receiving ART. At least one service point for AIDS-related care and treatment was established in all the health districts in South Africa. Although approximately 85,000 people were accessing ART in the public sector, an estimated 79 percent of South Africans in need of ART were not receiving it. In the same year the number of AIDS orphans in South Africa was estimated to be 1.2 million and 30.2 percent of pregnant women tested were found to be HIV positive. By 2006, an estimated 5.5 million people in South Africa were living with HIV, approximately18.8 percent of the adult population of the country. On World AIDS day of this year the South African Deputy President, as head of the new National AIDS Council, announced their aim of halving the number of new HIV infections in the country by 2011 and to provide treatment, care and support to at least 80 percent of the people, and their families, living with HIV and AIDS (Van Dyk, 2008:27-32). In 2007, an estimated 350,000 deaths were attributed to AIDS, 5.7 million adults and children were living with HIV and 1.4 million South African children were orphaned by AIDS. In the same year an estimated 460,000 people were receiving antiretroviral therapy, an approximate 28 percent coverage (UNAIDS, 2008:5-13). In 2010 the WHO recommended that antiretroviral therapy should commence earlier (WHO, 2010). In the same year the South African National Department of Health adopted the recommendations made by the WHO (DOH, 2010). Although HIV prevalence appears to be stabilising and scaling-up of antiretroviral therapy is generating public health benefits, the impacts of the pandemic on individuals, households and communities will be evident for a long time to come.

1.2 Rationale

More than 20 years after the first death attributed to AIDS was recorded in South-Africa, the longer term demographic, socio-economic and socio-cultural effects of what has become the HIV and AIDS pandemic are becoming visible. In 1992, Barnett and Blaikie emphasised the potential downstream impacts of AIDS describing AIDS as a ‘long wave’ disaster rather than a ‘discrete’ event, which is likely to result in exceptional and unusual demographic changes over the medium term with serious socio-economic effects. Impacts on households may be direct through AIDS-related morbidity and mortality and/or indirect through loss of income and pressure on existing resources with more ill persons and orphaned children requiring care. In large parts of Sub-Saharan Africa, including non-urban KwaZulu-Natal, households and families increasingly have to live with AIDS in their midst (Caldwell, 1993).

One major demographic impact is an increase in the age dependency ratio, while a major socio-economic impact is the increased burden placed on financial resources. Emerging socio-cultural changes include reversal in traditional roles, child migration and new living and care arrangements. As many people fall ill, there is an increased need for health-related care and support. Many models of formal care exist, where formal care

providers play the central role, yet formal health care facilities do not have the capacity to cope with the increased demand for care as resources are limited. Inadequate formal care shifts the burden of providing care and support to individuals back to households and communities. Community- and home-based care is also perceived as a cheaper and sometimes more acceptable alternative to institutional care. As a result, new models of community- and home-based care are emerging where family, household and community members play the central role in the provision of care and support. Although this sounds very positive, it may lead to stretching the resources of poor households to the limit. This not only increases the workload of women, but may also lead to the diverting of household resources towards the provision of care, increasing the vulnerability of the livelihoods of poor households. Poor households with limited human resources may not always have the capacity to provide adequate and quality care for people living with HIV and AIDS and for orphans and vulnerable children. As women become ill themselves, it may result in a reversal of traditional gender and age roles, with the elderly and children becoming the caregivers (Nombo, 2007). Where parents and grandparents have passed away, new living arrangements, such as households consisting of orphans, may emerge.

In most countries, the family household has always been and still is the major provider of care. This is because the household constitutes a context of 'condensed morality' (Pennartz and Niehof, 1999: 206) in which durable ties of and claims to support are developed. This is true for care for older persons (Keasberry, 2002) as well as care for patients with a chronic illness such as HIV and AIDS (Niehof, 2004). Due to an increase in the demand for care for people living with HIV and AIDS, the heavy burden of care cannot be shouldered by households alone. Barnett and Whiteside (2002) pointed out though, that, as household structures erode, households may operate together as clusters within a community to fulfill their functions and to survive. Due to a wide range of social, economic, demographic and epidemiological factors, in KwaZulu-Natal household resources are dwindling. In addition, the caregivers within the household need guidance, support and skills to manage complex care giving.

The secrecy and stigma that surround HIV and AIDS complicate care giving. HIV-positive persons often do not disclose their status to their family out of fear that their family will not be willing to take care of them when they get ill. Even when a family suspects that a member has AIDS, it will frequently not be discussed. This may be a strategy employed by care receivers and caregivers to deal with HIV and AIDS. On the other hand, health care workers see this secrecy as a major obstacle in accessing treatment and care and will put pressure on patients to disclose their HIV status, resulting in a problematic relationship between patients, care givers, and health care workers. It should thus never be assumed that HIV and AIDS are openly discussed and that families will automatically take care of a member with an AIDS-related illness. Because of this secrecy and the absence of reliable statistics, chronic illness such as TB, recent and multiple deaths, and the presence of orphans have to serve as indicators of high HIV prevalence (cf. Desmond and Gow, 2002).

AIDS-related morbidity and mortality and the resulting change in the size, composition and socio-economic status of households have an extensive impact on the resources and activities of households, especially those living in poverty. Although poverty cannot be perceived as directly increasing HIV prevalence, it increases people's vulnerability to ill health (De Haan, 2005) and negatively influences their prognosis (Uys, 2003). As a disease mainly affecting people between the ages of 15 and 50, some impacts include loss of labour, reduced food production and increased numbers of orphans. HIV and AIDS increase the demand for health-related care, while reducing the capacity to provide care at the macro (institutional), meso (community) and micro (household) levels of society. Changes in the size and composition of households may change traditional care arrangements, with gender and age reversal in roles where ill adults become socially and financially dependent on children and the elderly. Taking care of children and the elderly

has always been an important reproductive activity, requiring the utilisation of various types of resources. In the past, taking care of the sick was an occasional household activity, which only sometimes required the deliberate channelling of resources toward health care. The additional demand for provision of health-related care within the household should be seen within the context of other reproductive and productive activities as well as within the context of non-AIDS related changes in household size and composition.

My interest in how people live and make a living and how they cope with the additional burden of care brought about by AIDS coincided with the launch of the AWLAE PhD programme[1] which made it possible for me to pursue this study.

1.3 Research problem and questions

Very few households escape the impacts of HIV and AIDS, either the direct impacts as a result of illness and death, or the indirect impacts through providing care and support to family, friends and neighbours. HIV and AIDS becomes part of the context or situation within which households arrange their lives, generate livelihoods and arrange and provide care. The differential impacts of HIV and AIDS on male and female members of different ages within households in non-urban KwaZulu-Natal is poorly documented and understood. How people arrange care, especially for household members who are chronically ill, while generating livelihoods at the same time, is even less clear in the context of HIV and AIDS. This research will assess household living and care arrangements and livelihood generation in non-urban Mbonambi in the KwaZulu-Natal province of South Africa, in the context of HIV and AIDS.

From the research problem, four main research questions were derived:

1. What is the demographic, socio-economic and health profile of households in the research area?
2. How can households in the research area be categorized in relation to the context of HIV and AIDS?
3. What are the impacts of HIV and AIDS on the living arrangements and livelihoods of households in the research area?
4. How do households in the research area arrange and provide care for people living with AIDS and for orphans and vulnerable children?

1.4 Outline of the thesis

This thesis consists of seven chapters in addition to this first chapter and is organized as follows:

Chapter 2 presents the conceptual and theoretical framework. Key concepts which guided the research include household, livelihood, gender and care. The chapter is concluded with a framework, illustrating the relationship between concepts and operational definitions of concepts as used in this research.

Chapter 3 describes the research design, procedures and methods. It describes sampling, development of data collection instruments, and data management and analysis.

[1] AWLAE stands for *African Women Leadership in Agriculture and Environment*. It is a programme funded by the Netherlands Ministry of Foreign Affairs and jointly managed by Wageningen University, AWLAE-Nairobi, and Winrock International, USA, in the framework of which 20 women from 12 African countries pursued their PhD studies at Wageningen University.

The chapter also describes the characteristics of respondents and ends with a discussion on methodological challenges and ethical considerations.

Chapter 4 provides details on the context in which the research was conducted. It provides background information on South Africa, the KwaZulu-Natal province and Mbonambi, the research location.

Chapter 5 profiles households in the research area and categorize households based on whether and how they are affected by HIV and AIDS. The demographic, socio-economic and health characteristics of households are described. Similarities and differences between male- and female-headed households are outlined and categories of AIDS-affected and non-affected households are compared on selected demographic and socio-economic variables to asses the impacts of HIV and AIDS.

Chapter 6 examines the impacts of HIV and AIDS on the living arrangements and livelihoods of households by comparing case study households from the four clusters of AIDS-affected and non-affected households.

Chapter 7 assesses and describes the arrangement and provision of care for people living with HIV and AIDS and orphans and vulnerable children. The roles of different actors in the arrangement and provision of care and phases of care are presented.

Chapter 8 summarizes the main findings of the study based on the research questions, draws conclusions and poses recommendations for policies, interventions and further research.

Chapter 2

Conceptual and theoretical framework

This chapter discusses the main concepts used in the study, namely household, livelihood, gender and care. The chapter is concluded with a conceptual framework picturing relationships between the concepts and their operationalisation as was done in the research.

2.1 Household

The household is the unit of analysis in this study and below follows a discussion on the meaning of household and related concepts such as household headship and composition. Rudie (1995:228) describe a household as "a co-residential unit, usually family-based in some way, which takes care of resource management and primary needs of its members." This definition contains three important components, namely 'co-residence', 'family-based' and 'resource management', which can also be found in one way or another in many other definitions. According to Lipton et al. (1996:275), who conducted research in many parts of South Africa including KwaZulu-Natal, a household consists of a resident component and a migrant component and the interaction between the two. The resident component includes all those members who eat together and live under the same roof or cluster of roofs, thereby not implying that resources are equally distributed between the individuals within the household. The migrant component includes all those identified by the resident members as belonging to the household, provided that they do not have another home or household elsewhere. This very last part of Lipton et al.'s definition implies that an individual cannot be a member of more than one household at a time. In the African context, Kayongo-Male and Onyango (1984) referred to the household as being an economic unit regardless of whether its members are physically dispersed. According to Netting (1993:16), the household is "the scene of economic allocation, arranging collectively for food, clothing and shelter of its members and seeking to provide for these needs over the long term."

According to Pennartz and Niehof (1999:2) households are frequently defined in censuses as "spatial units where members live in the same dwelling and share basic domestic and/or reproductive activities such as cooking and eating". Such a definition will suffice as a group sharing a dwelling does not necessarily share resources and expenses. Extended families may share a house, but not a kitchen. Households may also contain non-related persons on a temporary basis, such as employees or friends. On the other hand in many cases a male or female may leave the shared dwelling temporarily for seasonal labour migration, or children may leave the parents' home for better opportunities somewhere else in the household's kinship network. Many of the reproductive functions of a household may be taken care of by the wider network of kin, friends, or neighbours. The concept of 'household' is thus broader than just a group of individuals living together and sharing meals. It is not a static group and household boundaries are thus not stable, but rather fluid (Pennartz & Niehof, 1999).

Pennartz and Niehof (1999:3) derived a definition of the household from Wallerstein and Smith's definition of 1991 which presents a main line, rather than a clear-cut concept. The definition is as follows: a household is "a social unit that effectively

over long periods of time enables individuals, of varying ages and of both sexes, to pool income coming from multiple sources in order to ensure their individual and collective reproduction and well-being". According to Pennartz and Niehof (1999:3) "reproductive needs imply several resources such as food, shelter, and clothing. Decisive is having entered into long-term income-pooling arrangements also if the member is an intermittent co-resident. Members of households are not necessarily biologically related and do not always share a common residence. Generally, a household is embedded in a network, which is called a 'domestic network', a vast kinship network comprising reciprocal relationships set up through children, marriage and friendship, which join together to satisfy domestic functions."

Writers on developing countries tend to use the term 'household' rather than 'family', because these households are usually embedded in a much wider network of family and kin (Chant, 1997). Some authors feel that both concepts, 'household' and 'family' are outdated, but they do not provide us with any alternatives. To further distinguish the different forms that households can take on, Pennartz and Niehof (1999) also differentiate between family households and non-family (institutional) households. This study is about family households in non-urban South Africa.

Statistics South Africa (2004:8) for the purpose of collecting data at the level of the household in South Africa defines a household as follows: "a group of persons who live together and provide themselves jointly with food and/or other essentials for living, or a single person who lives alone." For the local context it is important to realise that a household can take on a variety of forms and can vary greatly in size. Since there is no word for household in the Zulu language, the most common language spoken in non-urban KwaZulu-Natal, I have to rely on a description of the concept. Although co-residence is an important aspect, one should realise that this does not refer to 'under one roof', but that it also can be "a cluster of roofs", as Lipton, et al. (1996) put it. The other two dimensions included in Rudie's (1995) definition, namely 'family-based' and 'resource management' also form an important part of the Zulu understanding of the concept 'household'

Household headship, kinship, family units and homestead

The head of the household refers to the person perceived by the household members to be the head. Rather than only two possibilities, three are possible here, namely male-headed, *de jure* female-headed and *de facto* female-headed. The *de jure* female-headed households are those in which the male partner is permanently absent, due to separation or death, and the woman is legally single, divorced or widowed. The second, the *de facto* female-headed households are those in which the male partner is temporarily absent, due to long-term work migration, or refugee status. Here the woman is not legally the head of the household, and is often perceived as a dependent, despite the fact that she may have had the primary responsibility for the financial and organisational aspects of the household for most of her adult life. It is estimated today that one third of the worlds' households are headed by women. The economic conditions of female-headed households vary considerably, depending on such factors as the size and composition of the household and women's access to productive resources and income, but they are frequently very poor (Moser, 1989). According to Firebaugh (1994) the prevalence and circumstances associated with female-headed households vary greatly by region and country. Firebaugh also indicated that HIV/AIDS is also a factor contributing to the emergence of female-headed households, resulting from circumstance rather than choice. In the context of Zimbabwe, not only HIV/AIDS but also the economic crisis and political and social instability led to an increasing number of "single-women directed hearth-holds" (Makura-Paradza, 2010). According to Firebaugh (1994) the impact of female-headed households on food security can be attributed to the interaction between gender of the head of the household and income

rather than strictly to the one or the other. The concept of headship reappears in the section on household typologies.

According to Niehof (1997), kinship, family and household can be seen as partly overlapping institutions. She describes kinship in short as comprising social relationships that refer to biologically determined relationships, including the meanings attached to them. Hence, according to Niehof, kinship refers not just to biological relationships but to a whole set of social relationships. In a kinship system descent is important, and again it is social acknowledgement that is more important than the biological fact. A nuclear family is usually made up of three kinship relationships, the marital tie, the parent-child tie and the sibling tie. When there are other kinship ties involved, such as those with grandparents, aunts, cousins, etc., we speak of extended families. The kinship network of a family usually extends beyond the nuclear family and consists of a field of relationships characterised by social solidarity and obligations that function as a social security provision that one can fall back on. There are various strands relating kinship to household. In the first place, kinship and marriage patterns influence household formation and composition. A second reason why kinship is important, is that it determines access to resources, for example land in rural societies. Inter- and intra-household kinship relations are important for the division and allocation of labour. Furthermore, kinship is important for understanding social hierarchy. Finally, it is important for care giving, within and beyond the household. The latter is a crucial aspect in African countries where the role of kin in taking care of AIDS-patients and their families is becoming increasingly indispensible. In the earlier discussion of the concept 'household', its family-base was stressed, as well as the fact that households are usually embedded in a wider kinship and social network.

The homestead is strictly according to its dictionary meaning a house with its surrounding land and other buildings, while the 'house' in this context may refer to a cluster of dwellings (Lipton et al., 1996), also referred to by Ellis (2000) as a social grouping. This cluster of buildings provides the physical infrastructure for the fulfilment of domestic needs such as sleeping, eating, family life and caring for children, the ill and the elderly. Besides, it is also a farmstead where cattle are housed, agricultural products can be stored and processed and tools are kept. Similar to Niehof's (1985) example of the *tanéan* in Madura, the domestic tasks are not confined to one building, but are carried out all over the homestead, in more than one building. Groups of people that cook and/or eat together can be referred to as kitchen units. To reduce the large kinship network that frequently resides at one homestead, it can be grouped into smaller household or family units, where a family unit is defined as a family of which the members are related through one conjugal link only. This can be a husband and wife with or without children, or a divorced or widowed woman/man with children (cf. Niehof, 1985).

Typologies of household

Varied household classifications or typologies have evolved over time, illustrating that households can be classified in many different ways. The typologies presented below are by no means exhaustive and only some of those relevant to the study are presented on basis of classification rather than chronologically.

The first typology represents an economic classification based on sources of income or employment. Carter and May (1997:12) in their study on rural poverty in South Africa identified the following eight categories of households:

- Marginalised households that have no access to wages or remittances from formal sector opportunities, and have no access to welfare transfers (specifically referring to old age pensions);

- Welfare dependent households that have access to welfare transfers (pensions), and receiving no wage or remittance payment;
- Remittance dependent households that have access to a remitted income, although no wage is received. Transfer payments may be present;
- Secondary wage dependent households that have wage income earned by people living at home employed in the secondary labour market (formal workplace outside the domestic domain);
- Primary wage dependent households that have access to wages earned by people living at home employed in the primary labour market (informal domestic or local domain);
- Mixed income households with secondary wages that combine wages earned in the 'secondary' labour market;
- Mixed income households with primary wages that combine wages earned in the 'primary' labour market with small business and other self-employment income;
- Entrepreneurial households that earn incomes in excess of R1000.00 per month from agricultural activities, and/or business activities.

According to Mtshali (2002:19), these categories refer to "different packages of claims" made by the household. They can be regarded as comprising households with common sets of survival or livelihood strategies, and households can move between categories as the socio-economic status of their members' changes over time.

The second represents a socio-demographic typology of female-headed households based on relationships, generation and age. Chant (1997:10-26), identified seven types of female-headed households, moving beyond the limited classification of female-headed households as *de facto* or *de jure*.

- Lone-mother household, comprising a mother and co-resident children;
- Female-headed extended household, comprising a mother, children and other relatives;
- Lone-female households, referring to women, usually elderly, living alone;
- Single-sex or female-only households, referring to women living with other related or non-related women;
- Lesbian households, referring to women living with female sexual partners;
- Female-dominant or predominant households, referring to households headed by women, but where younger males may be present in the household;
- Grandmother-headed household, comprised of a woman and her grandchildren, but without intermediate generation;
- 'Embedded' female-headed units, consisting of young mothers and their children contained within larger households, usually that of parents, sometimes referred to as family units.

The third represents a typology of households by Wittenberg and Collinson (2007:132) who studied distribution across types over a period of approximately eight years. This typology focuses on relationships between members and heads and includes emerging types of households, such as child-headed households not documented by other authors, and which may be as a result of HIV and AIDS.

- Single-person households;
- Couples, defined as a Head plus spouse;
- Nuclear households, defined as a Head plus spouse plus children;
- Single parent households, defined as a Head plus children;
- Three-generation linear households, defined as a Head (with or without spouse) plus children plus parent (or parent-in-law), or a Head (with or without spouse) plus children plus grandchildren;

- Three-generation skip households, defined as a Head (with or without spouse) plus grandchildren, but with no children present;
- Multi-generation households, defined as households with great-grandparents and/or great-grandchildren;
- Sibling only households, defined as a Head with his/her siblings;
- Complex but related households, households that do not fit any of the previous categories, but in which everyone is related (directly or in-law) to the Head of the household;
- Complex plus unrelated households, in which at least one member of the household is not related to the Head.

The fourth typology by Wiegers (2008:79) represents categories of households based on the sex and age of the head and whether the household is taking care of people living with HIV and AIDS (PLWHA) or orphans. This classification thus provides for the impact of HIV and AIDS on households.

- Female-headed with PLWHA
- Female-headed with orphans
- Male-headed with PLWHA
- Male-headed with orphans
- Elderly-headed with PLWHA
- Elderly-headed with orphans
- Other female-headed
- Non-affected households

In this typology elderly heads refers to grandmothers or grandfathers aged 65 years and older. Households with PLWHA included at least one person between the ages of 15 and 49 requiring care for three or more consecutive months as a result of AIDS-related illnesses. Although in the case of Wiegers, these categories were mutually exclusive, households with PLWHA may also include orphaned children. Other female-headed households include single women, *de facto* heads, not caring for orphans or ill persons. Non-affected households are nuclear households that do not host orphans and that do not have members who are requiring long-term care as a result of AIDS-related illness. This typology does not provide for orphan-headed households as orphans are usually fostered by the extended family.

Although not referred to as a typology of households by the authors, Barnett and Blaikie (1992:86) identified three categories of households based on the impacts of HIV and AIDS experienced by households.

- Unaffected households are those in which no member is ill or has died from AIDS and which has not been affected by the illness or death of a member of any related household. No additional burden, either of time or economic or financial resources has accrued to a member an unaffected household.
- AIDS-afflicted households are those on which the impact of the epidemic has been direct, where a member of the household is either ill or has died from the disease and resources have to be reallocated in order to deal with the problem.
- AIDS-affected households are those that have been affected by the disease, either through the death of a family (not necessarily household) member who was contributing cash, labour or other support, or because the death or illness of a family member has meant that orphans has come to join the household. These are all events that place additional demands on existing resources.

Households can also be both AIDS-affected and AIDS-afflicted, experiencing direct and indirect impacts of HIV and AIDS.

Barnett and Whiteside (2006:203) identified eight new forms of households developing as a response to the impact of HIV and AIDS. This classification of emerging household types is based on the living arrangements of orphaned and vulnerable children.

- Elderly household heads with young children, grandparent-headed households;
- Large households with unrelated fostered or orphaned children attached;
- Child-headed households;
- Single-parent, mother- or father-headed households;
- Cluster foster care, where a group of children is cared for formally or informally by neighbouring adult households;
- Children in subservient, exploited or abusive fostering relationships;
- Itinerant, displaced or homeless children; and
- Neglected, displaced children in groups of gangs.

Similar to the classification of Barnett and Whiteside, Richter and Desmond (2008:1021) in their study of secondary general household survey data classified households in which children are residing as follows:

- Child-only, where all members are below 18 years of age;
- Skip-generation, which contains at least one child with all members either below 18 or over 59;
- Young adult, which contains at least one child and at least one adult below the age of 25 and no members over the age of 24;
- Single adult, which contains at least one child and only one adult, where the adult is over the age of 24;
- 'Other', all other households containing children not captured in one of the above.

It is evident from these typologies and classifications that households are experiencing changes in size and composition attributed to HIV and AIDS. Non-traditional types of households such as child-only and skip-generation households may be on the increase as a result of premature AIDS-related deaths of adults. In households consisting mainly of children and the elderly, dependency ratios are higher hinting at socio-economic impacts associated with changes in household size and composition.

2.2 Livelihood

Livelihood is a complex concept encompassing many other concepts warranting discussion in this chapter. According to Chambers and Conway (1992:6) "a livelihood in its simplest sense is a means of gaining a living" and according to Ellis (1998) also more than just income. Carney (1998:4) slightly modified the definition of sustainable rural livelihoods originally developed by Robert Chambers and Gordon Conway as follows: "a livelihood comprises the capabilities, assets (including material and social resources) and activities required for a means of living. A livelihood is sustainable when it can cope with and recover from stresses and shocks, maintain or enhance its capabilities and assets both now and in the future, while not undermining the natural resource base and providing sustainable livelihood opportunities also for the next generation". According to Niehof (1998:1) this ability of households to provide for their own basic needs in a sustainable manner can be referred to as livelihood security as opposed to livelihood vulnerability, referring to a situation in which households cannot provide for their own needs, either immediately so, or experience a lack of assets to do so in future.

The sustainable rural livelihoods framework

When this framework for analysing livelihoods, as it appears in Carney (1998:5) was developed by the Department for International Development (DFID) as part of its sustainable rural livelihoods (SRL) approach, one of its purposes was to help those concerned with SRL to understand and manage the complexity of rural livelihoods. This aim or purpose provides the motivation for its frequent use in research and inclusion in this chapter (see Figure 2.1). Sustainable rural livelihood was already defined above, but it is important to perceive it here from the perspective of the DFID. The DFID aims to improve the lives of poor people and to strengthen the sustainability of their livelihoods, believed to be in everyone's long-term interest. The approach starts with people, but does not compromise on the environment. The framework is thus holistic and dynamic and recognises the many complex interactions in rural livelihoods, including the natural and physical environment.

At the heart of this framework lies an analysis of the five different types of capital assets upon which individuals draw to build their livelihoods. These include natural capital (resources such as land, water and other natural resources), social capital (resources such as networks and membership of groups amongst others), human capital (including the ability to work and good health), physical capital (basic infrastructure) and financial capital (resources such as savings, credit and remittances). On the five-axis graph, household access, anything from individual ownership to customary use rights for groups, to each type of asset can be plotted. This should provide a starting point for thinking, holistically, about how and in what combination assets translate into sustainable livelihoods. Building up assets is a core component of empowerment.

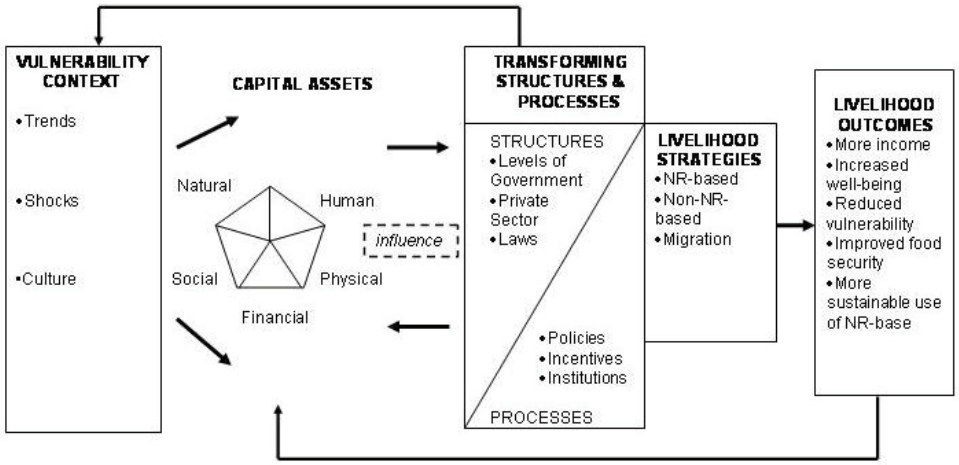


Figure 2.1 DFID's, 2000 sustainable livelihoods framework

The SRL framework is built around capital assets but also requires analysis and understanding in many other areas of which the first is the vulnerability context in which the assets exist. This context includes the trends, shocks and local cultural practices that affect livelihoods. In the second place it is also vital to understand the structures (organisations, from government to the private sector) and processes (policies, laws, etc.) which define people's livelihood options. According to Carney (1998) there are two main and related ways in which these structures and processes impact upon livelihoods. In the first place they are critical in determining both who gains access to which type of asset and what the effective value of the asset is. In conjunction with this they also, in the second place, help define which livelihood strategies or activities are open and attractive to people.

They will also determine the extent to which one asset can be converted into another type of asset, for example natural capital into financial capital. This convertibility is important especially where it concerns households' ability to withstand shocks and stresses. People aspire to a range of outcomes, with short-term survival rather than the sustainable management of natural capital often the priority of people living in absolute poverty. This holistic nature of the framework is both attractive and alarming since it suggests the need for extensive analysis of livelihoods before plans for support can be developed.

Components and flows in a livelihood

Chambers and Conway (1992:9) postulated four categories of a household livelihood, namely the livelihood capabilities of people, their activities, assets that provide them with the means to secure a living, and outputs or what they gain from what they do. According to Chambers and Conway (1992:5) capability refers to being able to perform certain basic functions, to what a person is capable of doing and being. It includes such things as being able to cope with stress and shocks, and being able to find and make use of livelihood opportunities. Activities refer to all the things people do to generate livelihoods and together with the 'people' component, Chambers and Conway (1992:9) refer to them as the "repertoire".

The most complex of the four components is this "portfolio of tangible and intangible assets" as they are referred to by Chambers and Conway (1992:9). There are three classes of assets, resources, stores and claims. Resources and stores are classified as tangible assets and claims and access as the intangible assets. Stores include food stocks, stores of value such as jewellery, cash savings and credit schemes, while tangible resources include land, water, trees, livestock, farming equipment, tools, and household equipment. Assets are often both stores and resources, as with livestock, trees, and savings. Intangible assets such as claims are demands and appeals which can be made for material, moral or other practical support or access. Support may take many forms such as food, equipment, loans, gifts, or work. According to Chambers and Conway (1992) claims are often made at times of stress or shocks or when something unexpected arise. Claims may be made on individuals or agencies, on relatives, neighbours, chiefs, social groups, government, or the international community. Claims are made on the basis of right, precedent, social convention, moral obligation and power. According to Carney (1998:7) access "can imply anything from individual ownership of private goods to customary use rights for groups". Access is the opportunity in practice to use a resource, store, or service or to obtain information, material, technology, employment, food or income. Services here include transport, education, health, shops and markets. Employment and other income-earning activities include rights to common property resources such as wood for fuel, and grazing on state or communal lands.

Carney (1998:7) referred to all these assets as "capital assets" that are used in different combinations to generate livelihoods:

- Natural capital, the natural resource stocks from which resource flows useful for livelihoods are derived (ex land, water, wildlife, biological diversity, environmental resources);
- Social capital, the social resources (networks, membership of groups, relationships of trust, access to wider institutions of society) upon which people draw in pursuit of livelihoods;
- Human capital, the skills, knowledge, ability to labour and good health, important to the ability to pursue different livelihood strategies;

- Physical capital, the basic infrastructure (transport, shelter, water, energy and communications) and the production equipment and means which enable people to pursue their livelihoods; and
- Financial capital, the financial resources which are available to people (whether savings, supplies of credit or regular remittances or pensions) and which provide them with different livelihood options.

Out of the tangible and intangible assets people construct a living, using physical labour, skills, knowledge and creativity. Chambers and Conway (1992:11) refer to indigenous technical knowledge passed on from generation to generation. Skills and knowledge are also acquired through formal or non-formal education, or through experiment and innovation. According to Chambers and Conway (1992:11) rural livelihoods frequently comprise a variety of activities such as cultivation, trading and wage labour. These activities provide a combination of food, cash and goods to either satisfy immediate human needs, or to be consumed later or to be invested in other assets.

Livelihood outcomes

According to Chambers and Conway (1992:11,12) "investments are made in enhancing or acquiring resources in establishing claims, in gaining access and in improving capabilities". Resources may be enhanced by investing labour to improve yield. Claims may be established by investing in relationships by giving gifts, while access to information may be obtained by investing in a radio or in education. Capabilities may also be enhanced by investing in education and training. These investments can reduce vulnerability to shocks and stress in the future. Livelihood outcomes are also indicated in the Sustainable rural livelihoods framework (see Figure 2.1) and according to Carney (1998:5) people aspire to a range of outcomes, including more income, increased well-being, reduced vulnerability, improved food security and more sustainable use of natural resources. These can also be used as indicators of sustainable rural livelihoods, but it should be understood that for vulnerable households short-term survival will take priority over sustainable resource use.

Livelihood vulnerability

Chambers (1989) describes vulnerability as defencelessness, insecurity, exposure to risk, shocks and stress, and the difficulty in coping with them. According to Chambers and Conway (1992) vulnerability has two aspects, namely external, the stresses and shocks to which they are subjected, and the internal aspect, namely the capacity to cope. The understanding of vulnerability is enhanced by distinguishing between baseline, current and future vulnerability assessment. According to Frankenberger (1992:4), "baseline vulnerability assessment focuses on the underlying factors that influence exposure to food insecurity and a household's predisposition to the consequences. It provides the context for interpreting indicators of the current household food security risk. These contextual factors may encompass the food insecurity events over the previous season or years. Current vulnerability is related to the shocks overlaying the baseline (ex. food shortages, exchange failure, institutional failure). Vulnerability is thus a composite of the status of past and current events and monitoring household food security requires an understanding of both the causal mechanisms of vulnerability and the current situation. Future vulnerability can also be determined from this analysis by matching the coping responses of vulnerable households to long-term food security risk."

According to Swift (1989:8) vulnerability is not just another word for poverty, although poor people are usually among the most vulnerable. Understanding vulnerability means "breaking down" poverty. A high income at risk makes some people more vulnerable than those with a guaranteed low income. According to Swift such things as drought, animal or plant disease, urban bias, agricultural pricing policies, civil war and many others, are primary factors in determining vulnerability, acting in different and often complex combinations through three closely related factors, namely production, exchange and asset processes. Production failures and exchange failures may increase vulnerability, while assets, including investments, stores and claims can create a buffer against vulnerability.

Carney (1998) also calls for an understanding of the vulnerability context (see Figure 2.1), the trends, shocks, and local cultural practices which affect livelihoods and within which assets exist. It is also important to note that the transforming structures, various organisations, and processes, such as policies and laws, will also have an effect on the vulnerability context since they define people's livelihood options. Carney (1998) lists possible trends, shocks and cultural aspects that can contribute to the livelihood vulnerability of rural households. Trends include the quality and quantity of natural resource stocks, population density, available technology, political representation and economic trends. Shocks include climatic effects on people's livelihoods and the effect of conflict on livelihood while cultural aspects refer to the way things are done and the effects thereof on people's livelihoods.

According to Niehof and Price (2001) the following distinction between livelihood systems can be made from the perspective that coping strategies exist and can be part of livelihood strategies: secure livelihood systems, based on effective and viable livelihood strategies, which do not need coping strategies; vulnerable livelihood systems which need coping strategies to bridge difficult periods but are normally able to develop effective coping strategies; and extremely vulnerable livelihood systems which break down in a situation of stress because of a inability to develop effective coping strategies and which are dependent upon external support. Niehof and Price (2001) see livelihood security and livelihood sustainability both as the opposites of livelihood vulnerability. According to Ellis (1998:7) livelihood sustainability includes two aspects, namely environmental sustainability as an external impact and social sustainability as an internal capacity. The latter can be reactive as in coping with stress and shocks or proactive as in enhancing capabilities. The question remains though, why some livelihood systems are secure while others are vulnerable or even extremely vulnerable. Some households are more resilient than others (Niehof, 2008). In high HIV-prevalence communities, where the majority of households is affected in some way, households 'fall through' the vulnerability threshold (Donahue et al., 2001: 9).

Livelihood security

Niehof and Price (2001) see vulnerability and sustainability of livelihoods as the opposing extremes of a continuum. They focus on the ways and strategies people use to achieve livelihood security. To contribute to a better understanding of this, they present a diagram tracing the backward linkages of livelihood security, where livelihood security is positioned at the end of the diagram as the objective or end product of the livelihood system. These backward linkages representing relationships of households to other actors and to domains of activities should provide some insight into the indicators of livelihood security. It is important to point out that it is about the dynamic process of achieving livelihood security rather than the end result and that it is done from the perspective of the household as the unit of analysis and here confined to rural households, thus including farming households.

To answer the question on what determines the viability of a livelihood system and the effectiveness of its strategies the components of the system should be specified. Households as collectives engaged in a range of activities to achieve livelihood security and to produce livelihoods they develop strategies. This integrated whole of arrangements and activities is referred to as a livelihood system. As mentioned earlier, livelihood security is at the end of the diagram as the result of livelihood generation, the ongoing process of activities. The activities comprise income or asset generation, assets that can yield income and when needed provide a buffer in a situation of stress. Generation of income and assets require resources such as labour and skills. Once generated, income becomes a resource that can be used by the household to create livelihood and provide food.

The rural household with their dynamic and fluid boundaries is placed in the centre of the diagram. In the case of farming households, there is an overlap between the farm and the household in terms of persons involved in farming and household activities and in the use of resources. Family, farm and household are seen as interdependent and together producing the livelihood system. The rural household has the dimensions of family, farming and food sharing with the boundaries of these not necessarily coinciding. Non-family members might be part of the farming and/or food sharing units. In the case of farming households agricultural production may be partly for own consumption and partly for the market. The yields are part of the household's livelihood generation. The income generated from selling agricultural products becomes part of the household's resources.

Households are always embedded in other social structures from which they can derive support, in the diagram referred to as support networks. Although it is especially kinship networks and structures that can be used as a resource for support, other local and community support networks can fulfil the same function. The arrows in the diagram run in two directions indicating that support networks are based on reciprocity in which households need to invest.

As already mentioned earlier, to generate livelihoods resources are needed. They provide the means necessary for livelihood generation and can be of several kinds, including human, material and environmental resources. For this discussion this broad classification will suffice since a more detailed classification of resources will be given in the next section of this chapter. There are though several issues involved in the use and management of resources. To be able to use resources one has to have access to them that is obtained through claims and entitlements at individual level (individual income) or collectively (land at household level and water at community level) and to be used effectively the resources need to be controlled. This emphasises the importance of resource management at household level that requires the making of choices and taking of decisions. The kind of choices made and decisions taken are as important as how and why they are made or taken, since the former reflect the household's livelihood strategies. In farming households there is no separate system for allocating and managing resources for farming and householding, it is an integrated system. The linkages discussed above represent relationships between households and other actors (Niehof and Price, 2001).

Household livelihood security is threatened by HIV and AIDS and commonly cited impacts are summarised by Wiegers (2008) according to the different capitals. Below are some impacts relevant to this research, with impacts on human, social and financial capital especially important to this study:

- Impacts on human capital: illness and/ or death of household member(s), fosterage of orphaned children, change in household size and composition, increased dependency and elderly assuming more responsibilities, temporary migration, increased care burden for women, intra-household reallocation of tasks and less time devoted to agricultural activity amongst others.
- Impacts on social capital: increased reliance on social network for labour, food and financial assistance, reduced outgoing support and remittances, increased burden on

community to support orphans and vulnerable children, reduced participation in community based activities and organisations and exclusion from institutions due to stigma.

- Impacts on financial capital: increased expenditure on medical care, transport and funerals, reduced income from on- and off-farm, use of savings or investments, increased reliance on informal borrowing and reduced access to credit.
- Impacts on physical capital: distress sale of household goods and equipment, grabbing of assets from widows and orphans and poor maintenance of assets amongst them.
- Impacts on natural capital: increased asset stripping (sales of firewood and harvesting of wild foods), land grabbing from widows and orphans and renting out or selling of land.

Livelihood strategies

In Niehof and Price (2001) the focus is on the ways and strategies people use to achieve a situation of livelihood security, assuming that this is what people strive for. By following such an approach, it also provides insight into the indicators of livelihood security. Apart from following this approach, the household as the "arena for everyday life" is the unit of analysis. The scope is limited to rural households, including farming households. Anderson et al. (1994) refer to a strategy as the way in which people, "consciously seek to structure, in a coherent way, actions within a relatively long-term perspective". It can prescribe actions or the conscious decision not to act. If the long-term perspective is not there, because of a situation of immediate stress, it is referred to as coping. Coping is defined by Davies (1993) as "a short-term response to an immediate and inhabitual decline in access to food". Niehof and Price (2001) also refer to Davies' concept of coping strategies, which are strategies for coping with recurrent situations of stress. This is probably best described by giving an example, namely, lean months in the agricultural cycle for which households are more or less prepared. This will require investments in social networks or stocks or assets before the actual situation requiring the coping arises. Although this can be seen as part of livelihood strategies it is short-term.

Niehof and Price (2001) also refer to household strategies. Only people can implement strategies, therefore one must take care when speaking about 'household strategies' and 'household decision making', because a household can also not take decisions. In the earlier definition of 'household' there is a focus on internal arrangement of resource management for primary needs. This requires us to look at intra-household relationships. Household livelihood strategies then refer to strategies that are jointly developed by probably the adult household members and that are aimed at strengthening the livelihood system of the household as a whole. One can thus assume that households can indeed have strategies which are more than the sum of the individual aspirations of their members.

Livelihood diversification is defined by Ellis (2000:15) as "the process by which rural families construct a diverse portfolio of activities and social support capabilities in order to survive and improve their standards of living". Ellis further indicates that diversification is not only a strategy associated with rural households, but also a well-documented survival strategy with urban dwellers. According to Ellis (2000:5) "diversification may occur both as a deliberate household strategy and as an involuntary response to crisis". Ellis (2000) identified the following types of diversification, those that are natural resource based, including gathering, food and crop cultivation, livestock holding and various crafts and those that are non-natural resource based including non-farm wage labour, pensions, and various types of migration to name a few. Ellis also indicated several reasons for diversification, including risk reduction, overcoming income instability, improving food security, generating cash to meet household objectives (e.g. children's education), decreasing vulnerability, gender benefits, etc. He also warned that

diversification can also have negative effects such as adverse gender benefits (the effect of male out migration on women), unequal rural income distribution, decline in farm output and diversion of resources into unproductive networking (Ellis, 2000).

2.3 Gender

Gender refers to the social construction of what it means to be male and female and the roles and expectations associated with each (Giddens, 1993). Gender roles change over time and vary across cultures. Access to and control over resources and assets are dictated by gender norms. Traditionally, men are seen as the breadwinners, the ones doing the productive work, working for long hours often far from home, and the women remaining at home to do the reproductive work. The reproductive or domestic work of women is only one of the three roles they perform. According to Moser (1993) women in most low-income developing countries have a triple role, including productive, reproductive and community work. Their reproductive work includes childbearing and rearing practices required to reproduce and maintain the labour force. It would also include the arrangement of health care within the household, or providing what Neal et al. (1993) refer to as dependent care. Women also engage in productive work; they usually are as or are seen as secondary income earners. In rural areas it can be any of, or a combination of agricultural and other income generating activities, such as craft work, or occasionally formal employment. As a third role, women engage in community managing work around what Moser (1993) refers to as the provision of items of collective consumption undertaken in the local community. Community work can be involvement in women's groups, but is often related to religion, including making preparations for funerals and weddings.

Women and men, as a result of their different roles have different needs. According to Moser (1993) all women have two different types of gender needs: practical gender needs and strategic gender needs. Practical gender needs arise from women's roles and gender division of labour, and strategic gender needs from women's subordinate position in society. There is a call for 'mainstreaming' or incorporating of gender concerns into every aspect of the priorities and procedures of organisations, but this requires a better understanding of gender (March et al., 1999). Gender analysis can explore and highlight inequalities in relationships between men and women. Various gender analysis frameworks have been developed to assess and promote gender issues in institutions. Some of these include the Harvard Analytical Framework, Moser Framework, Gender Analysis Matrix, Capabilities and Vulnerabilities Framework, Women's Empowerment Framework and the Social relations Approach (March et al., 1999).

2.4 Care

According to Nolan et al. (1996), the concept of 'care' is frequently used, but less frequently properly defined. Many care-related concepts exist and are defined and used by the WHO (World Health Organization) and the South African Department of Health (DOH). Some concepts commonly used in relation to care, and some of which will be discussed later, include: palliative care, community home-based care, comprehensive care, holistic care, etc. This research will though be guided mainly by one definition of care, namely that of Tronto (1993), which is more general and does not only refer to health care.

Tronto (1993:103) broadly describes care as "an activity that includes everything we do to maintain, continue and repair our 'world' so that we can live in it as well as possible." According to Tronto this 'world' includes our bodies, ourselves, and our environment, all

of which we seek to interweave in a complex, 'life sustaining web'. Tronto (1993) also identifies four interconnected phases of care and what is required in each phase:

- Caring about, identifying the need for care which requires attentiveness;
- Taking care of, responding to the need, requiring responsibility;
- Care giving, meeting the need and doing the physical work, requiring a competent care giver; and
- Care receiving, the care receiver's assessment of the care, requiring responsiveness.

A fifth requirement for good care is integrity, which refers to the follow-up between the phases and way the different phases of care are integrated into one process (Tronto, 1993).

The research also will use Niehof's (2004) micro-ecological approach to health, in which Tronto's phases of care are incorporated. She applied the approach to home care for AIDS patients in Sub-Saharan Africa. The phases in the process of care are gendered. Care giving also requires the mobilization of resources, while women's access to and control over resources are frequently severely constrained. Although the household is taken as the level of analysis, it is seen as embedded in an environment where it interfaces with many other structures and institutions. These institutions or structures can either provide direct support to households or provide access to resources needed for care provision. The capacity of households to produce health and provide adequate care is affected by characteristics such as headship (male or female), size, and composition (dependency ratio). Outcomes of care can either be subjective, such as satisfaction with care or can have measurable health effects, which can be positive or negative. Tronto's framework for assessing care was also used by Keasberry (2002) in her study on elder care in Indonesia.

Home-based care, is another concept relevant to this research, and is described by the World Health Organization (WHO) as the provision of health services by both formal and informal care givers in the home. The increasing need for health care and spiraling costs led to the trend and necessity to treat patients in the home. The WHO recognizes that the burden of care giving within the home is primarily on women, who often have little access to or control of the resources needed to assume this responsibility. Well-managed care can improve the quality of life of patients, which also applies to palliative care (WHO, 2005a; DOH, 2002a). Other formal models of care exist, including the following:

- Community-driven model,
- Formal government sector model,
- Integrated home/community based care centre model,
- NGO home/community-based care model, and
- Integrated community and home-based care model.

All of the above mentioned models include the positioning, relative importance, and relationships between each of the following: the family, people living with AIDS and the broader community (usually grouped together), the health sector (hospitals and clinics) and social development form part of all the models, while some models also include education, the business sector, employers and other care providers such as the hospice, and non-government and community-based, and faith-based organisations (NGOs, CBOs and FBOs) (DOH, 2002).

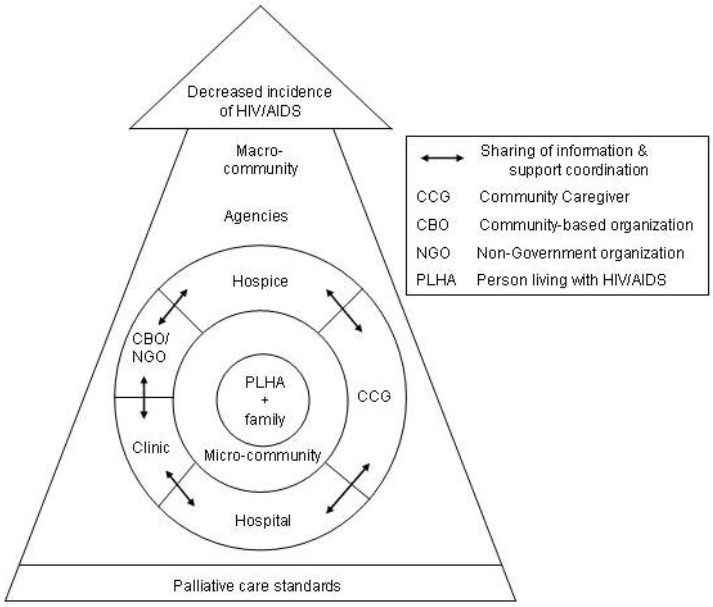


Figure 2.2 The integrated home-based care model (Source: Uys, 2003)

Community-based care is described as care provided at a patient's home to supplement or replace hospital-based care. It includes management of medication, palliative care and social support. If care is to be comprehensive and cost-effective, it must be conducted as much as possible in the community with hospitalisation only when necessary. The model that will be used as a point of departure in this research is the integrated home-based care model, depicted in Figure 2.2. The models shows how all the service providers are linked with patients and their families in a continuum of care. In this way, the model visualizes how mutual support and collaboration between different components or care providers (families, community care givers, clinics, hospitals, support groups, non-governments organisations, and community-based organisations) can be enhanced. This system allows for referral between all partners as trust is built and it develops capacity in all partners. Figure 2.2 depicts one model of care of this nature. It illustrates the central position of the person living with HIV/AIDS, the family, and the small network around the patient. This small group is supported by the large and growing network of services, and should also be supported by the larger community. All the care should be based on palliative care standards (Uys, 2003).

2.5 Conceptual framework and operationalisation

Conceptualisation

The conceptual framework presented below (see Figure 2.3) includes all the concepts relevant to this research and illustrates the relationships between the concepts.

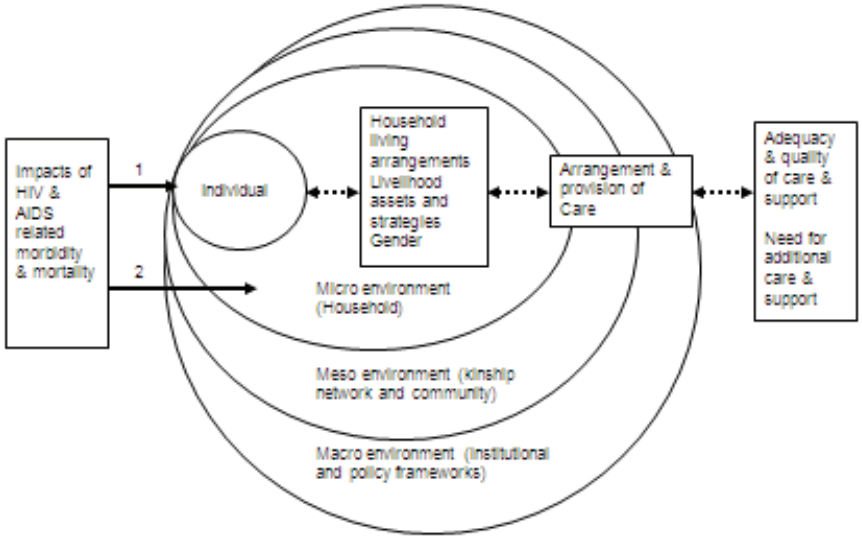


Figure 2.3 Conceptual framework

The household, the micro-environment consisting of a group of individuals, is dynamic and embedded in a broader meso- and macro-environment. The meso-environment comprises the kinship network, neighbours, other community members, NGOs and community-based organisations, and local-level health and education institutions, without which the household cannot properly function. These are part of the broader social, economic, natural and political environment, the macro-environment, of which the policies and institutions guide and affect the functioning of the micro- and meso-environment. The model further illustrates the direct and/or indirect impact of HIV and AIDS-related illness (morbidity) and death (mortality) on the household as a unit and its individual members. It is within this environment that households, the unit of analysis in this research, have to arrange care for people living with HIV and AIDS (PLWHA) and for orphans and vulnerable children (OVC). The adequacy and quality of care will depend on the livelihood security of the household and in turn may increase the vulnerability of household livelihood. To achieve a certain degree of well-being, households and individuals within households develop strategies to achieve a positive outcome, unfortunately outcomes can turn out to be negative, which in this case may be inadequate or poor quality care. The households remain to a more or lesser extent dependent on the environment for care and support.

Operationalisation

The operational definitions of selected concepts used in the research are summarised in Table 2.1.

Table 2.1 Operational definitions

Concept	Operational definition
Household composition or structure	The people living together at the homestead, at a specific point in time, and how they are related to head of the household. Has a boundary, but a fluid one.
Living arrangements	Emphasizes the dynamic nature of the household and changes in household structure over time. Who joins/leaves households and reasons for joining or leaving.
Household head	The person perceived by the household members to be the head the household, usually the main decision maker.
Kinship	The broader network of extended family or relatives within which the household is embedded and the rules that apply to relations between kin, within the patrilineal kinship system that prevails in rural Kwa-Zulu Natal.
Homestead	Refers to the physical location of the household, or where those perceived to be members live. It may consist of several living units and usually has a boundary.
Livelihood	Refers to how the household in this case generates a living, the activities they engage in and the resources they have access to and use.
Care	Anything and everything done for a person that s/he usually does for her/himself but as a result of illness now are done by someone else.

Chapter 3

Research design and methodology

This chapter provides a description of how the research was structured and the data collected to meet the objectives of the study. In the first part of the chapter the research design is discussed, with specific reference to the benefits of combining quantitative and qualitative methods and using a longitudinal approach. This is followed by a discussion on the household as the main unit of analysis with data collected at the level of the individual and the household. In the section on the research procedure, the orientation phase with reference to the selection of and gaining access to the research site is discussed, as well as the recruiting and training of research assistants.

The section on data collection provides a description of all the methods and techniques used to collect quantitative and qualitative data and overview of sources of secondary data. Key informants were interviewed to collect background information, aid development of data collection instruments and to clarify and verify tentative research results. In addition to this, several community health workers (CHW) and home-based caregivers (HBC) were interviewed and observed to collect information of care-related activities. The section on the descriptive survey includes information on sampling of households, development and testing of the questionnaire, a profile of respondents, and a follow-up telephone survey. Following this, the purpose the case studies, the selection of case study households, and the collection of case study data is discussed. A profile of focus group participants and topics discussed are also provided. This is followed by sections describing the management and analysis of quantitative and qualitative data, and validity and reliability. The chapter ends with a discussion on methodological challenges and ethical considerations relevant to the research.

3.1 Research design

Combining quantitative and qualitative methods

HIV/AIDS research is dominated by the use of survey methods and quantitative data collection. Reviewing 36 impact studies published between 1994 and 2000, Booysen and Arntz (2003) only found 11 that also used qualitative methods of data collection, such as focus groups and in-depth-interviews. According to them there is scope for more impact studies to be conducted in high prevalence areas and although large studies have more statistical power, smaller in-depth studies can be equally valuable. Barnett and Whiteside (2006) also indicated that household surveys do not collect data on complex relations between what they referred to as clusters of households. A combination of quantitative and qualitative approaches when collecting data, is advocated by various authors. According to DFID (2000), combining of approaches presents one way in which impact assessment can be more successfully attempted. Scrimshaw (1990) made a plea for combining approaches, where qualitative methods can enhance accurate measurement of actual rather than ideal behaviour as well as accurate understanding of the meaning of the behaviour. Scrimshaw (1990) also perceived the usefulness of qualitative methods in exploring sensitive topics to be one of its strengths. A combination of approaches also enhances both reliability and validity (Scrimshaw, 1990; Niehof, 1999). One can thus assume that qualitative

methods can complement survey-based studies and be especially useful in the study of a sensitive issue like HIV/AIDS.

This research followed a combination of qualitative and quantitative approaches to capitalise on the advantages of both. A first qualitative phase of key informant interviews served to identify the research site, to collect background information on the research area and research population, and to inform survey design. This was followed by a quantitative phase during which individual and household data were collected by means of a descriptive survey. A final comprehensive qualitative phase followed during which in-depth case study data were collected, focus group discussions (FGDs) conducted and additional key informants interviewed. The implementation of approaches and purpose of different methods are discussed in more detail in Section 3.4 of this chapter.

The longitudinal approach

"Longitudinal data can only be obtained when a population or population segments is followed through time, which requires access to a continuous flow of data", say Pennartz & Niehof (1999:151). According to them longitudinal research is appropriate for the study of a process. Barnett and Whiteside (2006) also described the impact of HIV/AIDS as it occurs over time and as a process rather than an event. Based on a review of 32 studies, Naidu and Harris (2005) expressed the need for further multi-disciplinary and longitudinal household-level research to assess the full and varied impacts of HIV/AIDS over time. In their study on HIV and AIDS impacts on households in rural Uganda, Seeley et al. (2008) illustrate how in-depth longitudinal research with a small number of households can explain results from quantitative research. While the quantitative analysis did not show the significant association between poverty and HIV-status that was expected, the qualitative research among 26 households could explain why. The support from other family and community members revealed in the qualitative research proved to be a major explanatory factor. Networks of kin and friends and links with people outside the household in general are important for understanding HIV and AIDS impacts. Similarly, Drinkwater et al. (2006) in their study on the effects of HIV and AIDS on agricultural production systems in Zambia identified clusters of households and showed how the links between different households in terms of making their livelihoods were influenced by HIV and AIDS.

Although this research is not an example of an impact study, nor an example of a true longitudinal study, it did illustrate that depending on the timing of data collection and household visits, impacts of AIDS on individuals and households are visible over periods of less than one year. By asking retrospective questions as part of the survey and doing a follow-up telephone survey to update data on morbidity and mortality, changes in household composition are illustrated. This is further supported by case study data where selected households were visited two to three times over a period of six months and the impact of HIV and AIDS on living arrangements and livelihood generation is revealed.

3.2 Unit of analysis

The household was selected as the unit of analysis for this research with data collected at the level of the individual and the household. According to Lipton et al. (1996), individuals in rural areas are generally organised into households and very few live alone or even as nuclear families. Niehof (1998) also indicated that rural people's livelihoods are shaped and built in the context of the household. Barnett and Whiteside (2006) emphasised that HIV/AIDS as a heterosexually transmitted disease frequently clusters in households. Although the household was the unit of analysis in this research, inter-household relations

were part of the analysis (cf. Drinkwater, 2003). Household headship and household membership was as perceived by respondents.

3.3 Research procedure

Orientation

After completing the research proposal the exact research site had to be identified and the research introduced and discussed with community representatives. For this purpose a few key informants were identified and interviewed and the Mbonambi local municipal area identified as the research site. Mbonambi was selected as it is characterised by a high HIV prevalence and varied livelihoods. Also see Section 3.4.2 for more information on sampling. Following the interviews, one of the key informants, a teacher and respected member of the Mbonambi community, made an appointment with the local tribal authority to discuss the research plans with the *indunas* (headmen). An abbreviated version of the research proposal was made available to the *indunas* for perusal prior to the meeting. The first attempt at a meeting failed due to a death in the family of one of the *indunas*, but another appointment was secured for one week later. At the meeting the researcher was introduced to the *indunas* and the nature of the research explained by the representative of the community. The *indunas* were then given the opportunity to put questions to the researcher to which the researcher responded. They all supported the research as they perceived HIV/AIDS to be a major problem in their community. Approval of the project was minuted and the *indunas* undertook to inform the community.

Recruiting and training of research assistants

One third-year Psychology, one third-year Social Work and five final-year undergraduate Consumer Science students registered at the University of Zululand were recruited to do the survey interviews. Because of the nature and level of their study, the three male and four female students all had some experience working with local communities. To be eligible, students had to be fluent in *isiZulu*, the native language of the research population, had to have a friendly personality, had to have at least one free day per week during the third term of the academic year, and had to be willing to work during their one-week Spring break. Students also had to agree to undergo training and adhere to ethical considerations, such as protecting the privacy of respondents.

A first training session at the University of Zululand was organised where assistants were provided with some background on the research project and the research population. The procedure to be followed was explained, that on arrival they would meet with a representative from the community to accompany them to the households and introduce them to the household head and/or other household members, after which s/he had to explain the purpose of the interview and identify the most suitable individual(s) to be interviewed. Assistants were given a copy of the survey questionnaire prior to training to familiarise themselves with the nature and phrasing of questions. General interviewing and probing techniques were discussed and questions raised by assistants addressed. The second and third day of training consisted of pilot work in the field under supervision of the researcher (also see 3.4.2 *Pilot testing of questionnaire*). The researcher accompanied each assistant on at least one interview, giving some pointers during interviewing and making notes of changes to be made to the questionnaire and issues to be discussed during follow-up training. The fourth day of training took place at the University with feedback from the pilot work, from the researcher and assistants, and additional interviewing instructions discussed with all assistants. A schedule was prepared, depending on the availability of

assistants, for the collection of the survey data over a period of 10 weeks, where two to four assistants at a time would go to the research on selected days.

After completion of the survey two of the initial research assistants were selected, based on their performance and availability, to assist with interviews, case study research and focus group discussions. They were given additional training on in-depth interviewing, observation, taking field notes, transcribing audio recordings and facilitating focus group discussions.

3.4 Data collection

Data collection was done in four phases and several methods and techniques were employed to collect quantitative and qualitative data. Table 3.1 provides an overview of the data collection phases. The duration of phases indicated in Table 3.1 does not reflect time spent on the development of data collection instruments prior to each phase.

Table 3.1 Overview of data collection phases

Phase	Duration	Approach	Purpose	Methods (techniques)	Data collected
I	2 months	Qualitative	Explore	Key informant interviews (semi-structured interview schedules)	Identification of research site. Background on research site and research population.
II	3 months	Quantitative	Describe	Survey (interviews following structured questionnaires)	Individual and household demographic, socio-economic and health data
III	6 months	Qualitative	Describe & explain	Case studies (in-depth interviews & observation) In-depth interviews and observations of CHWs and HBCs (semi-structured interview & observation schedules)	Living arrangements and livelihood generation. Household, community and institutional arrangement of care
IV	1 month	Qualitative	Explain & explore	Focus group discussions (pre-determined topics) Key informant interviews (semi-structured interview schedules)	Verify and clarify preliminary survey and case study findings. Explore potential socio-cultural impact of HIV/AIDS.

3.4.1 Key informant interviews

Key informant interviews were conducted as part of all the qualitative data collection phases. The purpose of the first phase was exploratory and key informants interviewed included an extension officer, social work, teacher, and managers of care projects and care facilities. The purpose of the third phase was descriptive and explanatory and specifically focused on care arrangements and included 11 interviews with community health workers (CHWs) and home-based caregivers (HBCs). During the final qualitative phase key informant interviews were conducted with the manager of the public health clinic and a specialist on Zulu culture to explain preliminary findings and explore the potential socio-cultural impact of HIV/AIDS. Semi-structured interview schedules were used to conduct the interviews.

Interview schedules used during the first qualitative phase, although adapted for each individual, included the following broad topics:

- Nature of work of interviewee and organisation s/he represents.
- Problems encountered in the community with reference to different gender and age groups.
- Community response to problems and resources available.
- HIV/AIDS as a problem and its impact on individuals, households and the community.
- Community response to HIV/AIDS and resources to mitigate impact.
- Personal and organisational experience of the impact of HIV/AIDS and response of the organisation to HIV/AIDS and other problems.
- Household and community arrangement of care for PLWA and OVC and information on individuals and organisations involved.
- Referrals to other individuals or organisations relevant to the research.
- Specific questions on the target population management of the organisation based on responses to general questions.

The key informants interviewed during the final stage were asked specific questions based on the preliminary findings of the survey and the case studies. The aim was to seek clarification and verification of some of the findings as well as to collect additional information on the potential socio-cultural impact of HIV/AIDS. All key informant interviews conducted during phase one and four were recorded and transcribed as soon as possible after the interview by research assistants.

Interviewing and observation of CHWs and HBCs

The interview schedule developed for the interviews with the CHWs and HBCs was more structured for two reasons, first to ensure that similar extensive data were collect for all of them, and second as the majority of interviews were to be conducted by research assistants. The interviews with the CHWs and HBCs had a dual purpose, first to provide a detailed description of the nature of their work, and second to explore their role in the arrangement of household and institutional care for PLWA and OVC. The interview schedule included the following questions and topics for discussion:

- Biographic information.
- Geographical area covered, working hours and initial and further training.
- Identification of PLWA and OVC and nature of their work with them, including home visits and work with patients, school visits, support groups and other activities.
- Supervision of their work.
- Needs and problems experienced.
- Support received and additional support required.
- Working relationships with other health care workers and institutions.

In addition to the interviews, one HBC and four CHWs were accompanied on home visits and observations recorded during these visits. Non-participant observation was done following an observation checklist which included the following:

- Duration of visit.
- Assessment of the person visited, as done by the CHW or HBC.
- Care-related activities carried out by CHW/HBC.
- Specific reference to medication and alternative treatments.
- Role of other person(s) present during the visit.
- Interaction between CHW/HBC, care receiver and other person(s).

Raw field notes containing observations were converted to more organised write-ups by the two assistants.

3.4.2 Descriptive survey

Sampling

The Uthungulu district, one of 11 in the KwaZulu-Natal province, was selected for its high HIV prevalence, the researcher's familiarity with the area, and its convenient location close to the home and place of work of the researcher. The district consists of six local municipal areas and Mbonambi was selected on the advice of the extension worker as access and safety was an issue in the other areas. Mbonambi, consisting of 13 wards, also provided a mix of urban and non-urban areas. Two wards were purposively selected based on criteria such as population density, infrastructure and economic activity. Ward 5 was selected for its location close to the big town of Richards Bay, high population density and relatively good infrastructure in terms of access to water, electricity, transport and health care. Ward 3 was selected for its location further from town, its lower population density, and its poorer infrastructure in terms of access to water, electricity, transport and health care.

Clusters of households were targeted with assistants moving from household to household in an area. If they found a suitable responded the household was included in the survey, if the head or another suitable adult to interview was not present they moved on to a next household. Between 12 and 24 interviews were conducted by assistants on a day before moving to a next cluster on a following day. A total of 354 households were surveyed, 137 in Ward 3 and 217 in Ward 5. Fewer households were surveyed in Ward 3 as households were more dispersed and difficult to access due to poor quality of roads, whereas the majority of households in Ward 5 were concentrated along the main access roads to the area.

Questionnaire

A questionnaire was developed to collect demographic, socio-economic and health data at the level of the household and, for some variables, at the level of the individual. The data were collected by means of interviews, as some respondents were not sufficiently literate to warrant a self-administered questionnaire and to ensure that all questions were answered. The questionnaire started with concrete, easy-to-answer questions, moving to questions at a more abstract level and of a more sensitive nature. The majority of questions were closed-ended and pre-coded. The questionnaire also included some retrospective questions on changes in household composition, morbidity and mortality. The following categories of questions were covered:

- General information (respondent details, location of the household and information about the perceived head of the household and household size),

- Demographic data, collected at the individual level, by means of a completing a household roster (name, relationship to head, sex, age, marital status and education),
- Socio-economic data collected both at the individual and household level (formal and informal employment, government and private grants, household income and assets, housing and access to land, and services and infrastructure),
- Health data collected at the individual and household level (health status, chronic illness, acute illness, treatment, access to and utilisation of medical facilities, care requirements and medical expenditure), and
- Changes in household composition and reasons for changes, retrospective questions on death(s) experienced by households and household needs and problems.

Pilot testing

The questionnaire was pre-tested during the field training of the research assistants. A few questions were rephrased to improve clarity and additional instructions added for interviewers. During testing the researcher also realised the household questionnaire was not suitable for persons living on their own, and an adapted version was developed for single-person households.

Interviewees

Table 3.2 Demographic profile of survey interviewees (N=354)

Variable	Ward 3 (n = 137) n (%)	Ward 5 (n = 217) n (%)
Gender		
Male	31 (22.6%)	53 (24.4%)
Female	106 (77.4%)	164 (75.6%)
Age		
15-24	20 (14.6%)	39 (18.0%)
25-34	27 (19.7%)	62 (28.6%)
35-44	29 (21.2%)	34 (15.7%)
45-54	14 (10.2%)	33 (15.2%)
55-64	21 (15.3%)	19 (8.7%)
65+	26 (19.0%)	30 (13.8)
Relation to head		
Head	64 (46.7%)	87 (40.1%)
Partner	38 (27.7%)	67 (30.9%)
Child	26 (19.0%)	38 (17.5%)
Other relative	9 (6.6%)	23 (10.6%)
Non-related person	0 (0%)	2 (0.9%)
Level of education		
No schooling	17 (12.4%)	30 (13.8%)
Some primary schooling	52 (38.0%)	64 (29.5%)
Primary school completed	8 (5.8%)	18 (8.3%)
Some secondary schooling	35 (25.5%)	62 (28.6%)
Secondary school completed	16 (11.7%)	28 (12.9%)
Some post-secondary education	4 (2.9%)	6 (2.8%)
Not applicable, attending school	5 (3.6%)	9 (4.1%)

Preference was given to interview the head of the household, but where the head was not available for interviewing research assistants interviewed the partner of the head or identified a suitable adult household member, preferably a child of the head, to be interviewed. Where other relatives or non-related persons were interviewed, they had to be older than 16 and had to be a member of the household. Table 3.2 provides a demographic profile of the survey interviewees.

Follow-up telephone survey

In January 2007, approximately three months after the initial survey was conducted all the households for which a telephone number was available were called with the purpose of following-up on selected survey questions. Since the survey included retrospective questions on morbidity, mortality, household composition changes and nursing care covering the first nine months of 2006, the follow-up telephone survey attempted to collect additional data on the same questions for the last three months of 2006. The following were included:

- Persons diagnosed with TB or testing positive for HIV in the three months following the survey.
- Deaths experienced and cause of death.
- Household members requiring nursing care.
- Maternal orphans joining the household.
- Other changes in household composition as a result of persons leaving or joining the household.

All respondents for whom telephone numbers were available were called, reminded of the survey they participated in the previous year and asked if they were willing to answer a few follow-up questions. The majority of respondents had access to a mobile/cell phone at the homestead (83,6%) with a few having access to a land line at home or at work. Assistants were unable to reach 24.0% of respondents after dialling their numbers at least three times while 2.0% of respondents refused to provide any further information. In the end the additional data were collected for 59.9% of all the households participating in the initial survey. The results of the follow-up telephone survey are reported separately at the end of Chapter 5 and not incorporated with the initial survey results, as the additional information could not be obtained for all of the 354 households included in the initial survey.

3.4.3 Case studies

According to Yin (1994:2) the case study method is especially useful when ‘how’ and ‘why’ questions are being posed, when there is little control over events and when the focus is on a contemporary phenomenon within a real-life context. Yin further indicated that it is a strategy arising from the desire to understand complex social phenomena while allowing an investigation to retain the holistic and meaningful characteristics of real-life events. Although according to Yin (1994:10) one cannot generalise to a population or a universe case studies can generalise to theoretical propositions. It does not represent a sample and the goal is to expand and generalise theories not to enumerate frequencies, thus analytic generalisation and not statistical generalisation. From Yin’s comments on the use of case studies outlined above the motivation for its use to meet the objectives of this research is clear. In this research case studies were used to describe and seek explanations for household living arrangements, livelihood generation and care arrangements as well as explore HIV/AIDS-related inter-household living and care arrangements of PLWA and OVC.

Table 3.3 Overview of Case Study Households

Case no	HH* size	Sex & age of HH head	Socio-economic position of HH	Health status and care needs of HH
Households neither affected nor afflicted by HIV/AIDS (Chapter 6)				
1	6	F (60)	High income and many assets	Good health
2	6	M (58)	Low income and few assets	Non-HIV/AIDS related health problems
3	10	M (50)	Very high income and many assets	Excellent health
4	9	F (65)	Average income and many assets	Social rather than health problems
5	5	M (68)	Low income and some assets	Non-HIV/AIDS related arrangement of nursing care
Households afflicted by HIV/AIDS (Chapter 6 & some again in Chapter 7)				
6	12	F (66)	Low income and few assets	HIV+ adult women
7	4	F (47)	Very low income and few assets	Adult women with AIDS, inter HH arrangement of care
8	4	F (31)	Low income and some assets	Child with AIDS, inter HH & community arrangement of care
9	10	M (51)	Low income and some assets	Young women with AIDS, intra HH arrangement of care
10	1	F (23)	Very low income and very few assets	Single woman with AIDS, role of neighbours in care
Households affected by HIV/AIDS (Chapter 6)				
11	8	F (64)	Low income and some assets	Young aunt and grandmother caring for three orphans
12	3	F (39)	Very low income and few assets	Unrelated caregiver living with two orphans
13	2	M (17)	Very low income and some assets	Two young orphaned brothers living together
14	5	F (55)	Average income and many assets	Multiple deaths, one due to AIDS-related illness
Households affected and afflicted by HIV/AIDS (Chapter 6 & some again in Chapter 7)				
15	11	M (46)	Average income and few assets	HIV+ grandparents caring for orphaned granddaughter
16	4	M (59)	Very low income and some assets	HIV+ grandfather and wife caring for orphaned grandchildren.
17	15	F (58)	Low income and few assets	Ill grandmother caring for seven orphans, several HH members with TB
18	9	F (54)	Low income and some assets	AIDS-related illness and death, intra-HH arrangement of care
19	5	M (72)	Low income and few assets	AIDS-related illness and death, inter-HH arrangement of care
Additional cases on arrangement of care (Chapter 7)				
20	3	M (44)	Low income and few assets	AIDS-related illness and death, care provided by male partner
21	3	F (40)	Average income and some assets	Female head with AIDS cared for by male partner and daughter
22	9	F (65)	Average income and some assets	Young adult male with AIDS-related illness, cared for by mother
23	1	M (31)	Average income and no assets	Single man with AIDS, role of neighbours in care

*HH=household

Selection and accessing of households

Potential case study households were identified from the surveyed households, deliberately seeking variety for purposes of comparison, using the following criteria:

- Household size.
- Sex and age of household head.
- Socio-economic position of household in terms of income and assets.
- Health status and nursing care needs (which determined whether and how households were affected by HIV/AIDS and Tuberculosis).

Several households were identified after scanning the survey questionnaires as potential case studies. Final selection was done with the assistance of CHWs and HBCs as only households known to them were included. This was necessary as they were vital in gaining access to the selected households considering the potential stigma associated with HIV/AIDS. Case study households were visited twice over a period of six months following the collection of survey data to update survey data and to collect additional qualitative data on living arrangements, livelihood generation and care arrangements. Afflicted households where nursing care of PLWAs was observed were visited three times over the six-month period. Table 3.3 provides an overview of the 19 cases discussed in Chapter 6 on living arrangements and livelihood generation. Further discussion of some of the cases outlined in Table 3.3, together with additional cases, follows in Chapter 7 on arrangement of care for PLWA and OVC.

Interviewing

Survey data were up-dated on a copy of the questionnaire completed during the descriptive survey. Changes in household composition including reasons for changes were documented and individual data on education, employment and health updated. Data on household income, sources of income, and assets were also updated. In addition to this in-depth interviewing was done to collect data on the following:

- Household division of labour, including domestic activities, provision of child, elder and nursing care, and agricultural and/or horticultural activities.
- Genealogical data covering kin relations of the household head and where applicable his/her partner and children.
- Arrangement of care for PLWA and OVC (where relevant).

The second visit was also used to update survey data and information collected during the first visit. In addition to this data on nursing care of PLWA were collected from HIV/AIDS afflicted households. Collection of data on nursing care necessitated a third visit to five of the households afflicted by HIV/AIDS. Interview schedules used to collect data on nursing care included questions on primary and secondary caregivers, care decisions, activities, resources, problems experienced, and support needed. Nursing care beyond the boundaries of the household was also covered, exploring the role of non-household family members, neighbours, friends, other members of the community, and health care workers.

Observation

Non-participant observation was used to collect additional information on livelihood generation, including observation of household access to and utilisation of resources, services and infrastructure, and condition of housing and immediate environment. Observation was also used to collect additional information on nursing care of patients with AIDS-related illnesses. A detailed observation schedule was developed for the latter providing spaces for recording the following information:

- Person perceiving the need for care.

- Person executing the care activity.
- Description of the activity.
- Duration of the activity.
- Resources used (human and material) and problems experienced during execution of the activity.
- Outcome of the activity and satisfaction of caregiver and care receiver.

In addition to the observation done for a limited period of time during the day, primary and secondary caregivers were asked about the frequency of activities over a period of 24 hours and additional activities not observed during the visit.

3.4.4 Focus group discussions

According to Morgan (1997) the aim of a focus group discussion is to allow a group to interact, to compare thoughts and experiences, based on topics supplied by the researcher and where the researcher's role is that of facilitator and moderator. Focus groups can be used on their own as a source of data or information, or in combination with other methods such as observations and interviews with each contributing something unique to the researcher's understanding. It can be the source of preliminary data in a primarily quantitative study as the basis for generating survey questions or as a follow-up to pursue poorly understood survey results. Groups can be natural, existing groups, or focused where participants are selected and invited to a discussion. In this research focus group discussions were used to complement data collected using other tools and to enhance understanding of findings. Focus group discussions were used to verify and clarify preliminary survey and case study findings and to explore the potential socio-cultural impact of HIV/AIDS.

Four focus group discussions (FGDs) were conducted with different sex and age groups. Participants were selected and invited with the assistance of a Community Health Worker and her young male assistant after explaining the purpose of the FGDs and selection criteria for participants with them. Each participant was compensated for travel costs and lunch was provided at the end of each discussion. A profile of focus group participants is provided in Table 3.4.

The same topics were covered in each of the discussions, although appropriately phrased for each sex and age group. Focus group discussions were conducted after completion of the descriptive survey and case studies with the dual purpose of clarifying and verifying preliminary findings and to collect additional information on the potential socio-cultural impact of HIV/AIDS. Discussions started with a general discussion on cultural practices and traditions, roles and obligations of different age and gender groups, challenges faced by the community and community response to challenges, with specific reference to HIV/AIDS. This was followed by the introduction of specific topics for discussion which emerged from preliminary findings, where these did not come up during the general discussion. Specific topics for discussion included the following:

- Marriage and bride price (polygamy and *ilobola*).
- Division of domestic work.
- Living arrangements.
- Acquiring and inheriting of land and property.
- Decision-making within the household.
- Household headship.
- Rituals associated with initiation into adulthood.
- HIV/AIDS – stigma, nursing care and consulting of spiritual and traditional healers.

Table 3.4 Profile of focus group participants

Characteristics of participants	Group and number of participants			
	Group I Young men (n=10)	**Group II Young women (n=9)**	**Group III Older men (n=6)**	**Group IV Older women (n=6)**
Mean age	22.5	22.2	67.2	69.3
Marital status				
Never married	10	9	-	-
Married	-	-	6	4
Widowed	-	-	-	2
Level of Education				
No formal schooling	-	-	-	4
Some Primary	-	-	3	2
Primary complete	-	-	2	-
Some secondary	-	3	1	-
Secondary complete	7	4	-	-
Post secondary qualification	3	2	-	-
Employment status				
Employed	3	2	-	-
Unemployed	7	7	2	1
Pensioner	-	-	4	5

Two research assistants were trained to facilitate the discussions, one acting as facilitator and the other as moderator, recording observations on non-verbal communication. The duration of each FGD was approximately two hours. All discussions were conducted in *isiZulu*, recorded on audio tape with the consent of participants and transcribed jointly by the facilitator and moderator.

In addition to the FGDs referred to above the researcher and assistants were also able to attend HIV/AIDS support group meetings as well as monthly meetings of CHWs and HBCs held at the local public health clinic. This provided the researcher of additional data and allowed for the clarification and verification of data collected as part of the survey and case studies.

3.4.5 Secondary data

In South Africa there is a wealth of data from a variety of national and international sources available to complement empirical data. Several of these sources are identified and their usefulness outlined by Barnett and Whiteside (2000) who encourage the use of existing data where available. Secondary data for this study were obtained from various sources as outlined in Table 3.5. This is not an exhaustive list. Although an attempt was made to obtain data at the local level on HIV prevalence, AIDS related illness and deaths, and access to treatment, it was unsuccessful.

Table 3.5 Overview of secondary data sources

Study	Year	Source	Level*				Data
			N	P	D	L	
Community survey	2007	Statistics South Africa	x	x	x	x	Demographic & socio-economic
General Household survey	2002 to 2007	Statistics South Africa	x	x	-	-	Demographic, socio-economic and health
Quality of life survey	2003 to 2007	Uthungulu District Municipality	-	-	x	x	Demographic, socio-economic
HIV & Syphilis survey	2000 to 2007	National Department of Health	x	x	x	-	HIV/AIDS
Report on global AIDS epidemic	2002/4/6/8	UNAIDS	x	-	-	-	HIV/AIDS
Demographic impact of HIV/AIDS in SA	2006	Actuarial Society of South Africa (ASSA)	x	x	-	-	HIV/AIDS, treatment and orphans

*Level: N=National, P=Provincial, D=District municipality, L=Local municipality

3.5 Data management and analysis

Management and analysis of quantitative data

Questionnaires were checked by research assistants under the supervision of the researcher at the end of each day for unanswered questions or incomplete responses. Research assistants either corrected these on the spot or where necessary returned to the households to correct or complete responses. All the closed-ended questions in the survey questionnaire were pre-coded, while open-ended questions were coded on completion of the survey preceding data entry. Where relevant, coding was done in line with the system followed by Statistics South Africa. This was done to enhance comparison of survey findings with census and survey data collected by Statistics South Africa. Illnesses were classified according to the International Classification of Diseases, ICD-10 (WHO, 2007). Data were entered on a spreadsheet by the researcher and exported to SPSS 15.0 for analysis of the data. With the main aim of using survey findings to describe the research community and to identify case study households, only limited statistical analysis was done.

Management and analysis of qualitative data

Interviews with key informants and focus group discussions were recorded on audio tape and transcribed by research assistants. All other interviews and observations were captured as extensive field notes and re-written by assistants as write-ups (cf. Welman et al., 2006). Most of the qualitative data were analysed manually according to themes after which information from different sources were compared. ATLAS.ti was used to code and create network displays of case study data collected by means of in-depth interviews (cf. Babbie and Mouton, 2001).

3.6 Validity and reliability

Although quantitative and qualitative research aim at producing reliable and valid results, quantitative research focuses more on reliability, while qualitative research focuses more on validity, where reliability refers to the consistent and stable measurement of data and replicability, and validity to the objective of the study being representative of what the researcher is investigating (Welman et al., 2006). Whereas quantitative data were used to describe the community from an outsider's or etic perspective, qualitative data were used to create a better understanding of, and to attach meaning to findings from an insider or emic point of view.

The survey questionnaire was designed with the inputs from key informant interviews and pilot tested to enhance reliability. In addition to this the questionnaires were completed by means of interviews conducted by trained assistants. Survey results were also verified and clarified by means of focus group discussions.

Triangulation is generally considered to be one of the best ways to enhance validity and reliability in qualitative research, with extensive field notes another (Babbie and Mouton, 2001). Triangulation in this research was done by collecting similar data from different sources (i.e. key informants, households and secondary data) and using different instruments to collect data from one source (i.e. interviewing and observation). In addition to this, two trained assistants or the researcher and one trained assistant always worked together to verify data collected by the other.

3.7 Challenges and ethical considerations

Methodological challenges

For various reasons HIV/AIDS research is methodologically complex (Wiegers, 2008). Conducting research in a language that is not your own is not an easy task and working with assistants has some disadvantages as some information gets lost and some interpretations are made during the translation from English to *isiZulu* or the other way around. It also resulted in what should have been open, unstructured interviews frequently becoming very structured to ensure that all the necessary questions were asked and observations done. Repeat visits to households to a certain extent made up for this drawback as matters not fully explored during one visit could be followed up on during a next visit.

A major problem is identifying AIDS impacts as distinct from other factors that impinge on rural livelihoods. This problem of 'inadequate impact attribution' (Murphy et al., 2005: 270) is particularly urgent in cross-sectional surveys that use proxy indicators for HIV-infection and where control households are lacking. In this study TB was used as a proxy indicator for HIV/AIDS in the classification of surveyed households based on whether and how they are affected and/or afflicted by HIV/AIDS and/or TB. It is estimated by the World Health Organisation (2007) that up to 80 percent of persons with TB, in high HIV prevalence countries, also test positive for HIV. In the selection of case study households TB was not used as a proxy indicator and only households where a member(s) was/were known to be HIV-positive of suffering from AIDS-related illness and where deaths and orphanhood could be attributed to HIV/AIDS were included. In addition to this, for purposes of comparison, control households, or households neither affected nor afflicted by HIV/AIDS were also included.

The survey questionnaire was not translated into *isiZulu* which allowed for variation in translation of questions by different assistants. Generalisability of survey findings is limited as a result of the method of sampling employed by the researcher, but the relative

large sample size partially compensates for the bias which occurred in the selection of households. In addition to this it should be emphasised that the aim was not to generalise to the whole district or beyond, but to describe the characteristics of those included in the survey.

Ethical considerations

The research was carried out with the approval of the local authorities and this guaranteed full cooperation from the community. Households and individuals were approached with the assistance of representatives from the community and/or health care workers. The researcher and research assistants were always introduced to the household by the field assistants, after which the research was explained to potential respondents. Participation was voluntary and informed consent was obtained verbally from all respondents before research assistants proceeded with interviews and observations.

In the research report privacy of all participants is protected by using pseudonyms. However, when visiting households, it was not always easy to ensure confidentiality and protect privacy as members of the community knew who we were and that we were conducting HIV/AIDS-related research. This was though not a problem for the majority of participants.

Chapter 4

Study area and context

This chapter sets the scene for the research by providing an overview of the country, province and research location. It also provides essential information on social development and health and sketches the policy environment.

4.1 South Africa

Diversity is the best adjective to describe the people, cultures and natural heritage of South Africa. The surface area is 1,219,090 km^2 and the country shares borders with Namibia, Botswana and Zimbabwe, while Mozambique and Swaziland lie to the north-east. Completely enclosed by South African territory in the south-east is the mountain kingdom of Lesotho. To the west, south and east, South Africa borders on the Atlantic and Indian oceans.

According to the mid-year population estimates for 2009, there are 49.3 million people living in the country, 52 percent of whom are female. Of the population 79.3 percent classified themselves as African (Statistics South Africa, 2009). The most common of the eleven official languages spoken in the country is isiZulu.

The political dispensation of South Africa changed with its first democratic elections in 1994, won by the African National Congress by a large majority, under an interim constitution. The new Government, in spite of many hurdles, scored well in various areas of socio-economic development, such as provision of housing, potable water, electricity and rural health care. In terms of the new constitution of South Africa of 1996, the Republic of South Africa was divided into nine provinces, in contrast with the four provinces and ten homelands that existed previously. Each of the nine provinces has its own Legislature, Premier and Provincial Members of Executive Councils. The nine provinces each feature their own distinctive landscapes, vegetation and climate.

South Africa is a middle-income developing country with an abundant supply of natural resources, well developed financial, legal, communication, energy and transport sectors and modern infrastructure. At the same time, the challenges which the country faces are to create a strong and balanced economy in order to eliminate poverty, develop a dynamic human resource capacity, facilitate the creation of a prosperous Southern African region and engage in the world economy in a sustainable manner.

The total contribution of agriculture to the economy increased from R38 billion in 2002 to R68 billion in 2008. South Africa's dual agricultural economy comprises a well-developed commercial sector and a predominantly subsistence-oriented sector in the rural areas. Agricultural activities range from intensive crop production and mixed farming to cattle ranching in the bushveld, and sheep farming in the more arid regions. About 12 percent of the country can be used for crop production. High-potential arable land comprises only 22 percent of total arable land.

The South African Constitution of 1996 stipulates that everyone has the right to a basic education, including adult basic education and further education. This resulted in an increase in the budget allocation for education over the past few years. In 2009, following

the appointment of the new administration, the ministries of basic education (covering Grades R to 12 and adult literacy) and higher education and training (dealing with tertiary and further education and training) were established.

The government aims to speed up the delivery of housing for the poor and have all South Africans accommodated in formally planned settlements by 2014. Following the appointment of a new administration in May 2009, the name of the Department of Housing was changed to the Department of Human Settlements. The aim is to transform the country's residential areas and build communities with closer access to work and social amenities, including sports and recreational facilities. The Department of Human Settlements determines, finances, promotes, coordinates, communicates and monitors the implementation of policies for housing and human settlement (CGIS, 2009). See Table 4.1 for selected characteristics of the country, province and research area from the Community Survey (Statssa, 2007).

Table 4.1 Summary of geographic, demographic and socio-economic characteristics

Indicator	South Africa (country)	KwaZulu-Natal (province)	Uthungulu district	Mbonambi local municipality
Surface area	1,219,090 km²	92,100 km²	8,214 km²	1,208 km²
Total population	47,850,294	10,152,570	884,722	117,719
Total number of households	12,500,609	2,234,129	184,506	21,632
Average household size	3.8	4.5	4.8	5.4
Households living in formal dwellings (%)	70.5	60.4	55.2	55.6
Households using electricity for cooking (%)	66.5	61.1	56.9	56.1
Household access to piped water (%)	88.6	79.3	75.0	62.6

Source: Community Survey (Statssa, 2007)

4.2 KwaZulu-Natal Province

KwaZulu-Natal, referred to as the "garden" province, is bordered on one side by the Drakensberg and on the other by the Indian Ocean. In the North the province shares a border with Mozambique and in the South with the former homeland, Transkei. KwaZulu-Natal (KZN) is one of South Africa's smaller of nine provinces, but with almost a quarter of the county's Black population living here. Within the province, Blacks comprise more that 80 percent of the total number of inhabitants, most of them Zulu speaking. Population density varies greatly within the province, with close to 60 percent of the population residing in non-urban areas.

According to the Human Development Index (HDI) calculated by the Central Statistical Services for the country, life expectancy in KZN is the third lowest of all the provinces and is drastically decreasing as a result of HIV/AIDS. The HDI is a measure of people's ability to live a long, healthy and productive life, be able to participate in community life and have sufficient means to afford a decent living. The HDI also measures adult literacy, indicating that close to 15 percent of persons over the age of 15, cannot read

and write their home language mainly Black people). Many Black people are still living without running water and electricity, with wood as their main source of energy for cooking and heating. More than a third of the people in the province are unemployed, the rate being higher for females than for males. Although the main contributor to the Gross Geographic Product of KwaZulu-Natal is manufacturing, sectors such as the wholesale and retail trade and accommodation and catering service industries are playing an ever increasing role in contributing to the economy of the province. All industries in the province are under threat though because of the high HIV prevalence (CGIS, 2009).

4.3 The uThungulu district and Mbonambi local municipality

The uThungulu district is located in the north-eastern part of the KwaZulu-Natal Province and comprises of six local municipalities of which Mbonambi is one of them (See Figure 4.1 for a map of the research area).

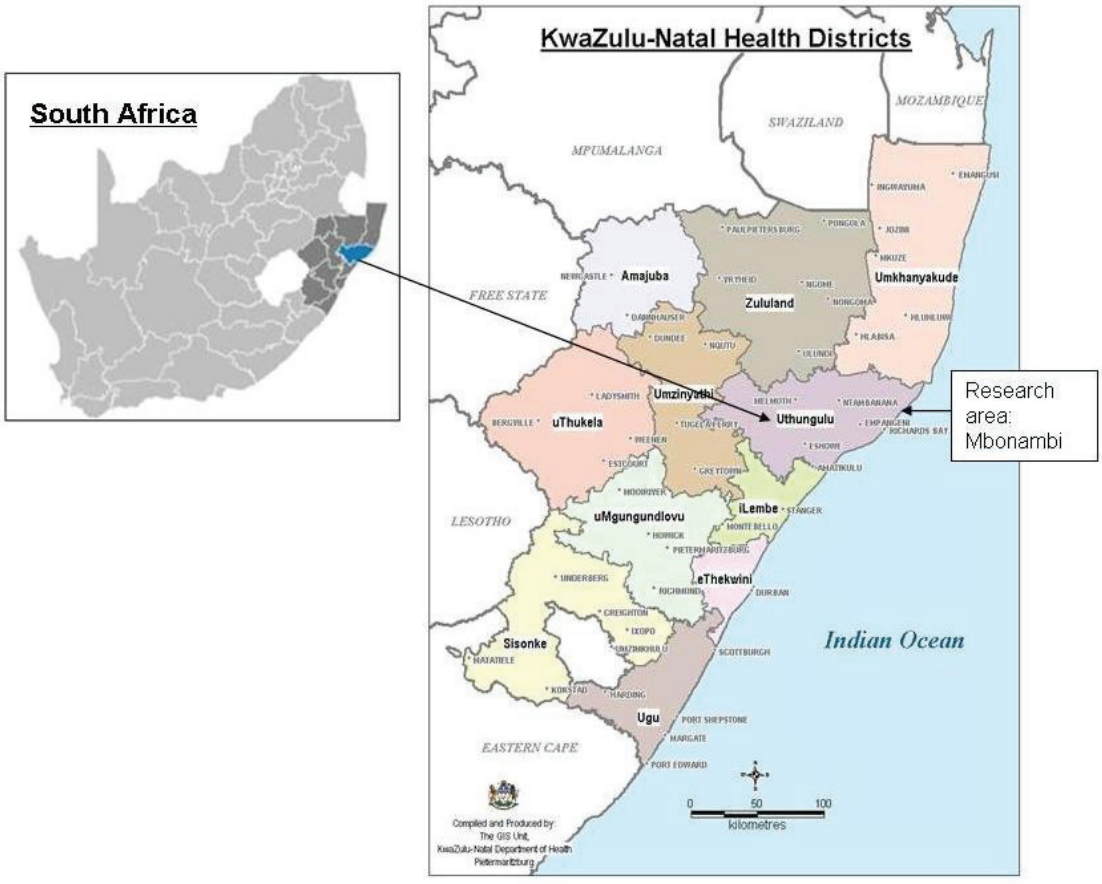


Figure 4.1 Map of research area (Source: KwaZulu-Natal Department of Health, **2005***)*

Important economic centres at the district and provincial levels are Richards Bay and Empangeni. Richards Bay is an industrial town and its harbour attracts people from surrounding towns and rural settlements. The area is characterised by low levels of urbanisation and a young population. A larger female population may be attributed to male out-migration. The district is characterised by infrastructure backlogs with several

households still without access to electricity, proper sanitation and potable water within easy reach. The district has an abundance of natural resources and available arable land is suitable for large-scale agricultural initiatives such as sugarcane and forestry as well as for fruit production. The good climate and intrinsic beauty of the area enhances the opportunities for tourism in the district. As one moves inland, access to services and economic opportunities lessen (uThungulu District Municipality, 2010).

4.4 Social development

Social development is an integrated and comprehensive system of social services, facilities, programs and social security to promote social development, social justice and the social functioning of all individuals. Social development services and programs are part of a range of mechanisms to achieve social development. These include health, nutrition, education, housing, employment, recreation, rural and urban development and land reform. In South Africa, the provision of social development services is a partnership between the private and the public sectors. One of the Government's most effective poverty alleviation programs is its comprehensive and integrated social security system. Every month the Department of Social Development pays social assistance grants to millions of South Africans, including old-age pensions, disability grants and foster care grants. In many rural areas households of up to nine people are supported by one old-age pension (CGIS 2006). The total number of grant recipients increased from 2.5 million in 1998 to more than 13 million in 2009. From January 2010, 15-year-olds will also be eligible for child support grants, while 16-year-olds and 17-year-olds will qualify from January 2011 and January 2012 respectively, to eventually benefit an additional 2 million children from poor households. From April 2010, legislation also provides for men aged 60 to 64 years to qualify for old age grants (DSD, 2009).

Table 4.2 Social grants available in South Africa

Grant type	Eligibility criteria (2006)	Grant amount in ZAR 2006 (2009)	Total number of beneficiaries 2006 (2009)
Old age	South African citizen/permanent resident Staying in SA Males 65 years or older/females 60 years or older Not receiving another grant Not in a subsidised institution Submit identification	R820 (R1010)	2,131,820 (2,390,543)
Disability	South African citizen/permanent resident Staying in SA Males aged 18 to 64/females aged 18 to 59 Not receiving another grant Not in a subsidised institution Medical assessment report Submit identification	R820 (R960)	1,312,726 (1,286,883)
Care dependency	South African citizen/permanent resident Applicant and child must be staying in SA Child aged 18 or younger No other grant Not in a subsidised institution Medical assessment report Applicant submit identification Birth certificate for child	R820 (R1010)	91,604 (107,065)
Foster Care	Foster parent must be a South African citizen/permanent resident Applicant and child must be resident in SA Court order indicating foster care status Child must remain in care of foster parent(s) Child aged 18 or younger No other grant Applicant submit identification Birth certificate for child	R590 (R680)	300,119 (474,759)
Child support	Primary care giver must be a South African citizen/permanent resident Child aged 14 or younger No other grant Not in a subsidised institution Applicant submit identification Birth certificate for child	R190 (R240)	7,044,901 (8,765,354)
Grant-in-aid	Person already receiving old age pension or disability grant who needs intense continuous care (bedridden) and is not institutionalised	R170 (R210)	unknown (46,069)

* 1 USD (dollar) = 7 ZAR (South African Rand)
Source: Department of Social Development (DSD, 2009)

4.5 Health

The South African Department of Health aims to transform the public health system to reduce its inequalities, improve quality of care and public facilities, boost human resources and step up the fight against HIV and AIDS, tuberculosis (TB) and other communicable diseases as well as lifestyle and other causes of ill-health and mortality. During 2008/09, about 33 hospitals were under construction as part of the Hospital Revitalisation Project and 11 more hospitals were in the planning phase. In 1994, the government started providing free primary healthcare services for children under six years old, and pregnant and lactating women. During the same period, the government initiated a program that resulted in more than 1,600 clinics being built.

Access to public health services, as measured by headcounts, reflects a consistent upward trend with more than a million people accessing services in 2007/08. Public health services include immunisation, communicable and endemic disease prevention, maternity care, child healthcare, health promotion, counselling, management of chronic diseases and diseases of older persons, rehabilitation, accident and emergency services, family planning and oral health. Where necessary, patients with complications are referred to higher levels of care, such as hospitals.

In October 2009, government announced an additional R5,4 billion for spending on its HIV and AIDS programs, taking into account further policy measures to broaden access to those co-infected with TB and women and children with CD4 counts lower than 350 (see Table 4.2). By February 2010, about 920,000 people were on antiretroviral treatment, with the budget providing for this number to rise to 2.1 million in 2012/13. Care and support are enhanced through community-based services. About 27,000 community caregivers were expected to be receiving a stipend by March 2010, but with the Community Care Worker Management Policy Framework not yet finalized it was not possible to reach this target (DOH/DSD, 2009). One of the priorities of government was to increase the national TB cure rate from 60 percent in 2008 to 70 percent by 2010, by improving interventions for TB control and management. Reaching this target was hampered by HIV and TB co-infection as well as treatment-resistant TB, which will remain a challenge for the Department of Health. The Department of Health seeks to establish a National Health Insurance system, which will introduce the necessary funding and service-delivery mechanisms to enable the creation of an efficient, equitable and sustainable health system in South Africa.

In 2007, approximately 18.1 percent of South African adults between the ages of 15 and 49, were living with HIV (UNAIDS, 2008). The number of women aged 15 years and older living with HIV was 3.2 million. The number of orphaned children was estimated to be 1.4 million, including a combination of maternal and dual orphans. The number of people receiving antiretroviral therapy reached 460,000, but with a further 1.7 million in need of treatment (UNAIDS, 2008). The HIV prevalence amongst women attending antenatal clinics in KwaZulu-Natal was 38.7 percent, an estimated 35.9 percent for the uThungulu district (DOH, 2008). Table 4.2 provides a summary of relevant information on HIV and AIDS.

Table 4.3 HIV/AIDS timeline and symptom progression without antiretroviral intervention

WHO Staging of HIV and AIDS				
Primary HIV infection	**Clinical Stage 1 Asymptomatic latent**	**Clinical Stage 2 Minor symptomatic**	**Clinical Stage 3 Major symptomatic**	**Clinical Stage 4 Severe symptomatic**
Description				
Seroconversion (status change from HIV negative to HIV positive)	No symptoms, virus remains active and continues to damage and undermine the immune system	Minor and early symptoms of HIV infection begin to manifest	More severe HIV-related and opportunistic diseases appear as immune system deteriorate	Symptoms become more acute, persistent and untreatable opportunistic AIDS-defining conditions
Selected symptoms				
Some individuals display flu-like symptoms	None, persistent generalised lymphadenopathy (infection of lymph nodes)	Moderate unexplained weight loss. Recurrent respiratory tract infections.	Severe unexplained weight loss. Unexplained chronic diarrhoea. Unexplained persistent fever.	Wasting syndrome. AIDS with severe infections, opportunistic diseases and cancers.
Performance				
Normal activity	Normal activity	Normal activity despite symptoms	Bedridden for less than 50% of the day.	Bedridden for more than 50% of the day. Difficult to work.
Viral load – amount of virus particles detectable in the blood of an infected person.				
Very high during first few weeks	Reaches a steady state 16 to 24 weeks after infection	Increasing	High and increasing rapidly	Very high
CD4 Cells – T helper lymphocytes (a type of white blood cell) important in keeping the immune system healthy. CD4 Count refers to counting of the CD4 cells Note: A normal CD4 count in healthy non-infected individuals is 600-1500cells/mm³. In an infected person CD4 cells decrease by 40-80 cells/mm³ per year.				
Decreasing	500-800 cells/mm³	350-500 cells/mm³	200-350 cells/mm³	Fewer than 200 cells/mm³
Treatment (revised guidelines for 2010)				
Treat if CD4 cell count is ≤ 350 cells/mm³	Treat if CD4 cell count is ≤ 350 cells/mm³	Treat if CD4 cell count is ≤ 350 cells/mm³	Treat irrespective of CD4 cell count	Treat irrespective of CD4 cell count
Infection	**Approximate time in years**[2]			**Death**
4-6 weeks	6 years	9 years	12 years	

Source: Adapted from Van Dyk (2008), WHO (2005b), WHO (2010)

[2] Illustrates timeline and symptom progression without treatment

4.6 The policy environment

The White Paper of Social Welfare of 1997 and the Population Policy of 1998 emphasised the needs and concerns of people living with HIV/AIDS. The AIDS crisis poses a number of special challenges in the field of social development as it will impact on social security and community-based models of care and support. Since 1997 many policy documents addressing HIV/AIDS in one way or another have been developed by the Department now known as the Department of Social Development. Below are references to some relevant policy and other documents:

- The Poverty and Inequality report of 1998 clearly expressed the links between poverty and HIV/AIDS (May, 1998).
- The National Guideline for Social Services to Children Infected and Affected by HIV/AIDS of 2002, recognising the increase in affected children and their needs (DSD, 2004).
- A paper on Care and Support for people who are affected and infected by HIV/AIDS of 2002, supplying information available support and accessing of support (DSD, 2004).
- The Strategic Plan of 2003/4 to 2005/6 in which the then minister of Social Development said: "Improved services for people affected and infected by HIV/AIDS, especially children, child headed households and orphans remain at the top of our development agenda." As part of the Plans' 10-point plan, it provides for rapid expansion of Home-based and Community-based care and support to children to mitigate the social and economic impact of AIDS (DSD, 2004).
- In the Draft National Policy for Families of 2004, the increased need for care for sick people and orphans is emphasised and the household or family as key care giver recognised (DSD, 2004).
- Two of the objectives under the theme 'social cohesion' of the Department of Social Development's Strategic Plan for 2008-2011 are to mitigate the social impact of HIV and AIDS and to reduce HIV infections through behaviour change (DSD, 2008).
- The Department of Social Development and the Department of Health are jointly working on developing a policy framework to address the needs and formalise the work of volunteer and remunerated home- and community-based carers (DOH/DSD, 2009).

The following are relevant policies and documents from the department of health, addressing HIV/AIDS, developed by the department over the last few years:

- The National AIDS plan for South Africa of 1994 emphasized prevention through a range of activities (especially the promotion of condom use), reducing transmission and mobilizing resources (DOH, 1994).
- The National HIV/AIDS policy of 1997 coordinated efforts of various role players for prevention and education (DOH, 1997).
- The HIV/AIDS/STD Strategic Plan for SA 2000-2005, clearly recognizes HIV as a mainly heterosexually transmitted disease (DOH, 2000b).
- The policy for Managing the Impact of HIV/AIDS in SADC of 2000, emphasize the scale of the problem in the Southern African Development Community and the need for cross border cooperation (DOH, 2000c).
- In 2000 a policy for managing HIV/AIDS and STDs in the Workplace appeared to serve as a guideline for the business sector and employers to deal with HIV/AIDS in the workplace (DOH, 2000d).
- In the Health Research Policy for South Africa of 2001 I expected to find a lot of emphasis on HIV/AIDS related research, but disappointingly the policy refers mainly to the reforming of health systems (DOH, 2001).

- Towards the end of 2003, after pressure from the Treatment Action Campaign, a National Task Team was appointed to coordinate and draft an operational plan on an Anti-retroviral treatment program. The plan was adopted and distribution of treatment commenced early in 2004 through various centres across the country (DOH, 2004).
- In the Strategic Priorities for the National Health System paper of 2004, although the emphasis is shifting towards care, it is also emphasized that prevention and treatment should form part of what they refer to as the "continuum of care" (DOH, 2004).

The Department of Health has adopted a 10-point plan for the 2009 to 2012 period (DOH, 2009). The plan includes:

- Providing strategic leadership and creation of a social compact for better health outcomes
- Implementing the National Health Insurance (NHI) system
- Accelerated implementation of the HIV and AIDS plan and increased focus on TB and other communicable diseases
- Overhauling the healthcare system
- Improved human-resource planning, development and management
- Improving the quality of health services
- Revitalising the health infrastructure
- Mass mobilisation for better health for the population
- Reviewing the drug policy
- Strengthening research and development.

Although many policies address HIV and AIDS in some or other way, it is mainly the Departments of Health and Social Development which has taken on the challenge, while many other sectors still view HIV and AIDS mainly as a health problem. The way forward will thus be to recognize HIV and AIDS not only as a health problem, but also as a serious socio-economic problem impacting on all people at all levels of the South African society. Although many policies addressing HIV and AIDS exit, the rate of infection, the number of people dying, and the number of orphans left behind increase daily, which indicates that there may be a problem with the implementation of the many policies.

Chapter 5

Profiling and classification of households

This chapter focuses on characteristics of individuals and households in Mbonambi where a survey was conducted in 354 households among two locations, 137 in Ward 3 and 217 in Ward 5, comprising 2393 individuals. Sampling of wards and households is described in Chapter 3. Demographic, socio-economic and health data were collected by means of interviews using a questionnaire. The dual purpose of the survey was to become familiar with and describe the research area, and to facilitate the selection of case study households for further assessment of living arrangements, livelihoods and care arrangements of people living with HIV and AIDS, and orphans and vulnerable children.

In the first section of this chapter the demographic, socio-economic and health characteristics of individual members of households are described, followed by a description of household characteristics in the second section. The implications of HIV and AIDS-related, as well as non-AIDS-related, morbidity and mortality for individuals and households are presented in the third section. The chapter concludes with a classification of households based on whether and how they are affected and/or afflicted by HIV and AIDS-related illnesses and deaths, and a comparison of the households on selected variables.

5.1 Demographic, socio-economic and health characteristics of individuals

All the individuals in the sample are Black African and the main language spoken in all the households is isiZulu. Below follows an overview of the demographic, socio-economic and health characteristics of the individuals in the sample.

5.1.1 Sex and age

The sex-by-age distribution of males and females in the research area is illustrated in Figure 5.1. The total sample of 2393 individuals comprised 1137 (47.5%) males and 1256 (52.5%) females, with ages ranging from less than one year to a few individuals over the age of 80. The 975 individuals from Ward 3 consist of 468 (48%) males and 507 (52%) females and the 1418 individuals from Ward 5 of 669 (47.2%) males and 749 (52.8%) females. Thus, there is little difference between the wards, and the overall distribution compares with the findings of the 2007 Quality of Life Survey (QLS) conducted by the uThungulu District Municipality with the population of Mbonambi composed of 52 percent males and 48 percent females (uThungulu District Municipality, 2007).

In both wards there are more males than females aged 0 to 14, with a total of 881 (36.8%) of all individuals in the sample aged 14 years or younger. Among the young adults aged 15 to 39 there are more males than females in three of the age categories for the two wards combined, while there are more females than males in all the categories for Ward 5. The category of young adults comprises 1061 (44.3%) of all individuals in the sample, 45.5 percent of them male and 55.5 percent female. The category of older adults including those aged 40 to 64 comprises 342 (14.3%) of all individuals in the sample, with 44.2 percent

of them male and 55.8 percent female. In the category of older adults, fewer males than females could, according to the 2007 QLS, be explained by outmigration of individuals working in other parts of the province or country (uThungulu District Municipality, 2007). It should be noted that a person working in another part of the province may be seen as a member of the household if s/he spends significant time at the homestead and contributes regularly to the household income, as is the case with two young adults referred to in one of the cases presented in Chapter 6 (Case 3).

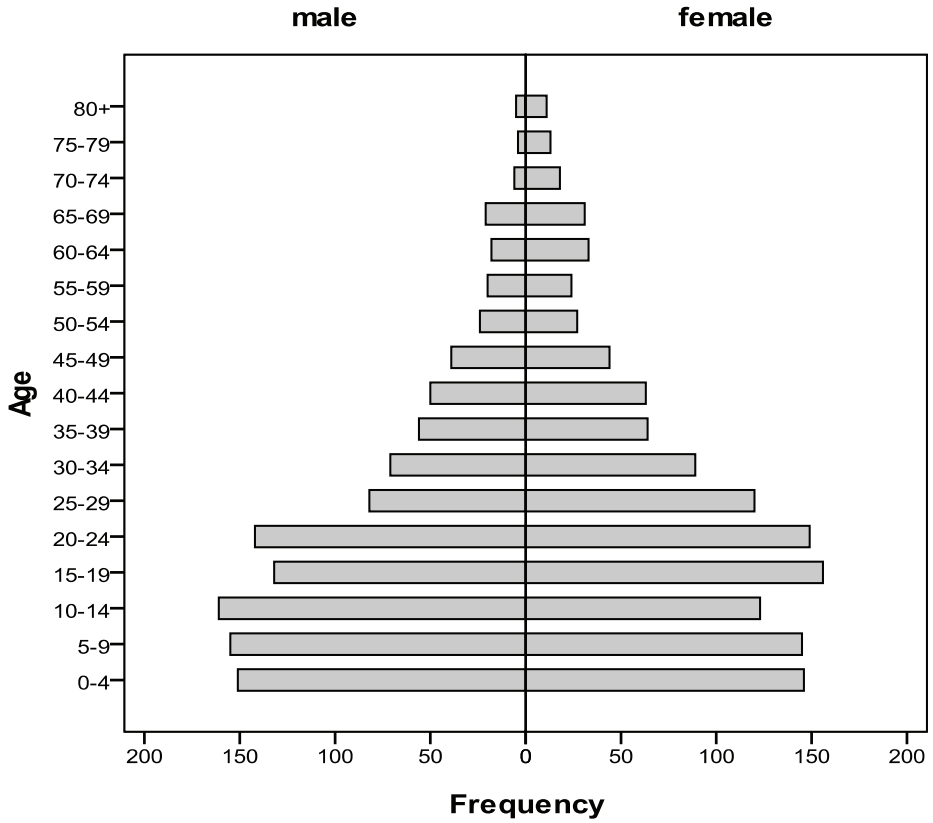


Figure 5.1 Age-sex structure of all individuals (N=2393)

In addition to the factor of outmigration, the fewer individuals in the 'older adults' age category, leading to a skewed sex-age distribution, may be attributed to premature deaths of adults as a result of AIDS-related illnesses (Statistics South Africa, 2009). The age category '65 years and older' comprises 109 (4.6%) of all individuals in the sample, 66.9 percent of them female and 33.1 percent male. The 2007 QLS reported approximately 26 percent of all individuals to be aged 0-14 years, 49 percent aged 15 to 39 years, 19 percent aged 40 to 64 years and 6 percent aged 65 years and older (uThungulu District Municipality, 2007).

The demographic dependency ratio for the total sample is 70.56 dependents, aged 14 years or younger and 65 years and older, for every 100 persons in the economically active group ages of 15 to 64 years. There is no significant difference between the dependency ratios of the two wards, but there is a difference between male- and female-headed households. In male-headed households there are 67.06 dependents and in female-headed households 74.84 dependents for every 100 persons aged between 15 and 64 years.

5.1.2 Marital status

The marital status of individuals, aged 17 years and older, is presented in Table 5.1. The minimum age of 17 was prompted by one 17-year old female living with a male partner. The majority of males and females have never been married with slightly more males than females. The high percentage of individuals in the 'never married' category can be attributed to 51.6 percent of them aged between 17 and 24 who may still marry when they are older. It should be noted that many females in this category have one or more children, but are residing without male partners at the homesteads of their families instead of with their partner's family as it is customary in Zulu tradition. This practice can be seen in several of the case studies presented in Chapter 6 where it is further discussed (Cases 1, 6, 7, 9, 11, 14, 15, 17 & 18). There are only five men aged 50 years and older who were never married compared to 30 women, but there are more women aged 50 years and older than men.

Table 5.1 Marital status of individuals aged ≥17 by sex (N=1387)

Marital status	Male		Female		Total	
	freq	%	freq	%	freq	%
Never married	380	62.2	452	58.2	832	60.0
Married	96	15.7	113	14.6	209	15.1
Living together/traditional marriage	125	20.5	125	16.1	250	18.0
Widowed*	7	1.1	81	10.4	88	6.3
Divorced/separated	3	0.5	5	0.7	8	0.6
Total	611	100.0	776	100.0	1387	100.0

Source: Household Survey 2006
* Chi-square significant at p≤0.05

Whereas married men usually reside with wives, several married women are living without their husbands. In this sample only two married men are living without female partners as apposed to 32 women, 18 of them heads of households and the remainder daughters-in-law. Reasons for married women residing without husbands include the following: 'husband working in another part of the country', 'husband residing with another partner' or, 'whereabouts of husband unknown'. An example of the latter can be seen in Case 1 presented in Chapter 6. 'Living together', in the majority of cases, refers to a customary or traditional marriage where the female is allowed to go and live with the male partner, at his family's homestead, once the *ilobolo* (bride wealth) is paid to her family. Examples of 'living together' that cannot be seen as traditional marriages are few and usually occur when a male partner lives with a female partner at her homestead, where she is the head of the household, as can be seen in the case of the young widow referred to in one of the case studies presented in Chapter 6 (Case 8). In many cases the traditional marriage is not followed by a legal wedding ceremony where the bride will take the last name of the groom. There are only two cases in the sample where men are living with two female partners at their homesteads. The one, a 38-year old man living with female partners aged 30 and 26, and the other a 75-year old male living with female partners aged 61 and 46. Polygamy will only be visible in survey data if all the female partners reside at his homestead, which is not always the case. Second or third wives may live, with their children, at homesteads separate from the main homestead where the first wife resides. Although polygamy is decreasing it is still practiced and acceptable to both young and old, men and women, as reported in focus group discussions FGD1, FGD2, FGD3 and FGD4.

According to the men, a man with more than one wife earns more respect, while the women indicate that it is acceptable to them if it is not done behind their backs.

There are significantly more women who are widowed than men. This can be explained as the majority of those who are widowed are 60 years and older, and 66.9 percent of the individuals in this age category are female; on the other hand men may choose to remarry rather than live without a partner. The mean age of the widows is 63.9 years, the youngest a 31-year old whose husband died of AIDS-related illness. The few individuals in the category 'divorced or separated' can be explained partially, as only legal marriages can be legally dissolved and categorized as divorce. Very few individuals classify themselves as 'separated' or 'deserted', although some married women refer to the whereabouts of their husbands as unknown. There are no significant differences in marital status between the two locations.

5.1.3 Education

The highest level of education completed by individuals aged 20 years and older is presented in Table 5.2 by sex only, as there are no significant differences between the two locations.

Table 5.2 Level of education of individuals aged ≥20 by sex (N=1224)

Level of education	Male		Female		Total	
	freq	%	freq	%	freq	%
No formal schooling	38	7.1	70	10.2	108	8.8
Some primary school education	132	24.5	178	25.9	310	25.3
Primary school completed (grade7)	39	7.2	52	7.6	91	7.4
Some secondary school education	172	32.0	229	33.4	401	32.9
Secondary school completed (grade 12)	121	22.5	123	17.9	244	19.9
Tertiary education	26	4.8	28	4.1	54	4.4
Unknown	10	1.9	6	0.9	16	1.3
Total	538	100.0	686	100.0	1224	100.0

Source: Household Survey 2006

Although only 8.8 percent did not receive any formal schooling, this figure is slightly higher for females compared to males. It is concerning to see that only 24.3 percent of all individuals in the sample completed secondary school or higher. Significantly more males (27.3%) than females (22.0%) completed secondary school, with Chi-square significant at $p \leq 0.05$. Very few individuals continue into tertiary or further education and training even though there are several institutions nearby. In Table 5.3 the school attendance of individuals aged 6 to 24 is presented. Attendance is presented by sex and location as there are significant differences between the two research locations.

Almost half (48.9%) of all the individuals in the sample are 19 years or younger, with the majority of those between the ages of 6 and 19 attending school at the time of data collection. In the age category 6-14 year olds, the vast majority of children (95.9%) is attending school, with little difference between boys and girls in both locations. Of the 22 (4.1%) children who are not attending school, nine are six years old and to start attending in the following year. In the case of three girls and one boy aged seven commencement of schooling is delayed because of insufficient money to pay school fees, this is in spite of two of them receiving state child support grants. Six children are not attending school because of physical and/or mental disability, one child is not attending due to illness and one 14-

year old girl is not attending because she is pregnant. A 12-year old boy is not attending because he looks after cattle and for one child the reason for not attending is not known.

In the category for individuals aged 15-19 years, the majority (83.7%) of males and females are attending school, with slightly more females than males not attending. Ten (3.5%) of the males and females in this age category completed their secondary schooling. Four of the 10 who completed grade 12 are attending university, 2 are employed, while the remaining 4 are unemployed. Of the individuals in this age category who are attending school, 83 percent are attending secondary school and 27 percent are attending primary school. By the age of 15 children who started school at the age of 6 or 7 should have completed their primary school education of 7 years. Many children fall behind at school and are in grades below those appropriate for their age and are at risk of dropping out of school. Of the 37 (12.8%) who are not attending school, 17 are looking for work, 7 are working, 2 are sick or disabled, 6 are doing nothing and 5 females are pregnant or has a child to care for.

Table 5.3 School attendance of individuals aged 6-24 by sex and location (in %)

School attendance of individuals in three age categories	Ward 3 (n=467)		Ward 5 (n=654)		Total
	Male (n=247)	Female (n=220)	Male (n=326)	Female (n=328)	(N=1121)
Age 6-14 (n=542)					
Attending	98.4	96.0	94.3	95.8	95.9
Not attending	1.6	4.0	5.7	4.2	4.1
Total	100.0	100.0	100.0	100.0	100.0
Age 15-19 (n=288)					
Attending	87.3	84.7	85.5	78.6	83.7
Not attending	9.5	11.1	10.1	19.0	12.8
Completed secondary school	3.2	4.2	4.3	2.4	3.5
Total	100.0	100.0	100.0	100.0	100.0
Age 20-24 (n=291)					
Attending*	41.0	32.6	12.3	16.0	23.0
Not attending	29.5	28.6	43.2	47.0	39.2
Completed secondary school	29.5	38.8	44.4	37.0	37.8
Total	100.0	100.0	100.0	100.0	100.0

Source: Household Survey 2006
* Chi-square significant at $p \leq 0.05$

In the category of individuals aged 20-24 years, there is a difference between the two locations. Although more individuals in Ward 5 completed secondary school compared to Ward 3, more individuals in Ward 3 who did not yet complete grade 12 are attending school. Many young people leave school without completing their secondary school education, while completing may improve a young person's chances of getting formal employment. In both wards 20 percent of individuals who did not complete grade 12 and who are not attending school, are working, while a further 50 percent are looking for work and another 20 percent are not working for reasons such as illness or disability, pregnancy, or caring for children or ill persons. The remaining 10 percent is not doing anything and according to respondents not looking for work either, as can be seen in some of the case studies presented in Chapter 6 (Case 6, 7 and 19). The number of females who completed secondary school is almost the same for Ward 3 and Ward 5, while almost half (45.7%) of the males in Ward 5 completed secondary school as opposed to 29.5 percent in Ward 3. In

both wards between 30 and 40 percent of males and females who completed grade 12 are working, with a further 40 to 50 percent looking for work, approximately 10 percent are attending at a university or college, and less than 10 percent are not working for various reasons or doing nothing. Significantly more individuals in Ward 3 compared to Ward 5, who have not completed grade 12, are attending secondary school. A possible reason for this, although it could not be confirmed by key informants, can be that Ward 5 is closer to town and that young people are tempted to go and look for work rather than to stay in school.

5.1.4 Employment

In Table 5.4 the work status of individuals aged 15 through 64 is summarized. Of the total number of individuals (N=2393), 58.6 percent (n=1403) are between the ages of 15 and 64, inclusive, and could be expected to be economically active. A total of 33.6 percent (n=471) of all the individuals between the ages of 15 through 64 are working, with the remaining 66.4 percent of individuals not working for various reasons.

More individuals from Ward 5 than from Ward 3 are working, which may be attributed to Ward 5 being closer to the big industrial town, Richards Bay, where more employment opportunities exist. Significantly more men than women and significantly more individuals from Ward 5 than Ward 3 are formally employed. Only 12 individuals are working for more than one employer, the majority of them women working as domestic workers for two or three employers on different days of the week. Significantly more men than women, and significantly more individuals from Ward 3 than Ward 5, are doing odd jobs or piece work, which is irregular or seasonal. Odd jobs amongst men mainly involve work in the construction industry, or work as forest or sugarcane cutters, while women doing odd jobs also work as forest or sugarcane cutters. Very few individuals are self-employed with the men mainly working as taxi drivers and women doing craft work or working as street vendors.

Table 5.4 Work status of individuals aged 15-64 by sex and location (in %)

Work status	Ward 3 (n=571)		Ward 5 (n=832)		Total
	Male n=266)	Female n=305)	Male (n=368)	Female n=464)	(N=1403)
Working					
Work for one or more employer*	21.1	15.1	36.3	18.8	23.0
Self-employed	4.5	2.6	3.3	6.0	4.3
Odd jobs/piecework*	10.5	4.3	10.1	2.2	6.3
Not working, reason					
Unemployed*	25.6	34.8	24.7	37.5	31.3
Not working, attend school*	30.7	25.8	19.0	20.0	23.1
Not working, sick/injured/disabled	6.4	7.9	4.4	7.5	6.6
Not working, pensioner	0.0	4.9	0.0	3.9	2.3
Not working, care for child/ill	0.0	3.3	0.0	2.2	1.4
person	1.2	1.3	2.2	1.9	1.7
Not working, other/unknown reason					
Total	100.0	100.0	100.0	100.0	100.0

Source: Household Survey 2006

* Chi-square significant $p \leq 0.05$

Approximately 45 percent of employed males and females in Ward 3 are working in the Mbonambi area, including the small town of KwaMbonambi, with a further 45 percent working in Richards Bay, and 5 percent in Empangeni, another neighboring town further away. No women and only five percent of male household members from this ward worked in other parts of the KwaZulu-Natal province or in other parts of the country. Approximately 70 percent of the men and 60 percent of the women from Ward 5 are working in the nearby town of Richards Bay, 10 percent of the men and 7 percent of the women are working in Empangeni, while 10 percent of the men and 20 percent of the women are working in the Mbonambi area. In Ward 5, 12 percent of female and 8 percent of male household members are working in other parts of the province or country.

The majority of individuals who are not working are either unemployed or attending school, with significantly more women than men at 36.2 percent citing unemployment as the reason for not working. The majority of individuals aged 15 through 19 as well as 23 percent of those aged 20 through 24, with significantly more in Ward 3 than Ward 5, attending school (also see Table 5.3). Few individuals (6.6%), slightly more females than males, cited illness or disability as the reason for not working. Women aged 60 years and older are eligible for state old-age grants[3] and are therefore not formally employed. Only 3.3 percent of the individuals in Ward 3 and 2.2 percent in Ward 5, all of them female, are not working because they are taking care of children or ill persons.

Occupations

In the survey questionnaire respondents were asked to supply information on actual occupations or nature of work. Data were coded according to the Occupational Classification of Statistics South Africa (not dated). In Table 5.5 the occupations of individuals between the ages of 15 through 64 who are working at the time of data collection are presented by sex and location. With no individuals employed as legislators, senior officials or managers, this category is not included in Table 5.5. The category for professionals is combined with the category for associate professionals and technicians as there are few individuals in each.

Table 5.5 Occupation of employed individuals by sex and location (in %)

Occupation category	Ward 3 (n=163)		Ward 5 (n=308)		Total
	Male n=96)	Female (n=67)	Male n=183)	Female (n=125)	(N=471)
Professionals/associate	3.1	4.5	4.3	9.6	5.5
profess/technicians	1.1	3.0	3.3	9.6	4.5
Clerks	10.4	1.5	2.7	8.8	5.7
Service workers and shop/market sales	1.1	1.5	0.5	0.8	0.8
Skilled agriculture and fishery workers	17.7	0.0	31.8	7.2	17.8
Craft and related trades workers	8.3	0.0	18.6	1.6	9.3
Plant and machine operators	58.3	89.5	37.7	61.6	55.6
Elementary occupations and unskilled labour*	0.0	0.0	1.1	0.8	0.8
Unknown/not specified					
Total	100.0	100.0	100.0	100.0	100.0

Source: Household Survey 2006
* Chi-square significant at $p \leq 0.05$

[3] Men at the time of the research qualified for state old age grants from the age of 65.

The category of professionals, associated professionals and technicians, in the sample mainly includes engineers, teachers and nurses. The category of clerks includes financial and administrative clerks, secretaries, cashiers and receptionists, while the category of service workers and market sales workers includes individuals working in police and protective services, as shop and market operators and in the food service and tourism industry. Skilled agriculture and fishery workers also includes skilled forest workers, while the category of craft and related trades workers includes individuals working as miners, builders, metal workers and handicraft workers. Plant and machine operators include individuals working as operators of stationary machinery and drivers.

At 55.6 percent the majority of individuals work in elementary occupations and as unskilled labourers, including significantly more women than men and significantly more individuals from Ward 3 than Ward 5. This include women working as domestic workers, and men and women working as street vendors, general cleaners, farmers, farm and forestry labourers, gardeners and coal makers.

Secondary employment

Secondary employment or 'Other work' can be described as work done by an individual who is already employed or receives a state grant and is therefore engaging in secondary work to supplement income. Other work for women usually involves craft work or street vending, while a few men are collecting water or wood for others. In the research area, 25 individuals are doing other work, 19 women and 6 men. Eleven of the women and three of the men are receiving state old-age grants, one male and one female are unable to work full time, respectively as a result of illness and disability, while the remaining nine men and women are employed and doing the additional work to supplement income from formal employment.

5.1.5 State and private grants

State/Government grants

Eligibility and access of males and females in different age groups to state grants[4], are presented in Table 5.6. There are no significant differences between the two locations. Just more than half (51.6%) of all the children in the sample aged 14 years and younger are receiving state child support grants. The maximum age for receiving this grant, at the time of the research, was 14 with household income also serving as a criterion for eligibility. Two 15-year old males in Ward 5 are receiving child support grants as both recently turned 15 and grants were not yet discontinued. Several children eligible for grants do not receive grants, either as a result of bottlenecks in processing of applications or because parents are unable to apply for grants as they are unable to supply documents such as birth certificates required for applications.

Children may receive foster care grants up to the age of 18, with the possibility of extending it up to the age of 21 if it can be proven that the child is still dependent. Only 12 of the 144 orphaned children in the sample receive state foster care grants. Some of the orphaned children receive child support grants but the guardians are hesitant to apply for foster care grants as time may lapse between discontinuation of the one grant before commencement of the other (see Chapter 6, Case 16 as an example). In addition to this,

[4] An overview of criteria for eligibility to various grants and amounts at the time of the research appears in Chapter 4.

guardians have to supply death certificates of the parents of the orphans on application for foster care grants, which may not always be available.

In the age category of 15 to 64 years, only women aged 60 to 64 years are eligible for state old age grants or pensions. The coverage of old age grants is very good, with only two women, both aged 60 and still working, and two men, aged 68 and 79, not receiving state pensions. The two men are not eligible for state grants because they are receiving support from private sources, as can be seen in the section on private grants.

The main caregivers of ill and disabled children aged 18 years or younger who are dependent on care as a result of their illness or disability qualify for care dependency grants. Disabled or ill adults above the age of 18, but younger than the pensionable age of 65 years for men and 60 years for women, are eligible for disability grants. These grants can only be accessed when children or adults are unable to attend school or work and are not institutionalized. The grants lapse when the condition of the child or adult improves sufficiently for him/her to attend school or to work. In some cases the criteria used, especially to assess illness, are subjective and may disadvantage those who should receive grants. Very few individuals in the sample were eligible for, or able to access care dependency or disability grants.

Table 5.6 Individual eligibility and access to state grants by sex and age group

Type of grant by age	Male (n=1137)		Female (n=1256)		Total (N=2393)	
	freq	%	freq	%	freq	%
Age 0-14						
Child support grant	245	52.5	210	50.7	455	51.6
Foster care grant	4	0.9	5	1.2	9	1.0
Care dependency grant	2	0.4	2	0.5	4	0.5
Not eligible/no access to grants	216	46.2	197	47.6	413	46.9
Total	467	100.0	414	100.0	881	100.0
Age 15-64						
Child support grant	2	0.3	0	0.0	2	0.1
Foster care grant	3	0.5	0	0.0	3	0.2
Care dependency grant	0	0.0	2	0.3	2	0.1
Disability grant	9	1.4	30	3.9	39	2.8
Old age pension	0	0.0	30	3.9	30	2.1
Not eligible/ no access to grants	620	97.8	707	91.9	1327	94.7
Total	634	100.0	769	100.0	1403	100.0
Age ≥65						
Old age pension	34	94.4	73	100.0	107	98.2
Not eligible/no access to grants	2	5.6	0	0.0	2	1.8
Total	36	100.0	73	100.0	109	100.0

Source: Household Survey 2006

Private grants

Only 22 individuals receive financial support from sources other than state grants. Six children receive financial support from their non-resident biological fathers[5], while 10

[5] Although very few absent biological fathers provide financial support, some provide support in the form of food.

adults and children receive financial support from other family members. An example of financial support received from a non-resident father can be seen in Case 11 presented in Chapter 6. Another four individuals receive financial support from former employers and two from private insurance funds. The majority receive less than R600.00 per month, with only two of the individuals receiving more.

5.1.6 Health

Self-reported health status

Respondents were requested to report on the health status of all household members, rating it as excellent, good, average or poor. Health status by age and sex is presented for the two research locations in Table 5.7.

Table 5.7 Self-reported health status of individuals by age group, sex and location (in %)

Health status by age	Ward 3 (n=975)		Ward 5 (n=1418)		Total
	Male (n=468)	Female (n=507)	Male (n=669)	Female (n=749)	(N=2393)
Age 0-14 (n=881)					
Good to excellent health	88.1	90.1	88.7	85.6	88.0
Average to poor health	11.9	9.9	11.3	14.4	12.0
Total	100.0	100.0	100.0	100.0	100.0
Age 15-39 (n=1061)					
Good to excellent health	85.3	80.7	88.6	82.8	84.4
Average to poor health	14.7	19.3	11.4	17.2	15.6
Total	100.0	100.0	100.0	100.0	100.0
Age 40-64 (n=342)					
Good to excellent health	49.1	34.5	58.3	41.3	45.6
Average to poor health	50.9	65.5	41.7	58.7	54.4
Total	100.0	100.0	100.0	100.0	100.0
Age ≥65 (n=109)					
Good to excellent health	47.1	35.5	36.8	28.6	34.9
Average to poor health	52.9	64.5	63.2	71.4	65.1
Total	100.0	100.0	100.0	100.0	100.0

Source: Household Survey 2006

The vast majority (88.0%) of individuals in the age category 0-14, is reported as having excellent or good health status. Twelve percent are reported to have average or poor health status, with little difference between males and females and between the two research locations. In the age category 15-39, 15.6 percent with slightly more females than males and slightly more individuals in Ward 3 reported average to poor health status. In the age category 40-64, the percentage reporting average to poor health status significantly increases to 54.4 percent. Also in this age category, did more women than men and more individuals from Ward 3 report average to poor health status. In the age category 65 years and older the majority (65.1%) of individuals are reported to have average to poor health status.

Chronic disease

A chronic disease is described as a disease which produces symptoms over an extended period of time, or a recurring condition, from which an individual may not fully recover (De Haan, 2005). The question on self-reported health status served as a filter question after which respondents were requested to describe the disease(s) or the nature of health problems experienced by those reported to have average to poor health status. Diseases/health problems are classified according the International Statistical Classification of Diseases and Related Health Problems, ICD-10 (WHO, 2007). In Table 5.8 chronic disease by age group, sex and location for the 529 individuals with average to poor health status is summarised. In this table 'other diseases' refers to a combination of ICD-10 categories with few individuals reported to have diseases in those categories. 'Unspecified' refers to undiagnosed chronic conditions where descriptions of symptoms are insufficient or where respondents were unable to supply the information required to facilitate classification.

At 56.6 percent (n=60) diseases of the respiratory system, mainly asthma, are the most common amongst children aged 0 to 14 years. The second most common category at 16.0 percent (n=17) is 'certain' infectious diseases, which in this sample include HIV/AIDS and TB (tuberculosis) only. Diseases of the nervous system, mainly epilepsy, are the third most common amongst the children. 'Other' diseases or conditions amongst the children include mainly physical and/or mental disability.

Amongst the young adults, aged 15 to 39, 'certain' infectious diseases (HIV/AIDS and TB) at 47.0 percent is the most common category. Diseases of the respiratory system, mainly asthma, are second amongst the young adults, while diseases of the circulatory system, mainly high blood pressure and heart disease, are third. Other common conditions in this age category include diseases of the nervous system and mental and behavioral disorders, all of which may also be AIDS-related. In the age category for older adults, aged 40 to 64, diseases of the circulatory system, mainly high blood pressure and heart disease, are the most common, with 'certain' infectious diseases at 22.6 percent the second most common and diseases of the respiratory system the third most common. Diseases of the muscuskeletal system mainly include arthritis, while endocrine and metabolic disorders mainly include diabetes, and diseases of the nervous system mainly include epilepsy. The category 'other' includes individuals with cancer and those injured in accidents.

The most common category amongst those aged 65 years and older is diseases of the circulatory system, such as high blood pressure and heart disease. The second most common is diseases of the muscuskeletal system and mainly includes arthritis, while the third, endocrine and metabolic disorders, mainly refers to diabetes. Most of these diseases can be associated with old age. Only three individuals in this age category are reported to have 'certain' infectious diseases (TB) and another three have diseases of the respiratory system.

Across all age categories there may be individuals who have HIV, but are still in good health and therefore did not yet get tested. In addition to this there may be individuals with respiratory or 'other' undiagnosed conditions who reported average to poor health status who may also have HIV, but did not yet get tested or who do not want to reveal their HIV status due to the stigma associated with the disease.

Table 5.8 Individuals with chronic disease by age group, sex and location (in %)

Chronic disease by age	Ward 3 (n=226)		Ward 5 (n=305)		Total
	Male (n=90) %	Female (n=136) %	Male (n=115) %	Female (n=188) %	(N=529) %
Age 0-14 (n=106)					
Diseases of respiratory system	77.4	52.9	50.0	51.4	56.6
Certain infectious diseases	13.6	29.4	12.5	14.3	16.0
Diseases of nervous system	0.0	5.9	12.5	11.4	8.5
Other diseases	4.5	11.8	18.7	8.6	11.4
Unspecified	4.5	0.0	6.3	14.3	7.5
Total	100.0	100.0	100.0	100.0	100.0
Age 15-39 (n=166)					
Certain infectious diseases	41.9	38.1	45.1	56.5	47.0
Diseases of respiratory system	35.5	21.4	19.4	9.7	19.3
Diseases of circulatory system	3.2	4.8	0.0	6.4	4.2
Diseases of nervous system	3.2	2.4	6.5	4.8	4.2
Mental and behavioral disorders	6.5	7.1	3.2	1.6	4.2
Other diseases	9.7	11.9	12.9	11.3	11.5
Unspecified	0.0	14.3	12.9	9.7	9.6
Total	100.0	100.0	100.0	100.0	100.0
Age 40-64 (n=186)					
Diseases of circulatory system	17.9	47.4	15.0	24.6	28.5
Certain infectious diseases	28.6	14.0	25.0	26.2	22.6
Diseases of respiratory system	17.9	8.8	20.0	3.3	10.8
Diseases of muscuskeletal	7.1	8.8	5.0	18.0	10.8
system	7.1	8.8	10.0	4.9	7.5
Endocrine and metabolic					
disorders	17.8	7.0	15.0	14.8	12.8
Other diseases	3.6	5.2	10	8.2	7.0
Unspecified	100.0	100.0	100.0	100.0	100.0
Total					
Age ≥65 (n=71)					
Diseases of circulatory system	33.3	45.0	25.0	30.0	33.8
Diseases of muscuskeletal	44.4	35.0	25.0	30.0	32.4
system	22.2	10.0	8.3	16.7	14.1
Endocrine and metabolic					
disorders	0.0	10.0	33.4	20.0	16.9
Other diseases	0.0	0.0	8.3	3.3	2.8
Unspecified	100.0	100.0	100.0	100.0	100.0
Total					

Source: Household Survey 2006

5.2 Household characteristics

5.2.1 Household religion

In Table 5.9 the main religious faith subscribed to by households in both locations are summarized. It should be noted that the same faith is not necessarily shared by all the household members.

Table 5.9 Household subscription to religious faith by location (in %)

Faith	Ward 3 (n=137)	Ward 5 (n=217)	Total (N=354)
Christian Zion denominations	32.1	38.7	36.2
African Churches	32.1	36.9	35.0
Mainstream denominations	24.1	15.7	18.9
Other or unknown religions	6.6	6.4	6.5
None	5.1	2.3	3.4
Total	100.0	100.0	100.0

Source: Household survey 2006

Mainstream denominations include the Anglican, Lutheran, Methodist, Presbyterian, and Roman Catholic Church. African Churches include the Nazareth and St John's Apostolic churches established by African spiritual leaders. Other or unknown religions include churches not belonging to one of the three main categories or where the religion could not be classified. Very few households in both locations do not subscribe to any religious faith. Although not further explored in this study, religious faith is a strong form of social network and may determine the nature and amount of social, financial and moral support received from the church (Mtshali, 2002). The religious faith subscribed to may also influence beliefs concerning traditional and spiritual healing.

5.2.2 Household heads

Selected characteristics of heads of households in the sample are presented by sex and location in Table 5.10. Just more than half 200 (56.5%) of the 354 households are headed by males, while 154 (43.5%) are headed by females. In Ward 3, 52.6 percent of households are headed by males compared to 59.0 percent in Ward 5.

Age

There is a significant difference in the mean age of male and female heads of households. Female heads are older than male heads in both locations with the mean age of female heads at 57.3 years (SD=15.06) and male heads at 47.0 years (SD=14.45), making female heads on average almost 10 years older than their male counterparts. This can be explained as the majority of females mostly become heads of households when they are widowed. The youngest female head is 23 years old and the oldest 86, while the youngest male head is 17 years old and the oldest 92. Two male heads are orphans, aged 17 and 18, with the 17 year-old living with a younger brother since his mother passed away in 2004 (see Chapter 6, Case 13), and the 18 year-old living on his own since his stepmother passed away in 2006. The mean age of household heads in Ward 3 is higher than those in Ward 5, but this difference is not statistically significant.

Table 5.10 Characteristics of household heads by sex and location (in %)

Variable	Ward 3 (n=137)		Ward 5 (n=217)		Total
	Male (n=72)	Female (n=65)	Male (n=128)	Female (n=89)	(N=354)
Age					
15-24	1.4	0.0	3.9	2.2	2.3
25-34	13.9	3.0	21.1	7.9	13.0
35-44	18.0	18.5	29.7	16.9	22.0
45-54	25.0	13.9	21.9	18.0	20.1
55-64	25.0	23.1	9.4	15.7	16.6
≥65*	16.7	41.5	14.0	39.3	26.0
Total	100.0	100.0	100.0	100.0	100.0
Marital status					
Married	41.7	15.4	40.6	12.4	29.1
Live together/traditional marriage	48.6	0.0	43.8	4.5	26.8
Widow*	2.8	44.6	2.3	49.4	22.0
Never married*	6.9	40.0	12.5	31.5	21.2
Divorced/separated	0.0	0.0	0.8	2.2	0.9
Total	100.0	100.0	100.0	100.0	100.0
Level of education					
No formal schooling	13.9	16.9	15.6	25.8	18.1
Some primary	41.7	53.8	35.2	42.7	41.9
Primary completed (grade 7)	11.1	7.7	4.7	9.0	7.6
Some secondary	20.8	15.4	25.7	13.6	19.7
Secondary completed (grade 12)	9.7	1.5	10.2	6.7	7.6
Tertiary education	1.4	0.0	6.3	2.2	3.1
Unknown	1.4	4.6	2.3	0.0	1.9
Total	100.0	100.0	100.0	100.0	100.0
Work status					
Employed	29.2	16.9	55.5	18.0	33.3
Self-employed	12.5	3.1	6.3	12.4	8.5
Odd jobs/piecework	12.5	3.1	13.3	0.0	7.9
Not working, unemployed	19.4	13.9	4.7	10.1	10.7
Not working, pensioner	16.7	53.8	14.1	48.3	30.5
Not working, ill/disabled	9.7	7.7	3.9	10.1	7.4
Not working, other/ unknown reason	0	1.5	2.2	1.1	1.7
Total	100.0	100.0	100.0	100.0	100.0
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Age of Household Head**	50.14 (13.32)	58.58 (13.47)	45.21 (14.81)	56.40 (16.13)	51.5 (15.57)

Source: Household Survey 2006

* Chi-square significant at $p \leq 0.05$

** One way between groups analysis of variance (ANOVA) significant at $p \leq 0.05$

Marital status

There is a significant difference between the marital status of male and female heads of households. The majority (86.5%) of male heads is either married or living together in a traditional marriage, while the majority (82.5%) of female heads is widowed or were never married, making them *de jure* heads. Only five of the male heads are widowed and one divorced, while two of the female heads are separated. Eight of the 21 male heads who were never married are living on their own, while the remaining 13 are living with other relatives, mainly siblings. A total of 21 female heads are legally married, three of them have male partners residing with them while the remaining 18 do not, with some of the male partners residing with other wives/partners and some working in other parts of the province or country, making them *de facto* female heads. Four unmarried and three widowed female heads are living with male partners. These women are the heads of their households in spite of having a male partner for one or both of the following reasons: they have children, of whom the current partner is not the father, or the homestead belongs to her and the partner is residing with her (see Chapter 6, Case 8 as example).

Level of education

Level of education refers to the highest level completed, also for those attending school at the time of data collection. The majority (41.9%) of male and female household heads only has some primary schooling. Two of the young men, aged 17 and 19 respectively, are attending secondary school full time, while another man aged 33 and women aged 25 are attending academic institutions part-time. More male than female heads, in both locations, completed grade 12 or have a tertiary education.

Work status

The majority (67.5%) of male heads are working, either employed fulltime, self-employed or doing odd jobs, while the majority (50.6%) of female heads are pensioners. The latter is in line with the higher mean age of the female heads and females receiving state pensions at a younger age than males. Three male heads and one female head are not working as they are attending school or other academic institutions. One woman is not working as she is taking care of a sick household member and another is taking care of the children of another household member. All of these are included in the category, 'not working, other reason'. Although approximately 50 percent of the heads reported average to poor health status, only 7.4 percent of them indicated illness or disability as the reason for not working.

5.2.3 Household size and composition

Household size

In Table 5.11 household size is presented by sex of the household head and by household location. Households vary greatly in size, from 18 persons living on their own (also see Table 5.13) to a male-headed household in Ward 3 comprising 27 individuals and a female-headed household in Ward 5 comprising 25 individuals. Although not statistically significant, the mean size, 7.18 (SD=4.0), of female-headed households is higher than the mean size, 6.44 (SD=3.92), of male-headed households. Though also not statistically significant, households in Ward 3 are also bigger than those in Ward 5, irrespective of the sex of the head of the household. Female-headed households in Ward 3 are the biggest, with a mean size of 7.43.

Table 5.11 Household size by sex of head and location (in %)

Household size	Ward 3 (n=137)		Ward 5 (n=217)		Total
	Male (n=72)	Female (n=65)	Male (n=128)	Female (n=89)	(N=354)
single person	4.2	4.6	3.9	7.9	5.1
2-5 persons	43.0	27.7	48.4	33.7	39.8
6-9 persons	26.4	43.1	29.7	32.6	32.2
≥10 persons	26.4	24.6	18.0	25.8	22.9
Total	100.0	100.0	100.0	100.0	100.0
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean(SD)
Household size	6.83 (4.27)	7.43 (3.54)	6.22 (3.71)	6.99 (4.32)	6.76 (3.97)

Source: Household survey 2006

Household units

One household may consist of two or more household units with one overall head. Only 10 of the households in this study reported to have two or more units, but this may have been underreported due to a lack of probing by interviewers. Six households consist of two units each, another three of three units each, while one household has six units. Seven of the 10 households have an elderly male or female as the overall head, with adult sons or daughters heading household units. The remaining three households consist of siblings living together with one of the siblings, male or female and not necessarily the eldest, as the overall head. Units usually consist of a couple, married legally or traditionally, with children, or a single mother with children, occupying their own living unit at the homestead. Units within households are not only associated with big households, as these households vary greatly in size, with the smallest having seven members living across two units and the biggest having 23 members living across six units. One of the case studies revealed that this situation may change when the head passes away. Then, what used to be household units, become independent households (see Chapter 6, case 11). When households consist of units it may have implications for decision making, resource allocation and arrangement of care.

Household composition

Table 5.12 provides a classification of households based on how members are related to the head of the household.

Table 5.12 Household composition by sex of head (N=354)

Household composition	Male-headed		Female-headed		Total	
	freq	%	freq	%	freq	%
Single person	8	4.0	10	6.5	18	5.1
Head ±other relatives ± non related persons	13	6.5	2	1.3	15	4.2
Head + partner ± other relatives ± non related persons	19	9.5	2	1.3	21	5.9
Head + partner + children ±other relatives ± non related persons	88	44.0	3	1.9	91	25.7
Head + partner + children + grand-children ± great grandchildren ± other relatives ± non related persons	58	29.0	4	2.6	62	17.5
Head + partner ± grandchildren ± great grandchildren ± other relatives ± non related persons	8	4.0	1	0.6	9	2.5
Head + children ± other relatives ± non related persons	3	1.5	28	18.2	31	8.8
Head + children + grandchildren ± great grandchildren ± other relatives ± non related persons	3	1.5	94	61.1	97	27.5
Head ± grandchildren ± great grandchildren ± other relatives ± non related persons	0	0.0	10	6.5	10	2.8
Total	200	100.0	154	100.0	354	100.0

Source: Household Survey 2006

The majority (86.5%) of male heads reside with partners, 44 percent with children in two-generation households and 29 percent in three- or four-generation households, which may include other relatives and non-related persons. Only 10 female heads live with male partners. The majority (61%) of female-headed households consist of three generations where heads live with children and grandchildren, or of four generations where they also have great grandchildren living with them. Several of these households include single daughters with their children and sometimes grandchildren living with maternal parents, as can be seen in several of the case studies presented in Chapter 6 (see cases 1, 6, 9, 14 & 17). Nineteen households, eight headed by males and 11 headed by females can be referred to as 'skip-generation' households, where there are no children, but grandchildren and/or great grandchildren present in the household. 'Other relatives', or members of the extended family, mainly include siblings, in-laws, nephews, nieces, and other distant relatives, while non-related persons include friends or employees, such as domestic workers.

Single-person households

Eighteen persons in the sample live alone. Table 5.13 provides an overview of selected characteristics of the eight male and ten females residing on their own.

The youngest person is a male aged 18 and the oldest a female aged 79. Males who stay alone are young and unmarried, as opposed to females who are older, with half of them widowed. Individuals live on their own mainly as a result of relatives/friends moving away or passing away, thus out of necessity rather than by choice. Males have also been living on

their own for a shorter period of time than most of the females. Thirteen of them have only been staying on their own for the last one or two years, following the death or departure of a relative or friend. Five of them, all female, have been living on their own for several years. One widow without any children has been staying on her own since 1980 when her husband passed away.

Table 5.13 Profile of single person households (N=18)

Variable	Male	Female
	freq	freq
Age:		
15-39	6	2
40-64	2	3
65+	0	5
Marital status:		
Never married	8	5
Widowed/divorced/separated	0	5
Reason for staying on his/her own:		
Relatives/friends passed away	5	4
Relatives/friends moved out	3	6
Duration of stay on his/her own:		
Less than one year	3	3
One to three years	5	2
Extended period of time	0	5
Employment status:		
Employed	3	0
Unemployed, looking for work	2	1
Not working, ill/disabled	3	4
Not working, pensioner	0	5
Source of income:		
Employment	3	0
State old age or disability grant	1	7
Goodwill of family/neighbours	4	3
Total	8	10

Source: Household Survey 2006

Seven of them are unable to work as a result of illness or disability and although some are receiving grants, several are dependent on the goodwill of distant relatives and/or neighbours for financial and material support. Neighbours also play an important role in providing support in the form of labour and emotional support, especially for ill and disabled individuals. The living arrangements and livelihood generation of a young woman living alone is presented in Chapter 6 (see Case 10).

5.2.4 Income and assets

Income

Although respondents were asked to state the total monthly household income, the estimated incomes presented in Table 5.14 were calculated by combining individual incomes from different sources. Respondents easily under- or overestimate household

income, especially if income is generated by several household members through employment and grants.

Five of the six households with no regular income are single-person households, three men and two women, all relying on the charity of family, friends and neighbours (also see Table 5.13). The remaining household with no regular income is headed by a male who is living with his wife and their young grandchild. They also rely on neighbours and distant relatives for financial support. More than half of the households (50.6%) are earning between R601 and R2500 per month, some of them very poor and living on less than US$1 per person per day. A very small percentage (7.6) of households is earning more than R7501 per month. Only one small male-headed household in Ward 3 earns in excess of R18,000 per month. He and his wife are self-employed commercial farmers, growing and selling a variety of crops, fruit and vegetables.

Table 5.14 Estimated household income per month by sex of head and location (in %)

Income by category in South African Rand	Ward 3 (N=137)		Ward 5 (N=217)		Total (N=354)
	Male (n=72)	Female (n=65)	Male (n=128)	Female (n=89)	
R0-R600	13.9	9.2	10.9	9.0	10.7
R601-R1500	25.0	30.8	20.3	38.2	27.7
R1501-R2500	15.3	32.3	21.9	23.6	22.9
R2501-R3500	18.1	16.9	13.3	6.7	13.3
R3501-R5000	15.3	4.6	16.4	7.9	11.9
R5001-R7500	6.9	0.0	8.6	5.6	5.9
R7501 and more	5.5	6.2	8.6	9.0	7.6
Total	100.0	100.0	100.0	100.0	100.0
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Household income*	R2863.89 (3301.34)	R2228.46 (2153.24)	R3372.11 (3311.02)	R2592.13 (2551.11)	R2862.66 (2964.11)

Source: Household Survey 2006
R = South African Rand, R1.00 = US$0.13
* One way between groups analysis of variance (ANOVA) significant at $p \leq 0.05$

Although not statistically significant, the mean household income of R3052.21 (SD=3040.57) in Ward 5 is higher than that of Ward 3 at R2562.41 (SD=2823.67). The mean income of male-headed households at R3189.15 (SD=3308.28) is significantly higher than that of female-headed households at R2438.64 (SD=2390.64).

Sources of income

Sources of income include formal employment, self-employment, piece work and income from state and private grants. Proportionate household income from different sources is presented by sex of head and location in Table 5.15.

Only 21.8 percent of the surveyed households do not access any grants, some of them (1.7%) not having access to any regular source of income. This can either be as a result of none of the household members being eligible for grants, or because they are for various reasons unable to apply for grants (also see section 5.1.5).

Old age pensions and child support grants are the most common grants accessed by households with few individuals accessing foster care, disability and care dependency grants. The individual at whom a grant is targeted does not always benefit from the grant. Children, the target of child support grants, do not necessarily benefit from these grants collected by their mothers or other caregivers. An example of this is the three year-old girl in Case 18, Chapter 6. Older persons receiving old age pensions are also vulnerable to exploitation and some have to surrender their grants to younger family members.

Income from employment frequently includes a combination of small amounts earned by more than one household member from formal, self and secondary employment. The majority (59.6%) of households, with little difference between male- and female-headed households, rely on a combination of income from employment and grants for the household income. One should though not assume that individual incomes are combined at the household level, and that all household members equally benefit from this combined income.

Table 5.15 Proportionate income from employment and grants by sex of head and location (in %)

Sources of income	Ward 3 (N=137)		Ward 5 (N=217)		Total
	Male (n=72)	Female (n=65)	Male (n=128)	Female (n=89)	(N=354)
No income	2.8	1.5	1.6	1.1	1.7
Income from employment only	25.0	6.2	27.3	15.7	20.1
Income from grants only	15.3	32.3	7.8	27.0	18.6
Combination	56.9	60.0	63.3	56.2	59.6
Total	100.0	100.0	100.0	100.0	100.0
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Employed HH members*	1.33 (1.09)	1.03 (0.92)	1.53 (1.03)	1.26 (1.07)	1.33 (1.04)
HH members receiving state grants	1.89 (2.13)	2.22 (1.59)	1.62 (1.65)	1.85 (1.64)	1.84 (1.75)

Source: Household Survey 2006

* One way between groups analysis of variance (ANOVA) significant at $p \leq 0.05$

The mean number of employed household members in male-headed households at 1.46 (SD=1.05) is significantly higher than the 1.16 (SD=1.01) in female-headed households. Households in Ward 5 also have significantly more employed members with a mean of 1.42 (SD=1.05) compared to the mean of 1.19 (SD=1.02) for Ward 3. This may be because Ward 5 is closer Richards Bay with more employment opportunities. More female-headed (29.7%) than male-headed (10.5%) households are dependent on grants as their only source of income. Although not statistically significant, the mean number of household members receiving state grants, 2.01 (SD=1.62), is higher in female-headed households compared to the mean of 1.72 (SD=1.84) in male-headed households. This can be partially explained by female heads being older than, and receiving old age pensions from a younger age, than their male counterparts. The mean number of 2.04 (SD=1.89) household members receiving grants in Ward 3 is also higher than the mean of 1.71 (SD=1.65) in Ward 5. This can be explained by the lower average household incomes associated with female-headed households and households in Ward 3, as household income is one of the criteria in determining eligibility for grants.

Assets

Although assets such as a tractor, computer, electric cleaning appliance (vacuum cleaner or floor polisher) and hot water geyser were included in the questionnaire, they are not included in the discussion. None of the households owns a tractor or hot water geyser, while only two households own cleaning appliances and three households own computers. Assets owned by households in the two locations are presented in Figure 5.2.

Availability of an asset in a household does not automatically translate into the asset being equally accessible to individual household members. The most common asset in both wards is a mobile telephone (cell phone). Mobile telephones are owned by individuals and often more than one household member owns one. As these telephones are owned by individuals it cannot be assumed that all household members have access to a telephone. A household owning a car does not necessarily mean equal access for all household members to it as a mode of transport. When respondents were asked about the main mode of transport used by the household, only one female-headed household indicated that traveling by car is the main mode of transport used by the household. The head of this household is a 40-year old teacher who lives with her two children and another relative, and the car belongs to her. A car is indicated as the main mode of transport used by household members in 10 male-headed households. The remaining 6 female-headed and 21 male-headed households, where one of the household members owns a car, indicated that they use other modes of transport.

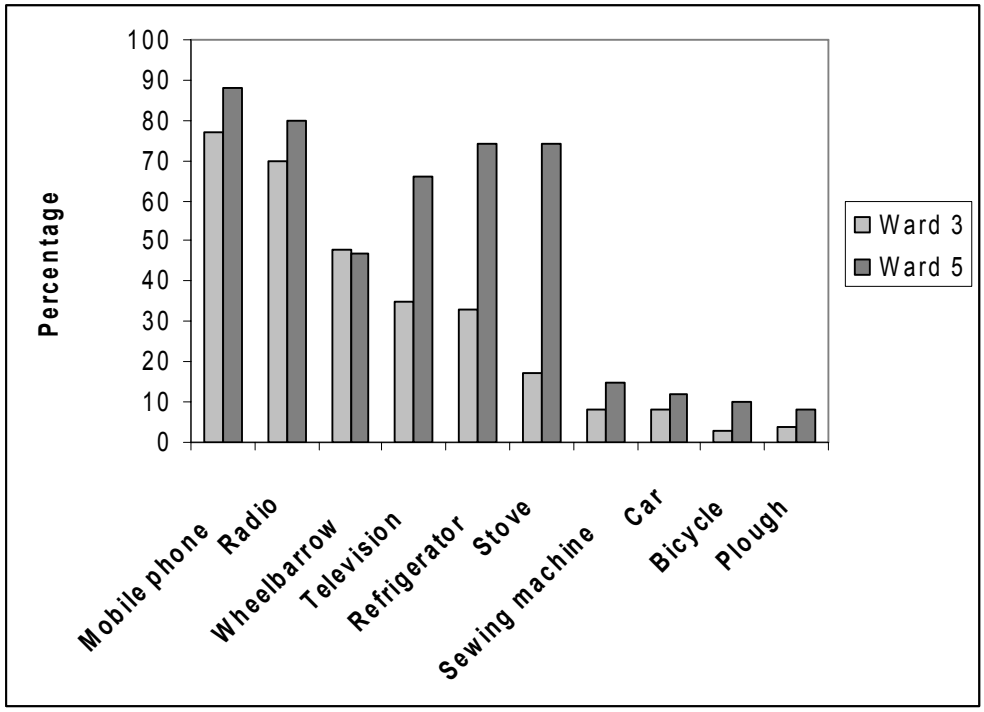


Figure 5.2 Number of household assets by location expressed as a percentage (N=354)

Assets also greatly differ in value, from a car in fairly good running condition valued at thousands of Rands, to a wheelbarrow valued at less than R100. The value of an asset can also not only be measured in its resale or money value, but also in terms of its income-generating potential or time, human energy and money-saving value. A car can be used to generate income by transporting people, especially in this area where very few people own cars and where access to public transport is limited. Using a stove, rather than an open fire, for cooking does not only save time when preparing food, but also saves time and human energy required to collect firewood. A refrigerator may contribute to saving money, and

time, with less frequent trips to buy perishables and the opportunity to buy in bulk at lower prices.

After a mobile telephone, a radio is the most common asset, owned by 76.3 percent of the households. Close to half (47.2%) of all the households own a wheelbarrow, with little difference between households in the two locations and between male- and female-headed households. Wheelbarrows are mainly used to transport containers of water to the homestead. In addition to this wheelbarrows are also used to transport ill and disabled persons to clinics and hospitals. Significantly more households in Ward 5 than in Ward 3 own stoves, refrigerators and televisions. The most obvious explanation is that these appliances usually work with electricity, which the majority of households in Ward 3 does not have access to. Very few households own sewing machines with the difference between the two locations again partially explained by the limited access to electricity in Ward 3. Very few households own bicycles, which is not a common mode of transport used by the Zulu people. Only 23 households own a plough, which can be associated with more than 60 percent of the households not producing any crops. Some households may have access to land, but are unable to prepare the land without access to a plough, on the other hand households that do not have access to land to grow crops may not deem it necessary to invest in buying a plough.

Thirteen households did not own any of the assets referred to in this section. Only one household has all the assets included in Figure 5.2 as well as those which were in the initial list, but excluded from the figure. This is the male-headed household with the highest household income referred to in the previous section. In both wards, female-headed households own fewer assets than male-headed households. The maximum number of assets owned by female-headed households is eight, while four male-headed households own nine or more assets. The mean numbers of assets owned by male- and female-headed households in the two locations are summarized in Table 5.16.

Table 5.16 Mean number of assets by sex of head and location (N=354)

	Ward 3 (N=137)		**Ward 5 (N=217)**		Total
	Male (n=72)	**Female (n=65)**	**Male (n=128)**	**Female (n=89)**	(N=354)
Mean number of assets* (SD)	3.32 (2.29)	2.72 (1.60)	4.88 (1.95)	4.51 (1.96)	4.07 (2.14)

Source: Household Survey 2006

* One way between groups analysis of variance (ANOVA) significant at $p \leq 0.05$

The mean number of assets owned by male-headed households is 4.32 (SD=2.21), significantly higher than the 3.75 (SD=2.01), owned by female-headed households. The mean number of assets owned by households in Ward 5 at 4.73 (SD=1.96) is also significantly higher than the mean number of 3.04 (SD=2.01) owned by those in Ward 3. The lower household income associated with female-headed households and households in Ward 3 may explain this difference. In addition to this, the lack of access to electricity in Ward 3 may also explain why the households in this ward do not invest in electrical equipment (see Table 5.19).

5.2.5 Housing, access to land and agricultural activity

Home ownership and building materials used

The majority of households, 92.0 percent in Ward 3 and 94.5 percent in Ward 5, indicated that they own the homestead, including the physical structures and surrounding land. Thirteen households headed by males and 10 headed by females indicated that they do not own the homestead. Where the homestead did not belong to the household, it either belongs to a family member who passed away less than one year ago or to a family member who lives elsewhere. The main building materials used by households in the construction of living units are presented by research location in Table 5.17, with no significant difference between male- and female-headed households. A homestead usually includes two or more living units differing in size, construction and purpose, surrounded by some land, and usually fenced. The amount of land surrounding living units varies, with less land surrounding units in the more densely populated Ward 5, compared to the less densely populated Ward 3.

Traditional structures are usually built using a frame consisting of wood and wire, filled with stones, broken bricks and cement. The majority of traditional or wooden structures have one or two rooms. Structures built from bricks or concrete blocks usually have more than two rooms. Homesteads where structures are mainly built using bricks or concrete blocks, often include at least one traditional/wooden structure, usually a traditional kitchen where cooking can be done on an open fire.

Table 5.17 Main building material used to construct living units by location (N=354)

Building material	Ward 3		Ward 5		Total	
	freq	%	freq	%	freq	%
Bricks/concrete blocks	54	39.4	111	51.2	165	46.6
Traditional/wood only*	83	60.6	106	48.8	189	53.4
Total	137	100.0	217	100.0	354	100.0

Source: Household Survey 2006

* Chi-square significant at $p \leq 0.05$

Access to land and agricultural activity

Table 5.18 provides an overview of household's access to land and agricultural activity by sex of head and location. A few households (n=11) indicated that they do have access to land for keeping livestock and/or growing crops, but that they are for reasons unknown not currently utilizing the land. On the other hand, some households indicated that they do not have access to land, but they grow some fruit and/or vegetables at the homestead and some kept cattle at the homestead. More than half (56.2%) of the households indicated that they did not have any access to land for keeping livestock and/or growing of crops. It was expected that households in the less densely populated Ward 3 with less sandy soil would have greater access to land, but although slightly more male-headed households in this ward kept livestock and grew crops, there are little difference between the two wards.

Very few households (7.1%) kept livestock, with less female than male-headed households. Livestock mainly includes cattle and/or goats. The few heads of cattle owned by most of the households, as revealed by the case studies (see Case 6 in Chapter 6) and focus group discussions (FGD3 and FGD4), are usually part of the *ilobolo* or bride wealth received for a daughter. Cattle graze on communal land in between homesteads. .Goats are kept for slaughtering at traditional ceremonies as an alternative to the more expensive

cattle. Cattle and/or goats are usually kept in a small kraal at the homestead. Small stock such as chickens is owned by many households, but since they are roaming freely, few households can indicate exactly how many chickens they own. No households had any pigs and only very few households have ducks or geese.

Table 5.18 Access to land and agricultural activity by sex of head and location (in %)

Variable	Ward 3 (n=137)		Ward 5 (n=217)		Total
	Male (n=72)	Female (n=65)	Male (n=128)	Female (n=89)	(N=354)
Access to land					
No land available for agriculture	48.6	60.0	57.8	57.3	56.2
Land for growing crops only	38.9	32.3	34.4	36.0	35.4
Land for keeping livestock only	8.3	4.6	3.1	2.2	4.2
Growing crops and keeping livestock	4.2	3.1	4.7	4.5	4.2
Total	100.0	100.0	100.0	100.0	100.0
Keeping livestock					
Not keeping any livestock	88.9	93.8	93.0	95.5	92.9
Cattle and/or goats	11.1	6.2	7.0	4.5	7.1
Total	100.0	100.0	100.0	100.0	100.0
Growing crops					
Not growing any crops	55.6	61.5	69.5	62.9	63.6
Maize	22.2	10.8	10.9	10.1	13.0
Amadumbe (taro potato)	5.6	6.2	3.9	5.6	5.1
Sugarcane	1.4	3.1	1.6	5.6	2.8
Sweet potato	1.4	1.5	0.8	3.4	1.7
Combination of two/more crops	13.8	16.9	13.3	12.4	13.8
Total	100.0	100.0	100.0	100.0	100.0
Growing fruit and/or vegetables					
Not growing any fruit or vegetables	30.6	27.7	35.2	37.1	33.3
Growing some fruit and vegetables	20.8	30.8	21.9	25.8	24.3
Growing some fruit only	29.2	30.8	17.2	15.7	21.8
Growing some vegetables only	13.9	10.7	19.5	18.0	16.4
Variety fruit and/or variety vegetables	5.5	0.0	6.2	3.4	4.2
Total	100.0	100.0	100.0	100.0	100.0

Source: Household Survey 2006

Only 36.4 percent of all the surveyed households grow crops, and except for more male-headed households in Ward 3 growing maize, there is little difference between male- and female-headed households in the two locations. The main crop grown by households is maize, with 13 percent of all households growing maize only and a further 12.7 percent growing maize in combination with sweet potato and/or *amadumbe.* Only three households grow beans together with some other crops. It is interesting to see that sugar cane, which is a commercial crop, is grown by more female than male-headed households.

Fruit and/or vegetables are mainly grown in home gardens with few individuals involved in community gardens. The majority of households (66.7%) grow at least some fruit and/or vegetables. Households in Ward 3 grow more fruit than those in Ward 5, which may be attributed to Ward 3 having more land available at homesteads. Commonly grown

fruit includes mango, orange, banana, pawpaw and avocado, while commonly grown vegetables includes cabbage, spinach, tomatoes, onions, green peppers and beetroot. Very few households grow a variety of fruit and vegetables, with the well-off commercial farmer referred to earlier in this chapter as one of the few. With the exception of the commercial farmer, households grow crops, fruit and vegetables on a small scale and mainly for own consumption.

5.2.6 Services and infrastructure

Energy

One of the main differences between the two wards is that significantly more households in Ward 5 than in Ward 3 have access to electricity. In Ward 3 access to grid electricity is still very limited, with only 21 (15.3%) households, and more male- than female-headed households, having access. In Ward 5, the majority of households (84.8%) has access to grid electricity. Electricity in this area, as in nearby Richards Bay, operates with a prepaid system where electricity units must be bought and a code then entered on a panel on a metred box to activate it. In Table 5.19 the main sources of energy used for cooking and lighting are summarized.

Table 5.19 Access to electricity and sources of energy used for cooking and lighting by household location (N=354)

Variable	Ward 3		Ward 5		Total	
	freq	%	freq	%	freq	%
Households with access to electricity *	21	15.3	184	84.7	205	57.9
Source of energy used for cooking						
Electricity	17	12.4	143	65.9	160	45.2
Wood	103	75.2	46	21.2	149	42.1
Other	17	12.4	28	12.9	45	12.7
Total	137	100.0	217	100.0	354	100.0
Source of energy used for lighting						
Electricity	21	15.3	181	83.4	202	57.1
Candles	113	82.5	35	23.6	148	41.8
Other	3	2.2	1	0.5	4	1.1
Total	137	100.0	217	100.0	354	100.0

Source: Household Survey 2006
* Chi-square significant at $p \leq 0.01$

In Table 5.19 it can be seen that not all households with access to electricity use it for cooking and lighting. Out of the 205 households with access to electricity, 160 use it as the main source of energy for cooking and 202 households use it as the main source of energy for lighting. One of the latter does not have access to electricity at the homestead, but 'borrows' electricity from neighbours by using an extension cord. Although 'borrowing' of electricity may occur in other households, it was not further explored in this study. Four households with access to electricity, neither use it for cooking, nor for lighting. A further 41 households with access to electricity, do not use it as their main source of energy for cooking, either because they do not have an electric stove, or because they give preference to other cheaper sources of energy. Some households cook on the open fire and use other sources of energy for cooking only when the weather does not allow them to cook outside. Using wood for cooking does not only require more time to cook, but also time and human

energy to collect firewood. Using electricity only for lighting is a strategy followed by some poor households to save money.

Alternative energy sources used for cooking, other than wood, include gas and paraffin. Candles are used for lighting by those without access to electricity or as an alternative to electric lighting. Very few households use the more expensive gas or paraffin lamps for lighting.

Water

Clean water and proper sanitation is important to promote and maintain health. In Table 5.20 the main source of water used by households are summarised. Only one household in Ward 3 has piped water inside the dwelling, while a further nine households have access to piped water in the yard. Significantly more households in Ward 3 as opposed to Ward 5 use public taps as the main source of water as opposed to significantly more households in Ward 5 as opposed to Ward 3 using boreholes. Other sources of water include communal water tanks and water tankers delivering water. Even though the majority (62.4%) of households have access to reliable sources of clean water, 30.5 percent of households still rely on rivers or streams for their water. Even though distance from the main source of water was not measured in this study, it should be noted as an important factor contributing to an increase in domestic work, especially if long distances have to be covered once or twice a day to fetch water.

Table 5.20 Main source of water for household use and sanitation by location (N=354)

Water and sanitation	Ward 3		Ward 5		Total	
	freq	%	feq	%	freq	%
Main source of water						
Borehole*	53	38.7	125	57.6	178	50.3
River or stream	44	32.1	64	29.5	108	30.5
Piped water, public tap*	25	18.2	8	3.7	33	9.3
Piped water in dwelling/yard	2	1.5	8	3.7	10	2.8
Other	13	9.5	12	5.5	25	7.1
Total	137	100.0	217	100.0	354	100.0
Sanitation						
Basic pit latrine	86	62.8	128	59.0	214	60.5
Ventilated improved pit (VIP) latrine	13	9.5	42	19.4	55	15.5
Septic tank	0	0.0	12	5.5	12	3.4
Flush toilet	1	0.7	0	0.0	1	0.3
No toilet*	37	27.0	35	16.1	72	20.3
Total	137	100.0	217	100.0	354	100.0

Source: Household Survey 2006

* Chi-square significant at $p \leq 0.05$

Sanitation

Only one household, the household with piped water in the dwelling, has a flush toilet inside the living unit. The main toilet facility used by 76.0 percent of the households is either the basic pit latrine, or the slightly improved ventilated pit latrine. It is of great concern that 20.3 percent of the households, with significantly more households in Ward 3 than in Ward 5, do not have access to any type of toilet facility.

Refuse removal

Although refuse removal was included in the survey questionnaire, none of the households have their refuse removed by the local authorities and all the households dispose of waste in a similar manner; by dumping it in a pit and burning it.

Transport

The majority (85.6%) of households, irrespective of location, relies on minibus taxi's for transport, which for many individuals still means walking some distance to be fetched/dropped off along one of the main roads. Some taxis will fetch/drop individuals closer to their homesteads at additional cost. Busses, which are less frequent and serve a limited area, are used as they main mode of transport by 9.3 percent of the households. The remaining households have access to a car owned by a household member. Using public transport is costly and can be time consuming.

Primary health care facilities

There are two public health clinics in the research area. The majority of households in Ward 5 are less than three kilometres from the nearest public health clinic, whereas the majority of households in Ward 3 are more than three kilometres from the nearest clinic, several of them more than five kilometres away. The clinic situated in Ward 5 is also bigger and better resourced than the one situated in Ward 3, which sometimes makes it necessary for those living in Ward 3 to travel to the clinic further away to access certain care and treatment. The nearest public hospital is approximately 30 kilometres from the majority of those living in Ward 5 and further from those living in Ward 3.

5.3 Individual and household impacts of HIV/AIDS and/or TB

5.3.1 Morbidity, mortality and orphans

Morbidity

Morbidity is described by De Haan (2005) as the state of being sick or diseased or the incidence of disease. Table 5.21 provides an overview of the prevalence of AIDS and/or TB as opposed to other chronic diseases amongst the 529 individuals in the sample who reported average to poor health status (also see Table 5.7 and Table 5.8).

Of the 529 individuals with chronic diseases, 140 were diagnosed with AIDS and/or TB. More than half (n=78) of those with AIDS and/or TB are young adults aged between 15 and 39. It can also be seen that this prevalence (56.5%) is highest amongst the females aged 15 to 39 residing in Ward 5. Those with AIDS are in different clinical stages of the disease.

Table 5.21 Individuals with AIDS and/or TB or other chronic diseases by age, sex and location (in %)

AIDS and/or TB and other chronic diseases by age	Ward 3 (n=226)		Ward 5 (n=305)		Total
	Male (n=90)	Female (n=136)	Male (n=115)	Female (n=188)	(N=529)
Age 0-14 (n=106)					
AIDS and TB	13.6	29.4	12.5	14.3	16.0
Other chronic diseases	86.4	70.6	87.5	85.7	84.0
Total	100.0	100.0	100.0	100.0	100.0
Age 15-39 (n=166)					
AIDS and TB	41.9	38.1	45.1	56.5	47.0
Other chronic diseases	58.1	61.9	54.9	43.5	53.0
Total	100.0	100.0	100.0	100.0	100.0
Age 40-64 (n=186)					
AIDS and TB	28.6	14.0	25.0	26.2	22.6
Other chronic diseases	71.4	86.0	75.0	73.8	77.4
Total	100.0	100.0	100.0	100.0	100.0
Age ≥65 (n=71)					
AIDS and TB	0.0	5.0	8.3	3.3	4.2
Other chronic diseases	100.0	95.0	91.7	96.7	95.8
Total	100.0	100.0	100.0	100.0	100.0

Source: Household Survey 2006

The 140 individuals with AIDS and/or TB live in 107 households. Twenty-four of these households have two or more individuals diagnosed with AIDS and/or TB. In Ward 3, seven households have two members each with HIV/AIDS and/or TB and one female-headed household has five members with AIDS and/or TB. In Ward 5, five male-headed and 10 female-headed households each have two or three members with AIDS and/or TB and one male-headed household has five members with AIDS and/or TB.

If AIDS and TB are combined with other chronic diseases, then 75.7 percent of all the households have at least one member suffering from a chronic disease. The majority of households without chronically ill members are male-headed households in Ward 5, while the majority of those with three or more chronically ill members are female-headed households in Ward 3. Two female-headed households, one in Ward 5 and one in Ward 3, have respectively six and seven chronically ill persons residing at the homestead. Some of the other chronic diseases may be AIDS-related, but cannot be classified as AIDS either because individuals have not been tested for HIV or they are unwilling to disclose their HIV status.

Mortality

Mortality refers to the death rate or the number of deaths occurring in a unit of population over a prescribed period of time (De Haan, 2005). Table 5.22 provides an overview of the deaths which occurred in the research area from January 2006 through September 2006.

Table 5.22 Number of deaths by age category, cause of death, sex and location (N=150)

Cause of death by age	Ward 3		Ward 5		Total	
	Male	Female	Male	Female		
	Freq	freq	freq	freq	freq	%)
Age 0-14 (n=23)						
Deaths attributed to AIDS or TB	0	0	2	0	2	(1.3)
Deaths attributed to other causes	5	4	6	6	21	(14.0)
Age 15-39 (n=64)						
Deaths attributed to AIDS or TB	8	14	7	7	36	(24.0)
Deaths attributed to other causes	9	7	7	5	28	(18.7)
Age 40-64 (n=42)						
Deaths attributed to AIDS or TB	4	3	0	3	10	(6.7)
Deaths attributed to other causes	5	8	12	7	32	(21.3)
Age ≥65 (n=21)						
Deaths attributed to AIDS or TB	0	0	0	1	1	(0.7)
Deaths attributed to other causes	6	6	2	6	20	(13.3)
Total	37	42	36	35	150	(100)

Source: Household survey 2006

With 150 deaths over a period of 9 months in a population of 2393, the crude death rate for 2006 is 83.6 per 1000 population. The majority (70.6%) of those who passed away were in the economically active age group of 15 to 64, with 30.7 percent of the total number of deaths in this age group attributed to AIDS or TB. A total of 26 individuals died of AIDS[6] and a further 23 of TB. Eighteen of those who died of AIDS were between the ages of 20 and 38 and the remaining eight between the ages of 40 and 48. Two children and one elderly person died of TB.

The majority of children who passed away, 19 out of 23, were below the age of five. Four children died of unnatural causes, two drowned and a further two died after accidentally consuming poisonous substances. The remaining children died of natural causes, in the majority of cases described by respondents as “sickness” or “natural death”.

Amongst the adults age 15 to 64 another 50 individuals died of causes other than AIDS and/or TB. In the majority of cases, causes of death were described by respondents as “natural disease/death”, “sick/sickness”, “do not know” or stating symptoms such as s/he “had a headache” or “used to faint”. Some of the latter may be related to AIDS, but is not classified as such. In a few cases, asthma, cancer, epilepsy or diabetes was indicated as the cause of death. In one case the cause of death was indicated as “witchcraft sickness”. The deaths of seven adults, six males and one female were caused by unnatural causes, namely as a result of crime or accidents and one male committed suicide. The main cause of death amongst the elderly was stroke while in several cases cause of death is only described by respondents as “old age” or “natural causes”.

Of the 137 households in Ward 3, 51 (37.2%) experienced one or more death compared to 56 (25.8%) out of 217 in Ward 5. Fifteen of the households in Ward 3 and ten of the households in Ward 5 experienced multiple deaths, with as many as five deaths each in two households in Ward 3. A total of 42 households experienced deaths attributed to TB or AIDS over the period of nine months. Four children, between the ages of 29 and 38, of one female household head died of AIDS, leaving behind three orphaned children. In

[6] Although AIDS is not usually indicated on death certificates as the cause of death, the cause of death in these cases were specified by respondents as AIDS.

another male-headed household four of his children, between the ages of 20 and 39, died of natural causes, leaving behind five orphaned children.

Orphans

An orphan, for the purpose of this research, is described as a child, 18 years or younger, of whom the biological mother *and* father passed away (double orphan), or where the biological mother *or* father passed away and the whereabouts of the other parent is not known to the primary caregiver of the child (Uys, 2003). The latter is referred to as a virtual orphan. The sample includes 144 orphaned children aged 0 to 18 years. Table 5.23 provides an overview of the ages of the orphaned children by sex of child and location.

The entire sample includes 1118 children aged 18 years and younger which means that 12.9 percent of them are either double or virtual orphans. This number may increase significantly if single orphans[7] are included, but they are not included in this study as many children are living with their biological mothers at the homestead of the maternal grandparents and questions on non-resident biological fathers were not included in the survey questionnaire. The majority of orphaned children is between 10 and 14 years of age and resides in Ward 3.

Table 5.23 Ages of orphaned children by sex and location (N=144)

Age group	Ward 3 (n=67)		Ward 5 (n=77)		Total (N=144)	
	Male	Female	Male	Female		
	freq	freq	freq	freq	freq	%)
0-4 years	2	3	0	3	8	(5.5)
5-9 years	9	12	9	8	38	(26.4)
10-14 years	10	12	23	18	63	(43.8)
15-18 years	9	10	10	6	35	(24.3)
Total	30	37	42	35	144	(100.0)

Source: Household survey 2006

The 144 orphaned children reside in 70 households, with 59 living in 32 male-headed households and the remaining 85 living in 38 female-headed households. The male heads include one 17-year old living with his brother while their sisters are living elsewhere with their maternal grandparents (see Case 13 in Chapter 6). The majority of households (n=51) includes one or two orphans, while 12 households include three orphans each and a further four households include four orphans each and three household respectively include five, six and seven orphans each. The female-headed household with seven orphans is included as a case study in Chapter 6 (see Case 17).

The majority of households (n=39) with orphaned children is multigenerational where the orphaned children are living with their grandparent(s), uncles and/or aunts and cousins. Thirteen of the households are skip-generation households where the orphaned children are living with their grandparent(s) with no uncles and/or aunts present in these households (see Case 16 in Chapter 6). The remaining orphans are living with other relatives or non-related persons, an example of the latter, Case 12, is included in Chapter 6.

The majority of orphaned children (n=125) are attending school, with only seven school-age children not attending, while a few are not yet of school going age and two 18-year olds already completed school. Only 12 (8.3%) of the orphaned children receive foster care grants (see Table 5.6). Orphaned children up to the age of 18 qualify for foster care

[7] A single orphan refers to a child who has lost one parent and is living with the remaining parent.

grants with a possibility of extending the grant up to age 21 if evidence can be supplied that the child is still financially dependent on the guardian. Many households find it difficult to access foster care grants mainly because they are unable to supply all the documents required when applying for the grants.

5.3.2 Classification and comparison of households

The classification of the 354 surveyed households which follows below is loosely based on Barnett and Blaikie's (1992) differentiation between households as afflicted, affected and not affected by HIV/AIDS. According to them, afflicted households include those which experienced the direct impact of HIV/AIDS through AIDS-related illness or death, while affected households are indirectly affected through the loss of resources or additional members to care for and not affected households those which did not experience direct or indirect impacts as a result of HIV/AIDS.

Tuberculosis is used as a proxi indicator for AIDS, with an estimated 60 to 70 percent of those with TB, according to the World Health Organisation, also being HIV-positive. The classification presented here includes four clusters which can be described as follows:

Cluster 1: Households neither afflicted nor affected by HIV/AIDS and/or TB – including all those households, where at the time of data collection, none of the members were HIV-positive or diagnosed with TB, did not experience any deaths attributed to AIDS or TB and did not take care of any orphaned children.

Cluster 2: Households afflicted by HIV/AIDS and/or TB – including households where at least one of the members, at the time of data collection, was HIV-positive and/or had TB. These households did though not experience deaths attributed to AIDS or TB and are not taking care of orphaned children.

Cluster 3: Households affected by HIV/AIDS and/or TB – including households where none of the members are HIV-positive or has TB, but where these households experienced at least one death attributed to AIDS or TB and/or are taking care of at least one orphaned child.

Cluster 4: Households afflicted and affected by HIV/AIDS and/or TB – including households where at least one member is HIV-positive or has TB, and experienced at least one death attributed to AIDS, and are taking care of at least one orphaned child.

Table 5.24 provides an overview of the number of households in each cluster, by sex of household head and by household location.

Table 5.24 Cluster by sex of head and location of household (N=354)

Cluster	Sex of head				Location				Total	
	Male (n=200)		Female (n=154)		Ward 3 (n=137)		Ward 5 (n=217)		(N=354)	
	n	%	n	%	n	%	n	%	n	%
Cluster 1	116	58.0	75	48.7	72	52.5	119	54.8	191	54.0
Cluster 2	41	20.5	30	19.5	24	17.5	47	21.7	71	20.0
Cluster 3	25	12.5	31	20.1	22	16.1	34	15.7	56	15.8
Cluster 4	18	9.0	18	11.7	19	13.9	17	7.8	36	10.2
Total	200	100.0	154	100.0	137	100.0	217	100.0	354	100.0

Source: Household survey 2006

Cluster 1 includes some households with members with 'other chronic diseases' which may be AIDS-related, while some also experienced deaths which may be attributed to AIDS, but

which were not specified as such. Although it is known in some cases, it is not certain that all the orphaned children are AIDS-orphans. Irrespective of cause of death of parents, all the households with orphaned children are included in Cluster 3 or 4. Almost half (46%) of all the surveyed households are known to have experienced, or are continuing to experience direct and/or indirect impacts attributed to AIDS-related disease and death. At 58 percent almost 10 percent more male-headed than female-headed households escaped the impacts of HIV/AIDS and/or TB, this difference may though also be attributed to a greater willingness of female-headed households to reveal HIV status. In Cluster 1, there is little difference between the two research locations. Households in Ward 3 have fewer ill persons, but experienced more deaths and as a result are taking care of more orphaned children. Female-headed households have more ill individuals, and also experienced more deaths and as a result have more orphaned children residing at their homesteads.

Table 5.25 provides a comparison of the households in the four clusters on selected demographic and socio-economic variables. Households in Clusters 2, 3 and 4 are significantly bigger than those in Cluster 1, with on average one to two more members. Average household size is highest in Cluster 4 where households include orphaned children as well as ill adults. Heads of households in Clusters 3 and 4 are slightly older than those heading households in Clusters 1 and 2, but this difference is not statistically significant. Households which are afflicted and/or affected by HIV/AIDS and or TB have significantly more members aged 14 years of younger and/or 65 years and older. This may be attributed to ill persons with children or orphaned children joining households of elderly parents/grandparents (see Case 19 in Chapter 6 as an example). Although afflicted and/or affected households do not have fewer employed members than unaffected ones, the bigger household size and greater number of ill persons and orphans increases the pressure on the income generated by them.

Table 5.25 Selected demographic and socio-economic characteristics by cluster (N=354)

Selected variables	Cluster 1 (n=191) Mean (SD)	Cluster 2 (n=91) Mean (SD)	Cluster 3 (n=56) Mean (SD)	Cluster 4 (n=36) Mean (SD)
Demographic				
HH size*	6.04	7.08	7.71	8.44
	(3.6)	(4.35)	(4.29)	(3.95)
Age of HH head	50.45	50.24	55.71	52.86
	(15.07)	(15.07)	(17.88)	(14.48)
Number of demographic dependents*	2.37	2.96	3.52	3.61
	(1.88)	(2.40)	(2.40)	(2.31)
Effective dependents*	2.37	4.08	3.52	4.72
	(1.88)	(2.47)	(2.40)	(2.35)
Socio-economic				
Income in South African Rand	3159.95	2594.08	2506.07	2369.72
	(3426.91)	(2423.93)	(2469.52)	(1563.42)
Assets	4.31	4.06	3.61	3.58
	(2.16)	(2.04)	(2.30)	(1.86)

Source: Household survey (2006)

* One way between groups analysis of variance (ANOVA) significant at $p \leq 0.05$

Adults aged between 15 and 64 may not be productive as a result of chronic illness and can therefore be referred to as effective dependents (De Waal and Whiteside, 2003). This is

visible in the higher number of effective dependents, ill adult household members, in Clusters 2 and 4. In addition these ill household members not being productive, they may require nursing care which places additional strain on the human, material and financial resources of the households (see Cases 18 and 19 in Chapter 6 as examples). Although not statistically significant, households which are afflicted and/or affected by HIV/AIDS and/or TB (Clusters 2, 3 and 4) have lower incomes and fewer assets. Considering that these households are also bigger and have more dependents, it places tremendous strain on already limited financial resources. Illness and death entail additional medical expenses and funeral costs, and, with few assets that can be converted to cash, push these households further into poverty.

5.4 Discussion

The two research locations, Ward 3 and Ward 5, were selected for their differences in population density, services and infrastructure. Ward 3 is further from Richards Bay, is less densely populated with bigger homesteads, and fewer households have access to electricity, clean water at the homestead and proper sanitation. Being far from a big town, means being further from medical facilities and employment opportunities. Lack of access to electricity and clean water close to the home means additional domestic work, having to collect fire-wood and water. In addition to these differences, Ward 3 also has fewer individuals who are working, and of those who are working, many are employed in low paying elementary occupations or working as unskilled labourers. Households in Ward 3 have lower household incomes, are more dependent on state grants and own fewer assets that can be converted to cash if need be. Households in Ward 3 also have more chronically ill members and experienced more deaths than those in Ward 5.

Female-headed households are bigger than male-headed ones, having significantly more demographic and effective dependents residing at their homesteads. Female heads are significantly older than their male counterparts, the majority of them widows relying on state old age pensions as a major source of household income. The average household incomes of female-headed households are also significantly lower than that of male-headed households and in addition to this they have significantly fewer assets.

What is described in Section 5.3.2 paints a very modest picture of the number of households afflicted and/or affected by HIV/AIDS and/or TB. Households in Cluster 1 may also experience impacts similar to those in other clusters as a result of other chronic diseases and deaths attributed to other causes, especially if these occur amongst economically active members. Some households in Cluster 1 may also experience indirect impacts such as providing emotional and financial support to neighbours, friends and family not residing at their homestead.

Chapter 6

Household living arrangements and livelihoods

At the end of the previous chapter, the 354 surveyed households were categorised based on whether and how they were afflicted and/or affected by HIV/AIDS. This procedure generated four clusters: Cluster 1, households neither afflicted nor affected by HIV/AIDS; Cluster 2, households afflicted by HIV/AIDS; Cluster 3, households affected by HIV/AIDS; and Cluster 4, households both afflicted and affected by HIV/AIDS. Households neither afflicted nor affected by HIV/AIDS, did not have any members suffering from AIDS-related illnesses[8], neither were they taking care of orphaned children[9] nor, did they experience deaths attributed to AIDS-related illnesses from January through August 2006. Households afflicted by HIV/AIDS had at least one member suffering from an AIDS-related illness, but were not taking care of orphaned children, and did not experience any deaths attributed to AIDS-related illnesses from January through August 2006. Households affected by HIV/AIDS had no members suffering from AIDS-related illnesses, but consisted of, or were taking care of orphaned children and experienced deaths attributed to AIDS-related illnesses prior to August 2006. Households both afflicted and affected included at least one member suffering from an AIDS-related illness, experienced deaths attributed to AIDS-related illnesses prior to August 2006, and were taking care of orphaned children.

Four to five case study households from each cluster were selected using criteria such as household size, socio-economic status, and the sex of the head of the household. The sensitive nature of the research and the stigma attached to HIV and AIDS required the assistance of community healthcare workers to gain access to the selected households. Each case study household was visited two or three times from September 2006 through February 2007 to collect data by means of interviews and observation on living arrangements, livelihoods and care arrangements.

In this chapter the living arrangements and livelihoods of 19 households are presented. Although nursing care arrangements for people with AIDS-related illnesses are mainly discussed in Chapter 7, some care arrangements impacting on living arrangements and livelihoods are referred to in this chapter. A table summarising selected household characteristics precedes the presentation of living arrangements and livelihoods of the case study households in each cluster. The household characteristics date from the beginning of September 2006, with changes up to the end of February 2007 described in the text. Figures representing genealogies or living arrangements are included for all the households.

[8] For the purpose of this research TB is seen as an AIDS-related illness as at least 60 percent of South Africans diagnosed with TB also has HIV.

[9] In this study, a child is deemed an orphan if s/he is 18 years or younger and both parents passed away (double orphan) or when one parent passed away and the whereabouts of the other parent are unknown (virtual orphan).

Table 6.1 Selected characteristics of households in Cluster 1 (September 2006)

Variable	Case 1	Case 2	Case 3	Case 4	Case 5
Household size and composition					
Size	6	6	10	9	5
Sex distribution					
Male	2	3	3	4	2
Female	4	3	7	5	3
Age distribution					
≤14	1	4	3	1	1
15-64	5	2	7	7	2
≥65	0	0	0	1	2
Household head					
Sex	Female	Male	Male	Female	Male
Age	60	58	50	65	68
Marital status	Widow	Married	Married	Widow	Married
Level of education	Some primary school	Some primary school	Some secondary school	Some primary school	No formal schooling
Health status	Excellent	Average	Excellent	Good	Good
Work status	Not working, pensioner	Yes, odd jobs	Yes, crane operator	Not working, pensioner	Not working, pensioner
Socio-economic status of household					
No of employed HH members	3	1	5	2	0
Estimated monthly HH income	R10,000	R1,550	R14,380	R3,850	R1,640
Main source of HH income	Formal employment	Social grants	Formal employment	Formal employment	Social grants
Effective dependency ratio	0.20	2.00	0.43	0.29	1.50
Household resources and assets					
Building material (main dwelling)	Brick	Traditional	Brick	Brick	Brick
Access to land to grow crops	Yes, grows maize	Yes, grows maize	No	No	No
Own livestock	Yes, cattle	No	No	No	No
Number of assets (various)	8	3	8	8	5
Services and infrastructure					
Main source of water	River/stream	River/stream	River/stream	Borehole	Piped water, yard
Type of sanitation	Basic pit latrine	Basic pit latrine	Basic pit latrine	Basic pit latrine	Ventilated pit latrine
Access to electricity	Yes	Yes	Yes	Yes	Yes
Energy source used for cooking	Electricity	Wood	Electricity	Electricity	Electricity
Energy source used for lighting	Electricity	Electricity	Electricity	Electricity	Electricity

Source: Household survey 2006

6.1 Cluster 1: households neither afflicted nor affected by HIV/AIDS

The households discussed below were, at the commencement of the fieldwork, neither afflicted nor affected by HIV/AIDS, though they may have members suffering from chronic illnesses other than AIDS-related illnesses and may have experienced deaths attributed to causes not explicitly attributed to AIDS-related illnesses. Table 6.1 provides an overview of selected characteristics of the five case study households in this cluster.

6.1.1 Case 1: Thuli

Thuli, a 60-year old widow, lives at her homestead with her two daughters, Precious (44) and Nokuthula (38), son Xolani (28), granddaughter Rosy (26) and grandson Thabo (9). Precious is not married and has three children, two of whom, Rosy and Thabo, living with her at the homestead of her mother. Her three children all have different last names, those of their respective fathers. Rosy's six year old son joined the household in January 2007 when he started school nearby. Before that he lived with his father at the homestead of his paternal grandmother. Nokuthula is married but has no children and the whereabouts of her husband are unknown. Xolani is not married and has no children. Thuli had three more children, two daughters and a son, but they all passed away of unknown causes a number of years ago. None of them were married and they did not have any children. See Figure 6.1 representing genealogy of Thuli's household at the commencement of the study in September 2006.

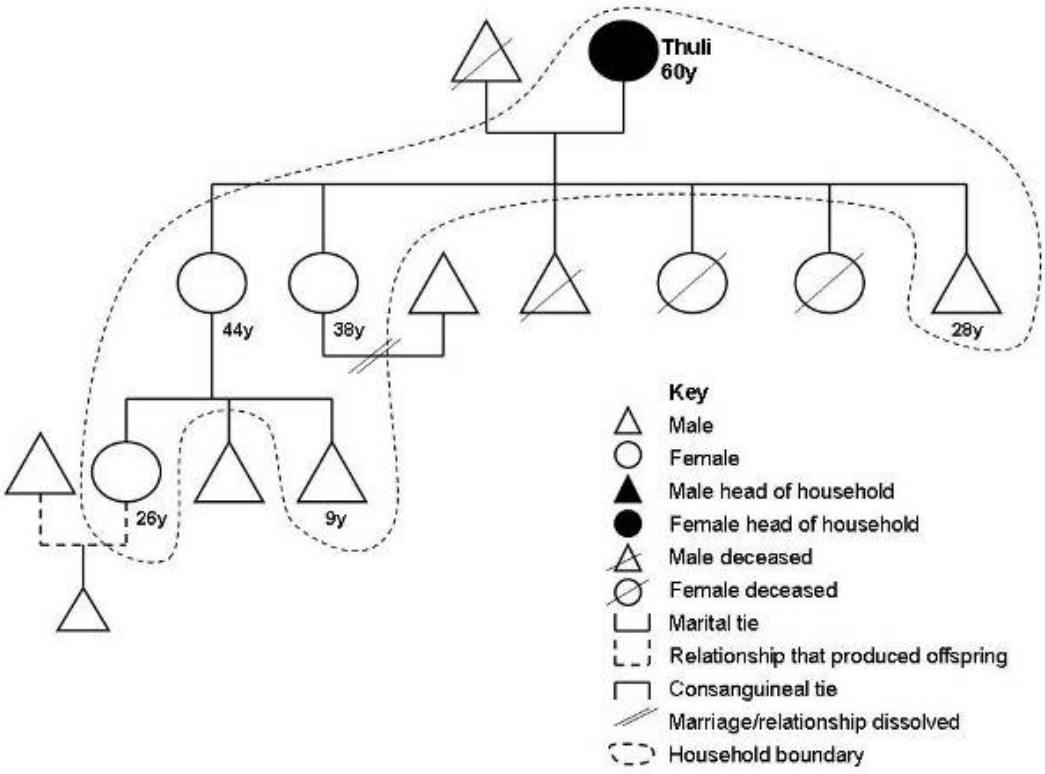


Figure 6.1 Genealogy of Thuli's household (Sept 2006)

Precious completed primary school, Nokuthula has some secondary school education, but Xolani never attended school. Rosy completed secondary school and also obtained a diploma in engineering and her son and her brother Thabo are attending primary school. Precious is a self-employed dressmaker and Nokuthula works as a street vendor in the area around the homestead. Xolani occasionally does some odd jobs, but too irregular to contribute significantly to the household income. Rosy is employed by one of the local industries as an engineer and contributes most to the household income. Thuli receives a state old age grant and the household receives state child support grants for Thabo and Rosy's son. The household owns a number of household appliances and productive and other assets, including a television, radio, stove, refrigerator, sewing machine, computer, mobile telephone and wheelbarrow. Thuli has access to land where she grows maize and keeps cattle. She is also involved in a local community garden where she grows a variety of vegetables, and at the homestead there are some fruit trees and chickens. All household members are in excellent health, with none of them consulting any medical facilities or receiving any treatment in the three months prior to and during the fieldwork. Rosy and her son have joined a medical aid scheme, provided by her employer.

Cooking is mainly done by Rosy, with occasional assistance from Thuli. Thuli cleans the house, assisted on weekends by Rosy. All adults are responsible for doing their own laundry and where applicable, that of their children. Maintenance of buildings is done by Thuli and Xolani cleans the yard. During the day Thuli looks after Thabo and Rosy's son, but in the evenings and on weekends this is the responsibility of Rosy.

6.1.2 Case 2: Cebani

Cebani, the 58-year old head of the household, lives with his wife, Sanele (48), and their three youngest children, a daughter of 14 and a twin boy and girl aged 12. Also residing with them is their three-year old grandson, the younger of the two children of their eldest daughter. Their eldest daughter lives and works in another part of the province where her daughter resides with her. Cebani and Sanele also have an unmarried son (24) living elsewhere in the province. See Figure 6.2 representing the genealogy of Cebani's household at the commencement of the study in September 2006.

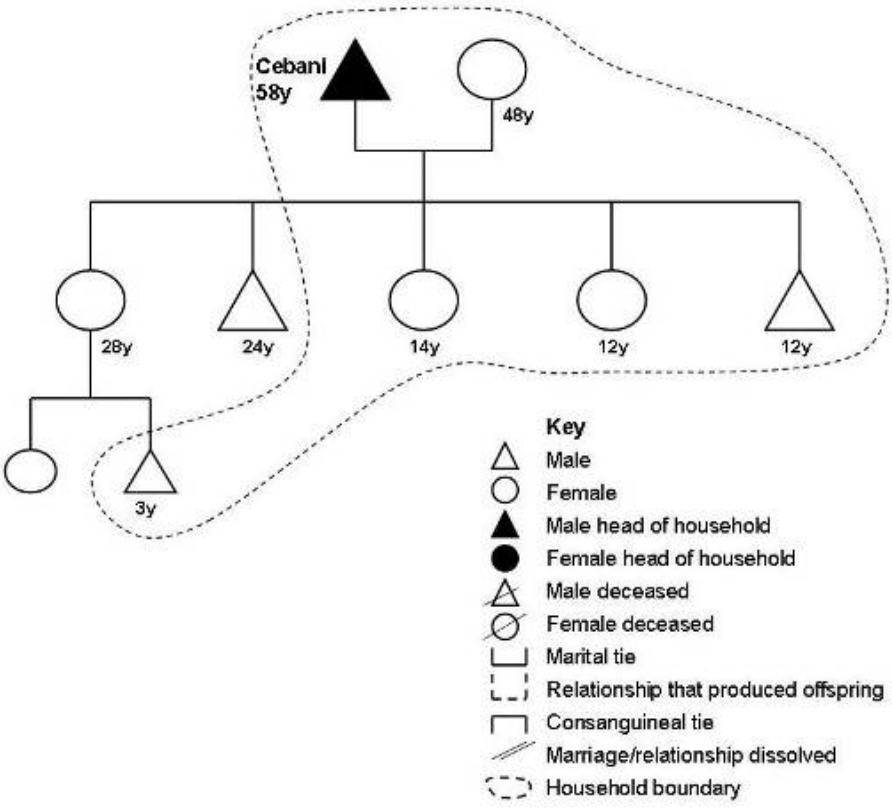


Figure 6.2 Genealogy of Cebani's household (Sept 2006)

Sanele never attended school, but all three the children are attending primary school. Cebani does some odd jobs, such as sweeping and fetching of firewood, for other people in the community and his wife makes and sells grass mats, both of them earning only a small amount of money per month. Cebani has a chronic kidney problem and receives a state disability grant. The household receives state child support grants for the twins as well as for their grandson. Cebani, two of the children and the grandchild suffer from asthma and Sanele has high blood pressure and had an operation in July 2006. They had to pay an admission fee of R50 for Sanele to be admitted to the district hospital. In addition to this they also had to pay for transport to take her to the hospital 40 kilometres away. Although Cebani is chronically ill and therefore unable to work full-time, he is able to take care of himself.

The household owns a television, refrigerator and mobile telephone and has access to land which Sanele prepares and where she grows maize. She is also involved in a local community garden, where she grows some vegetables for household use. Sanele does most of the domestic work, including cooking, laundry and fetching firewood, sometimes with the assistance of one or both daughters. She is also the one responsible for the maintenance of the buildings. Their daughters are responsible for cleaning the house and fetching water and their son cleans the yard. Sanele takes care of the children and grandson and when they are not at school, the daughters take care of their nephew.

6.1.3 Case 3: Sandile

Sandile (50) lives with his wife, Jabu (44), and their six children as well as a niece (19) and her baby who moved in with them early in 2006 when her mother passed away. Their four daughters are aged 28, 23, 19 and 6, and their two sons aged 25 and 8, respectively. Their son (25) and daughter (23), though regarded as members of the household, work in other parts of the province and do not spend every night at the homestead. In December 2006 Sandile's niece and her baby left the homestead to live with an aunt. See Figure 6.3 representing the genealogy of Sandile's household at the commencement of the study in September 2006.

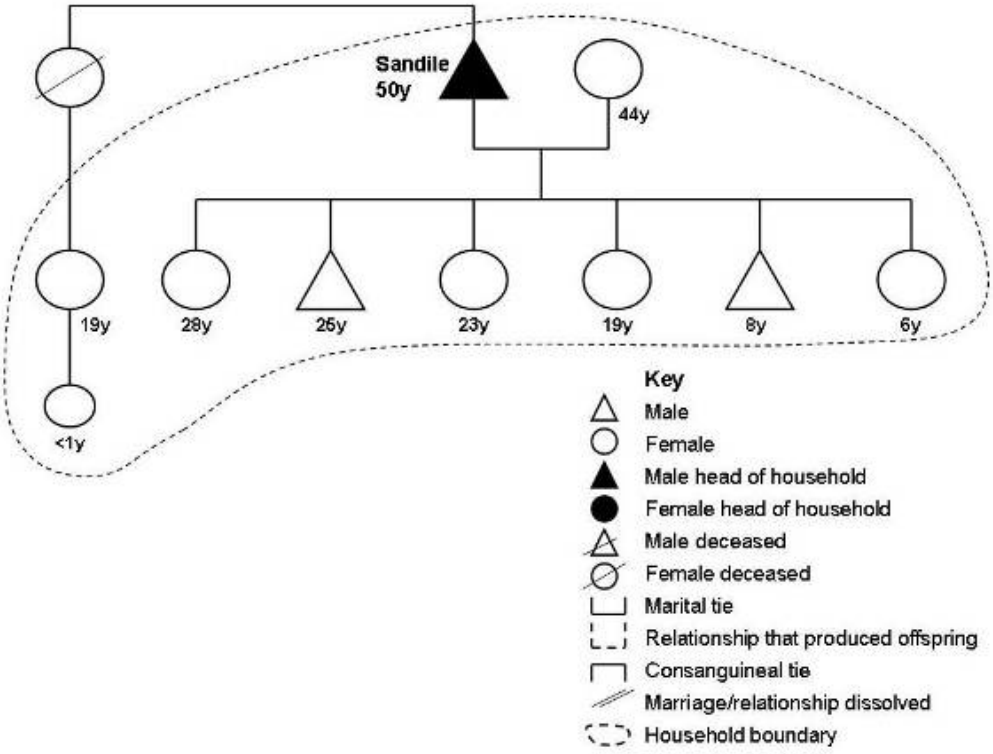


Figure 6.3 Genealogy of Sandile's household at the start of the study (Sept 2006)

All the members of the household are in excellent health. At the beginning of 2007 the 23-year old daughter discovered that she was pregnant. Sandile, his wife and their two youngest children joined a medical aid scheme provided by his employer. Both Sandile and Jabu have some secondary school education and the four oldest children completed secondary school. The two youngest children are attending primary school. Sandile's niece completed grade 9, but dropped out of school when she had her baby, she plans to return to school in 2007, the reason why she is going to stay with another relative. Sandile and three of the children are formally employed and his wife is self-employed. He works as a crane operator, Jabu as a dressmaker, their 28-year old daughter as a secretary at a private hospital in a nearby town, their 23-year old daughter as a counsellor at a clinic and their son as a boilermaker. The household receives state child support grants for the children aged eight and six. The household owns several assets, including a car, television, radio, stove, refrigerator, sewing machine, mobile telephone and wheelbarrow. Jabu makes use of public

transport most of the time as Sandile uses the car to travel to work. They do not have access to land to grow crops or keep livestock but Jabu grows *amadumbe* at the homestead where they also have some fruit trees. Jabu pays somebody to prepare the land and do the weeding.

Cooking and cleaning of the house is mainly done by the daughter (19) with some assistance from Jabu. All adults, except Sandile, have to do their own laundry, Jabu does his and that of their two youngest children. Sandile does the maintenance of the house and they pay somebody to clean the yard and fetch water. Jabu takes care of the two youngest children, with assistance from the older daughters when they are not at work. Sandile's niece takes care of her baby and assisted with domestic work before she left the household.

6.1.4 Case 4: Gugu

Gugu, the head of the household, is a 65-year old widow. Three of her children live with her, including her eldest daughter Ayanda (43) and her two youngest sons, Bongani (30) and Lucky (27), both with their respective partners Nqobile (28) and Fezile (22). Although not legally married, the *lobala* was paid for the partners of the sons, enabling the partners to live at Gugu's homestead. Three of Gugu's grandchildren also live at the homestead. Gugu's son Simon (36) joined the household in December 2006 after he was released from prison. In January 2007 Bongani and his partner had a baby girl. Gugu's oldest son, with his wife and three children, and her youngest daughter, she is unmarried and does not have children, stay elsewhere in the province. She also had another daughter who died of unknown causes in 2004, she was unmarried and had no children. Born from a previous relationship, the last name of Gugu's two oldest children differs from that of the other children. See Figure 6.4 representing the genealogy of Gugu's household at the commencement of the study in September 2006.

Ayanda and Lucky have some primary school education and Bongani has some secondary school education. Ayanda's son dropped out of school without completing his secondary school education and Simon's daughter completed grade 12 at the end of 2006. Fezile completed secondary school and has a secretarial certificate and Nqobile has some secondary school education. No member of the household is currently attending school.

Ayanda works as a cook in the food service industry and Fezile is employed as a secretary in a neighbouring town and also works part-time at the community radio station. Neither Bongani nor Lucky are working, and according to their mother, not actively looking for work either. Gugu receives a state old age grant and also earns a small income from making and selling grass mats. The household also receives state child support grants for Bongani's two small children. The household owns several assets, including a car, television, radio, stove, refrigerator, mobile telephone, bicycle and wheelbarrow. The household does not have access to land for growing of crops or keeping livestock and does not grow any fruit or vegetables. Gugu would like to grow some vegetables at the homestead, but struggles with high blood pressure. Her condition improved after she started taking treatment, for which she has to pay. Nqobile had to go to the district hospital for the birth of the baby, where they had to pay a fee of R50 for her to be admitted and they incurred costs for transport.

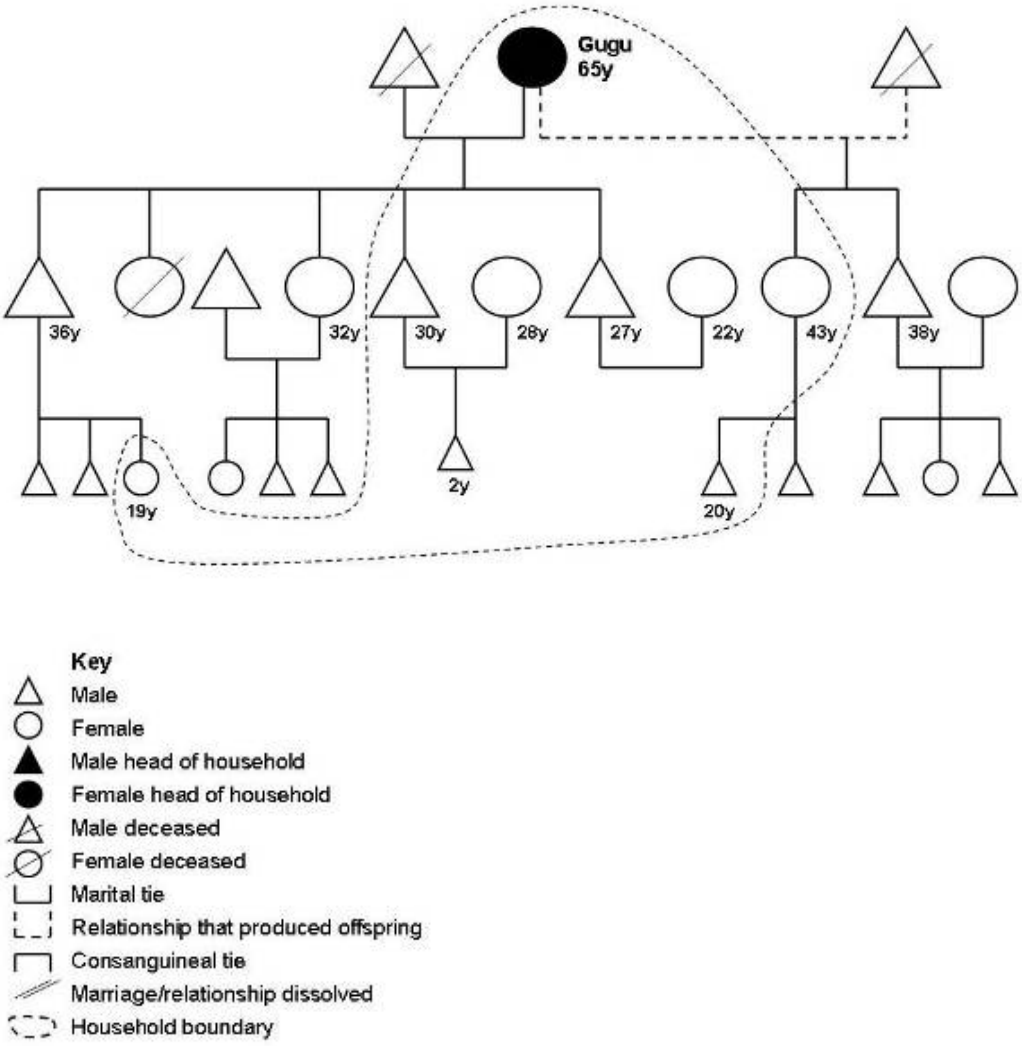


Figure 6.4 Genealogy of Gugu's household at the start of the study (Sept 2006)

Nqobile is responsible for cooking, with some assistance from Gugu. Each person is responsible for cleaning their own living unit while Nqobile also cleans that of Gugu and Gugu takes responsibility for the maintenance of the living units. Gugu and her 19-year old granddaughter do their own laundry and Ayanda, Fezile and Nqobile do the laundry for their respective family units. Bongani cleans the yard, and Lucky and Ayanda's son assist him with fetching water. Nqobile takes care of her and Bongani's two children and Bongani and Gugu assist with feeding and supervising of the children. Nqobile is responsible for taking them to the clinic regularly and for collecting the child support grants every month. When Gugu is not well, Nqobile also takes care of her.

6.1.5 Case 5: Sfiso

Sfiso (68) lives with his wife Thofo (67) and a granddaughter Thembi (23). Also living with them is a domestic worker (24) and her son (2). Sfiso and Thofo have two daughters, aged 42 and 40 respectively, and had a son who passed away in 1996. One daughter lives with her two children, the orphaned son of her late brother and the two-year old child of her niece in the nearby town of Richards Bay and the other lives with her son in

Pietermaritzburg approximately 250 kilometres away. See Figure 6.5 representing the genealogy of Sfiso's household at the commencement of the study in September 2006.

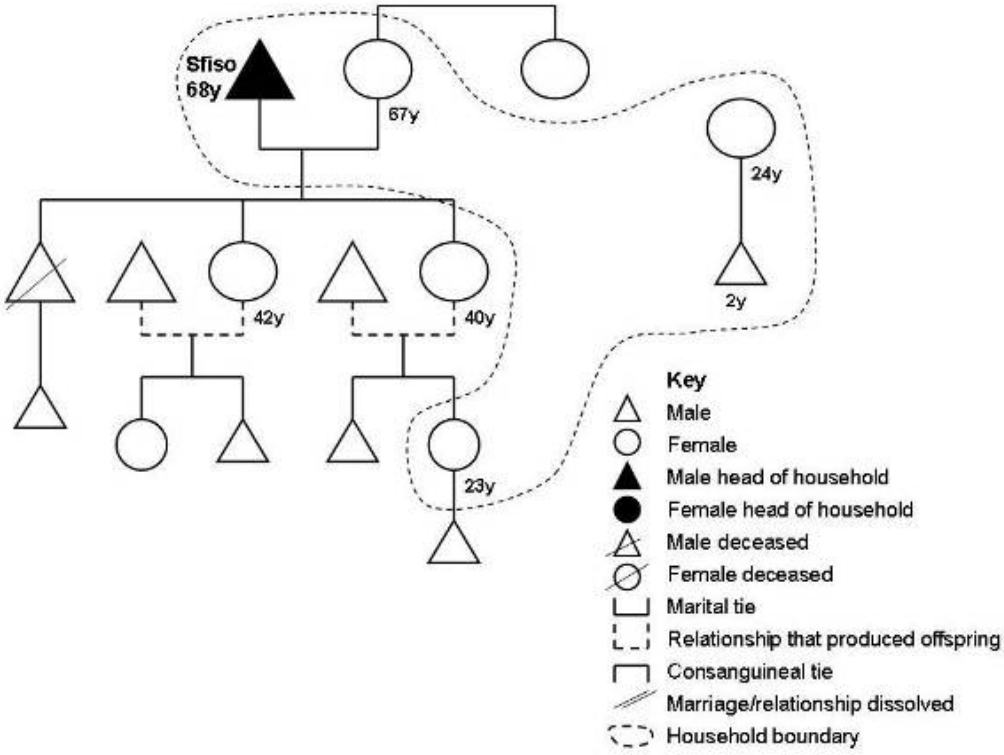


Figure 6.5 Genealogy of Sfiso's household at the start of the study (Sept 2006)

Thofo has some secondary school education and Thembi completed her secondary school education. Both Sfiso and his wife receive state old age grants. Their granddaughter is not working, and according to her grandmother, not actively looking for work either. They are frequently visited by their two daughters who always bring some food and are willing to assist with money if necessary. The household owns a number of assets, including a television, radio, stove, refrigerator and mobile telephone. Although they do not have access to land to grow crops, Sfiso grows some vegetables at the homestead where they also have some fruit trees.

Thofo had a stroke early in 2006 and also suffers from diabetes for which she takes medication and she has to go to the local clinic regularly to check her blood sugar levels. Thofo spent some time in the district hospital following her stroke. The stroke left her partially paralysed, confined to a wheelchair, and in need of full-time care. The couple decided to find a domestic worker to assist with Thofo's care and to take care of household tasks, as their daughters, who are working full-time, are unable to help. They employed 24-year old Nelisiwe who is from the area. Thofo paid her R500 per month, almost two thirds of her old age grant. Nelisiwe has no training or experience in caring for an ill person, but learned quickly with the assistance of a local community health worker.

During the day it is mainly Nelisiwe who takes care of Thofo, helping her to wash, dress and eat, sometimes with assistance from Thembi. Sfiso assists Nelisiwe when Thofo needs to be moved in and out of the wheelchair. At night Sfiso takes care of Thofo, should she need anything. Although Sfiso is in relative good health, he has high blood pressure. Thofo has a sister living next door who also keeps an eye on her and can assist when necessary. In December 2006, Nelisiwe decided to leave as she was getting married and moving to another part of the province, and they were in need of a domestic worker and

caregiver again. As this coincided with the school holidays, Thofo's daughter (40) who is a teacher in Pietermaritzburg, could come home to take care of her mother until they could find a replacement for Nelisiwe. In January the 35-year old Busi, from a village near Pietermaritzburg came to stay at the homestead to take care of Thofo. Busi came without her children, but goes home once a month to visit them and when she goes home, Thembi has to help her grandfather take care of her grandmother. Thembi does some of the cooking and assists the domestic worker with other tasks such as cleaning of the house and laundry and Sfiso does the maintenance of the house and cleans the yard.

6.2 Cluster 2: households afflicted by HIV/AIDS

The households discussed below, are afflicted by HIV/AIDS and have at least one member who tested positive for HIV, some of them displaying symptoms associated with AIDS-related illnesses and in need of varying degrees of care. These households did not experience any deaths attributed to AIDS-related illnesses from January through August 2006 and were not taking care of orphaned children. Table 6.2 provides an overview of selected characteristics of the five case study households in this cluster.

Table 6.2 Selected characteristics of households in Cluster 2 (September 2006)

Variable	Case 6	Case 7	Case 8	Case 9	Case 10
Household size and composition					
Size	12	4	4	10	1
Sex distribution					
Male	3	2	2	3	0
Female	9	2	2	7	1
Age distribution					
≤14	5	1	2	5	0
15-64	6	3	2	5	1
≥65	1	0	0	0	0
Household head					
Sex	Female	Female	Female	Male	Female
Age	66	47	31	51	23
Marital status	Widow	Never married	Widow, now living together	Married	Never married
Level of education	No formal schooling	Some primary	Some primary	Some primary	Some primary
Health status	Average	Poor	Average	Average	Poor
Work status	Not working, pensioner	Not working, ill	Yes, domestic worker	Yes, labourer	Not working, ill
Socio-economic status of household					
Number of employed HH members	2	0	2	1	0
Estimated monthly HH income	R2,550	R290	R1,040	R1,360	R150
Main source of HH income	Grants	Grant	Employment	Employment	Private support
Effective dependency ratio	1.40	1.00	1.00	1.20	n/a
Household resources and assets					
Building material (main dwelling)	Traditional	Traditional	Brick	Traditional	Traditional
Access to land to grow crops	No	Yes, grows maize	No	Yes, grows *amadumbe*	No
Own livestock	Yes, cattle	No	No	No	No
Number of assets (various)	2	4	5	5	2
Services and infrastructure					
Main source of water	Borehole	Public tap	Public tap in yard	River/stream	Public tap, neighbours
Type of sanitation	Ventilated pit latrine, neighbours	Septic tank	Septic tank	Ventilated pit latrine	Septic tank, neighbours
Access to electricity	No	No	Yes	Yes	Yes, neighbours
Energy source used for cooking	Wood	Paraffin	Electricity	Wood	Electricity
Energy source used for lighting	Candles	Candles	Electricity	Electricity	Electricity

Source: Household survey 2006

6.2.1 Case 6: Lina

Lina, the head of the household, is a 66-year old widow. She lives with her daughter Nompume (42) and 10 other people at her homestead. Also residing with them are Nompume's three children and two grandchildren, daughter Sindi (39) with the youngest of her three children, a three-year old girl, and daughter Londeka (23) with her two-year old son. Nompume had four children, but her youngest daughter died of unknown causes at the age of two in 2000. Nompume's children and grandchildren residing with her include, her daughter Lungi (24), with her two daughters aged 2 and 1 respectively, son Muzi (21) and another daughter Tholiwe (12). Sindi's two older children, reside with their father. Lina's nephew (22) has also been living with them since his father died of unknown causes more than ten years ago. See Figure 6.6 representing the genealogy of Lina's household at the commencement of the study in September 2006.

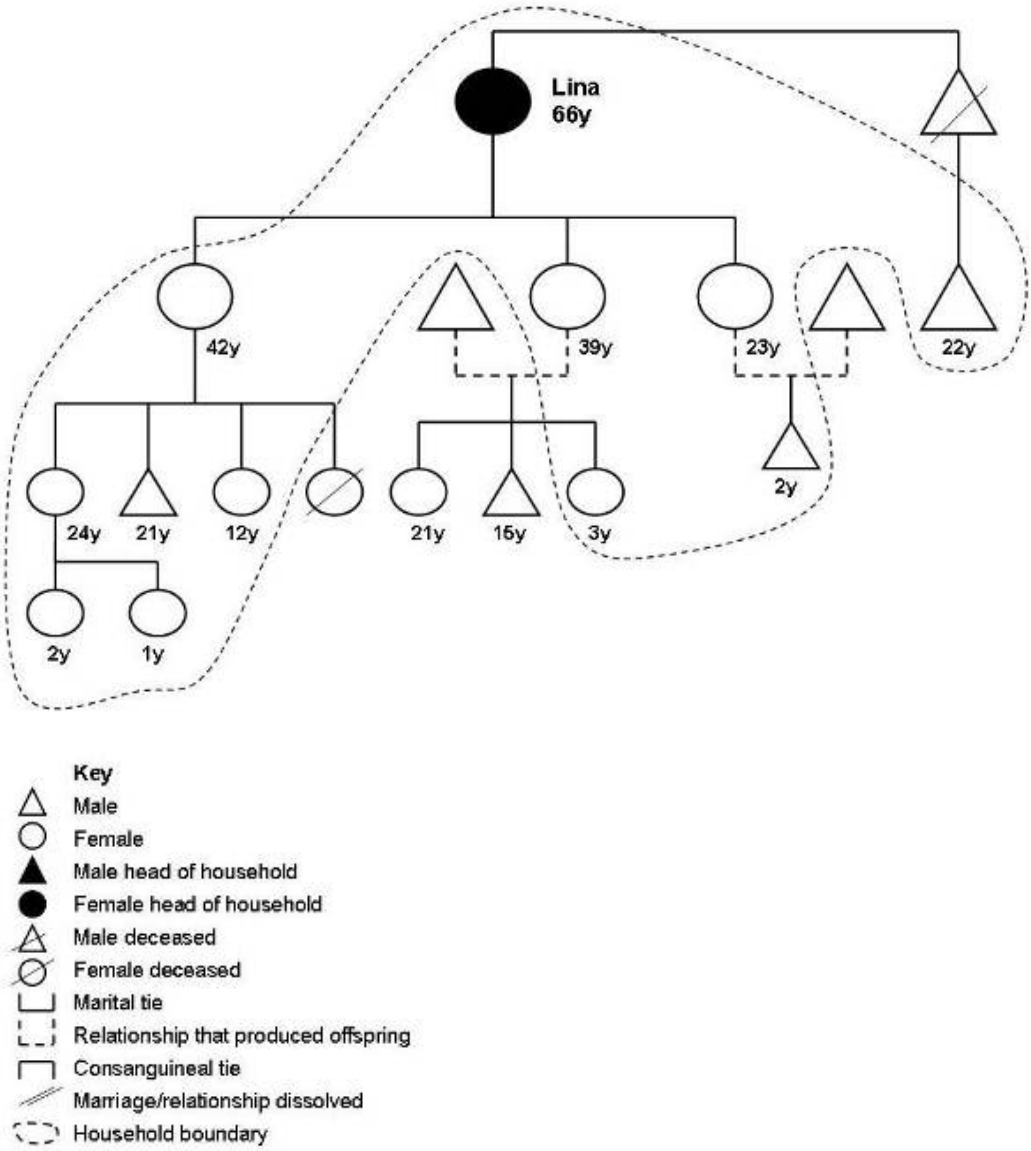


Figure 6.6 Genealogy of Lina's household at the start of the study (Sept 2006)

Lina never attended school and Nompume and Sindi have some primary education. Londeka completed grade 12 at the end of 2006 and Lina's nephew has been in and out of school and has some secondary school education. Lungi completed secondary school, Muzi completed primary school, and Tholiwe is progressing well at primary school. Lina receives a state old age grant and the household also receives child support grants for each of the five children below the age of 14. Nompume is not working due to ill health, Sindi is unemployed, while Londeka was doing her final year at school in 2006 and did some odd jobs in the afternoons after school. Muzi is not working and according to his mother not looking for work, while Lina's nephew works for minimum wage as a forest cutter. The household only has two assets, a radio and a mobile telephone. They do not have access to land for growing crops or keeping livestock, but they do have two cows in a small kraal at the homestead. Lina received them as *ilobolo* for Londeka from the family of Londeka's boyfriend who is also the father of her child.

Nompume tested positive for HIV towards the end of 2004 when she started displaying symptoms associated with AIDS-related illness. She is well enough to take care of herself and assist with domestic work and look after her grandchildren. Nompume is not on antiretroviral treatment, but is maintaining her health by taking vitamin and mineral supplements, which she collects, free of charge, once a month from the local public health clinic approximately 5 kilometres away. Her health is closely monitored by having regular blood tests at the clinic and visits from a community health worker. Nompume receives a lot of emotional support from a neighbouring household, of which the male head is also HIV-positive. She also belongs to an AIDS support group that meets twice a month at the home of the community health worker. Lina and one of Lungi's children suffer from asthma and Sindi has swollen legs.

In January 2007 Londeka left the household to study at a college in another town. A sponsor will pay for her study. Her son is now staying with the family of his father and the child support grant now goes to the paternal grandmother. Lina's nephew also left the household in January 2007 to stay with another aunt but, the reason why he left is not clear. Londeka, her child and her cousin's leaving resulted in a R790 loss in income for the household, almost one third of the total household income.

Nompume and Lina do most of the cooking, sometimes with the assistance of Sindi and Londeka. Everybody cleans their own living unit, as all the adult members with their children live in their own small traditional one-roomed structure. Each adult member of the household do their own laundry as well as that of their children. Cleaning the yard is not a task allocated to any one person but is done by any member when necessary. Londeka and Tholiwe are responsible for fetching water every afternoon, while Lina, sometimes with Nompume's help, fetches the firewood. When the mothers are not around, Nompume takes care of the four small children. She also takes the children to the clinic for immunisation. When Nompume requires care, her mother and Sindi take care of her. Lina's nephew used to look after the cattle, but since he left it has become Lina's responsibility.

6.2.2 Case 7: Bongi

Bongi, the 47-year old head of the household, initially lived with her daughter, Thobi (25), son, Philani (23), and Thobi's three-year old son. Thobi's two older children, aged seven and five, live with their father at his homestead. Bongi also has another daughter, Nomcebo (23) who lives with her two sons aged four and two at the homestead of her partner. See Figure 6.7 representing the genealogy of Bongi's household at the commencement of the study in September 2006.

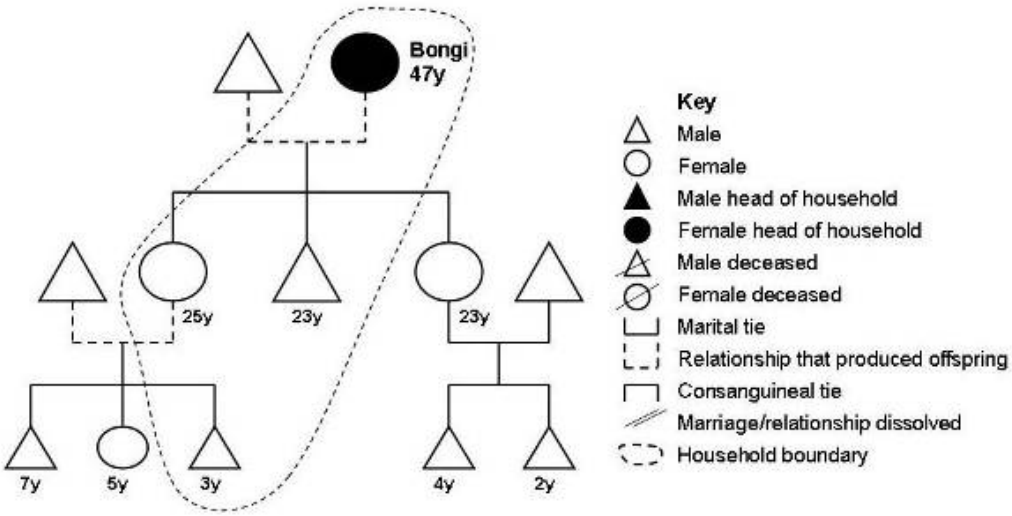


Figure 6.7 Genealogy of Bongi's household at the start of the study (Sept 2006)

Bongi and Philani have some primary education and Thobi has some secondary schooling. Bongi used to do some sewing, and occasionally worked in a small shop belonging to a family member, which provided her with a small monthly income. When she became seriously ill with TB, she could no longer do the sewing or help out at the shop. Neither Philani nor Thobi are working, and according to Bongi, are not looking for work either. The only other source of income is the state child support grant received for the three-year old. The household owns a television, radio and mobile telephone, and Philani owns a bicycle. They have access to land where they grow maize, cabbages and tomatoes for household use.

Both Bongi and Thobi are HIV-positive and Bongi is also treated for TB. Philani is also chronically ill, but has not been tested for HIV. Thobi is asymptomatic, but Bongi became seriously ill and in need of care in October 2006. Nomcebo, with her two children, decided to move in with her mother to help take care of her and to assist with domestic work. Coinciding with this Thobi's two older children also returned to live with their mother. All four the children joining the household receive state child support grants, increasing the household income by R760 per month.

Before Bongi became ill, she used to be responsible for most of the domestic work, including cooking and cleaning the house, with some assistance from Thobi. All adults do their own laundry, with Thobi and Nomcebo also doing that of their children. They each take care of their own children. After Bongi became ill her domestic tasks were taken over by Nomcebo. Philani is responsible for the cleaning of the yard.

In February 2007, Bongi's condition improved to such an extent that she could take care of herself as well as do some domestic work. At that time Nomcebo with her children and Thobi's two older children were still residing with Bongi. Bongi was though no longer willing to be interviewed, claiming that it is because of our visits that her neighbours now know that she has AIDS.

6.2.3 Case 8: Dudu

Dudu (31), the head of the household, lives with her son Sipho(14), daughter Siphiwe (11) and boyfriend Mnotho (33). Dudu's husband, the father of her two children, died of an AIDS-related illness in 2001. Even though Dudu's boyfriend lives with her, she is the head of the household as the homestead belongs to her since the death of her husband. See

Figure 6.8 representing the genealogy of Dudu's household at the commencement of the study in September 2006.

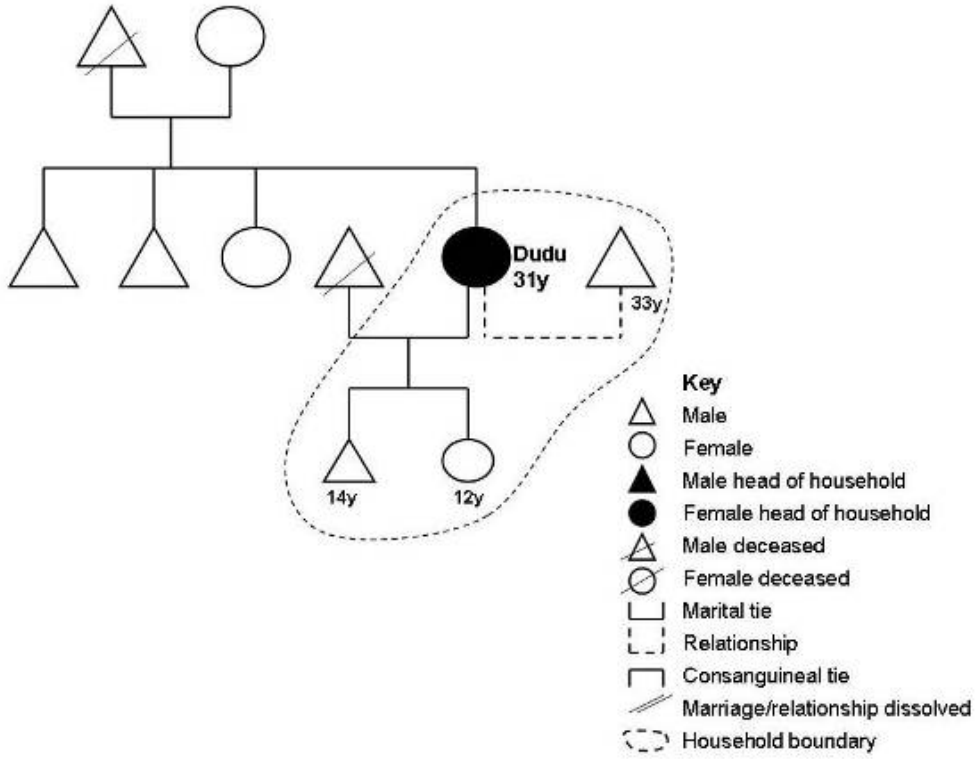


Figure 6.8 Genealogy of Dudu's household at the start of the study (Sept 2006)

Dudu has some primary school education and her boyfriend has some secondary school education. Siphiwe is attending primary school, but Sipho dropped out of primary school mid-2006 when he became seriously ill. Dudu works five days a week as a domestic worker in Richards Bay and Mnotho does odd jobs as a builder in the area where they live. Dudu also receives state child support grants for both her children, but when Sipho turns 15 in a few months, she will no longer receive a grant for him. The household owns a television, radio, stove, refrigerator and mobile telephone.

Dudu, Sipho and Mnotho are HIV-positive. Dudu is asymptomatic, Mnotho displays minor symptoms associated with AIDS, and Sipho is seriously ill with AIDS-related illness and TB. Sipho stays home allone during the day, visited once or twice a day by a volunteer home-based carer living next door. When she is not around, other neighbours check on Sipho during the day, or when he feels up to it, he goes to the house of his grandmother not too far away. When Sipho started taking treatment for TB and vitamin and mineral supplements at the end of 2006, his condition improved gradually and he returned to school in January 2007.

Dudu takes care of all the domestic work, including cooking and laundry, with Siphiwe assisting with cleaning of the house. Dudu also takes responsibility for maintenance of the house and Mnotho sometimes helps with cleaning the yard.

6.2.4 Case 9: Thulani

Thulani (51), the head of the household, lives with his wife Zethu (48), daughters Beatrice (28) and Ntokoza (25), as well as five grandchildren between the ages of 2 and 11. They have another daughter, Andile (21), who left to work in Durban in October 2006, leaving

her two-year old daughter to stay with her parents. See Figure 6.9 representing the genealogy of Thulani's household at the commencement of the study in September 2006.

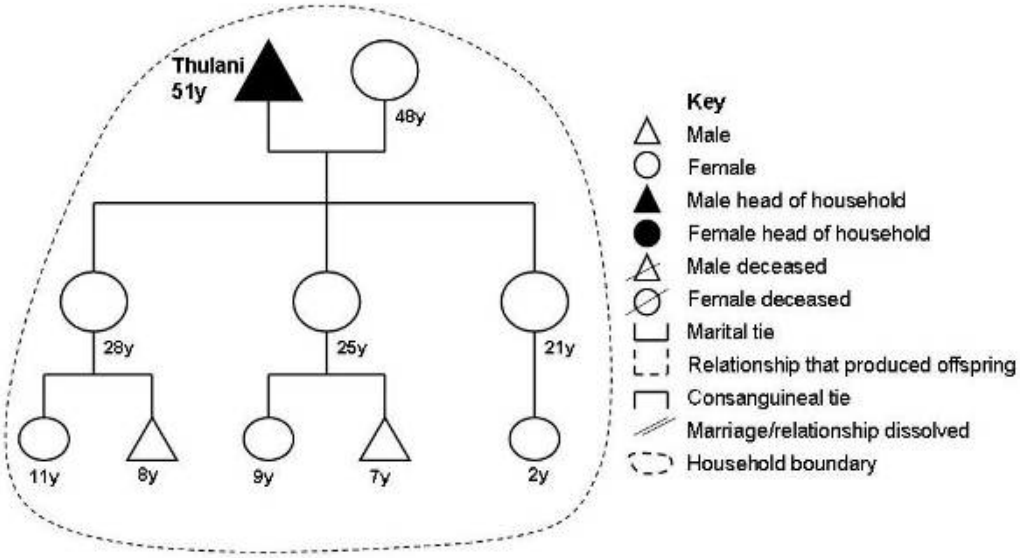


Figure 6.9 Genealogy of Thulani's household at the start of the study (Sept 2006)

Thulani and his wife both have some primary schooling, the two older daughters completed their primary school education and the youngest has some secondary school education. The grandchildren aged 8, 9 and 11 are attending school and are in grades appropriate for their respective ages. The seven-year old grandson is not attending school as he does not have a birth certificate and the school refuses to take him.

Thulani works as a labourer in Richards Bay, earning minimum wages. Zethu, Beatrice and Ntokoza are not working. The household receives state child support grants for four of the five children, without a birth certificate the seven-year old cannot receive a grant. The household owns a television, radio, stove, refrigerator and mobile telephone. Ntokoza is HIV-positive and is on treatment for TB. She recently became seriously ill with AIDS-related illness and in need of full-time care. Zethu takes care of her, with assistance from a volunteer home-based carer who visits once a week. In February 2007, Ntokoza's condition improved slightly and she was able to sit up, speak and feed herself. Thulani has high blood pressure and had to visit the district public hospital for treatment to control his blood pressure. Thulani incurred costs to travel to the hospital and has to pay for the treatment. Though Zethu is an alcoholic according to her family, she has not been drinking any alcohol since she has been taking care of Ntokoza.

Zethu has always been responsible for the cooking, maintenance of the house, laundry and fetching firewood, and Beatrice and Ntokoza cleaned the house and assisted with other domestic work. When Ntokoza got seriously ill, Beatrice had to take over the domestic tasks of her mother, who is now taking care of Ntokoza, as well as the care of Ntokoza's children. Ntokoza's seven-year old son cleans the yard and assists with fetching water and firewood. They use wood for cooking, and uses electricity only when it rains. Zethu used to grow some vegetables at the homestead, but since she's been taking care of Ntokoza she is neglecting her vegetable garden.

6.2.5 Case 10: Phume

Phume (23) has been living on her own since her boyfriend moved out six months ago and she sent their five-year old daughter, Nomsa, to live with her sister approximately 45 kilometres away. Phume's sister (18) who is living with distant relatives, is her only remaining close relative since their parents passed away several years ago. She sent Nomsa to stay with her sister as she was concerned that her deteriorating health will make it difficult for her to take care of Nomsa. See Figure 6.10 representing the genealogy of Phume's household at the commencement of the study in September 2006.

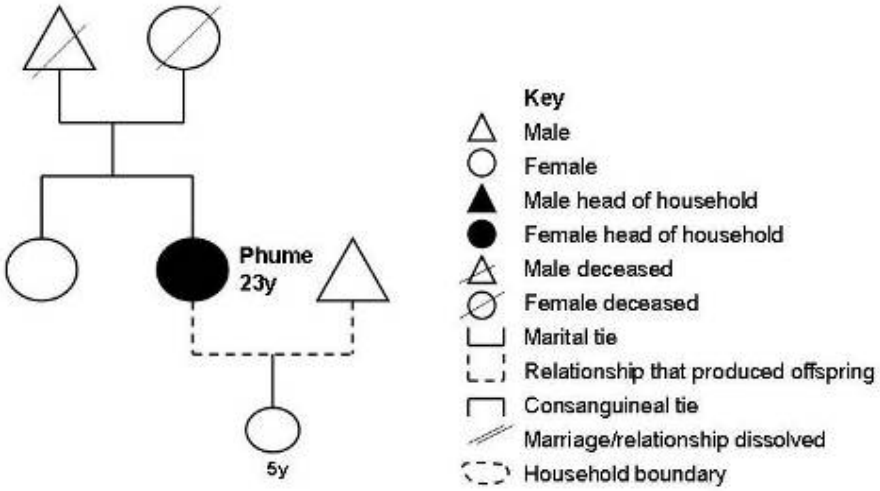


Figure 6.10 Genealogy of Phume's household at the start of the study (Sept 2006)

In January 2007, Nomsa's father decided that she should go and stay with his family at Mangusi, approximately 200 kilometres away. When Nomsa lived with her aunt, Phume was able to visit her once a month but since she moved to Mangusi she has been unable to visit her as it is too far for her to make the trip and too expensive to travel there.

Phume is HIV-positive and has TB, and recently started displaying symptoms associated with AIDS-related illness. Since then she has been unable to work. Her only source of income is the R150 per month she receives from a distant relative. The homestead where she lives belongs to her and she lives in a small two-roomed traditional structure. She owns a stove and a mobile telephone. Phume does most of the domestic work herself and hires somebody to clean the yard. She grows some cabbages, spinach and onion at the homestead. Her neighbours, who are aware of her HIV-status, are very supportive and assist her with domestic work when necessary. She is also visited twice a month by a volunteer home-based carer.

6.3 Cluster 3: households affected by HIV/AIDS and/or TB

Households affected by HIV/AIDS experienced the indirect impact of HIV/AIDS in that they experienced deaths attributed to AIDS-related illnesses prior to September 2006 and are either taking care of, or consist of orphaned children. Table 6.3 provides a summary of selected characteristics of the four case study households in this cluster.

Table 6.3 Selected characteristics of households in Cluster 3 (September 2006)

Variable	Case 11	Case 12	Case 13	Case 14
Household size and composition				
Size	8	3	2	5
Sex distribution				
Male	5	0	2	2
Female	3	3	0	3
Age distribution				
≤14	3	2	1	1
15-64	5	1	1	4
≥65	0	0	0	0
Household head				
Sex	Female	Female (de facto)	Male	Female
Age	64	39	17	55
Marital status	Widow	Never married	Never married	Widow
Level of education	No formal schooling	Some secondary school	Attending secondary school	Completed primary school
Health status	Good	Excellent	Excellent	Poor
Work status	Not working, pensioner	Paid caregiver	Not working, attending school	Not working, unemployed
Socio-economic status of household				
Number of employed HH members	0	0	0	1
Estimated monthly HH income	R2,160	R300	R200	R3500
Main source of HH income	Social grants	Private support	Private support	Employment
Effective dependency ratio	0.60	2.00	1.00	0.25
Household resources and assets				
Building material (main dwelling)	Brick	Brick	Brick	Brick
Access to land to grow crops	Yes, grows a variety of crops	No	No	Yes, grows maize and *amadumbe*
Own livestock	Yes, cattle and goats	No	No	No
Number of assets (various)	6	2	4	7
Services and infrastructure				
Main source of water	Borehole	River/stream	Public tap	River/stream
Type of sanitation	Basic pit latrine	Ventilated pit latrine	No facility	Basic pit latrine
Access to electricity	Yes	No	Yes	Yes
Energy source Used for cooking	Electricity	Wood	Electricity	Electricity
Energy source used for lighting	Electricity	Candles	Electricity	Electricity

Source: Household survey 2006

6.3.1 Case 11: Juliet

The former head of this household passed away in 1995, and since then, according to his youngest daughter, 'everything changed'. He had four wives and a total of 17 children, five sons and 12 daughters. His first born son, most eligible to take over the role of head of the household, passed away before his father. In total, six of his children passed away, two of them attributed to AIDS-related illnesses, leaving behind a number of orphaned children. It was not possible to establish the exact number of grandchildren and great grandchildren. Since his death the household split into increasingly independent household units consisting of wives, children and grandchildren and the homestead is now no longer occupied by his direct descendents only. Currently, there are more that 32 people living at the homestead spread over six household units. For the purpose of this study, units are seen as separate households, as they function independently with only some of them occasionally sharing resources. Each of the four widows heads a household unit, one is headed by one of his children and one consists of an unrelated family. Some of the children with their children and grandchildren still live at the homestead, while others established their own homesteads with their children and grandchildren close to the original homestead or in other parts of the province. The focus in this case study will be on one of the household units headed by one of the widows.

Juliet (64), the third wife of the former head, is the head of this household that comprises eight people. She lives in her own living unit and her youngest daughter Thandeka (29) lives with her two sons and three orphaned nephews, aged 21, 17 and 12, and a 17-year old orphaned niece in a separate unit. Juliet lives a fairly independent life from her daughter and grandchildren but is regarded as the head of the household when it comes to taking decisions relating to the orphans. Juliet had five children. Two of her daughters, who used to live with her, died of TB and AIDS-related illnesses in 2001 and 2002 respectively, leaving behind five orphaned children, four of them staying with Thandeka. Juliet's oldest son with his wife and three sons live at his own homestead nearby and her other daughter with her child live elsewhere in the district. Thandeka's brother, a teacher, is very important to her and she will always consult him in important decisions. He is also a very important source of emotional support for his orphaned nephews and niece and buys food for the household every month. See Figure 6.11 representing the genealogy of Juliet's household at the commencement of the study in September 2006.

Juliet did not receive any formal schooling and Thandeka completed secondary school, and obtained a certificate in travel-and-tourism, and received training in HIV/AIDS counselling, the latter forming part of a community project initiated by her brother. Thandeka's 21-year nephew completed secondary school, the two 17-year olds are attending secondary school and her 12-year old nephew and son of eight are attending primary school. Thandeka is unemployed and has applied for many positions, but thus far without success. She has applied for computer training offered by one of the local industries and is awaiting response. She hopes that further training will improve her chances of getting a job. Thandeka's 21-year old nephew worked for a local industry for a few months, but it was only a temporary position and he is now again unemployed and looking for work Juliet receives a state old age grant and sells vegetables to supplement her income. The household receives a foster care grant for the 12-year old orphan and Thandeka receives child support from the father of her oldest child. Thandeka's boyfriend, the father of her youngest child, buys food for the household.

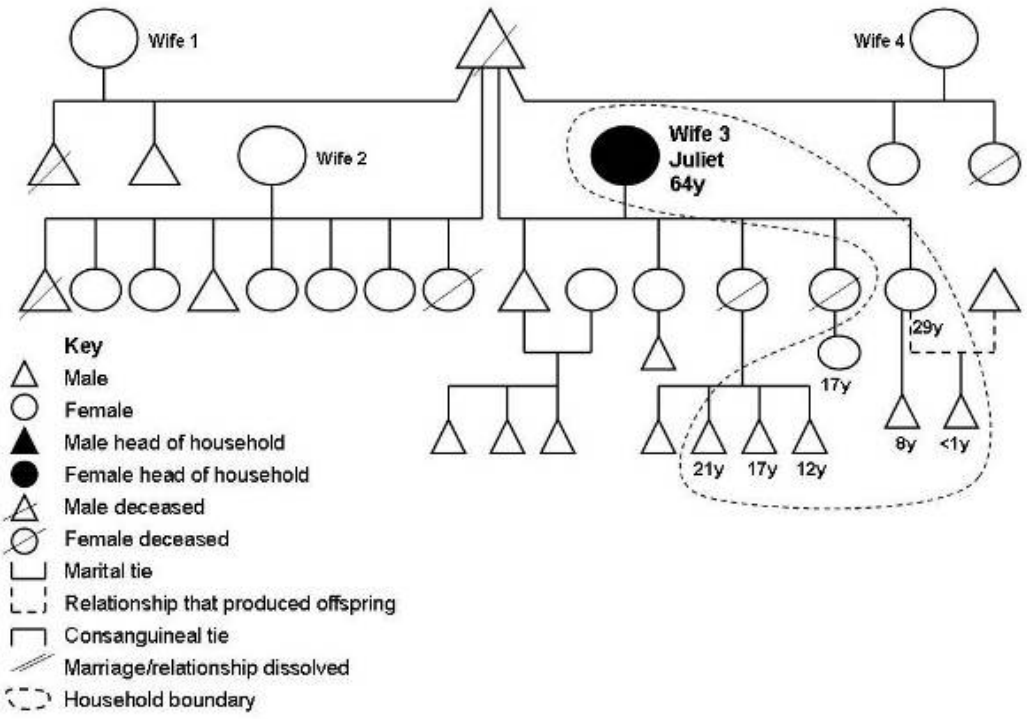


Figure 6.11 Genealogy of Juliet's household at the start of the study (Sept 2006)

Both Thandeka's brother and her boyfriend own cars, providing all household members with access to transport. In Thandeka's house there is a refrigerator and a television bought by Juliet for her grandchildren, and there is a stove in the kitchen, a separate traditional structure which is shared by Thandeka and her mother. The household also owns a radio, mobile telephone and wheelbarrow and Thandeka has access to a computer and sewing machine at the homestead of her brother. Both Thandeka and her youngest child belongs to the medical aid provided by her boufriend's employer. This enabled her to go to a private hospital in Richards Bay for the birth of their baby.

Juliet has access to land which she shares with the other widows and where they grow a variety of crops (maize, *amadumbe* and sweet potatoes) and vegetables, some fruit, and keep cattle and goats. The crops, vegetables and fruit are shared by the household units and surplus vegetables are sold. Juliet is also involved in a community garden. The cooking for the household is done by Thandeka and she does her and her children's laundry. The cleaning of the house and yard is done by the older children and each do their own laundry. Juliet sometimes eats with Thandeka and the children, but does her own laundry and cleans her own living unit.

In January 2007 Thandeka and her two children moved out to go and stay with her boyfriend at his homestead, approximately three kilometres away, where he lives with the two children of his late sister and two distant relatives who are looking for work in the area. The *ilobolo*, a combination of cattle and money, was paid to Thandeka's brother, enabling her to go and stay with her husband-to-be before their wedding in June 2007. Thandeka's oldest son often stays with his grandmother as the school he attends is close to her home.

Thandeka's orphaned nephews between the ages of 12 and 21, and niece age 17 are staying on their own in the house, under the watchful eye of their grandmother. Juliet is now doing most of the cooking, with her 17-year old grandson assisting her. Thandeka and her boyfriend as well as her brother continue to provide the orphaned children with food.

6.3.2 Case 12: Irene

Irene (39) takes care of two orphaned girls, aged 7 and 10 respectively. When the mother of the girls died of an AIDS-related illness early in 2006, their paternal grandmother, Thilda (62) employed Irene to stay with the girls at the homestead of their late parents. Thilda's homestead, where she lives with her husband, other children and grandchildren, is a few kilometres away. See Figure 6.12 representing the genealogy of Irene's household at the commencement of the study in September 2006.

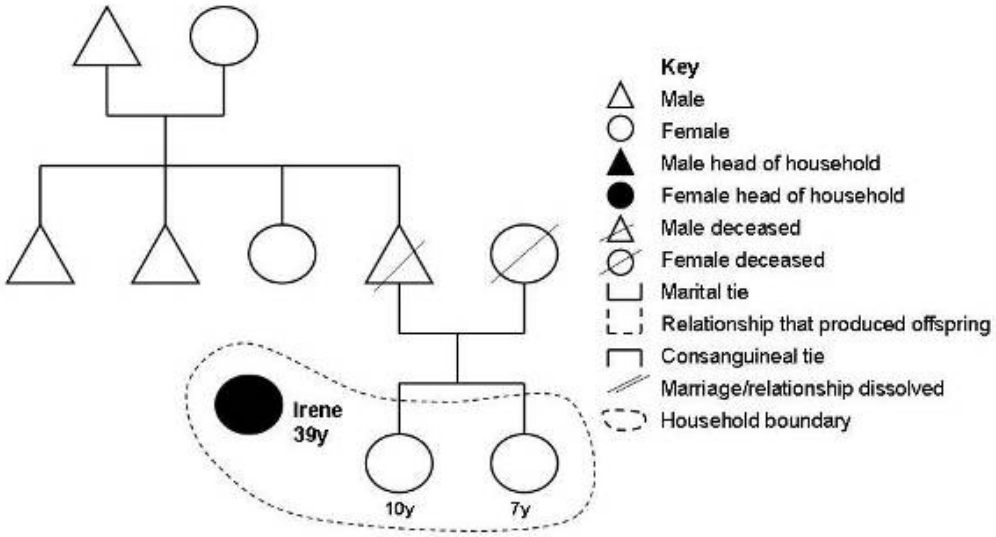


Figure 6.12 Genealogy of Irene's household at the start of the study (Sept 2006)

Thilda pays Irene R500 per month to take care of the children and gives her R300 to buy food and cover household expenses. The children do not receive any grants. Although Irene is responsible for the day-to-day lives of the children, she consults Thilda on decisions relating to the girls' health and schooling. Thilda visits the homestead of her grandchildren regularly to ensure that they are well taken care of and not in need of anything.

Both girls are attending a primary school close to their home and are progressing well at school. The girls are not healthy, with the 10-year old taking treatment for asthma. They own a television and Irene has a mobile telephone. Irene grows some vegetables at the homestead for household use. Irene does most of the domestic work, including collecting of firewood, cooking, laundry and cleaning of the house and the girls fetch water once a day and clean the yard on weekends.

6.3.3 Case 13: Themba

Themba (17) lives with his 12-year old brother. They have been living on their own since their mother died of AIDS-related illness in 2003. Their father died from TB in 2001. Themba also has four sisters, aged 20, 15, 12 and 7, living with their maternal grandparents. Apart from his grandparents and siblings, Themba, to his knowledge, has no other family. See Figure 6.13 representing genealogy of Temba's household at the commencement of the study in September 2006.

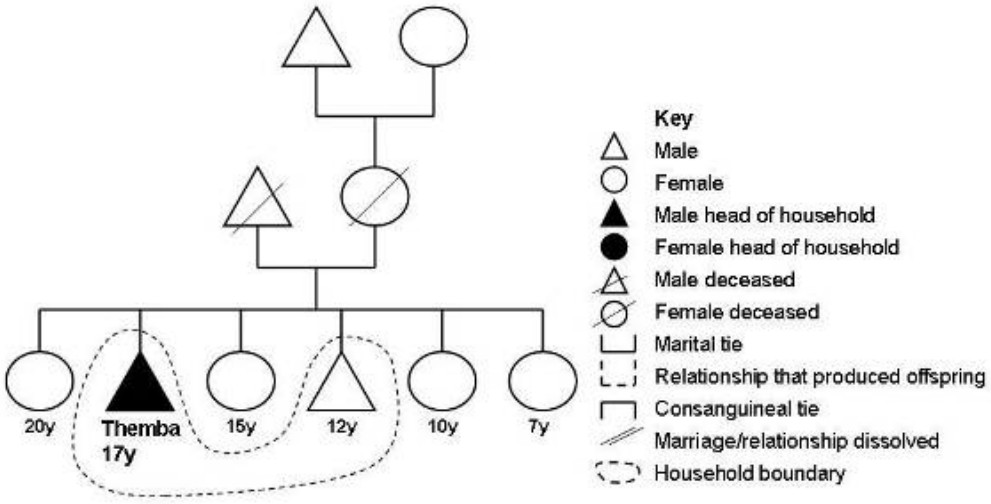


Figure 6.13 Genealogy of Themba's household at the start of the study (Sept 2006)

In 2006, Themba was doing grade 10 for the second time and struggling to stay in school. He occasionally missed school and did not give sufficient attention to his school work as a result of his responsibilities as head of the household. In spite of working as a gardener in Richards Bay on Saturdays and during school holidays, he was not able to pay his school fees every term. Because he is an orphan, his brother, attending primary school does not have to pay school fees, and he is progressing well at school.

Themba chose to stay at the homestead he inherited from his parents, rather than with his grandparents and loose the homestead. His younger brother could have gone to live with his grandparents but chose to stay with him. Both grandparents receive state old age grants and Themba's grandmother gives him a small amount of money every month which he mainly uses to buy prepaid electricity and airtime for his mobile telephone. Themba receives food parcels every month as part of a community project and received some money to cover his school fees. Themba and his brother have one meal per day three to four times per week with their grandparents. Apart from the mobile telephone, they also have a radio, stove and refrigerator. Themba also tries to grow some vegetables at the homestead, but he does not have much time to tend to the garden. Themba does the cooking, laundry and cleaning of the house, with his brother assisting him when cleaning the yard. They are visited at least once a month by a volunteer home-based carer who also delivers the food parcels.

In February 2007, two young men aged 17 and 20, both unemployed and hardly known to Themba, apparently attracted by the availability of food, moved in with them. As Themba was not in a position to request them to move out, the volunteer home-based carer, with the assistance of his grandfather intervened and they moved out in March 2007. Themba's grandparents were also not happy that he receives food parcels, while they do not receive anything. By the second term of 2007 Themba dropped out of school and started looking for work. The financial support for school fees he received from the community project was terminated at this time.

6.3.4 Case 14: Constance

Constance, a 55-year old widow lives with her son Sabelo (32), daughters Buhle (23) and Zamo (21) and a two-month old grandson. In 2006 Constance lost four family members, her husband died, he had diabetes, her eldest son died of an AIDS-related illness, another son of a gunshot wound, and a granddaughter died after accidently consuming a poisonous substance. See Figure 6.14 representing the genealogy of Constance's household at the commencement of the study in September 2006.

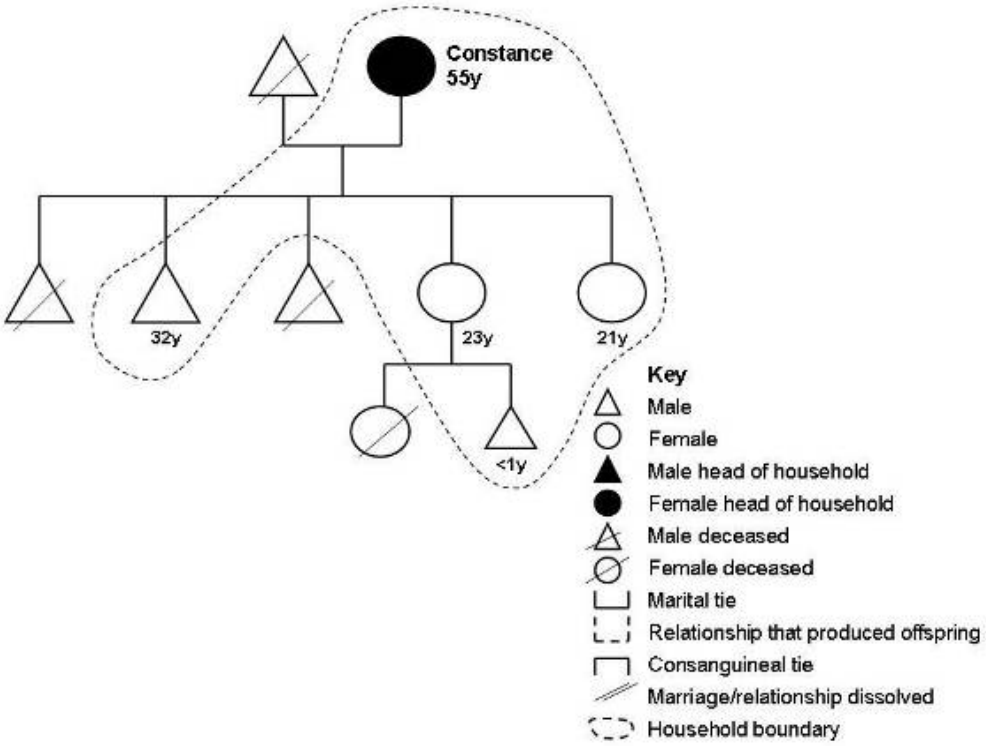


Figure 6.14 Genealogy of Constance's household at the start of the study (Sept 2006)

Sabelo, Buhle and Zamo completed secondary school and Buhle also completed a diploma in nursing. Buhle is the only member of the household who is employed and works as a nurse at a hospital in Richards Bay. One of the benefits associated with Buhle's employment is that she belongs to a medical aid which covers medical expenses for her and her son. Although Sabelo and Zamo are looking for work, they have been unsuccessful thus far. Constance wants to work, but her poor health status makes it difficult to look for and find employment. Although her eldest son did not work for several months before his death, her husband and other son did odd jobs and contributed some money to the household income before they passed away. The household do not receive any state grants and all household members depend on Buhle's income. Except for Constance, who has high blood pressure and heart problems, all household members are in good health. The household owns a number of assets, including a bicycle, mobile telephone, radio, television, refrigerator, stove and wheelbarrow.

Constance has access to land where she grows maize and *amadumbe (taro potatoes)* and she also grows some fruit and vegetables at the homestead. Sabelo assists with land preparation and Zamo with harvesting of the crops. Zamo is responsible for most of the domestic work, including cooking, cleaning the house, doing the laundry, fetching water and taking care of Buhle's baby during the day. When Zamo is not at home, Constance

takes care of her grandson. In the evenings and on weekends Buhle takes care of her son and on weekends she also assists with the domestic work. Constance is responsible for the maintenance of the house and Sabelo cleans the yard.

6.4 Cluster 4: households afflicted and affected by HIV/AIDS and/or TB

The households in this cluster have at least one member suffering from an AIDS-related illness and in need of some degree of care. These households also experienced deaths attributed to AIDS-related illnesses prior to September 2006, and are taking care of orphaned children. Table 6.4 provides an overview of selected characteristics of the five case study households in this cluster.

Table 6.4 Selected characteristics of households in Cluster 4 (September 2006)

Variable	Case 15	Case 16	Case 17	Case 18	Case 19
Household size and composition					
Size	11	4	15	9	5
Sex distribution					
Male	4	1	4	3	3
Female	7	3	11	6	2
Age distribution					
≤14	6	2	9	3	1
15-64	5	2	6	6	2
≥65	0	0	0	0	2
Household head					
Sex	Male	Male	Female	Female	Male
Age	46	59	58	54	72
Marital status	Married	Married	Widow	Never married	Married
Level of education	Some primary school	Some secondary school	Some primary school	Completed primary school	No formal schooling
Health status	Poor	Average	Poor	Good	Good
Work status	Not working, ill	Unemployed	Not working, ill and caring for orphans	Not working, caregiver	Not working, pensioner
Socio-economic status of household					
Number of employed HH members	2	0	1	1	0
Estimated monthly HH income	R3,150	R820	R2,190	R1,290	R1,830
Main source of HH income	Employment	Social grant	Social grants	Employment	Social grants
Effective dependency ratio	1.75	1.5	1.5	1.25	1.5
Household resources and assets					
Building material (main dwelling)	Traditional	Brick	Traditional	Brick	Traditional
Access to land to grow crops	Yes, grows *amadumbe*	Yes, grows *amadumbe*	No	No	Yes, not growing crops
Own livestock	No	No	No	No	No
Number of assets (various)	2	5	1	5	2
Services and infrastructure					
Main source of water	River/stream	Borehole	Water tanker	Public tap	Borehole
Type of sanitation	Basic pit latrine	Basic pit latrine	No facility	Septic tank	No facility
Access to electricity	No	Yes	No	Yes	No
Energy source used for cooking	Wood	Wood	Wood	Electricity	Wood
Energy source used for lighting	Candles	Electricity	Candles	Electricity	Candles

Source: Household survey 2006

6.4.1 Case 15: Emanuel

Emanuel (46) lives with his wife Gloria (42), three sons aged 23, 16 and 8 and four daughters aged 19, 13, 11 and 7. Also living with them is their five-year old orphaned granddaughter and one-year old granddaughter. They had two older daughters who died of AIDS-related illnesses in 2004 and 2005 respectively. See Figure 6.15 representing the genealogy of Emanuel's household at the commencement of the study in September 2006.

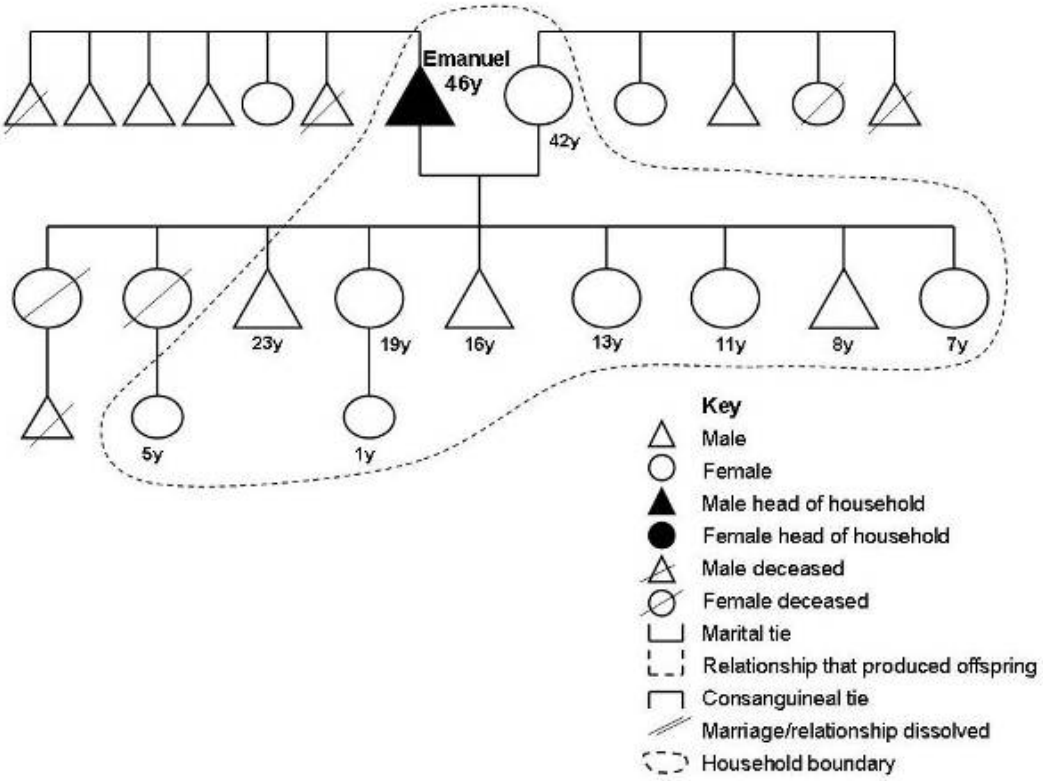


Figure 6.15 Genealogy of Emanuel's household at the start of the study (Sept 2006)

Both Emanuel and Gloria have some primary school education. Their 23-year old son completed secondary school and their 19-year old daughter returned to school in 2006 after the birth of her child, but dropped out before the end of 2006 without completing her secondary school education. Their 16-year old son is attending secondary school and the other children are all attending primary school. Their five-year old granddaughter started primary school in January 2007.

Emanuel and Gloria are HIV-positive, but while she is asymptomatic, he is displaying symptoms associated with AIDS-related illnesses and also has TB. He is not able to work due to his illness, whereas Gloria occasionally does odd jobs in the area as a labourer. Their 23-year old son started working in September 2006 as a security guard at a local industry and their 19-year old daughter started working, producing coal, in January 2007. Before they started working, the household was dependant on state child support grants and Gloria's small income. Since their daughter started working, the household income increased from 3150 to R4,150, with the majority of the household income now coming from employment. They receive child support grants for their four youngest

children. The mother of the 18-month old child applied for a state child support grant, but she is still awaiting a response. Their five-year old granddaughter used to receive a child support grant before her mother passed away. Recently Gloria applied for a state foster care grant, but they are still awaiting a response and in the meantime do not receive any state support for her. The household owns a radio and a mobile telephone.

Emanuel recently completed treatment for TB, and he and Gloria take vitamin and mineral supplements which they monthly collect free of charge from the local public health clinic. All the children and the five-year old granddaughter are in good health, but their 18-month old granddaughter shows signs of mental and physical retardation. In January 2007 their 11-year old daughter went to stay with her aunt in a settlement approximately 30 kilometres away. The aunt offered to take her in to help the family. A sister of Emanuel lives next door, and although she is unable to provide financial support, she provides emotional support.

They have access to land where Gloria grows *amadumbe* (taro potatoes) and a variety of vegetables, and they have some fruit trees at the homestead. Gloria is also involved in a local community garden, with all produce for household use. Gloria is responsible for most of the domestic work, including cooking, cleaning and laundry with assistance from Emanuel as far as his illness allows. Their 23-year old son cleans the yard and the daughters of 13 and 11 are responsible for fetching water and collecting firewood. Since the 11-year old left, the 13-year old is occasionally assisted by the younger children. Gloria takes care of the children and grandchildren during the day and when she works Emanuel takes care of their 18-month old granddaughter. In the evenings and on weekends their 19-year old daughter looks after younger siblings and the grandchildren. Although Emanuel can take care of himself most of the time, Gloria is the one to take care of him when necessary. According to them, they take care of each other. Apart from Emanuel's sister checking on them, they are also regularly visited by a local community health worker and belong to an AIDS support group.

6.4.2 Case 16: Mandla

Mandla (59) lives with his wife Nonto (49) and their two orphaned granddaughters aged 12 and 10. They have been taking care of their grandchildren since the death of their son and daughter-in-law. Both died of AIDS-related illnesses in 2002 and 2000 respectively. Their son and his family already lived with them before he and his wife became ill. Mandla also has two sons and a daughter from another relationship but they live with their mother and Mandla has very little contact with them. See Figure 6.16 representing the genealogy of Mandla's household at the commencement of the study in September 2006.

Mandla has some secondary school education, but Nonto only attended one year at primary school. Both granddaughters are attending primary school and are in grades appropriate for their ages. Mandla worked for a local industry for 15 years, after which he owned and drove a taxi for a further seven years. He had to stop working in 2003 when he became ill and tested positive for HIV. Although able to work since he started ARV treatment, he only manages to find occasional odd jobs. Nonto is also not healthy and has diabetes, but has not been tested for HIV. She is not working because of her poor health and receives a state disability grant. Mandla has some savings from the time he worked. The household received child support grants for their granddaughters until the beginning of 2005, when Nonto applied to have these converted to foster care grants. The child support grants have since been cancelled but they are not yet receiving the foster care grants.

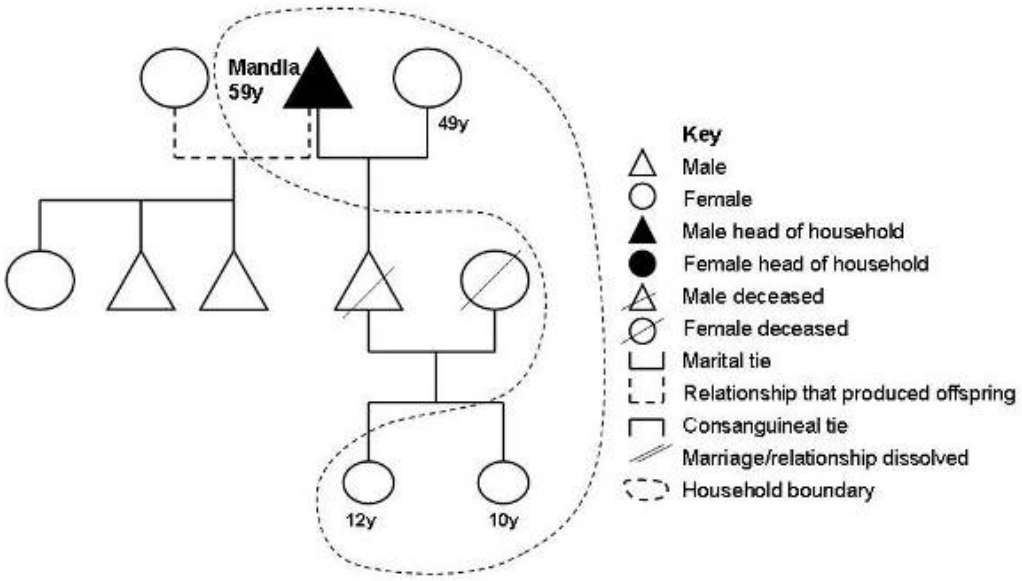


Figure 6.16 Genealogy of Mandla's household at the start of the study (Sept 2006)

Mandla has been on AVR treatment for a few months, and although the treatment is free of charge, he has to travel to the district hospital once a month to collect his treatment. After being on treatment for six months, he will be able to get the treatment from the local clinic, much closer to the homestead, which will reduce travel cost. Nonto goes to the clinic regularly to have her blood glucose level tested and has in the past stayed there overnight when the blood glucose level was not in order.

The household owns a television, radio, stove, refrigerator and mobile telephone. Even though they do not own land for the growing of crops, Nonto has access to some land nearby where she grows *amadumbe* (taro potatoes) and she also grows some fruit and vegetables at the homestead. Nonto does most of the domestic work, including cooking and laundry and her granddaughters assist with the fetching of water and firewood, as well as with the cleaning of the house. Mandla maintains the house and cleans the yard as far as his health allows, and both Mandla and Nonto take care of their granddaughters. Although Mandla is currently well enough to take care of himself, Nonto is the one to take care of him when needed. They are also frequently visited by a community health worker and Mandla belongs to an AIDS support group. Nonto goes with him twice a month to the group meetings at the home of the community health worker.

6.4.3 Case 17: Busi

Busi (58) is the head of the household since her husband passed away in 2001. She lives with three daughters, Zodwa (29), Slindile (21) and Bonakelo (17), as well as 11 grandchildren, seven of whom are orphaned. Busi had eight children, of whom her two eldest daughters and one son passed away between July 2004 and April 2006, all of them as a result of TB. Her two remaining sons do not live at her homestead. Each of the daughters left three children orphaned, the eldest, two daughters aged 16 and 12 and a son aged 10, and the other, two sons aged 15 and 7 and a daughter aged 1. The whereabouts of the respective fathers, and whether they are still alive is not known. The four-year old son of Busi's late son has also been living with her since he was two months old. The whereabouts of his mother are unknown. Zodwa has three daughters aged six, four and one, living with her. The two-year old daughter of Busi's 23-year old son, also lives at the homestead, she is

occasionally visited by her mother who lives elsewhere. Slindile also had a child, but he passed away in December 2005 when he was five months old. Bonakelo is seven months pregnant. Busi has three sisters living nearby, and although they cannot offer financial support, they offer emotional support and can assist with domestic work when needed. See Figure 6.17 representing the genealogy of Busi's household at the commencement of the study in September 2006.

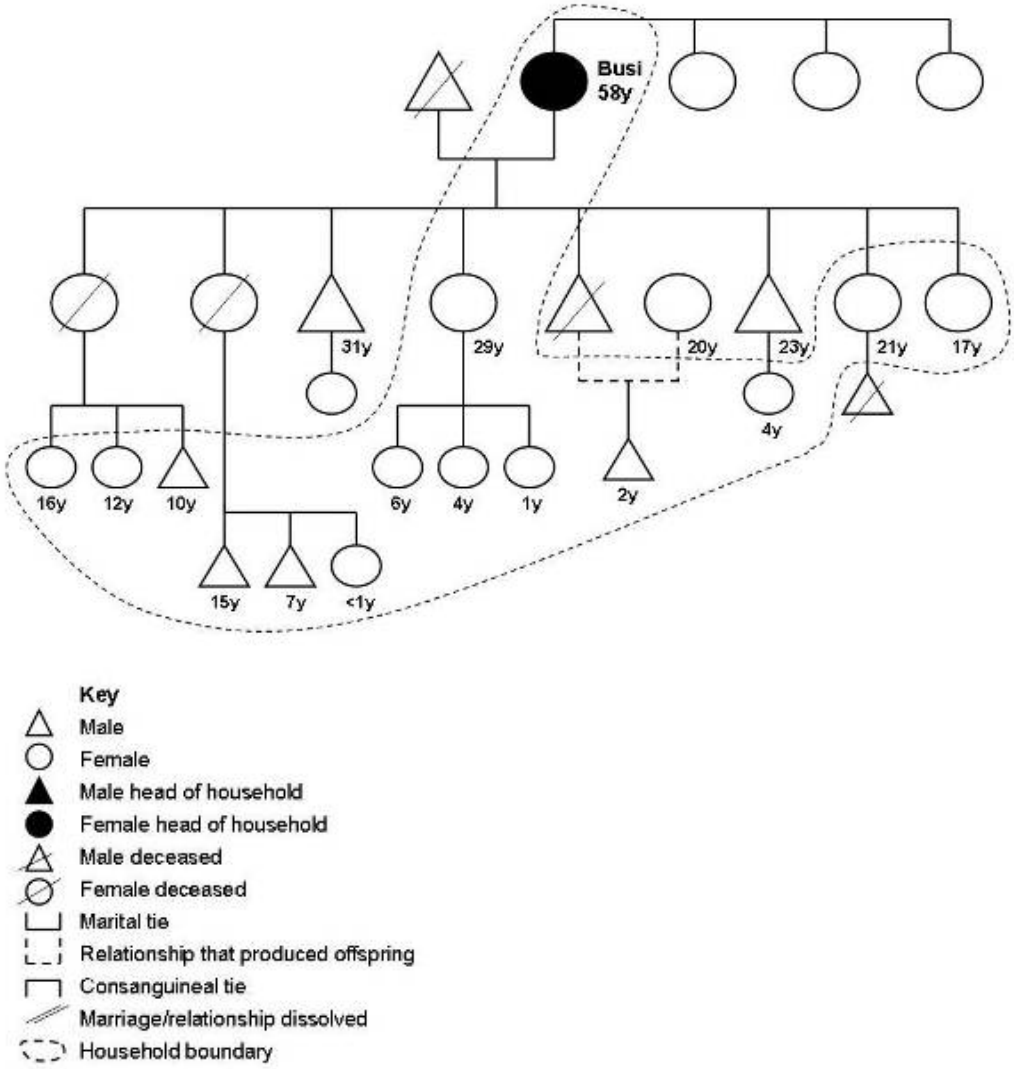


Figure 6.17 Genealogy of Busi's household at the start of the study (Sept 2006)

Busi and Slindile have some primary school education and Zodwa some secondary school education and Bonakelo is attending secondary school. The six grandchildren of school going age are all attending school, but the eldest three are in grades below those appropriate for their age. The five remaining grandchildren are not yet of school going age. Zodwa is the only employed member of the household, working for a minimum wage as a gardener at a local industry. Busi is not able to work as she is not well, and has to take care of the orphans. Slindile is not working, and according to Busi, not actively looking for work either.

Busi have been receiving a state disability grant since she had a stroke a few years ago. Zodwa receives state child support grants for each of her three children. None of the orphaned children receive state child support or foster care grants, either because Busi does

not have birth certificates for them or death certificates for the parents and is therefore unable to apply for state grants. Apart from Busi who had a stroke and has a problem with her eyesight, a number of other household members are also not healthy. Zodwa has a kidney problem, the 16-year old orphan and one of Zodwa's children have asthma, and the 12-year old orphan just completed treatment for TB and one of Zodwa's children spent time in hospital being treated for TB.

Apart from Zodwa's mobile telephone, they do not own any assets. They live in dilapidated traditional structures without a toilet facility. Once a week they fetch water from a tanker which stops at the main road approximately 500 metres away, being dependent on nearby streams for the remainder of the time. As water have to be fetched twice a day, Busi's three daughters and oldest granddaughter take turns, two of them going at a time. Wood for cooking is fetched by Slindile, Bonakelo or Nonkululeko. Most of the domestic work is shared by Busi, Slindile and Bonakelo, with Nonkululeko assisting with some of the tasks. Slindile and Bonakelo do the cooking and cleaning, with assistance from Nonkululeko. Busi does the laundry and cleans the yard and when she is not well this is done by Slindile and Bonakelo. Shortly after Busi had her stroke, she was taken care of by her eldest daughter who has since passed away. When Busi's daughters became ill, she took care of them until their respective deaths. Busi and her daughters take care of the small children, but after school and on weekends the older children also have to take care of their younger siblings and nieces.

6.4.4 Case 18: Alexina

Alexina (54), is the head of this household that comprises nine people. Living with her is her daughter Sizwe (31) and grandson (10). Also living at the homestead are Alexina's two younger sisters, Phumzile (52) and Bonisiwe (43), Bonisiwe's 16-year old daughter and Phumzile's two orphaned grandsons aged 17 and 14. Phumzile's only daughter died of an AIDS-related illness in June 2006. The three-year old daughter of another niece of Alexina also resides with them. The niece is HIV positive and her other child, a baby boy recently died. Alexina and Phumzile decided that the three-year old should stay with them as her mother is not capable of caring for her. See Figure 6.18 representing the genealogy of Alexina's household at the commencement of the study in September 2006.

Alexina and both sisters completed primary school and Sizwe completed secondary school. All children of school going age are currently attending school although not all of them are in grades appropriate for their respective ages. Sometimes the children do not attend school as a result of illness or death in the household, while rainy weather conditions also occasionally prevent them from going to school. Alexina worked as a domestic worker for a family from Richards Bay for several years, relocating with them to Johannesburg for some time. When the HIV-positive Sizwe became seriously ill in June 2006, Alexina had to stop working to take care of her. Since then Alexina has been selling snacks and cold drinks from her home to generate a small income. At the end of 2005 Sizwe became ill for the first time and tested positive for HIV. She still managed to work for a while, but in March 2006 she became too ill to continue her work as an administrative assistant in Richards Bay. Phumzile is not working as she is HIV-positive and displaying symptoms associated with AIDS-related illnesses. Bonisiwe works four days a week as a domestic worker in Richards Bay. The household receives a state child support grant for Sizwe's son. The child support grant for the three-year old goes to her mother who is not living at the homestead. The household owns a television, radio, stove, refrigerator and mobile telephone.

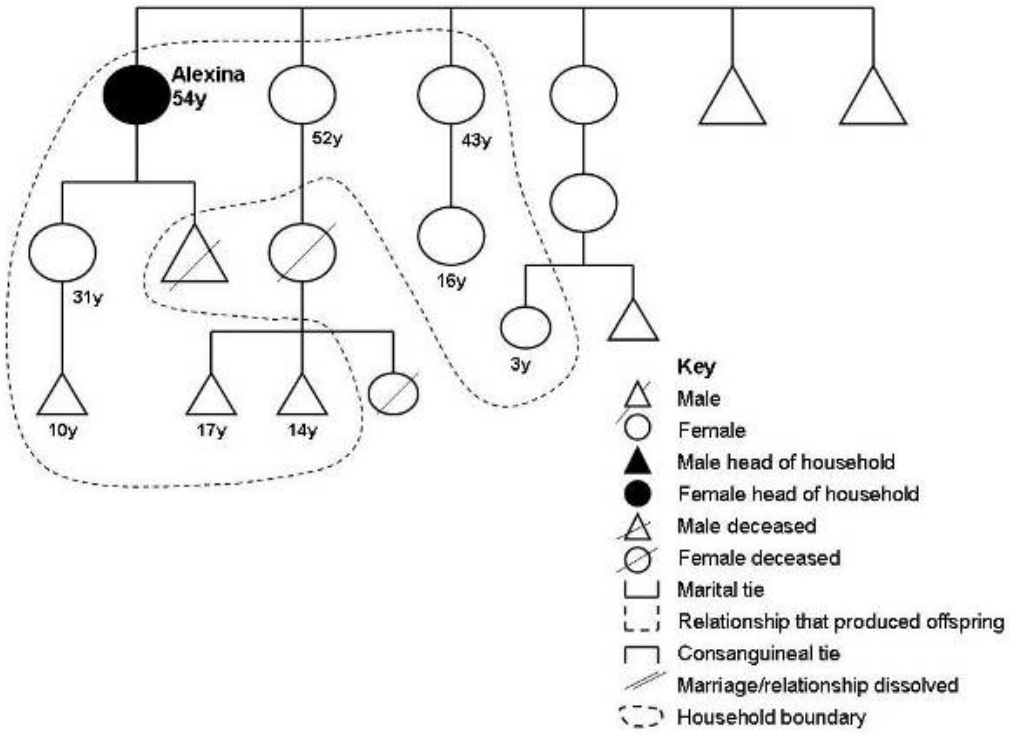


Figure 6.18 Genealogy of Alexina's household at the start of the study (Sept 2006)

Sizwe's condition deteriorated in November 2006 and she spent two weeks in the district hospital. Unable to access ARV treatment in time, she passed away at home on 29 December 2006. Alexina took care of Sizwe at home with assistance from a volunteer home-based carer living nearby. Sizwe's former employer occasionally assisted Alexina and her daughter financially, and when Sizwe had to go to hospital and Alexina had to arrange private transport to take her there, they also paid for it.

Initially Alexina did most of the domestic work, including cooking, laundry and the cleaning of the main house with Phumzile's assistance. When Alexina had to devote all her time to take care of her daughter, Phumzile took over her tasks. The children clean the yard and assist with the maintenance of the living units. Respective mothers or grandmothers take care of children or grandchildren and everybody help to take care of the three-year old. Alexina hopes to find full-time employment as a domestic worker again as soon as a suitable period of mourning has passed. Phumzile acquired land nearby where she is building a house for her and her orphaned grandchildren. She plans to move there as soon as the house is completed.

6.4.5 Case 19: Velaphi

Velaphi (72) lives with his wife Sarah (68), daughter Grace (30) and two orphaned grandsons aged 19 and 13 respectively. Their grandsons have been living with them since their father passed away approximately 10 years ago. The whereabouts of their mother are unknown. Grace's 12-year old daughter stays with a sister of Grace in a neighbouring town. The 12-year old wanted to go and stay there because there are cousins her age. About one kilometre from Velaphi and Sarah, at her own homestead, lived their 39-year old daughter Nomali, with her five children, four daughters aged 19, 2 and 1-year old twins, as well as a 16-year old son (See Figure 6.19 phase 1). Velaphi and Sarah have five other children living, with their respective families, in neighbouring towns.

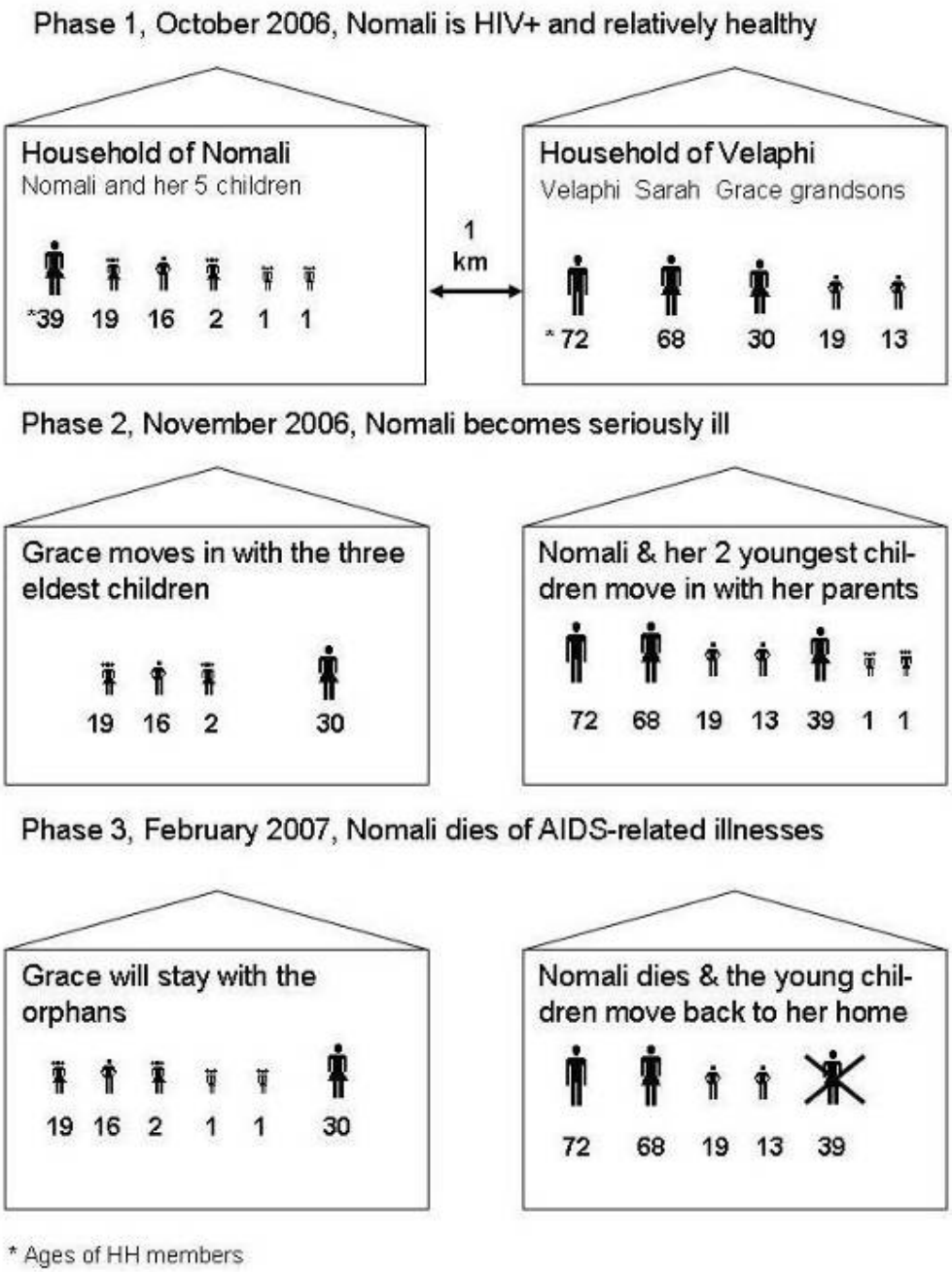


Figure 6.19 Living arrangements of Velaphi's household

Sarah did not receive any formal schooling, Grace completed secondary school and their 19-year old grandson has some primary school education. Their 13-year old grandson is currently attending primary school and in a grade below that appropriate for his age. Both Velaphi and Sarah receive state old age grants as well as a state child support grant for their 13-year old grandson. Neither Grace nor the 19-year old grandson is working, and according to Sarah, the grandson is not actively looking for work either. The household owns a radio and refrigerator. Nomali has some secondary school education and her two oldest children attend secondary school. Nomali receives state child support grants for the three youngest children.

In November 2006, Nomali became seriously ill with AIDS-related illnesses, including TB. It is not known when she tested positive for HIV. Initially Nomali's 19-year old daughter took over her domestic work and the care of the three young children, but soon Nomali became too ill to take care of herself. At first Sarah spent most of the day and occasionally a night at Nomali's place to take care of her, but eventually Sarah decided that Nomali with her two youngest children should move to their homestead so that she could take care of them. At the same time she sent Grace to go and live at Nomali's homestead to take care of the other three children (See Figure 6.19 phase 2). At the end of November 2006 Nomali's condition deteriorated and she had to be hospitalised. She passed away in hospital a few weeks later. In February 2007 Sarah took the twins back to the late Nomali's homestead, where Grace will now remain to take care of all the children (Figure 6.19 phase 3). In February 2007 Sarah still spent a lot of time at her late daughter's homestead with Grace and the children. The two eldest children did not yet return to school and it was not clear whether they are going to. The whereabouts of the respective fathers of the two oldest and three youngest children are unknown. Grace applied to have the child support grants converted to foster care grants, but by the end of February 2007 there was no response yet.

All other members of Velaphi's household as well as Nomali's children were reported to be in good health. At Velaphi and Sarah's homestead Grace used to do most of the domestic work, but since she moved Sarah had to take over the domestic work with some assistance from her two grandsons. Nolmali's 19-year old daughter, already before her mother became seriously ill, did most of the domestic work and helped to take care of her three young siblings. Although Velaphi and Sarah have access to land to grow crops, they were not planting any as the land is not fenced to protect crops from animals. While Velaphi and Sarah live in a traditional structure with no toilet facility, Nomali's family live in a brick house where they have access to electricity, used for lighting and cooking, as well as a pit latrine.

6.5 Discussion and conclusions

Case study households range in size from 1, an ill young woman living on her own, to a household comprising 15, including 7 orphaned children. Eight of the households are headed by males, seven of them married and one, the 17-year old orphan, not married. Eleven of the households are headed by females, seven of them widows and the other four have never been married. One of the widows has a male partner residing with her, but she is the head of the household as the homestead belongs to her and her children (Case 8). Amongst the female heads, who have never been married, is a *de facto* head, a non-related caregiver of two orphaned girls, where the grandmother of the girls residing at a different homestead is seen as the head when it concerns major decisions (Case 12). Case 11 illustrates how a household formerly headed by a man with four wives split into independent units headed by widows and children following his death.

In several households single women were found to be living with their children, some of them having different fathers, at the homesteads of their mothers (Cases 1, 3, 4, 6, 7, 9, 14, 15 & 17). In this patriarchal society, sons living with their partners, at their parental homestead were found to be the exception, with only one example from the cases (Case 4). In two cases *ilobolo*[10] was paid for the women, each of them already having a child with the man. In Case 6 two cows were paid to the mother of the woman and in Case 11 a combination of cows and cash was paid to the oldest brother of the woman. *Ilobolo* is negotiated between the families and is either paid in cattle, cash or a combination, these

[10] The payment of the bride wealth to the family of the women as traditional protocol followed in customary marriages (Mtshali, 2002).

days frequently only a cash amount. When it is paid in full it enables the woman to leave the homestead of her family and live at the homestead of the man, this may precede a ceremony formalising the relationship. Children of unmarried women are apparently free to move between the homesteads of the mother and the father regardless of whether *ilobolo* have been paid (Case 1 & 7), or may live at the homestead of the father (Case 6).

Where deceased parents of orphaned children were married before they passed away, the orphaned children may reside with the paternal grandparent(s) as can be seen in Case 16. Orphaned children of unmarried mothers on the other hand frequently stay with the maternal grandparent(s) (Cases 11, 15, 17 & 18). Orphaned children may also choose to stay on their own as not to lose the homestead (Case 13). None of the orphaned children in the case study households, except for the female children in Case 13 who went to stay with their grandparents, moved after they became orphaned as the majority of them already stayed with extended family. Where orphaned children are not staying with extended family, care may be arranged by their grandmothers, either paying someone to take care of them (Case 12), or sending someone, where possible a family member, to take care of them (Case19) at the homestead of their deceased parents.

Vulnerable[11] children may be sent by a parent to live elsewhere when they are concerned about the care of the child as is the situation in Case 10 where Phume, who lives on her own and is ill with AIDS-related illnesses, sent her daughter to live with her sister as she was concerned that she may not be able to take care of her. On the other hand, it may be a relative who perceives a child to be vulnerable and then intervene to take the child to live elsewhere, as can be seen in Case 18. Individuals may be deemed members of a household even when they spend several nights per week away from the homestead to work in other parts of the province (Case 3). For a migrant to be seen as a member of a household, s/he must return to the homestead frequently and must send remittances regularly.

Changes in living arrangements occurred across all clusters and in male- and female-headed households. Table 6.5 provides an overview of members leaving households indicating reasons for leaving and implications for the livelihoods of the households they leave.

[11] Vulnerable children, in the context of HIV/AIDS, are seen as children who are at risk of becoming orphaned.

Table 6.5 Implications for households of members leaving

Cluster no	Case no	Individual leaving		Reason for leaving	Implications for livelihood and workload	
		Sex	Age		Activities	Resources
1	3	F	19	Returning to school, live with aunt near school	Loss of domestic labour	Reduced pressure on existing HH resources
		M	0	Accompany mother	Reduced child care	Reduced pressure on existing HH resources
	5	F	24	Getting married	Increase in nursing care burden	Reduction in HH expenditure
		M	0	Accompany mother	Reduced child care	Reduced pressure on existing HH resources
2	6	F	23	Study in another town in the province	Loss of domestic labour	Reduction in HH income
		M	2	Live with father	Reduced child care	Reduction in HH income (child care grant)
		M	22	Live with other relatives	No change	Reduction in HH income
	9	F	21	Work in Durban	Loss of domestic labour	Reduced pressure on existing HH resources, potential for remittance income
3	11	F	29	Getting married	Loss of domestic labour	Reduced pressure on existing HH resources
		M	8	Accompany mother	Reduced child care	Reduction in HH income (financial support from child's father)
		M	0	Accompany mother	Reduced child care	Loss of food for HH provided by child's father
4	15	F	11	Live with aunt	Reduced child care, some loss of domestic labour	Reduced pressure on existing HH resources, but reduction in HH income (child care grant)
	19	F	30	Leave to care for sister's children	Loss of domestic labour	Reduced pressure on existing HH resources

Source: Case studies, 2006/7

From the cases presented in Table 6.5 it can be seen that young adult women and small children, many of them accompanying their mothers, were the most common to leave households. The reasons why women left ranged from 'getting married' to 'work or study in another part of the province'. Only in two of the cases can the leaving of a child (11) and

a young woman (30) be attributed to AIDS. The child's aunt offered that she can stay at her homestead to assist this AIDS-afflicted and -affected household, to reduce the pressure on the existing resources of the household. In the case of the 30-year old adult, she left her parents' homestead to take care of her ill sister's children at the homestead of the sister.

When children leave households it usually implies a reduction in childcare, often the responsibility of grandmothers, however, if children leave with their mothers it may not have a major impact on the activities of the household. When adults, especially young women, leave households it results invariably in a loss of domestic labour and the potential for providing nursing care and child care. It was only in Case 6 where the leaving of the two young adults resulted in a loss of income from employment for the household. Loss of income may though not only be a result of employed household members leaving, but also a result of a loss of income from grants or private support when children aged 14 years or younger leave as can be seen in Cases 6, 11 and 15. Any household member leaving, regardless of sex and age, will result in reduced pressure on the existing physical and social resources of the household. When adults leave to work in another part of the province or country there is potential for the household income to increase, if they receive remittances.

Table 6.6 provides an overview of persons joining households, their reasons for joining and the implications of additional household members for the livelihoods of these households.

Table 6.6 Implications for households of persons joining

Cluster no	Case no	Individual joining		Reason for joining	Implications for livelihood	
		Sex	Age		Activities	Resources
1	1	M	6	Starting school close to grandmother's homestead	Increased child care	Increase in HH income (child care grant)
	4	M	36	Released from jail	Increase in labour, provided person is healthy	Increase in pressure on existing HH resources
	5	F	35	New domestic worker and caregiver	Reduction in burden of nursing care and domestic work	Increase in pressure on existing HH resources & increase in HH expenditure
2	7	F	23	Take care of ill mother	Reduction in burden of nursing care and domestic work	Increase in pressure on existing HH resources
		M	4	Accompany mother	Increased child care	Increase in HH income (child care grant)
		M	2	Accompany mother	Increased child care	Increase in HH income (child care grant)
		M	7	Return home from stay with father	Increased child care	Increase in HH income (child care grant)
		F	5	Return home from stay with father	Increased child care	Increase in HH income (child care grant)
3	13	M	±20	Benefit from HH resources	Increase in domestic workload	Increase in pressure on existing HH resources
		M	±20	Benefit from HH resources	Increase in domestic workload	Increase in pressure on existing HH resources
4	19	F	39	Ill, requires nursing care	Increase in burden of nursing care	Increase in pressure on existing HH resources
		F	1	Accompany mother	Increase in burden of child care	Increase in HH income (child care grant)
		F	1	Accompany mother	Increase in burden of child care	Increase in HH income (child care grant)

Source: Case studies, 2006/7

In Table 6.6 it is shown that male and female adults and young children joined case study households for various reasons including adults seeking or providing nursing care, and children accompanying their mothers or returning from staying at the homesteads of their fathers. In Case 5, a non-related person is employed by the household to take care of an elderly member, in spite a young female adult residing at the homestead whereas in Case 7, a daughter temporarily leaves the homestead of her husband to assist with the care of her mother who is ill with AIDS-related illnesses. In Case 19 an ill daughter joined the homestead of her parents when she became seriously ill with AIDS-related illnesses. In the latter two cases the daughters are accompanied by their small children which means there are now also additional children to be taken care of.

When new persons join households it places additional pressure on the existing physical and social resources of the households, especially if it is adults who are not earning an income. On the other hand, the household may financially benefit from young children joining, when these children receive state child support grants and are 'followed' by their grants (Cases 1, 7 & 19). Children are though not always 'followed' by their grants as is the situation in Case 18.

Demographic dependency refers to children aged 14 years and younger and older adults aged 65 years and older as dependents. It is clear from the cases presented that grandparents aged 65 years and older or productive older adults have to take care of ill adult children and/or orphaned grandchildren (Cases 18 & 19). Although economically inactive, the elderly of 65 years and older (women from the age of 60) receive state old age grants and children 14 years and younger qualify for state child care grants. From the cases it is clear that several households rely on grants as the only or main source of income. In addition to this, there were several examples in the cases of healthy young adults who are not working and according to respondents not actively looking for work either. It has thus become a kind of 'reverse' dependency where adults, even healthy ones, are economically and socially dependent on the elderly and children. Hence, in circumstances such as in this study, demographic dependency does not necessarily reflect actual economic or financial dependency relationships.

Households are dynamic and have fluid boundaries with especially children moving frequently between homesteads of parents, either on their own or accompanying the mother. Households in all clusters experienced changes in their living arrangements for a variety of reasons, the majority of them non-HIV/AIDS related. Where changes in living arrangements are related to AIDS it is frequently out of necessity rather than choice, either to seek or provide nursing care.

Chapter 7

Arrangement and provision of care

In general terms, with reference to the Oxford dictionary, caring can be described as "feeling concern for, and taking charge of, the well-being of others", says Graham (1983:13) in the book *A Labour of Love – Women, Work and Caring*, edited by Janet Finch and Dulcie Groves. Hilary Graham refers to care as 'a labour of love'. This phrase captures two important elements of care: care as an emotion and care as an activity. The phrase 'care for' is sometimes used as an alternative to the word 'love', where the latter may seem inappropriate to express how one feels about family, friends, or acquaintances. "Although a universal need, only certain social relations are seen to facilitate the giving and receiving of care" (Graham, 1983:15). Frequently these caring relationships involve women, a mother, daughter or wife, and are associated with the private sphere of the home, household and family where informal care-giving takes place. Men have more access to the public sphere where solutions to problems of care arrangements can be found. Women's reproductive role lies at the basis of this division of labour, the assignment of women to the private domestic sphere, and hence, the vision of women as 'natural' care givers. The key to seeing caring as women's work lies in an understanding of the nature of the family. In the first place, caring by mothers is identified as the process by which the construction of gender takes place, while in the second place, caring by wives and mothers is the mechanism by which families are reconstituted on a daily basis (social reproduction). The family unit, in turn, provides the structure in which caring is carried out: "in which children are nurtured, husbands sustained, and the elderly and handicapped supported" (Graham, 1983:23). This caring role of women also extends outside the home to caring professions such as nursing and social work, dominated by women.

The fact that care has these two dimensions has the following implications. *First*, if care is emotion (love) it means that it is relational; there is always a social relationship involved between the object and the subject of care or the caregiver and the care receiver. *Second*, if care is an activity (work) it means that resources are needed to carry it out. Care work includes a range of activities, depending on the condition of the care receiver, and requires access to and utilisation of a variety of resources. At the very least care requires time and the expenditure of human energy, but usually also tangible resources. In the same book, Rimmer discusses the costs of care. Home-based care is seen as a more cost-effective alternative to institutional care, mainly because family caregivers are not compensated in any way for their work. Rimmer (1983:131) refers to this as the private costs of care, which include both direct costs, in terms of additional expenses, as well as opportunity costs, a large part of which is loss of income when carers are forced to give up employment.

In this chapter arranging and provision of care are discussed. The phases of care and types of social capital required are outlined and linkages between them explained. This is followed by a presentation of the levels of care and an overview of care provision and utilisation in the research area. Case studies are presented as evidence relating to the phases of care, referring to relationships between caregivers and care receivers, care-related activities, and resources required to provide care. The chapter is concluded with a short discussion.

7.1 Phases of care

The approach to care presented in this chapter is largely based on the framework by Joan Tronto, presented in her book *Moral Boundaries – A Political Argument for an Ethic of Care* (1993). The word ethic in the title shows that Tronto sees care as a moral issue. But also to Tronto care is not just a disposition or emotion but also an activity. All these meanings of care were taken together in the definition by Tronto when she refers to care as a kind of activity "that includes everything that we do to maintain, continue, and repair 'our world' so that we can live in it as well as possible." She sees this 'world' as including "our bodies, ourselves, and our environments, all of which we seek to interweave in a complex, life-sustaining web" (1993:103). It is a very comprehensive description that includes care as maintenance and as restoring or healing, and not only of our selves but also of our environment, including our social environment, with social relations being part of our world.

Care is both emotional and instrumental. Care may take the form of emotional care (as between close friends, spouses, parents and children) or instrumental care (helping somebody with activities that this person cannot carry out him or herself). Care is embedded in societal structures, norms and morality, and based on values that underpin the "life-sustaining web". Starting from her comprehensive definition, Tronto develops a framework in which she distinguishes four phases of care and relates these to distinctive requirements. When these requirements are not fulfilled care is not adequate. The framework can be made operational to yield standards for good care. The moral dimension of care is not only in the disposition or emotion but also in the way the different phases of care should be carried out. According to Pennartz and Niehof (1999:206), "there seems to be a consensus that being physically close and sharing daily life reinforces people's moral commitments towards each other. In this way the households can be seen as a context of condensed morality." The four phases of care and the requirements associated with them are summarized in Table 7.1.

Table 7.1 The framework of care (Tronto, 1993)

Phase	Requirement
1. *Caring about* – the recognition that care is necessary, identification of care needs (relates also to social consciousness)	*Attentiveness* – not be self-centred and looking the other way or turning a blind eye or deaf ear (not saying "I didn't know", while you could have known)
2. *Taking care of* – feeling responsible and doing something about it	*Responsibility* – taking responsibility, not just seeing and leaving it to others
3. *Care-giving* – directly meeting the needs for care by physical work in face-to-face contact	*Competence* – care-giving should be done in the right way, quality of care-giving is at stake here
4. *Care-receiving* – acknowledgement and feed back by the person receiving care	*Responsiveness* – allows for assessing the adequacy of care as perceived by the care-receiver
All phases	*Integrity* – the phases should be linked into a well-integrated care process

The word phases implies follow-up. You are only going to 'take care of' a care need if you (want to) see it (care about), and without somebody taking care of the problem there will be no care giving. Adequate care thus requires attentiveness in identifying care needs, taking responsibility for care needs, making sure care-givers are competent, and finding out how the care-receiver experiences the care. It may, or may not be the same person caring about, taking care of and giving the actual care, but phases should be well integrated to provide quality care. All phases of care include an emotional component or require 'love'. Without 'love' one will not see the problem and be motivated to take the action required. In the fourth phase, 'love' enables perceiving the care receiver's experience of the care.

Care is gendered. Because of its association with the private sphere of the household and the family, where care needs arise and are initially responded to, it tends to be seen as a female activity. Care giving is also part of social reproduction. Although the actual balance in the division of reproductive and productive labour between the sexes differs according to time and place, it is universally skewed, with women dominating in reproductive labour (Niehof, 2004). Good care requires a variety of resources, including time and human and material resources. Scarcity of resources may generate conflict in care, as does the cultural diversity in the notions of what constitutes good care (Tronto, 1993).

7.2 Care and social capital

Because care involves social relations, social capital is important for both care receiver and caregiver to make care-giving possible. Sara Ferlander (2007) argues that different forms of social capital are important for health. These different forms of social capital include bonding social capital (horizontal ties with friends or family with similar social characteristics), bridging social capital (horizontal ties with people with different social characteristics), and linking social capital (vertical ties with people with different hierarchical positions). These horizontal or vertical ties may be strong, or weak, which influences access to care. Ferlander cites empirical studies of a positive relationship between social capital and health. The question is whether the different forms of social capital have a different meaning for the different phases of care from the perspective of the care receiver (see Table 7.2).

Table 7.2 Linking phases of care to social capital

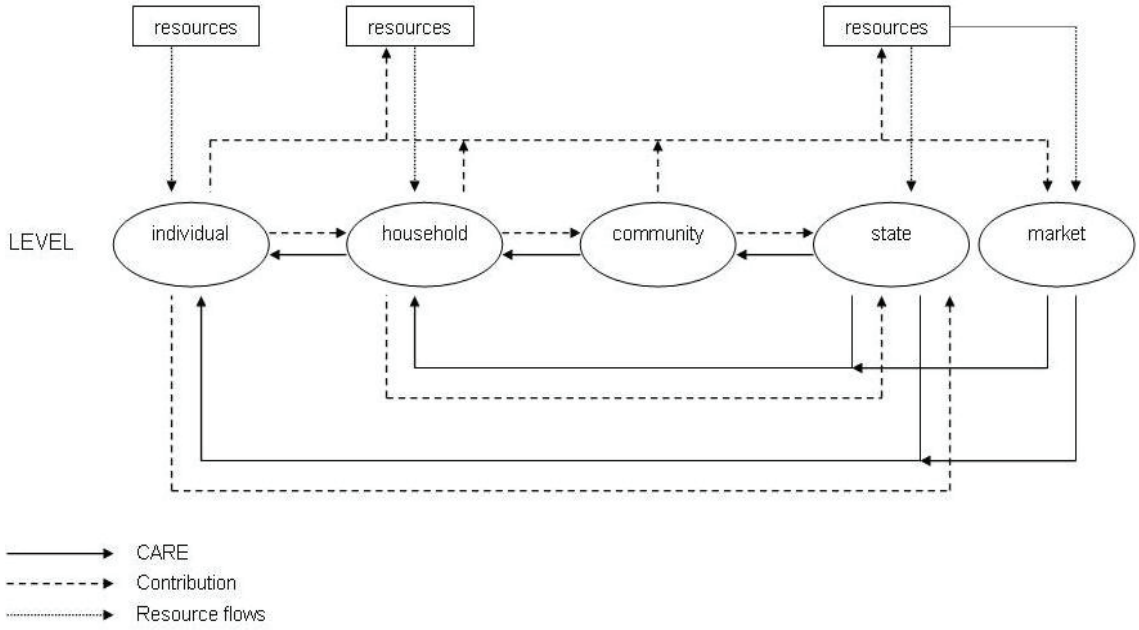
Phase	**Type of social capital**
1. Caring about	You need to have especially *bonding social capital* for others to recognize your problems. If you don't have close and strong ties your needs may go unnoticed.
2. Taking care of	For people to take care of the problem it helps if they have *bridging* and *linking* social capital, or if they can use the *bridging* and *linking* social capital of the patient.
3. Care-giving	Actual care-giving if not in an institutional (formal) setting is something you need *bonding social capital* and *strong ties* for.
4. Care-receiving	Depends on the relationship between caregiver and care-receiver (see 3).
All phases	For a well-integrated care process you need all forms of social capital.

'Caring about' in a more general sense requires exposure to the world around you, whether it is the small world of strong and horizontal ties or the bigger world of the weak and vertical ties. It seems problematic to expect from people who are poorly embedded in social networks of whatever kind that they care about others and the world around them. 'Care-giving' in an informal setting draws on the strength of close relationships and on the moral underpinnings of such relationships. In families, norms about kinship obligations (between spouses, siblings, parents and children) structure the expectations people have of each other and the legitimacy of the claims they make on each other. However, such norms function as guidelines, not as a blue print (Finch and Mason, 1993). Close ties create moral obligations and expectations of care-giving that are – especially in the case of family – based on strong societal norms and values, the principle of reciprocity playing a role as well. However, there are limits to the capability, resources and competence of informal caregivers in the own close social network. When these limits are reached professionals and support agencies have to take over, which requires a new assessment of the situation and somebody else taking care of it.

7.3 Micro-macro linkages

Several institutions at different levels are involved in care provision. Care is provided by family members in the private sphere of the household, but also by the community, including neighbours and community health workers, by the state, mainly through public health clinics and hospitals, and by the private sector or market which – in the case of South Africa – includes traditional nursing care. Although the emphasis in this paper is on the micro-level of the household where home-based care is provided essentially by the family with assistance from community-based health workers, linkages with other levels of care, including the state and the market should not be overlooked. Gradually the state or public sector has taken over forms of care provision that formerly took place in the private sphere. The micro level, however, remains the starting point. Only when care needs exceed the resources, capabilities and competence of the household and family, other actors, such as health workers, various types of professionals, specialized institutions, the state or the market, step in or take over. Figure 7.1 provides an illustration of the connections between the different levels at which care is provided and the flows of resources, contributions and benefits. Care by the state includes, for example, social grants and nursing care supplies, while the state derives its resources from taxes and premiums. At the household level care is provided to individuals, for which household resources are mobilized, and individual household members contribute labour or money to the household and have their own human resources.

The conceptualization of care as outlined above was applied to assess the quality and limitations of informal care as provided by the household and the community for people living with AIDS (PLWA) in rural KwaZulu-Natal, South Africa. It also looked at the role of other actors such as non-governmental organisations and the state in the provision of care and support.



Source: Niehof (2002:184).

Figure 7.1 Model of care arrangements

7.4 Provision and utilisation of care

This section provides an overview of the care providers, or actors in the care process, and facilities available in the research area of Mbonambi and individual utilisation of these facilities and providers. In the household survey, respondents were requested to answer retrospective questions on in-patient and out-patient use of care facilities and needs for home care for the three months prior to the survey interview. The survey also included questions on subscription to medical aids, medical expenses and treatment.

7.4.1 Public and private hospitals and clinics

The nearest public hospital is located at Ngwelezana suburb outside Empangeni, approximately 35km from the research area. The hospital has 544 beds and provides district and regional in-patient and out-patient services. Ngwelezana hospital was visited by 120 (5.0%) of the individuals in the research sample as out-patients between July 2006 and September 2006, while 82 (3.4%), 23 of them with AIDS and/or tuberculosis (TB), stayed in hospital for at least one night during this time. HIV and AIDS-related services include voluntary counselling and testing (VCT), prevention of mother to child transmission of HIV (PMTCT), treatment for patients with TB and antiretroviral (ARV) treatment for AIDS patients. Potential receivers of ARV treatment are identified by public health clinics in the district and referred to the hospital for clinical assessment. Those who qualify for ARV treatment have to follow treatment literacy training for one week after which they have to collect their medication from the hospital once a month for the first six months. Once the hospital is satisfied that patients are receiving appropriate combinations of ARV

drugs and adhering to treatment, they may collect the treatment from selected clinics for the seventh month onwards. Patients pay between R50 and R100 as out-patients, to see a doctor, or to be admitted to the hospital, after which the majority of treatment is free. The nearest private hospital in Richards Bay is approximately 15km from the research area. Private health care is expensive, and with only 84 (3.5%) individuals having access to medical aids, very few are able to access private health care. Only 136 (5.7%) individuals in the research sample visited private doctors, specialists and hospitals in the three months prior to the survey.

There are two public health clinics in the research area, Mbonambi clinic located in Ward 5 and Nhlabane clinic located in Ward 3. Nhlabane is a small clinic offering fewer services than the bigger and better equipped Mbonambi clinic. As opposed to Nhlabane clinic, Mbonambi clinic offers HIV and AIDS-related services, including voluntary counselling and testing (VCT), prevention of mother to child transmission of HIV (PMTCT), and antiretroviral (ARV) treatment. Both clinics offer a variety of other services as well as treatment for other chronic diseases, such as TB, and acute illnesses, and are open on weekdays from 07h00 to 16h00. Public health clinics provide mainly out-patient service and were visited by 498 (20.8%) of the individuals in the research sample. In-patient services are only provided by selected clinics and 14 (0.6%) individuals spent at least one night in Mbonambi clinic. Nhlabane clinic, the clinic used by the majority of individuals residing in Ward 3, does not provide in-patient services. Table 7.3 provides an overview of household access to public health clinics in the research location. The majority of households in Ward 3, 59.9 percent, are five or more kilometres from the nearest public health clinic.

Table 7.3 Household access to public health clinics by research location

Variable	Ward 3 (n=137)	Ward 5 (n=217)	Total (N=354)
	freq (%)	freq (%)	freq (%)
Name of nearest clinic			
Mbonambi	51 (37.2)	206 (94.9)	257 (72.6)
Nhlabane	77 (56.2)	1 (0.5)	78 (22.0)
Other clinics	9 (6.6)	10 (4.6)	19 (5.4)
Distance from clinic			
Less than 3 kilometres	24 (17.5)	135 (62.2)	159 (44.9)
3 or more kilometres*	113 (82.5)	82 (37.8)	195 (55.1)

Source: Household Survey 2006
*Chi-square significant at $p \leq 0.01$

Problems experienced by households at public health clinics include the following: long wait (72%), medication not available (45.5%), rude staff (20.6%), and inconvenient opening hours (19.8%). Other problems expressed by a few households included 'shortage of staff', 'incorrect diagnoses' and 'facility not clean', while 32 households indicated that they did not experience any problems. Of those individuals with chronic illnesses, 422 (17.6%) are receiving treatment. Of the 140 individuals with HIV/AIDS and/or TB, 114 are receiving treatment. Direct medical expenses for consultations and treatment were incurred by 206 (8.6%) of the individuals in the sample, 27 of them with HIV/AIDS and/or TB. Eleven of the 140 individuals in the sample with HIV/AIDS and/or TB did not visit any medical facility or consult any health practitioner in the three months prior to the survey.

Twenty-eight (1.2%) individuals, only one with AIDS, visited traditional and/or spirituals healers in the three months prior to the survey, one of them stayed with the

traditional healer for an extended period of time. Thirteen of them also consulted medical facilities or practitioners.

7.4.2 Non-governmental organisations

Ethembeni Care Centre, with 12 beds at the time, was established as a medical clinic in 1999 by the Zululand Chamber of Business Foundation (ZCBF) with the assistance of six Richards Bay industries. In 2002 it became clear that it was hopelessly inadequate and that substantial expansion was required. Amangwe Village, occupying an area of eight hectares and with 54 cottages, located at KwaMbonambi approximately 20 kilometres from Richards Bay, previously hosting employees of one of the industries, was offered as a new location for the Care Centre. After extensive consultation with non-governmental organisations working in the field of HIV and AIDS, and government departments, the substantial facilities were renovated to more holistically meet the needs for care and support of adults and children infected and affected by HIV and AIDS, especially those who had been deserted by their families. Cottages were renovated to accommodate the medical clinic, administration blocks and training facilities, and a paediatric ward was added to provide for a range of other services, including facilities catering for orphans and vulnerable children. In 2005, Ethembeni Care Centre was registered as a non-governmental organisation. Amangwe village is made up of three core categories of interventions providing an integrated set of services: Ethembeni Care Centre; orphans and vulnerable children (OVC); and outreach, education and training.

Since 2008, following extensive infrastructural development, Ethembeni Care Centre has a 45-bed facility providing care mainly for people with AIDS and TB as well as an 18-bed paediatric centre. Professional staff offer individual and family counselling and in-patient, out-patient and community care services. Although initially established to provide care for employees of the industries, the Centre became an invaluable resource to all community members. Although the aim was to provide care for people from the area surrounding the Village, the manager of the Care Centre indicated in an interview that the Centre is frequently used by people from other areas in an attempt to escape the stigma surrounding AIDS.

Some of the objectives of the orphans and vulnerable children programme of the Village are: the protection of children and their inheritance and property rights; and improving the capacity of primary caregivers to meet the basic needs of the children in their care. A database of orphans and vulnerable children was compiled to enable monitoring of the children and to ensure that they are the first to benefit from funding and other donations. Peer educators and teachers from the area are trained to identify and adequately address the needs of orphans and vulnerable children and child-headed households. A crèche and Toy Library were established to provide daily care and educational stimulation for underprivileged children, especially those living in child-headed households. Some of the cottages are used as temporary foster care facilities, where foster parents live with up to four children until plans can be made for their permanent placement, preferably with extended family.

Through outreach, education and training initiatives, Amangwe Village aims to achieve three main objectives. The first is to provide services to communities outside the confines of the Village through its Home Based Care Programme which comprises 25 well trained volunteer carers who visit poverty stricken households on a daily basis to assist in caring for critically ill loved ones. The second objective is to assist affected households with income generation through skills training and support of community based projects. Through this initiative food gardens and an on-site catering service were established. The third objective is to generate income for Amangwe Village through delivery of workplace

HIV and AIDS programmes to businesses in the region (Zululand Chamber of Business Foundation, 2009; Rein et al., 2005).

7.4.3 Community- and home-based care

Community-based care can be described as the care occurring at a patient's home to supplement or replace hospital care. It includes medication management, palliative care (a holistic approach to improve the quality of life of terminally ill patients), and social support. Home-care programmes provide an alternative to expensive hospital care, or where hospitals are unable to cope with demand for care of people with AIDS, but where family and other household members find it difficult to cope on their own with the demanding care of people living with AIDS (Uys, 2003).

Health workers are described by the WHO (1987:10) as "men and women chosen by the community, and trained to deal with the health problems of individuals and the community, and to work in close relationship with the health services." In this research, on the work of the community based health workers, care is described as including anything and everything done for an ill individual that he/she would normally do for him-/herself appropriate for his/her gender and age, that he/she is now unable to do as a result of his/her illness. In this research, the 'anything and everything' refer to a range of nursing care and domestic activities, with the person doing it, being a community health worker or home-based caregiver often in cooperation with a family or household member, and illness specifically referring to AIDS and/or TB. In the research sample, 94 (3.9%) individuals, 37 of them with AIDS and/or TB, required some form of home-based care in the three months prior to the survey.

At a monthly community meeting in 1995, the community of Mbonambi raised their concerns about problems in their community. A range of health and social problems were expressed, and committees to address different problems were selected. Many of the women attending this meeting were already, since the early 1990's, visiting elderly and ill persons at their homes, assisting them with a range of domestic and other activities. They specifically expressed their concern about elderly and ill persons living on their own, without the emotional and financial support of family. They also saw the increasing demand for nursing care brought about by AIDS-related illnesses and TB, and the demand for family/household caregiver support. One of the committees selected at this occasion, chaired by one of the community health workers referred to in Table 7.4, CHW7, was a committee to address needs related to nursing care. This was a first step in the direction of recognising and formalising the work done by several women over many years in Mbonambi.

Following the selection of the committee to address health problems, ten female members of the community were selected to be trained as community health workers, all of them already involved in volunteer work in the community. A major local industry, situated in Mbonambi, was approached to fund their intensive one-year training which commenced in 1996. The main aim of their initial training was to prepare them to conduct home visits to households with chronically ill and elderly members and to educate family/household members about HIV and AIDS and other chronic illnesses and how to care for an ill person at home. In 1997 after completing their training they started working independently, remunerated by the same industry that sponsored their training and supervised by the local public health clinic. In turn the community health workers trained selected volunteer home-based caregivers, also already working in the area, to assist them with their work.

This research included interviews with eight of the community health workers (CHW) and three of the home-based caregivers (HBC), as well as observation and detailed documentation of the work of six of them (see Chapter 3 for a profile of the 11 health

workers). Table 7.4 provides an overview of the activities of the health workers, which goes beyond home visits and providing of care for people with AIDS and/or TB.

Table 7.4 Overview of the activities of community-based health workers

CHW/ HBC	Home visits		School visits		Support groups	
	No. of homes	Frequency of visits	No. of schools	Frequency of visits	No. of groups	Frequency of meetings
CHW 1	11	1-3 times/month	4	2 times/month	0	n/a
CHW 2	11	1-2 times/month	2	1 time/week	0	n/a
CHW 3	13	2 times/month	1	1 time/week	0	n/a
CHW 4	11	2 times/month	2	1 time/week	0	n/a
CHW 5	14	1-3 times/month	2	1 time/month	0	n/a
CHW 6	33	1-2 times/month	2	2 times/month	1	1 time/month
CHW 7	5	1 time/month	14	1 time/month	0	n/a
CHW 8	27	1 time/month	3	2 times/month	2	1 time/week
HBC 1	4	2 times/month	0	n/a	0	n/a
HBC 2	35	1-3 times/month	0	n/a	2	2 times/month
HBC 3	12	2 times/month	5	2 times/month	0	n/a
Total	176	-	35	-	5	-

Source: Interviews, 2006

All the community health workers and home-based caregivers conduct home visits, with the majority of them spending most of their time visiting chronically ill persons (including those with AIDS and TB), elderly persons, and orphaned and vulnerable children at their homes, and where necessary provide or assist with nursing care and/or domestic work. One home may have more than one chronically ill person and may or may not include orphaned and/or vulnerable children. The majority of the health workers also visit schools to educate children about HIV and AIDS and to identify orphans and vulnerable children, and some also facilitate support group meetings for people living with HIV and AIDS where they can share their experiences in a safe and comfortable environment. Some of the health workers also engage in other activities, such as hosting of public talks related to HIV and AIDS and engaging in community gardens and other community projects, while one of the community health workers (CHW7) is responsible for the training of volunteer caregivers.

Although the formal system of referral is through the public health clinic supplying names and addresses of clients to be visited, individuals or households requiring assistance, and concerned friends and neighbours also approach health workers directly. The main aim of home visits is to ensure that ill persons and orphans receive appropriate care from family/household members. Health workers usually approach neighbours to assist with the care of ill persons and orphaned children who live on their own, therefore playing an important liaison role in the arrangement of care. They visit as many as six homes per day and try to visit clients at least once a month, but if a person is critically ill they will visit at least once a week or even as frequently as once or twice a day. Clients vary in age, including children from as young as eight years old to elderly persons of 80 years and older, and approximately 75 percent of them are female. The majority of those visited are

HIV positive (44%) or have TB (33%), while some of them are HIV positive and co-infected with TB (10%). The majority (97%) of those with TB, also those who are HIV positive and co-infected with TB, are receiving treatment for TB. Approximately 40 percent of those with AIDS are receiving antiretroviral treatment (ARV), while a further 53 percent who are HIV positive are taking boosters, usually a combination of vitamin and mineral supplements, aimed at maintaining the immune system. Approximately 50 percent of their clients who are HIV positive are asymptomatic or experience mild symptoms associated with AIDS and therefore not yet eligible for ARV treatment. AIDS-related symptoms documented by the health workers include coughing, diarrhoea, vomiting, skin rashes, thrush, swelling, fatigue, loss of appetite, weight loss and general weakness. Mild symptoms and side effects of ARV treatment are treated with traditional remedies which include garlic, ginger, spices such as cinnamon and turmeric, and herbs including *imifino*[12].

The duration of home visits depends on the condition of clients and the availability of care within the household, but may last anything from 30 minutes to a whole day. When the health worker arrives at the home of the client she first does a visual assessment of the condition of the patient. The health worker also asks about symptoms and where possible minor symptoms are then treated with traditional remedies. If patients are on TB or ARV treatment they will request to check treatments to see if patients are adhering to the treatment. They will emphasise the importance of accurate and regular taking of medication to both patient and caregiver(s). Health workers will also ask about the diet of the patient, ensuring that they eat regularly and consume nutritious food, giving specific instructions to the person who prepares the food on what the patient should and should not eat. Health workers may assist household caregivers with preparation of a nutritious meal as well as assisting with the personal hygiene of the patient.

Where a patient lives on his/her own, health workers may stay the whole day to take care of domestic work such as fetching water, cleaning the house, doing laundry and preparing food for the patient. A very important component of visits is to educate caregivers on how to care for a person with AIDS while preventing themselves from becoming infected, and counselling of patients on the progression of the illness and how to take care of themselves. Caregivers and patients are also encouraged to ask questions and express problems and where health workers cannot deal with these themselves, they relay these to their supervisors at the public health clinic when they meet once a month to report on their clients. Where necessary, health workers also provide caregivers with supplies of rubber gloves, disinfectant soap, adult nappies, protective bed sheets, and male and female condoms, provided by the local Department of Health and distributed through the clinic.

Although details of deaths of patients were not recorded by all the health workers, the majority of them recorded between three and five patient deaths in the last two months of 2006. Most of these were young women between the ages of 20 and 40 who died of AIDS-related illnesses. After a patient passed away, the health worker continues to visit the household to provide bereavement counselling throughout the period of mourning, and may continue visiting the household to monitor orphaned children. Health workers face many challenges in caring for people living with HIV and AIDS, such as dealing with stigma and lack of resources.

[12] *Imifino* is a spinach like, leafy green plant; leafs are crushed in water to produce a kind of tea used to treat coughs .

7.5 Evidence relating to the four phases of care

Phase 1, caring about

"He is my son, I have to take care of him. Who else will? He doesn't have a wife and in our (Zulu) culture, another woman may not look after him."
(65 year-old widow taking care of her 31 year-old unmarried son, Case 22)

"I love her, she is my only child. I thought she would take care of me when I am old, now she is sick and I take care of her. I cannot ask somebody else to take care of her, not with this illness."
(54 year-old mother taking care of her 31 year-old daughter, Case 18)

"I worry about the people who live on their own, with nobody to take care of them. I care about the sick people in my community. I want to see them get better."
(44 year-old female volunteer home based caregiver)

"There are many sick people and orphans around me. I want to make sure that they are well taken care of."
(52 year-old female community health worker)

Statements by family members and health workers such as these illustrate how care needs are perceived. When health workers were asked why they became health workers, the majority of them indicated that it is because they 'care about' the people around them. Whether it is a family member, a friend, a neighbour or somebody they hardly know, people are generally sensitive to the needs of others. Occasionally, the need for care is also perceived by formal care institutions, such as the local public health clinic, and then communicated to community health workers, to 'take care of'. The person perceiving the need for care or 'caring about' may not be the one arranging the care or 'taking care of', though more frequently than not, the one 'caring about' is motivated to at least 'take care of' as illustrated in the next section.

Phase 2, taking care of

This section describes who 'takes care of' and what it means to 'take care of' or make arrangements for care-giving. Characteristics of caregivers and care receivers, of the 14 case study households visited, are outlined in Table 7.5. The condition of the person with AIDS and/or TB in the second column provides an indication of the care they may require, while the relationship of caregivers to care receivers is indicated in the last column.

Table 7.5 Characteristics of caregivers and care receivers and their relationship

Case No*	Characteristics of care receiver	Condition of care receiver (WHO stage of disease)	Characteristics of primary caregiver(s)/ potential caregivers	Relationship of caregiver(s) to care receiver
6	Female (42), unmarried, living with her children and grandchildren at the homestead of her mother	AIDS-related illness, stable condition, not in need of full-time care (stage II)	Female (39), unemployed and also lives at the homestead of her mother, with one of her children	Sister

Case No*	Characteristics of care receiver	Condition of care receiver (WHO stage of disease)	Characteristics of primary caregiver(s)/ potential caregivers	Relationship of caregiver(s) to care receiver
7	Female (47), unmarried head of HH, living with her are some children and grandchildren	Very ill with TB and other AIDS-related illnesses, requires full-time care (stage III)	Female (23), left homestead of partner to care for ill mother	Daughter
8	Male (14), living with his mother	Very ill with TB and other AIDS-related illnesses, requires full-time care (stage III)	Female (31), head of HH, living with her children and partner, provides care at night Female (44), volunteer health worker living next door, provides care during the day	Mother & health worker
9	Female (25), unmarried, living with her children at her parent's homestead	Seriously ill with TB and other AIDS-related illnesses, requires full-time care (stage III)	Female (48), married, living with husband, children and grandchildren	Mother
10	Female (23), unmarried, living on her own	AIDS-related illness, stable condition, not in need of full-time care (stage II)	Neighbours, sex and ages unknown, with occasional assistance from a volunteer health worker	Neighbours
15	Male (46), head of HH and wife (42) living with children and grandchildren	Both have AIDS-related illness, condition of head worse than wife, he requires intermittent care (stage II)	Female (42), when she is not doing some piece work, sister (age unknown) living next door	Wife & sister
16	Male (59), head of HH, living with wife and orphaned grandchildren	AIDS-related illness, but on treatment and currently not requiring care (stage III)	Female (49), has diabetes and requires intermittent care	Wife
17	Female (58), head of HH, living with children and orphaned grandchildren	Ill with TB and other illnesses (HIV status unknown)	Female (52), community health workers visits regularly, no HH member taking responsibility for care	Health worker
18	Female (31), lived with son and other family members at mother's homestead	Seriously ill with AIDS-related illnesses, required full-time care (stage IV) until she passed away in December 2006	Female (54), was working, but left job to take care of daughter	Mother

Case No*	Characteristics of care receiver	Condition of care receiver (WHO stage of disease)	Characteristics of primary caregiver(s)/ potential caregivers	Relationship of caregiver(s) to care receiver
19	Female (39) lived with children at her own homestead, moved to her parent's homestead when she became too ill to take care of herself	Seriously ill with AIDS-related illnesses, required full-time care (stage IV) until she passed away in December 2006	Female (68), pensioner, living at husband's homestead with another daughter and orphaned grandsons	Mother
20	Female (42), lived with partner and adult son.	Seriously ill with TB and AIDS-related illnesses, required full-time care (stage IV) until she passed away in November 2006	Male (±40), working full-time, provided care at night Female, age unknown, living next door, provided care during the day	Male partner & neighbour
21	Female (40), head of HH, living with partner and adult daughter	Very ill with TB and other AIDS-related illnesses, requires full-time care (stage III)	Male (35), working full-time, provides care at night Female (22) not working and pregnant, provides care during the day with assistance from a volunteer health worker	Male partner & daughter
22	Male (31), unmarried, living with other family at mother's homestead	Very ill with TB, requires full-time care (stage IV)	Female (65) widowed pensioner head of HH	Mother
23	Male (31), unmarried, living on his own since his grandmother passed away earlier in 2006.	Very ill with TB and other AIDS-related illnesses, requires full-time care (stage IV)	Neighbours, sex and ages unknown, with regular assistance from a paid health worker	Neighbours & health worker

Source: Interviews and observations September 2006 – March 2007
* Case numbers correspond with those allocated in Chapter 3, see Table 3.3

Table 7.5 thus provides an indication of who will take primary and where necessary secondary responsibility for 'care-giving'. How the care was arranged and what it involves is described in the text. The living arrangements and livelihoods of the households in Cases 6 to 10, and 15 to 19 are presented in Chapter 6, while Cases 20 to 23 are only referred to in this chapter.

Where persons living with AIDS reside with relatives or partners, or have relatives living nearby, it was always the same person who perceived the need for care and made the arrangements for care-giving, many of them becoming the primary caregivers as well. Frequently the close relative is the mother of the person living with AIDS residing at the same homestead (Cases 8, 9, 18, 19 and 22). Occasionally there is not an appropriate person at the homestead to take care of the person with AIDS, in which case either a relative living nearby has to move in with the ill person (Case 7) or the ill person has to go and stay at the homestead of a relative (Case 19). Where a person with AIDS lives on her/his own (Cases 10 and 23) the need for care was frequently perceived by a neighbour and then communicated to a health worker to 'take care of'. When family cannot be located to provide the actual care, the health workers then may approach the same neighbours, as in

both these cases, to assist with care-giving. When an ill person has to stay alone at home during the day while the primary caregiver is at work, health workers may provide care during the day, or again arrange with neighbours to do so (Cases 8 and 20). Family members who are primary caregivers themselves may also approach other relatives or neighbours to request assistance with care. Most of the time this will only be for respite care, where the primary caregiver need to leave the home for a while, but it may also be because they need assistance with a care activity, such moving a as the patient from a bedroom to a sitting room, as referred to in the next section. More often than not, the person to 'take care of' is also the person to give the necessary care.

Phase 3, care-giving

Care-giving implies physical involvement, work. Table 7.6 provides an overview of the kind of work that is done and the resources required to carry out the activities effectively.

Table 7.6 Care activities and resources required

Care activity categories	Description of activities	Resources required
Monitoring condition	Regular assessment of the condition of the PLWA and when necessary arranging for patient to go to a formal healthcare facility and accompanying the patient.	Knowledge, assistance from health workers.
Basic nursing care	Treating minor symptoms and pain relief.	Knowledge, skills and basic medical supplies including rubber gloves, dressings and ointments.
Physical care	Feeding, grooming, bathing, assist with use of toilet, turning and lifting the patient, assist with walking, etc.	Money, skill, assistance from another person, clean water, supplies such as adult nappies and plastic bed covers.
Treatment	Collecting treatment, supervise or assist with taking of treatment, preparing traditional remedies, etc.	Money, transport, environmental resources (herbs).
Rehabilitative care	Assisting the patient to do some exercises and massaging to prevent/reduce stiffness and pain.	Knowledge, skills, physical strength or assistance from somebody else.
Psycho-social and spiritual support	Talking or reading to the patient, keeping him/her company, spiritual guidance and dealing with nearing death.	Mainly time, but also dedication.
Household assistance	Assistance with domestic work such as cleaning, laundry, preparation of meals, shopping and childcare.	Money, cleaning agents and equipment, water, special foods.

Source: Interviews and observations September 2006 – March 2007

In column one, the activity category, followed by a description of what it entails in column two, with an indication of the resources required in column three.
All activities at the very least require time, human energy and patience, and can be carried out more effectively with relevant knowledge and skills. The majority of activities though also require social capital or resources, such as assistance from a neighbour; financial resources, to access treatment and supplies; environmental resources, such as clean water; and material resources such as basic medical supplies. All the households described in Table 7.5 are visited by health workers on a regular basis and more frequently when the clients are bedridden. Apart from providing practical assistance with care-giving, they also share their knowledge and skills with primary caregivers enabling them to do their work in a more time and cost effective manner.

The activities which need to be carried out by caregivers depend on the condition of the person with AIDS, whether he/she is still able to do something for him/herself or bedridden and completely dependent for all activities on a caregiver. Caring for a person with AIDS, who is bedridden and completely dependent, is a full-time job, and thus very demanding if there is only one caregiver. It is also more time and energy consuming to carry out an activity, such as feeding, when the person is very ill and sometimes unable to cooperate with the caregiver.

Phase 4, care-receiving

People with AIDS are very aware of their helplessness and extreme dependence on their caregivers, and some of them feel guilty because they cannot do anything for themselves. They also experience the physical discomfort of being unable to, for example, go to the toilet on their own, which may make them impatient and demanding. Some of them also do not want to be left on their own, demanding the constant attention of their caregivers. Outcomes of care activities are not always positive or successful, leaving not only the care receiver dissatisfied, but also resulting in frustration of the caregiver. In advanced stages of AIDS-related illness, as was observed in Cases 18, 19 and 20, the patients experience extreme pain and discomfort, which makes them very difficult to care for. At this stage, they may also suffer from cryptococcal meningitis which causes behavioural changes and mood swings, at times displayed as aggression (WHO, 2005). In Case 19 this was so severe, that the patient had to be hospitalised, where she passed away a few weeks later. The response of care receivers to care may thus result either from their dependence and inability to do anything about their situation, and/or it may be associated with specific symptoms of AIDS-related illnesses in the final stage of the syndrome.

7.6 Integrity of the care process

To gain a better understanding of the integration of the different phases of care and the contributions to care of all actors involved, several cases are presented. Patients referred to below were visited at their homesteads two or three times between September 2006 and March 2007 (also see Table 7.5).

Case 6: Nompume

Nompume (42) lives with her children and grandchildren at the homestead of her widowed mother. Nompume's youngest child died in 2002, at the age of two, of unknown causes. In 2004 Nompume tested positive for HIV after she became ill and showed symptoms

associated with AIDS-related illnesses. When I visited her for the first time, she was displaying symptoms, a skin rash, general tiredness and weakness, associated with AIDS-related illnesses, but she was well enough to take care of herself and to assist with domestic work and the care of her grandchildren. Her HIV status and vulnerable health prevents her from seeking employment. Nompume does not yet qualify for antiretroviral treatment and maintains her health by taking vitamin and mineral supplements[13] which she collects once a month from the local public health clinic. Although the supplements are free of charge, Nompume has to take a taxi to the clinic located more than five kilometres from her homestead. Nompume's condition is closely monitored by a community health worker who visits her at least once a month. She also has blood tests done at the clinic every three months to determine her CD4 count and viral load. When her CD4 count becomes too low and the viral load increases, she will be recommended for ARV treatment and referred to the public hospital for further assessment. In addition to regular visits from a community health worker, Nompume also has very supportive neighbours who know her HIV status and provide her with emotional support. She also attends a support group meeting once or twice a month at the home of the health worker, where she can share her experiences with other HIV positive individuals. Although she is not currently in need of care, she can rely on her 39-year old unemployed sister to take care of her.

Case 7: Bongi

Bongi, the 47-year old head of the household, lives with her son (23), daughter (25) and a grandson. The daughter also has two older children who, at the time of my first visit, were staying with their father's family. The first time I met Bongi, she was on treatment for TB and healthy enough to work, either part-time in the small shop of a family member or doing sewing. Apart from her small income, the household's only other source of income was one childcare grant. When I returned to the homestead three months later, Bongi's health had deteriorated to such an extent that she was bedridden. Bongi's other daughter (23), previously living at the homestead of her in-laws, decided to return with her two children to the homestead of her mother to take care of her mother and assist with domestic work. Coinciding with this, the other two grandchildren also returned to the homestead of their grandmother. As a result of her illness, Bongi was no longer able to work, and with none of her children employed, the household's only income comes from childcare grants received for the five small children. Bongi's 25 year old daughter is also HIV positive and is beginning to display mild symptoms associated with AIDS. Her son did not yet get tested for HIV, even though he also displays symptoms which may be AIDS-related such as chronic diarrhoea. When I visited the household in February 2007, Bongi's condition had improved, probably as a result of TB treatment and several vitamin and mineral supplements. Her health improved to such an extent that she was able to take care of herself and do some domestic work, still with the assistance of her 23 year old daughter. In February, Bongi was no longer willing to be interviewed, claiming that it is because of our visits that her neighbours now know that she has AIDS.

Case 8: Sipho

Sipho (14) is HIV positive, has TB and suffered what can best be described as an AIDS-related stroke, which left him partially paralysed on the right side of his body, shortly before I visited him for the first time. He lives with his widowed mother (31), his younger

[13] A combination of supplements taken by patients with AIDS and/or TB which they receive from the local public health clinic is commonly referred to as 'boosters'.

sister and his mother's boyfriend. Sipho's mother and her boyfriend are both HIV positive, and his father died of AIDS-related illnesses in 2001. Sipho's mother is still in good health and works as a domestic worker. Sipho was in his second last year at primary school when he became very ill in August 2006 and had to drop out of school. After Sipho had the stroke he spent a few weeks in the nearby public hospital, but recovered sufficiently to return home shortly before my first visit. During the day when his mother is at work, he usually stays at home on his own. A volunteer home-based caregiver, who at the time lived next to them, visited Sipho during the day, ensuring that he eats and helping him to exercise his paralysed limbs. He initially needed assistance to wash himself, but was able to dress and feed himself. When she was not available, another neighbour stayed with him during the day. Sipho is on treatment for the TB and also takes vitamin and mineral supplements. When I visited Sipho a second time, his health had improved. He was able to walk independently and he started to practice to write. His condition improved to such an extent that he would occasionally walk to the nearby homestead of his grandmother to stay with her during the day. After recovering sufficiently, he returned to school in January of 2007, this time a special school as he still suffers from partial paralysis.

Case 9: Ntokoza

Ntokoza (25) lives at the homestead of her parents with her two children. Her older sister with her two children, and the daughter of another sister who works in the city, also live with them. Apart from her father working part-time, the household's only source of income is the grants received for four of the children. The first time I visited the HIV positive Ntokoza, she was on treatment for TB, and although she was thin and weak, she was able to take care of her children and assist with domestic work. The TB-medicine is collected every month, free of charge from the local public health clinic, approximately three kilometres away, either by Ntokoza's mother or by the health worker. When I visited Ntokoza a few weeks later, her symptoms became more severe. A stroke had left her paralysed on the left side of her body. She was unable to walk and talk, and completely dependent. She required full-time care, provided by her 48-year old mother with some assistance from the volunteer home-based caregiver. Ntokoza depended on her mother to take care of all her physical needs, including personal hygiene, dressing and feeding. Her sister now had to take care of all the children, including Ntokoza's, and had to take responsibility for all the domestic work. A month later Ntokoza was on new treatment for her TB, and her condition improved slightly. She was able to sit up, talk and eat again. The home-based caregiver passes by as often as possible, at least once a week, to check on Ntokoza's condition, and to ensure that she is taking her medication and eating properly, as well as help her to exercise her paralysed limbs. She also supplies them with adult nappies and rubber gloves. Ntokoza's mother finds it very difficult to take care of her ill daughter, but receives a great deal of encouragement and advice from the health worker.

Case 10: Phume

Phume (23) has been living by herself since mid-2006 when her boyfriend moved out and she decided to send her five-year old daughter to live with her sister. She was concerned that her deteriorating health would make it impossible for her to take care of her daughter. Phume also had to stop attending college. At the beginning of 2007, her boyfriend decided that their daughter should go and live with his parents living much further away and Phume is no longer able to visit her as frequently. Phume's parents passed away a few years ago, and she only has the one younger sister who lives with distant relatives approximately 45 kilometres away. Phume is HIV positive and is co-infected with TB, and started showing

symptoms associated with AIDS-related illness around the time I visited her for the first time. Shortly after my first visit, she was hospitalised for a few days after she experienced problems with her breathing. As a result of her illness and weakness, she was unable to work and her only financial support is a small amount of money she receives every month form a distant relative. Phume lives in a small one-roomed traditional structure, surrounded by neighbours who know her HIV status, who are very supportive. They assist her with domestic work such as fetching water and cleaning the yard. After her health improved slightly at the beginning of 2007, she was able to get part-time employment as a domestic worker. A volunteer health worker visits Phume twice a month to monitor her condition and to ensure that she takes her medication. In the absence of family, Phume also relies a great deal on the health worker for emotional support.

Case 15: Emanuel and Gloria

Both Emanuel (46) and his wife Gloria (42) are HIV positive. Emanuel's illness is at a more advanced stage than that of Gloria. Whereas he shows signs of wasting and suffers from weakness and coughing and recently had TB, she is asymptomatic and appears to be in good health. They both visit the nearby public clinic regularly and are taking supplements to boost their immune systems and to prevent their condition from deteriorating. Emanuel spent a few weeks in hospital in February 2006 as a result of TB. Their two eldest daughters passed away in 2004 and 2005 respectively, while the only child of the eldest daughter also passed away shortly after he was born. Both daughters died of AIDS-related illnesses. All the children and their five-year old orphaned granddaughter are in good health, but their 18-month old granddaughter appears under-nourished and small for her age. In January 2007 their 11-year old daughter went to stay with her aunt in a settlement approximately 30 kilometres away. The aunt offered to take her in to help the family. With both parents being HIV positive, at least some of their five children below the age of 16 are vulnerable and at risk of being orphaned. A sister of Emanuel lives next door, and although she is not able to provide financial support, she provides the household with emotional support and assists with child care and domestic work when necessary. Gloria does some piece work as a labourer and takes responsibility for most of the domestic work and also takes care of their 18-month old granddaughter during the day. Emanuel is unable to work as a result of his illness, but when Gloria works, he takes care of their granddaughter. They have a very loving relationship and say that they take care of each other. They are regularly visited by a local community health worker and also attend a support group meeting at the house of the health worker twice a month.

Case 16: Mandla

Mandla (59) is HIV positive and suffers from swelling of the legs, but the AIDS is under control as he is on ARV treatment. Nonto (49) struggles with stress. She is a diabetic and frequently spends a day in the local public health clinic as she experiences problems controlling her blood sugar levels. She has not been tested for HIV, but intends to get tested. Both their son and his wife died of AIDS-related illnesses in 2002 and 2000 respectively. They already lived with his parents before they passed away and Mandla and Nonto have since then been taking care of their two orphaned granddaughters. Mandla had to stop working in 2003 when he became seriously ill for the first time. Although he is well enough to work since starting ARV treatment in September 2006, he only manages to find occasional odd jobs. Nonto is not working as she also has health problems. Mandla has to collect the ARV treatment once a month from the public hospital for the first six months, after which he will be able to collect the treatment from the public health clinic much closer

to his home. Although the treatment is free of charge, it costs Mandla R70.00 ($10) for a return trip by taxi to the hospital, and with no regular income he struggles to every month to have sufficient money to make the trip. Although Mandla is currently well enough to take care of himself, he is assisted when necessary by his wife and checked on frequently by a community health worker. The community health worker monitors that he takes the medication correctly. Mandla, sometimes accompanied by his wife, attends support group meetings at the house of the health worker twice a month. Mandla has three children from another relationship, but has very little contact with them and cannot rely on them for any care and support.

Case 17: Busi

Busi (58) lives at her homestead with three daughters and eleven grandchildren, seven of them orphans. Three of Busi's children died of TB in 2004, 2005 and 2006 respectively. In 2000 Busi had a stroke which left her partially paralysed on the right side of her body. She frequently experiences pain and also has a problem with her eyesight. When Busi had her stroke, her two eldest daughters who have now both passed away took care of her. Busi and two of her grandchildren suffer from TB, with the four-year old having spent three months in hospital earlier in 2006 because of her TB condition, while the 16-year old granddaughter recently completed her TB treatment. When Busi's children became ill, she had to take care of them and take over the care of their children. Only one of Busi's daughters is working and with the household struggling to access grants, they find it very difficult to cope financially. Busi has three sisters living next door and she can rely on them for emotional support and some assistance with domestic work when necessary, but they also cannot assist the household with money.

Case 18: Sizwe

Sizwe (31) died of AIDS related illnesses in December 2006, just more than a year after she tested positive for HIV and four days before she was due to start ARV treatment literacy training. She lived with her mother aged 54, the head of the household, her 10-year old son, two aunts, three cousins and a three-year old foster child. Sizwe's one aunt is also HIV positive, and unable to work due to AIDS-related illnesses, including shingles. Her aunt will be assessed for ARV treatment readiness in January 2007. Her cousin also lived with them, and Sizwe's mother took care of her cousin until she died of AIDS-related illnesses early in 2006. Sizwe completed secondary school and had a good job, until she became too ill to work four months after she tested positive for HIV. At first Sizwe was able to take care of herself, but three months later, her mother, who was working as a domestic worker, had to give up her job to take care of Sizwe. Since she started taking care of her daughter, her only income comes from selling snacks and cold drinks from her home. Sizwe completed treatment for TB in October 2006, but she remained weak and in need of full time care. In November 2006 they hired a car at the cost of R200 ($28) to take Sizwe to the public hospital so that she could be assessed for ARV treatment. Sizwe's mother went to Sizwe's former employer to ask them for money to take her to the hospital. They gave her R500 ($71), enough to pay for the transport and to buy some food. After assessing her condition and doing the necessary blood tests at the hospital to determine the CD4 count and viral load, she was given a date early in January 2007 to receive training and commence ARV treatment. Towards the end of November 2006 Sizwe's condition deteriorated and she spent a few weeks in hospital. They were still hoping that her health would improve sufficiently for her to start with the ARV treatment in January. In hospital she became agitated and insisted to go home where she passed away a few weeks later.

Sizwe's mother sometimes found it very difficult to take care of her daughter and Sizwe became very impatient with her mother when she did not respond to her needs immediately; yet she did not always cooperate when her mother tried to feed her. During Sizwe's illness, she did not only receive assistance with care from the volunteer health worker living nearby, both Sizwe and her mother also received a lot of emotional support from her. The health worker visited Sizwe every day, sometimes twice a day to assist with her care, including personal hygiene, feeding and treatment of infections with traditional remedies.

Case 19: Nomali

Before Nomali (39), became critically ill she lived with her five children in a house approximately one kilometre from the home of her pensioner parents. At the time, a sister of Nomali and two orphaned nephews lived with her parents. When Nomali fell ill with TB and other AIDS-related illnesses, she could no longer take care of her home and the children, and her 68-year old mother decided that she had to move to their home. Nomali with, the smallest of her two children, twins aged one, went to stay with her parents, while her 30-year old sister went to stay with the other three children at her home (see Figure 6.19). Already before the illness of her mother, Nomali's 19-year old daughter assisted with the care of her younger siblings and domestic work. About one month after my first visit, Nomali's health deteriorated and she became aggressive to the extent that her family could no longer take care of her and she had to be hospitalised. At this time Nomali's mother took the twins back to Nomali's house and spent most of her time there. A few days later Nomali passed away in hospital. When I visited Nomali's house a few weeks after her funeral, her sister was still staying there with the children, while her mother returned to her own house, only helping out at Nomali's house occasionally. Nomali's two oldest children did not return to school after their mother became ill. Nomali's sister will stay with the children at their house as their guardian. The household lives on the childcare grants received for the smallest of Nomali's three children, with some financial support from Nomali's parents, both of whom receive old age pensions.

Case 20: Anna

Until her death Anna (42) lived with her boyfriend and her 21-year old son. She also has a daughter who lives in another town. I saw Anna for the first time at the local public health clinic when she went there to collect her TB medication. The next time I saw her was a few weeks later. She was at her house, a traditional structure in a dilapidated state. By this time her condition had deteriorated and she was very ill and weak as a result of AIDS-related illness, no longer able to take care of herself. Both Anna's boyfriend and her son worked full-time and were thus unable to take care of her during the day. A volunteer health worker visited Anna at her home as often as possible, but because she lived far away, could not go there every day. The health worker asked two neighbours to assist with Anna's care, mainly personal hygiene and feeding, during the day. In the evenings and at night, her boyfriend and son took care of her. The last time I visited Anna before she passed away was less than a month after my first visit to her home. By this time she became agitated and did no longer want to eat. Even though willing, her neighbours could not take care of her anymore as she chased them away when they came to her house. She passed away approximately two weeks after my last visit in November 2006.

Case 21: Rosa

Rosa (40) lives with her boyfriend (35), daughter (22) and baby granddaughter. Rosa also has a son (13) who lives with her mother about two kilometres away. They recently moved into an unfinished house closer to town. The first time I visited Rosa at her home she was very ill with TB and other AIDS-related illnesses, and only returned home recently after spending a few weeks in public hospital. She was still very weak and was coughing and had diarrhoea. As a result of her illness, she was unable to work and take care of herself. At the time her daughter was pregnant and took care of her mother, with the help of a volunteer health worker, during the day. Rosa's boyfriend has a full-time job in Richards Bay, but took care of her in the evening and at night. Rosa started TB treatment and started ARV treatment literacy training shortly after my first visit, and when I visited her a few weeks later her health improved drastically, and she was able to take care of herself and her home and was looking for a job.

Case 22: Petros

Petros (31) lives with his widowed mother (65), the head of the household, two brothers, a sister-in-law, two nieces and a nephew. Also living with them is a twenty year-old orphaned cousin who has been living with them since she was one month old. Thabo's one brother, the only employed member of the household, works in Richards Bay. His mother receives a pension and one of the children gets a childcare grant from government. The home is far from town with only a small public health clinic a few kilometres away where Petros collected his TB medicine every month. Petros is also HIV positive and when I visited him at home the first time he was very ill and weak and had come home from hospital a week before. He is taken care of only by his mother as Zulu culture does not allow a sister-in-law or other distant female relative to take care of a young Zulu man. Shortly after my first visit he started intensive treatment for the TB and his health gradually improved. Petros had to go to the nearby clinic for an injection every day for one month to treat the TB. He had to walk to the clinic most of the time and only occasionally got transport. Petros already lost a brother to AIDS and a sister to TB earlier in 2006. Petos's older brother is also on treatment for TB. Most of the domestic work and childcare is done by Petros's sister-in-law and cousin, allowing his mother to take care of him. When I visited the home of Petros again a few weeks later his condition had improved and he was able to walk with less difficulty to the clinic to receive the injection.

Case 23: James

James (31) has been living on his own, most of the time, since his grandmother, passed away in 2005. James is HIV positive and is seriously ill with TB and other AIDS-related illnesses. He is very weak and walks with great difficulty with the aid of a walking stick. He is on treatment for the TB and takes supplements, and should start ARV treatment, but is too weak to travel to the hospital by means of public transport. Although both his parents and two younger siblings live in the same area, he has little contact with them and receives no financial or emotional support from them and cannot rely on them to take care of him. His younger brother stayed with him for a while after their grandmother passed away, but then moved back to stay with their parents. He has never been to school and is not working, as he is currently too ill with AIDS-related illness to work. James receives a monthly care dependency grant from the government. He occasionally has a friend or relative staying with him to take care of him, but such arrangements usually does not last. When James does not have anybody living with him, his neighbours cook for him and assist with some of the domestic work, such as fetching of wood and water, cleaning and laundry. When I

visited him for the second time he did not have anybody staying with him, with nobody assisting him with personal hygiene, he was living in very poor and unhygienic conditions. Although not completely dependent, he was in desperate need of assistance. He is visited regularly by a community health worker assisting him with personal hygiene, nursing care and domestic work. Although she visits him as frequently as possible, sometimes for more than half a day, he heavily relies on his neighbours for assistance.

The cases show how around every person with AIDS, there is a care arrangement that involves several actors with different roles in the care process. In the cases, all actors pictured in Figure 7.1, except for the market, can be identified. There is a high degree of integrity, partly because often the crucial actor in phase 1 is the same person who takes action in phase 2 and does the actual care-giving in phase 3. Frequently this person is the mother. Integrity is also achieved because 'caring about' (phase 1) does not stop after somebody else takes responsibility or provides the actual care-giving. There is a concern about the situation that is more generally shared. In this way, love and solidarity become binding forces that result in a high degree of integrity of the caring process, confirming Tronto's (1993) point of the moral ethic underlying care. What the cases also show is that it is not only the person with AIDS who needs care but also her or his dependants (children) and the care-giver, who will need (and is given) the assistance and support (financial, physical and emotional) that fall within the broad definition of care.

7.7 Discussion and conclusions

Without social capital – family, friends, neighbours and caring health workers – people with AIDS do not have access to care. Somebody needs to perceive the need for care as well as be motivated to do something about it (Nombo, 2007). This may be problematic, as AIDS is still stigmatised in many areas in South Africa and the afflicted person may be hesitant to reveal the nature of his/her illness and seek help. It is also problematic for potential caregivers such as family members, friends and neighbours, who may be hesitant to become involved in the care process, frequently out of fear of becoming infected with HIV themselves.

Social capital is not only a crucial resource for the patient, but also for the one 'taking care of' and caregivers (Ferlander, 2007). Where the one perceiving the need for care is unable to provide the care-giving him/herself, he or she is still expected to take care of the situation by arranging with family, friends or neighbours to give care. Frequently the health workers are the ones to negotiate for care-giving, when family members are hesitant or patients live on their own, and neighbours are approached for assistance. Caregivers also need social capital, as they often cannot do all the care work themselves and may need assistance with physically demanding tasks, such as moving the patient from the bed to a chair, or need respite care when they need to attend to other business, such as going to town for shopping. Unfortunately the social capital of caregivers often becomes eroded as they are unable to invest time in maintaining their social relations/ties. Because of the time spent on care-giving, they may be unable to participate in community work or they may not go to church as often, weakening their relationships with friends and acquaintances. The social cost of care thus may be so high that a household is unable to recover from the weakening of its social networks (Nombo 2007, Donahue, 2006; Akintola, 2004). Social capital may also serve as an intermediate resource through which one gains access to other resources (bridging resources), such as borrowing money from a former employer to travel to the hospital, as occurred in Case 18.

Although social capital is a crucial resource in all the phases of care, caregivers also need access to a range of other resources to provide quality care, including financial, human and material resources. For the supply of material resources, like rubber gloves, disinfectant soaps, and protective bed covers, community-based health workers act as liaisons between primary caregivers and formal care institutions such as public health clinics or hospitals to access such resources. Caregivers also need financial resources, to cover expenses such as travelling to health facilities or purchasing special foods and supplements. Many caregivers experience economic stress because they had to stop working to take care of patients and incurred loss of income. This is not typical for the situation in KwaZulu-Natal. The Socio-Cultural Planning Bureau in the Netherlands found that many informal caregivers (*mantel-zorgers*) reported that because of their care obligations they could not do paid work and seven percent of them got into financial trouble because of that (SCP, 2003).

The gendered burden of care is reinforced by cultural rules in Zulu culture, such as who is allowed to take care of whom, based on gender and age (Case 22). Married men should be taken care of by their wives or alternatively by their mothers, while single men should be taken care of by their mothers or alternatively by a male member of the family. In general women who are sick should not be seen by men, and can only be taken care of by other women. This pattern was also observed by Hutchings and Buijs (2005) in their research in KwaZulu-Natal. It should though be noted that in our research we found men willing to take care of their female partner. They were not willing or able to stop working to provide care during the day, but they arranged for alternative care for their female partner during the day and engaged in care-giving themselves after hours.

As observed above, to separate 'caring about', 'taking care of' and 'care-giving' proved to be difficult, especially when the same person is the main actor in all three phases. With a condition such as AIDS phases may also overlap, because AIDS is not a specific disease that will take a predictable course. Instead, persons living with AIDS suffer inter-mittently from AIDS-related illnesses and the seriousness of their condition fluctuates. When their condition takes a turn for the worse, somebody has to see that (phase 1) and take responsibility (phase 2) for adjusting the care arrangement, with in some cases hospital care being unavoidable. This implies that the phases in the framework should not be taken as exclusive phases of one unilateral process. The phases are sequential in the sense that they need follow-up, but they also represent analytical dimensions in the caring process.

While close relatives, especially mothers, could take the leading role in phase one to three, the role of community-based health workers was more clearly defined as one of 'taking care of' or arranging care in the absence of relatives or partners. The community-based health worker's role in 'care-giving' is more or less restricted to scheduled home visits with the aim of carrying out specific activities, such as assessing the condition of the patients and supervising the client's taking of medication. It was only where primary care givers were not available during the day or where persons lived on their own that their role extended to other care-giving activities.

It also proved very difficult to separate care-receivers' experience of care-giving from the responses of their caregivers. The interaction between caregivers and care receivers is a dynamic process, comprising a response to the care-giving by the care receiver, based on their experience of the care, followed by a response to that from the caregiver. Neither Tronto (1993) nor Niehof (2004) look into the issue of the caregivers' experience of the care process and the exchange of feedback between caregiver and care receiver. The experience of the caregiver is crucial as it may have implications for further arrangement of care. This is demonstrated by the case of Nomali (Case 19), where the care receiver became so agitated and aggressive that the primary caregiver, her mother, had to call the hospital to send an ambulance to fetch her daughter. In her study on elder care in the Netherlands, Luijkx (2001), who used Tronto's framework as well, also describes situations where care arrangements had to be changed because of changes in the care

situation. Hence, at case-level the care process is not a unilateral sequence of four exclusive phases, but phases may overlap and the whole process may have a cyclical structure that includes feed-back mechanisms.

Through history, carers testified that caring is motivated by love and is experienced as a labour of love. However, sometimes the labour must continue even where the love falters or it is the love which remains, but due to circumstances or a lack of resources the care-giving required exceeds the capability and competence of the caregivers.

Chapter 8

Conclusions and general discussion

This chapter presents conclusions and a general discussion based on research conducted on living and care arrangements in the context of HIV and AIDS amongst non-urban households in Mbonambi. Two sites were selected for data collection: Ward 5, close to town with a high population density and good infrastructure, and Ward 3, further from town with a lower population density and poorer infrastructure. Poor infrastructure includes limited access to public transport and public health facilities, fewer households having access to electricity and some households located far from safe and reliable sources of water.

The chapter consists of three sections. In the first section main findings and general conclusions are presented with regard to each of the research questions phrased in Chapter 1. This is followed by a general discussion on theoretical and methodological considerations in the second section. The last section poses some recommendations for policies, interventions and further research.

8.1 Summary and conclusions

8.1.1 Profile of individuals and households

Question 1: What is the demographic, socio-economic and health profile of households in the research area?

To answer this research question, a survey was conducted and data were collected at the level of the individual and the household. Results of the survey were verified and clarified where necessary by means of focus group discussion.

Demographic profile

The sex-age structure for the research sample, presented in Chapter 5, illustrates that there are fewer individuals in some of the adult age categories compared to the elderly, leading to a skewed distribution. This may be as a result of migration of adults to work in other parts of the province or country, but the survey results are inconclusive. It may also be attributed to premature deaths of adults as a result of AIDS-related illnesses, supported by the results that most of the deaths which occurred in the research were young adults and the majority of them died of AIDS-related illnesses or TB. Deaths of adults in the economically active age group of 15 to 64 years also result in a higher demographic dependency ratio, which in the research area is higher in female- than male-headed households.

The majority of those aged 17 years and younger has never been married although some of them are living with partners. Whereas almost all the married (traditional or civil) men are living with partners, several married women are not living with partners, some of them indicating that the whereabouts of their husbands are unknown. Polygamy is practiced and acceptable to young and old, but very difficult to detect in a survey as some female

partners are not residing at the homestead of the husband. The sample included significantly more females than males who are widowed, probably because men choose to remarry rather than live without a partner.

Female heads of households are older than their male counterparts and usually widowed which is supported by the tradition that a woman becomes the head of the household when her husband passes away, referred to in literature as a *de jure* head. The sample included very few married female heads, whose husbands are working in other parts of the country and who are taking over responsibilities of the absent male head, referred to as *de facto* heads. This sample also included some females, married or unmarried, but living with male partners who are perceived by themselves and household members to be the heads of their households, blurring the traditional distinction between *de facto* and *de jure* headship. It should be noted though that this sample also included several unmarried female heads, not living with male partners, many living with children and grandchildren.

Household size varied greatly, from households consisting of single males and females of different ages, living on their own for varies reasons, to more than twenty persons living at the same homestead sharing resources. Although not significant, the average household size of female-headed households is higher than that of male-headed households. Evident from the higher demographic dependency ratio associated with the female-headed households is that additional household members are often 14 years or younger. The majority of male heads live with partners in two-generation households, while the vast majority of female heads live in three- or four-generation households. Many of the three- and four-generation households include unmarried daughters living with their children and sometimes grandchildren at the homesteads of their mothers. The sample also included a few male- and female-headed skip-generation households where the elderly live without adult children but with grandchildren. Households also frequently include other relatives such as nephews, nieces and distant relatives, and unrelated persons, usually employees. Households may include more than one household unit, usually consisting of married sons with their nuclear families. The occurrence of household units is not related to household size and units vary in their autonomy and may still share some household resources. Household size and composition are important factors when it comes to the capacity of a household to provide care, a matter which will be discussed further in the answer to the last research question.

Socio-economic profile

Very few individuals aged 20 years and older, and significantly fewer females than males completed their secondary school education, yet completion of grade 12 will significantly increase a person's chances of being employed. Although the majority of children aged 19 years and younger are attending school many of them are in grades below that appropriate for their ages. By the age of 20 the majority of those who have not yet completed secondary school drop out with significantly more of those who drop out residing in Ward 5, the research site closer to town. This may be attributed to the attractiveness of potential employment opportunities in town, but there is no evidence in the results to support this statement.

Approximately one third of the individuals aged between 15 and 64 years, with significantly more women than men, are unemployed. Individuals are not working for various reasons, but surprisingly, in the context of HIV and AIDS, very few of them offered illness or caring for an ill person as the reason for not working. The majority of young people between the ages of 15 and 19 are not working because they are attending school. More than half of those who are employed, and significantly more women than men, and individuals residing in Ward 3, are working in low paid elementary occupations or as unskilled labourers, most of them working as farm and forest labourers, and many women

working as domestic workers and street vendors. Very few individuals are engaged in any form of secondary income generation. Very few members of households work in other parts of the province or country, but depending on their financial contribution to the household and frequency of visits to the homestead, migrants may not be perceived as members of the household.

The average income of male-headed households is higher than that of female-headed households and higher for households residing in Ward 5 than Ward 3, with female-headed households in Ward 3 having the lowest incomes. The majority of male- and female-headed households depend for their income on a combination of employment and grants, but significantly more female- than male-headed households, and households residing in Ward 3, rely on grants as the only source of household income. Government social transfers, especially child care grants and old age pensions, contribute significantly to household income. These households are thus characterised by a reversed economic dependency where the economically active age category aged between 15 and 64 depends on economically inactive children and the elderly for their financial security. While good use is made of non-contributory old age pensions, there are still many children who are for various reasons not able to access grants, even though they are eligible for child care grants. Whereas household income is not a criterion for the elderly to access old age pensions, it is one of the criteria for access to child care grants. The general assumption that the grant follows the child is not always true, as illustrated by one of the case studies presented in Chapter 6. Although children should be the main beneficiaries of child care grants, the grants are collected by their mothers or guardians and there is no guarantee that children benefit from these grants. Very few caregivers of orphaned children are able to access foster care grants as they are not always able to supply the documents required from guardians to access these grants. Very few individuals in the research area were accessing care dependency or disability grants.

Female- compared to male-headed households, and households residing in Ward 3 have fewer assets. This can partially be explained by these households having lower household incomes, and therefore, may not be in a position to purchase assets. Household ownership of assets in Ward 3 may also be affected by limited access to electricity, as many of the assets referred to in the study, like televisions, stoves and refrigerators, usually require electricity for their operation. Some assets like mobile phones and cars are owned by individual household members and therefore not accessible to all household members. Very few households own productive assets such as ploughs and sewing machines that can be used to generate income. Assets also vary in their money value and not all assets can necessarily be converted to cash when necessary.

Health profile

As can be expected, health status deteriorates with age. Adults in Ward 3, which is further from public health facilities, were reported to have poorer health status than those in Ward 5. Data on health status may not be accurate for all individuals in the sample considering that interviewees reported on the health status of other household members and perception of health status is subjective. The majority of young adults with poor health status either have TB or AIDS-related infectious diseases, or diseases of the respiratory system some of which may also be TB or HIV/AIDS-related, but have not been diagnosed as such, or individuals are not willing to reveal HIV status due to the stigma associated with HIV as an essentially heterosexually transmitted disease. Good health status does not automatically imply that an individual is not suffering from a chronic illness, as the health status of an individual who is receiving treatment (including ARV treatment for AIDS) may improve significantly over a short period of time.

Key differences between the two research sites

Households in Ward 3 compared to Ward 5:

- Very few have access to electricity, resulting in women spending more time on reproductive work, collecting firewood and cooking on an open fire;
- Slightly more depend on rivers or streams for water;
- Several do not have access to toilet facilities and poor hygiene contributes to the spread of disease;
- The majority of the people lives further than five kilometres from public health facilities resulting in ill people having to cover long distances on foot or spend money on public transport to access health care;
- The majority lives in traditional structures;
- Slightly more have access to land for growing crops and keeping livestock and male-headed households keep more cattle and/or goats and grow more maize;
- People grow more fruit and/or vegetables;
- People have fewer employed members and the majority of those who are employed work as unskilled labourers;
- More young people are attending school, which improves their chances of being employed upon completion of school;
- Heads of households are older and households are bigger;
- Average household income is lower and there is a greater dependency on social grants;
- People have fewer assets that can be converted to cash when necessary and fewer productive assets that can be used to generate income;
- Older adults reported poorer health status and diseases of the respiratory system are the most common amongst children and young adults with poor health status.

Differences in terms of infrastructure and services, such as limited access to electricity, and public transport were expected. It was also expected that households in Ward 3 would have access to more land for agricultural activity, but there is little difference between the two locations. Both locations are characterised by limited utilisation of available land.

Key differences between male- and female-headed households

Almost half of the households are headed by females. Compared to male-headed households,

- Female heads are older, have lower levels of education, are mainly pensioners, and are either widowed or have never been married;
- Female-headed households are bigger and the majority consist of three or four generations;
- Female-headed households have fewer employed household members and are more dependent on social grants;
- Average household income is lower and they own fewer assets;
- Similar in access to land, but utilise land better and grow more fruit and/or vegetables.

Households headed by females, and especially those residing in Ward 3, are more vulnerable to livelihood insecurity.

8.1.2 Household classification in the context of HIV and AIDS

Question 2: How can households in the research area be categorized in relation to the context of HIV and AIDS?

The question addresses AIDS-related illness, deaths attributed to AIDS, and presence of orphans at the level of the household. At the end of Chapter 5, all the surveyed households are categorised based on whether and how they are afflicted and/or affected by HIV and AIDS. Afflicted here refers to the direct impact of the disease through illness or death and affected refers the indirect impact of additional household members or loss of resources. Tuberculosis is used as a proxy indicator for AIDS as the majority of persons with TB are also co-infected with HIV.

Households were allocated to one of four clusters:

Cluster 1 includes just more than half of the surveyed households and these households are neither afflicted nor affected by HIV/AIDS and/or TB. At the time of data collection these households did not have any members who were HIV-positive or diagnosed with TB. These households also did not experience any deaths attributed to AIDS or TB and did not take care of any orphaned children.

Cluster 2 is comprised of households afflicted by HIV/AIDS and/or TB and these households include at least one member who is HIV-positive and/or has TB. These households did though not experience deaths attributed to AIDS or TB and were not taking care of orphaned children.

Cluster 3, the affected households, includes those which experienced the indirect impacts of HIV/AIDS and/or TB; these household experienced at least one death attributed to AIDS or TB and/or are taking care of at least one orphaned child. Death was categorised as an indirect impact as it is perceived as a loss of a resource. These households do not include any members with HIV/AIDS and/or TB.

Cluster 4 includes those households which are both afflicted and affected by HIV and AIDS and/or TB. These households included at least one member who is HIV-positive or has TB, and experienced at least one death attributed to AIDS, and are taking care of at least one orphaned child. Afflicted households include members who are at different stages of the illness (see Table 4.2), and not all of them required nursing care at the time of data collection. Households in all the clusters may include members with other chronic illnesses and may have experienced deaths not attributed to AIDS or TB.

There is no significant difference between the numbers of male- and female-headed households across the clusters and also not between the numbers of households in the two research locations. Almost half of the households in the sample experienced direct or indirect impacts of HIV/AIDS and/or TB. This number will be much higher if other chronic illnesses, such as respiratory diseases commonly associated with AIDS, and premature adult deaths of unknown causes are considered. If these were to be considered as proxy indicators of HIV and AIDS, then more than two-thirds of the households are afflicted and/or affected by HIV and AIDS.

Progression from Cluster 1 to Cluster 4 showed a significant difference in household size, with households in Cluster 4 having on average two more members than households in Cluster 1. Households in Clusters 3 and 4 had significantly more demographic dependents that those in Clusters 1 and 2, while those in Clusters 2 and 4 that are hosting orphans had significantly more effective dependents than the households in the other clusters. Although not significant, households in Clusters 2, 3 and 4 had lower household incomes and fewer assets. Of all the households it is clearly visible that households in Cluster 4, which host ill persons and orphans and experienced deaths, are in all regards worse off than the households in the other clusters. Considering that these

households have more dependents they will be more severely affected by the lower household income that has to be shared by more persons. Having fewer assets also means that they do not have anything they can sell when necessary as a result of illness or death.

8.1.3 Impacts HIV and AIDS on household living arrangements and livelihoods

Question 3: What are the impacts of HIV and AIDS on the living arrangements and livelihoods of households in the research area?

To answer this question, for purposes of comparison, case study households were selected from each of the four clusters described in the previous section. Criteria used to selected household from each cluster included sex of household head, household size and socio-economic status of households. Households were thus deliberately selected to include male- and female-headed, big and small, and poor and better-off households from each cluster. Although findings from the case studies cannot be generalized to the entire sample or the population, it sheds light on how households experiencing varied impacts of HIV and AIDS arrange their lives and generate livelihoods.

Living arrangements

Many of the case study households, regardless of AIDS-related impacts, headship, size and socio-economic status experienced changes in household composition over the approximately six months that they were studied. Reasons for leaving or joining households can be AIDS-related or non-AIDS related. AIDS-related reasons usually involve the seeking or providing of care. When the household does not have the capacity to provide care, ill persons as well as orphaned and vulnerable children may move to other households where there are people who can take care of them. Alternatively, caregivers may move in with the ill persons or orphaned children, or care for them in their own home. These caregivers may be family members or non-related care providers who may or may not be compensated for their care work.

Households neither afflicted nor affected by HIV and AIDS also experience changes in their composition. Young people seeking employment in other parts of the province may leave with or without their children to go and stay elsewhere. Young women who are getting married leave the homestead of their parents, usually with their children, to go and stay at the homestead of the husband or husband-to-be. Children are also very mobile, usually between the homesteads of the mother and the father, when their mothers are not married to the biological father and for that reason not residing at the same homestead. It was evident from the case studies that unmarried daughters with their children often stay at the homestead of their frequently unmarried or widowed mothers in multigenerational households consisting mainly of women. The fluidity or flexibility of the boundaries of these non-urban households is evident from the case studies presented in Chapter 6.

The implications for the livelihoods of households when members leave, regardless of the reason for leaving, will be determined by the sex, age and employment status of the person who is leaving. If it is a young, healthy woman leaving, it translates into an additional domestic work burden for the remaining women. When children leave a household it means less work in terms of childcare. Young women usually join households where they are needed to take care of ill person or orphans and to assist with domestic work. Children moving between households may or may not be followed by the child care grants received by their main caregivers. If they are followed by their grants it can make a significant difference to the household income.

Livelihoods

Adult morbidity and mortality will invariably impact upon the human capital of the household. Not only will the ill adult be unable to do productive or reproductive work, but additional human resources have to be diverted to the care of the ill person(s). Additional orphaned or vulnerable children absorbed in households have similar implications, especially if these children are still very young, as is the case with most of the orphaned children in this study. Older children and more specifically girls, will contribute domestic labour by doing tasks and or taking care of younger children. It is especially the women who experience an increase in their workload as they are traditionally perceived as the natural caregivers. Social capital is eroded by premature adult deaths and other AIDS-related impacts, yet it is crucial for accessing and providing care. This research showed contradictory findings related to the impact of the stigma associated with HIV and AIDS. In one case a person experienced resistance from neighbours as a result of her HIV status. On the other hand, in more than one of the cases, neighbours were taking on the roles of family, providing care and support for HIV-positive neighbours.

This study did not collect detailed data on household expenditure, but detailed data on income and income sources were collected. This showed that there is a significant dependency on social grants as a source of income, in many households the only source of income. Increased demands for care of ill persons and orphaned children increases the effective dependency ratios in households. With ill adults who are unable to work, the dependency on the grants received by the elderly and children has to stretch further. Illness also reduces the income generating potential of the household, as it is often not only ill persons who cannot work, but also care givers who need to leave their employment, resort to low paying part-time employment, or miss out on employment opportunities as a result of the additional care burden. Although treatment and care accessed via the public health care system are usually free, additional costs are incurred for transport. Livelihood diversification is common, with the majority of households deriving income from a variety of sources of formal, informal and part-time employment.

It was already mentioned that households located in some areas, female-headed households and households afflicted and/or affected by HIV and AIDS, own fewer assets. This study did not establish whether households sold assets for reasons related to HIV and AIDS. The majority of households were though not able to buy any new or additional assets at the time when the study was conducted and very few households owned productive assets that could be used to generate income. Many households also did not own any time and human energy saving assets. The vast majority of households own the land they live on, even though many of them stay in informal or traditional and less durable structures. Although there is little evidence of distress sales of assets and of property or asset grabbing, there are opportunists trying to benefit from the limited resources owned or assistance given to orphaned children.

Although there is very little agricultural activity in the research area, this could not be attributed to HIV and AIDS. Some of the women who are caring for ill relatives and/or orphaned children did though indicate that they are neglecting their vegetable gardens due to time restrictions. It should though be noted that many households still make use of firewood for cooking and that some households also have to collect water from communal water sources or rivers far from their homesteads, which again increases the reproductive work burden of women and girls.

8.1.4 Arrangement of care

Question 4: How do households in the research area arrange and provide care for people living with AIDS and for orphans and vulnerable children?

This question was addressed by interviewing and observing home- and community-based caregivers. There is a variety of care providers in the formal and informal sector involved in caring for people living with AIDS. People living with AIDS seek treatment, care and support in all the sectors at different times. There is a variety of care providers in the formal and informal sector involved in caring for people living with AIDS. The informal sector here refers to home- and community-based care givers, consisting of household or family members, extended family, neighbours and volunteer and paid community health care workers. The formal sector provides in-patient and out-patient care at hospitals and clinics in the private and public sector. In this non-urban area very few people can afford to access care in the private sector or market and the majority therefore has to access treatment and care through the public health care system, with the clinic usually the first facility they will visit.

Care is both emotional, a feeling or caring about someone, and instrumental, as it involves certain activities. Four phases of care and the requirements associated with each can be identified; namely 'caring about' – requiring attentiveness, 'taking care of' – requiring taking responsibility, 'care-giving' – requiring competence to carry out certain activities, and 'care-receiving' – requiring responsiveness to the experience of the care receiver. All these phase should be linked into a well-integrated care process which requires integrity. It frequently involves different people during different phases, such as mother perceiving the need for care (caring about) and arranging the care (taking care of), but then a daughter may be responsible for the care work (care-giving) and one or both of them receiving the positive or negative feedback (care-receiving) from the care receiver.

Social capital is essential for accessing care, even more so in a non-urban community where the majority of people are too poor to access care in the market place. Different types of social capital can be linked to the different phases of care. Bonding social capital or strong ties with close family or friends are necessary for 'caring about', or noticing that care is needed. From the case studies it is evident that the need for care is usually perceived by a family/household member, close friend or neighbour in regular contact with the person requiring the care. 'Taking care of' requires bridging and linking social capital, or people who can arrange for care to be provided, which does not necessarily require strong close ties. Although care in the majority of cases studies are arranged by family/household members, it may also be arranged by a person not known to the person in need of care, such as a clinic sister or community health worker. 'Care-giving' again requires bonding capital or strong ties, especially to provide home-based care and in the majority of cases it is provided by mothers or daughters of the person requiring care. 'Care-receiving' or the care-receivers response to the care will depend on the relationship between the care-giver and care-receiver and thus the strength of the ties. For the all the phases to form an integrated whole, all forms of social capital are required. In the more advanced stages of the illness, more and stronger ties are required to provide adequate quality care.

People living with HIV and AIDS seek treatment, care and support in all the sectors depending on the stage of illness. Many HIV and AIDS-related services, such as testing and counselling are provided by clinics, usually the first port of call for poor people in rural areas. Although public health clinics are within easy reach of many people, the majority of households in the non-urban research area lives more than three kilometres from the nearest facility. To access ARV treatment, people with AIDS who qualify for treatment based on

clinical testing, have to complete treatment literacy training and collect treatment at a public hospital for the first six months, after which they can collect the treatment from selected clinics. Although treatment is available free of charge, many people are too ill to attend the training and/or they cannot afford to pay for transport to take them to the hospital, or they are too ill to make use of public transport, and therefore are unable to access treatment. People who are HIV positive or have AIDS often use a combination of food supplements and traditional herbal remedies to try to maintain their health.

Home- and community-based care is seen as a cheaper and more acceptable alternative to institutional care and although this may seem ideal, there comes a point when household members and even community health care workers are unable to take care of a person in the advanced stages of the illness (see Table 4.2) and when they need professional care. From the case studies presented in Chapter 7, it is evident that at some stage the care provided at home is not adequate and people need to be hospitalised. Some of them pass away in hospital without returning home, while some return home after they recover slightly, where some then pass away. The one system can thus not function without the other. The formal sector cannot meet the increased demand for care brought about by AIDS, but households do not always have the capacity to provide adequate care. Home-based care usually requires intra- or inter-household reallocation of labour, which may also necessitate the moving of the ill person to another household.

Women are not only the main providers of care, but also the decision-makers when it comes to arranging care. It is usually the older women, even in male-headed households, who will take decisions related to care, even if they will not provide the care themselves. Younger women are usually expected to care for ill persons, while girls may be expected to take care of younger siblings. Care is also guided by deeply entrenched cultural norms. In the case of men requiring care, it will usually be provided by the mother or the wife of the ill person, as is customary in Zulu culture. Although men are willing to care for female partners, they are only willing to do this after hours, as they are less likely to give up employment and stay at home to provide care. The men in this study took on the role of secondary caregivers, thus providing care when there is no female available to do so.

The majority of orphaned children in the sample are living with grandparents in three- or skip-generation households. The majority of them were already living at the homesteads of their grandparents, many of them with single mothers, before their mothers/parents passed away. The sample only included one child-headed household and one household where a caregiver is employed to take care of two orphaned children, at what used to be, the homestead of their deceased parents. The two boys staying on their own chose to do so, even though they had the option to go and stay with their grandparents as their sisters did. The eldest of the boys decided to stay at his late parents place to retain the property and his younger brother decided to stay with him. Living arrangements of orphaned children will be determined by the ages of the children and the capacity of household to provide care. Institutional care will be a last resort as cultural norms dictate that extended family should take care of children when parents pass away. Vulnerable children may be sent to live with family when single mothers feel that they are no longer able to adequately care for children. Relatives may also offer to take in vulnerable children as a way of helping ill persons.

In the research area paid and volunteer community-based health workers play an important role in the arrangement and provision of care for people living with HIV and AIDS as well as for orphans and vulnerable children. Their role in care is not restricted to the second phase, namely to ‘take care of’ or to arrange care. Health workers may perceive the need for care, for example where people live on their own, and then make arrangements with neighbours to provide care, but the majority of them will also be involved in the care-giving, whether it is by providing nursing care, and/or assisting with domestic work. Apart from often taking on the role of care ‘brokers’, they can also perceive if care provided is

adequate from the perspective of the care receiver. If care is inadequate, or not of good quality, they can assist care-givers, through skills training and/or provision of the necessary material resources to improve the quality and adequacy of care. The community-based health workers thus play an important role in the integration of the phases of care to form a whole. In addition to their role in the arrangement and provision of care, they also play an important role in educating people about HIV and AIDS, providing emotional support to people living with HIV and AIDS and orphaned and vulnerable children, and reducing the stigma associated with the illness. They also have an important liaison function between the individual and the household, as well as between the individual, household and formal care sector.

It should be emphasised that care for people with AIDS involves a range of nursing care and domestic activities and requires the mobilisation of a variety of human, material and financial resources. This often requires intra- or inter-household reallocation of work and resources where home- and community-based care givers work together to arrange and provide adequate care of good quality. People often utilise a combination of formal and informal care and combine western and traditional care and treatment practices. Although home-based care is a good alternative to institutional care, there comes a time when the family/household does not have the capacity to provide adequate care. Care is also an emotional burden, as the same strong ties that compel family members to take care of ill loved ones, make it difficult to provide care because of the close relationship

8.2 Theoretical and methodological considerations

8.2.1 Theoretical considerations

Household, homestead and living arrangements

In the 1990's many authors deliberated on the meaning of households and household headship. The universal definition of the household as group of people, related and/or non-related, living together and sharing certain resources is still relevant for most countries and in urban and rural areas, and as a unit of analysis. This research also used the concept 'homestead', in this context, referring to the setting, or place where the group of people live together. Preference was given to the term homestead rather than 'house' or 'home' as homesteads in non-urban areas usually consist of several living units rather than just one house. Regardless of whether the homestead consist of one or several living units and several family units, there will be one overall head.

This research also used the concept 'living arrangements' to emphasise the dynamic nature of the household with its fluid or flexible boundaries where people of different ages frequently move in and out for various AIDS-related and non-AIDS related reasons. The concept is used here to illustrate the dynamic nature of the household over time in contrast to the more static perception of household composition at a point in time. Although the concept has been used by several researchers in similar studies, it was frequently not clearly defined. In the context of HIV and AIDS many of these studies focus on the living arrangements of the elderly (Hosegood and Timaeus, 2006; Merli and Palloni, 2006; Madhavan and Schatz, 2007; Schatz, 2007; Zimmer, 2009) and of orphaned children (Madhavan, 2004; Ford and Hosegood, 2005; Heymann et al., 2007; Kuo and Operario, 2010). More general studies on living arrangements include Hosegood et al. (2004). It is hoped that this research can contribute to a theoretical discussion and better understanding of this concept and its use in research of the living arrangements of households in the context of AIDS and not only limited to the elderly and orphaned children.

Although the majority of children in the case study households manage to stay in school, as also found by Kakuru (2006), they are absent from school more often due to

HIV/AIDS-related morbidity and mortality. As a result they fall behind. All children aged 10 and older in the case study households were in grades below those appropriate for their respective ages. These children are at risk of eventually dropping out of school. Some children choose to stay at the homestead of their late parents, with or without adult supervision, rather than moving in with grandparents or other relatives. They do so in an attempt to retain the homestead and the land they inherited from their parents. But, this may make children vulnerable to exploitation. Child migration as a strategy to cope with HIV/AIDS-related morbidity, as described by Ansell and Van Blerk (2004) and Ansell and Young (2004), was employed by some of the households. Although migration in search of employment has long been common in Southern Africa, migration of ill persons and children seeking care is a much more recent phenomenon (Young and Ansell, 2003).

Afflicted and/or affected by HIV and AIDS

This study categorised households based on whether and how they are afflicted and or affected by HIV and AIDS for study of the impacts of HIV and AIDS on the households (cf. Barnett and Blaikie, 1992). Although it was probably never the intention of Barnett and Blaikie for their description of households in this manner to be used as a basis for categorisation in research, it proved to be a useful categorisation for studying the different impacts of HIV and AIDS on households. Wiegers (2008) also disaggregated households by sex and age of head and by whether households are caring for ill persons or orphans. Nombo (2007) and Karuhanga (2008) only classified households as affected and non-affected. From this study it is clear that impacts are more pronounced in households that experienced all the direct and indirect impacts of HIV and AIDS, including illness, death and orphans. However, one should not forget that other chronic illnesses and deaths that cannot be attributes to AIDS may have similar impacts on households, especially where illness and death occur amongst the economically active household members.

Phases of care

The four phases of care identified by Tronto (1993) have used previously by Luijkx (2001) and Keasberry (2002) in the assessment of elder care, respectively in the Netherlands and Indonesia. Since then Niehof (2004) applied the model phases to the results of a study on home-based care for people living with AIDS in Zimbabwe and formulated the micro-ecological approach to health, which incorporates Tronto's four phases. In this study, Tronto's framework was successfully used to illustrate the roles that different actors in the formal and informal care sector play during the different phases of care, linking the phases of care to the type(s) of social capital required during each phase, as well as – though to a lesser extent – to the stage of the illness. More recent references to Tronto's phases of care in the context of HIV and AIDS include Razavi (2007) and Makoae and Jubber (2008) referring extensively to gender and care, and Evans and Thomas (2009) and Mindry (2010) referring to family care giving.

When studying care using Tronto's framework, it not only brings out clearly the burden of care brought about by AIDS-related illness, but also illustrates that care at the household and community level is still mainly done by women. The gendered nature of care and the heavy reliance on women's unpaid care work is highlighted by Makina (2009), who studies family care in Zimbabwe. Makina also claims that the additional burden of care has the effect of impoverishing women and reinforcing gender stereotypes. However, there are examples of men's involvement in the provision of care for maternal orphans (Hosegood and Madhavan, 2010).

The cases discussed clearly reveal that women are still the main providers of health- and childcare. When the demand on their time to provide care increases, they have less time to devote to income generating and community activities, which means less time to invest in social networks (Ogden et al., 2006). Research in Tanzania has shown that at some point deteriorating material resources and dwindling social capital reinforce one another (Nombo and Niehof, 2008). This will cause already poor households with weak safety nets 'to fall through' the vulnerability threshold (Donahue et al., 2001; Donahue, 2006). All case households reveal the significance of social capital, the network of kin in particular, as a source of material and immaterial support. Relatives may take in a child to relieve the household's burden, may send money, or may provide emotional and practical support. When there are no relatives living nearby, the neighbours provide the latter kind of support. At the same time, the cases also show 'missing' partners and parents who have opted out and whose whereabouts are sometimes not even known.

Micro-ecological approach to home care

Niehof (2004) studies care from the perspective of the household, where care also for people with AIDS is produced and consumed in the household. To provide care, social capital and resources that are not always available in the household need to be mobilised. The link between social capital and care is highlighted in this study and was also investigated by Nombo (2007). The household as the first line or provider of care should always be seen as embedded in a meso- and macro-environment as illustrated in the conceptual framework (see Figure 2.3) which guided this study. In this study, the meso-environment study includes the community health care workers who play an extremely important role in the arrangement, provision and integration of care in the research area. The macro-environment, which includes the private and public health care services as well as the policies guiding their services, is equally important as households and community health care workers reach a point where they rely on treatment, care and support provided by this environment. Using the household as the unit of analysis when assessing home- and community-based arrangement and provision of care is essential. But it is also important to look beyond the boundaries of the household at inter-household arrangement and provision of care, as illustrated by two cases in this study.

8.2.2 Methodological considerations

For various reasons HIV/AIDS research is methodologically complex (Wiegers, 2008). A major problem is identifying HIV/AIDS impacts as distinct from other factors that impinge on rural livelihoods. This problem of 'inadequate impact attribution' (Murphy et al., 2005: 270) is particularly urgent in cross-sectional surveys that use proxy indicators for HIV-infection and where control households are lacking. HIV/AIDS research is dominated by the use of survey methods and quantitative data collection. Reviewing 36 impact studies Booysen and Arntz (2003) only found 11 that also used qualitative methods of data collection, such as focus groups and in-depth-interviews. Since then several qualitative studies on the socio-economic, socio-cultural and psychosocial impact of AIDS on the living and care arrangements of individuals and households have been conducted (Young and Ansell, 2003; Russell, 2004; Knodel, 2005; Mongomery et al., 2006; Hosegood et al., 2007; Swaans et al., 2008; Ardington et al., 2009; Hosegood, 2009).

Research approaches

In South Africa there are two major longitudinal research projects studying the demographic and socio-economic impacts over an extended period of time. Both these projects have been running for more than ten years and both illustrate the range of impacts on households over time (cf. Hosegood et al., 2007; Madhavan and Schatz, 2007). Impact needs to be studied over time , given that the full impact of the epidemic is not yet visible at all levels of society. This research illustrates though, that impacts on household living arrangements and livelihoods can be already seen in a relatively short period of time (six months).

In addition to this it is essential to combine quantitative and qualitative approaches to get a better understanding and clearer picture of household living and care arrangements and livelihood generations. This study provides and illustration of a combination of the two approaches and how they complement each other. In addition to this it is important to get the insider's view when studying the impacts of HIV and AIDS on living and care arrangements and livelihoods (Niehof and Price, 2008).

Ethics

Studying the care of ill persons is very personal, and easily invades the privacy, not only of the care receiver, but also of the caregivers, who are sometimes unsure of themselves. Observation of this nature should thus be done with great sensitivity and empathy. In this study, the observation of nursing care activities was therefore limited to only a few cases. The selection of these cases was also biased, as this kind of observation could only be done in cases where the researcher managed to establish a relationship with both caregivers and care receivers. Many decisions relating to their care are taken out of the hands of persons with AIDS.

8.3 Recommendations

8.3.1 Recommendations for policies and interventions

Treatment, care and support

Although the South African Department of Health (DOH, 2010) adopted the guidelines of the World Health Organisation (WHO, 2010) to start antiretroviral treatment at an earlier stage, implementation of this will be very difficult as there is still a backlog of individuals qualifying for treatment based on previous guidelines who are not yet receiving treatment. Adherence to ARV treatment is extremely important, hence the treatment literacy training before commencement of treatment. If people are to adhere to treatment, then providing treatment free of charge is still not sufficient, as the poorest of the poor still incur transport cost to collect treatment. Taking the treatment to the people will make it possible for more people living with AIDS to access ARV treatment in time. It will also contribute to reducing the travel cost for individuals. In addition to this it can be beneficial to allow the primary caregivers to collect treatment on behalf of the ill person.

Regulation and remuneration of community-based care as provided by community health workers is important and the development of the draft policy framework (DOH/DSD, 2009) is a step in the right direction. The reliance on unpaid care mainly provided by women may reinforce gender stereotypes viewing women as natural carers. Care and support should also be provided to family/household caregivers.

8.3.2 Recommendations for further research

Further research can be conducted in the same research area with the same case study households which will enable studying impacts over a longer period of time. This study can also be expanded to research the impacts of HIV and AIDS on food security. This research illustrates that household living arrangements are dynamic and that there may be emerging new types of households, or it may be history repeating itself (Preston-Whyte, 1978). This points at the importance of the study of household formation and life cycles of households, also in relation to development issues. Chazan (2008) identified several assumptions, including that grandmothers may still be doing what they have always been doing, namely care for their families, that skip-generation households are a common new type of household, and that grandmothers are old, frail pensioners. These assumptions, valid or not, warrant testing through research.

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Appendix

Household Survey 2006 C du Preez
Questionnaire number:

HOUSEHOLD SURVEY 2006

NAME OF INTERVIEWER: _____ **DATE OF INTERVIEW:** DD \ MM \ **2006**

NAME OF FIELD ASSISTANT: _____

INTRODUCTION

Good day, my name is … . I am part of a team conducting a survey on behalf of Ms CJ du Preez, a lecturer in the Department of Consumer Sciences (home economics) at the University of Zululand. Ms Du Preez is conducting research in the Mbonambi local municipality in the Uthungulu district. The aim of the research is to collect information from household members, to get a better understanding of the needs and current living conditions of your area.

Many households in Mbonambi will be surveyed and a report compiled. The report will be prepared in such a manner that the information you supply cannot be traced back to you. Confidentiality is guaranteed. The report will also be made public so that you, and the authorities working in this area, can see what the results of the survey are.

My job is to complete this survey by asking the questions to the head of the household or an adult member of the household. Your assistance will be appreciated.

If you require any information or explanations, please feel free to contact:
Ms C du Preez at the University of Zululand on 035-9026378

SECTION 1 GENERAL INFORMATION (FOR THE INTERVIEWER, RECORD ADDITIONAL INFORMATION PROVIDED ON THE BACK)

001 Household ID (number to be entered by researcher)			**Questionnaire number**			
Respondent						
02	**Respondent details** (preferably 18 years or older, permanently residing at homestead)		***Number**			
	Name (first name and surname)					
	Contact telephone number					
03	**Alternate Respondent** (If first respondent cannot complete the interview or answer all the questions)		***Number**			
	Name (first name and surname)					
	Contact telephone number					
04	**Alternate Respondent** (If second respondent cannot complete the interview or answer all the questions)		***Number**			
	Name (first name and surname)					
	Contact telephone number					

(Ensure that other respondent details, such as gender, age, relation to head appears on the household roster!)
*** Number, enter number from household roster after completion of roster.**

005 Geocoding information (to be completed by researcher)			
Latitude	N/S	Degrees	Decimal degrees
Longitude	E/W	Degrees	Decimal degrees
Waypoint	Centre of gravity of cluster	In front of the household	Nearby location, reference point

	Location of household (you can ask the field assistant for this information)	
006	Ward/subward number	
007	Name of area/settlement	
008	Name of Induna (headman)	
009	EA number(s)	

	Household size and headship		
010	**How many people in total reside at this homestead?** (cross check with number of names on household roster after completion of roster)		
011	**Is there more than one household unit at this homestead**	Yes	No
012	**If yes, how many** (indicate actual number of units)		
013	**Main or only household unit A/homestead**	**Number***	
	Name of head of homestead		
	Gender		
	Age		
014	**Household unit B** (not applicable if only one hh unit at homestead)	**Number***	
	Name of head		
015	**Household unit C** (not applicable if only one hh unit at homestead)	**Number***	
	Name of head		
016	**Household unit D** (not applicable if only one hh unit at homestead)	**Number***	
	Name of head		
017	**Household unit E** (not applicable if only one hh unit at homestead)	**Number***	
	Name of head		

*** Number, enter number from household roster after completion of roster.**

018 To which church does the head of the homestead belong? (faith religion subscribed to)			
Anglican (Church of the province of SA)	01	Rhema Bible Church	111
Apostolic Faith Mission of SA	02	Roman Catholic	112
Baptist Church	03	Seventh Day Adventist Church	113
Full Gospel Church of God in SA	04	Nazareth	114
Reformed Churches of SA	05	Traditional African Belief	115
Hindu	06	Zion Christian Church	116
Jehovah's Witness	07	None	117
Lutheran Church	08	Don't know	118
Methodist Church	09	Refused	119
Presbyterian Church	110	Other (specify):	220

019 Did anybody (other than babies born) join your household in the last year?

Yes	1
No	2

020 If yes, who and why. (can give more than one name) If more than three, write at bottom or on back of page)		
NAME	**REASON**	***Number**

SECTION 2 DEMOGRAPHIC AND SOCIO-ECONOMIC INFORMATION

100 HOUSEHOLD STRUCTURE (Include all people considered by the respondent to be members of the households, residing at the homestead most of the time, this may include “absent” members or migrant workers who are not there on the day of interview, but otherwise or occasionally stay (eat and sleep) there. Include names of heads and respondents.)

Member number	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
101 Household members, first and last name (write sideways, one name per column, if more than 15 members, use additional sheet, from here onwards every column represents a member with the same column used for that member throughout the questionnaire) — Surname															
Clearly mark orphaned children residing in the household using a * — First name															
102 Gender 1 Male 2 Female	□ 1 □ 2	□ 1 □ 2	□ 1 □ 2	□ 1 □ 2	□ 1 □ 2	□ 1 □ 2	□ 1 □ 2	□ 1 □ 2	□ 1 □ 2	□ 1 □ 2	□ 1 □ 2	□ 1 □ 2	□ 1 □ 2	□ 1 □ 2	□ 1 □ 2
103 Age (actual age in years at time of interview, or year of birth, children below one year use 0)															
104 Relation to head of household (mark appropriate block in column)															
1 head (of homestead) 2 spouse (wife/husband) 3 child 4 son/daughter-in-law 5 grandchild 6 sibling (brother/sister) 7 parent 8 grandparent 9 parent-in-law 10 brother/sister-in-law 11 nephew/niece 12 other relative	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □10 □11 □12	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □10 □11 □12	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □10 □11 □12	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □10 □11 □12	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □10 □11 □12	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □10 □11 □12	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □10 □11 □12	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □10 □11 □12	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □10 □11 □12	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □10 □11 □12	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □10 □11 □12	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □10 □11 □12	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □10 □11 □12	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □10 □11 □12	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □10 □11 □12

13 non-related person	□13	□13	□13	□13	□13	□13	□13	□13	□13	□13	□13	□13	□13	□13	□13
Member number	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
105 Marital status (you may read options)															
1 Married	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1
2 Living together	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2
3 Widowed	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3
4 Divorced/separated/deserted	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4
5 Never married	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5
6 Not applicable (use for children under 18)	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6
200 EDUCATION															
201 Highest level successfully completed (aged 6 and older)															
1 Never to school/no formal school	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1
2 Less than one year	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2
3 Grade 1/Sub A	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3
4 Grade 2/Sub B	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4
5 Grade 3/Std 1	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5
6 Grade 4/Std 2	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6
7 Grade 5/Std 3	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7
8 Grade 6/Std 4	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8
9 Grade 7/Std 5	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9
10 Grade 8/Std 6	□10	□10	□10	□10	□10	□10	□10	□10	□10	□10	□10	□10	□10	□10	□10
11 Grade 9/Std 7	□11	□11	□11	□11	□11	□11	□11	□11	□11	□11	□11	□11	□11	□11	□11
12 Grade 10/Std 8	□12	□12	□12	□12	□12	□12	□12	□12	□12	□12	□12	□12	□12	□12	□12
13 Grade 11/Std 9	□13	□13	□13	□13	□13	□13	□13	□13	□13	□13	□13	□13	□13	□13	□13
14 Grade 12/Std 10	□14	□14	□14	□14	□14	□14	□14	□14	□14	□14	□14	□14	□14	□14	□14
15 Grade 12/Std 10 + Certificate	□15	□15	□15	□15	□15	□15	□15	□15	□15	□15	□15	□15	□15	□15	□15
16 Grade 12/Std 10 + Diploma	□16	□16	□16	□16	□16	□16	□16	□16	□16	□16	□16	□16	□16	□16	□16
17 Bachelor Degree	□17	□17	□17	□17	□17	□17	□17	□17	□17	□17	□17	□17	□17	□17	□17
18 Honours degree and/or post grad diploma	□18	□18	□18	□18	□18	□18	□18	□18	□18	□18	□18	□18	□18	□18	□18
19 Higher degree (Masters or Doctorate)	□19	□19	□19	□19	□19	□19	□19	□19	□19	□19	□19	□19	□19	□19	□19
20 Don't know	□20	□20	□20	□20	□20	□20	□20	□20	□20	□20	□20	□20	□20	□20	□20
21 Refused	□21	□21	□21	□21	□21	□21	□21	□21	□21	□21	□21	□21	□21	□21	□21
22 Not applicable (for children below 6)	□22	□22	□22	□22	□22	□22	□22	□22	□22	□22	□22	□22	□22	□22	□22
202 Currently attending school or other education institution (read options) (Ask for members aged 6 to 25)															
1 full time	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1
2 part-time	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2
3 not at school/other institution (see Q203)	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3
4 Don't know	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4
5 Refused	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5
6 Not applicable (below 6/older than 25)	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6

Member number	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
203 If not in school/other institution, what is he/she doing? (Ask for members aged 6 to 25, where answer Option 3 was chosen in previous question)															
1 working for money	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1
2 looking for work	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2
3 pregnant/caring for own child	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3
4 sick/injured	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4
5 disabled	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5
6 caring for children of other hh member	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6
7 caring for sick/injured	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7
8 nothing (not looking for work)	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8
9 Other, specify:	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9
10 Don't know	□10	□10	□10	□10	□10	□10	□10	□10	□10	□10	□10	□10	□10	□10	□10
11 Refused	□11	□11	□11	□11	□11	□11	□11	□11	□11	□11	□11	□11	□11	□11	□11
12 Not applicable (in school)	□12	□12	□12	□12	□12	□12	□12	□12	□12	□12	□12	□12	□12	□12	□12

300 EMPLOYMENT (Ask for all members 15 years and older)															
301 Does he/she do anything to earn money? (Include any fulltime/ part-time, formal and informal activities to earn money)															
1 Yes (see Q303)	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1
2 No (see Q302)	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2
3 Don't know	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3
4 Refused	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4
5 Not applicable (for children younger than 15)	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5
302 Reason for not working (where answer to Q301 was no)															
1 Attending school/other institution	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1
2 Unemployed	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2
3 Homemaker	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3
4 Sick/injured	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4
5 Diabled	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5
6 Pensioner	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6
7 Caring for sick/injured	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7
8 Other, specify	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8
9 Don't know	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9

10 Refused 11 Not applicable	□10 □11	□10 □11	□10 □11	□10 □11	□10 □11	□10 □11	□10 □11	□10 □11	□10 □11	□10 □11	□10 □11	□10 □11	□10 □11	□10 □11	□10 □11
Member number	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
303 Nature of employment (where answer to Q301 was yes)															
1 work for one employer 2 work for more than one employer 3 work for themselves 4 work for another hh member 5 do odd jobs/piece jobs 6 Don't know 7 Refused 8 Not applicable	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8
304 Main occupation [Indicate actual main occupation (formal employment and self employment) of each working member of the household, use more than one word to describe occupation if necessary, write sideways]															
305 Indicate amount received in Rand per month from main occupation.															
306 Employment category (main occupation) (to be completed by researcher) Self employed Professional/semi-professional and tech Clerical and sales worker Managerial/executive and admin Transport and communication Service worker	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6

Farmer and farm worker Tradesman and apprentice Production foreman and supervisor	□ 7 □ 8 □ 9	□ 7 □ 8 □ 9	□ 7 □ 8 □ 9	□ 7 □ 8 □ 9	□ 7 □ 8 □ 9	□ 7 □ 8 □ 9	□ 7 □ 8 □ 9	□ 7 □ 8 □ 9	□ 7 □ 8 □ 9	□ 7 □ 8 □ 9	□ 7 □ 8 □ 9	□ 7 □ 8 □ 9	□ 7 □ 8 □ 9	□ 7 □ 8 □ 9	□ 7 □ 8 □ 9
Member number	**01**	**02**	**03**	**04**	**05**	**06**	**07**	**08**	**09**	**10**	**11**	**12**	**13**	**14**	**15**
307 Place of employment (main occupation) 1. Richards Bay 2. Empangeni 3. KwaMbonambi 4. Other part of KZN 5. Other part of country	□ 1 □ 2 □ 3 □ 4 □ 5	□ 1 □ 2 □ 3 □ 4 □ 5	□ 1 □ 2 □ 3 □ 4 □ 5	□ 1 □ 2 □ 3 □ 4 □ 5	□ 1 □ 2 □ 3 □ 4 □ 5	□ 1 □ 2 □ 3 □ 4 □ 5	□ 1 □ 2 □ 3 □ 4 □ 5	□ 1 □ 2 □ 3 □ 4 □ 5	□ 1 □ 2 □ 3 □ 4 □ 5	□ 1 □ 2 □ 3 □ 4 □ 5	□ 1 □ 2 □ 3 □ 4 □ 5	□ 1 □ 2 □ 3 □ 4 □ 5	□ 1 □ 2 □ 3 □ 4 □ 5	□ 1 □ 2 □ 3 □ 4 □ 5	□ 1 □ 2 □ 3 □ 4 □ 5
308 Secondary economic activity (Indicate other income generating, informal economic and employment activities, use more than one word to describe activity, write sideways)															
309 Indicate amount received in Rand per month from secondary activity.															
310 Any other income generating activities not mentioned earlier															
311 Indicate amount received in Rand per month from other activity.															

400 Income and Assets															
Member number	**01**	**02**	**03**	**04**	**05**	**06**	**07**	**08**	**09**	**10**	**11**	**12**	**13**	**14**	**15**
401 Does any member of the household receive any of the following social grants? 1. Old age pension (R820) 2. Disability grant (R820) 3. Child support grant (R190) 4. Care dependency grant (R820) 5. Foster care grant (R590) 6. Other, specify 7. Don't know 8. Refused	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8
402 Does any member of the household receive a monthly pension, grant or remittance from another source? 1. Yes 2. No 3. don't know 4. refused	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4
403 If yes, indicate name/nature of source (Can be the name of a person, the name of an organisation, or just indicate that it is from eg. A relative/friend, etc.)															
404 Indicate amount received in Rand per month from each source.															

405 Total Monthly Household Income (combined total money income of all individuals in the household) mark only one category)

Income category	Code	calculated
R0-600	1	
R601 to 1500	2	
R1501 to 2500	3	
R2501 to 3500	4	
R3501 to 5000	5	
R5001 to 7500	6	
R7,501 to 10,000	7	
R10,001 to 12,000	8	
R12,001 to 18,000	9	
R18,001+	10	

406 Does this household have any of the following?

ASSET/EQUIPMENT	YES	NO
Car/bakkie	1	2
Tractor	1	2
Telephone (TELKOM)	1	2
Cell phone (at least one at homestead)	1	2
Television	1	2
Radio	1	2
Hi-fi/music centre	1	2
Computer	1	2
Electric cooking appliances - stove	1	2
Electric cleaning appliances – vacuum cleaner/polisher	1	2
Fridge/ freezer	1	2
Piped hot water	1	2
Sewing machine	1	2
Plough	1	2
Wheelbarrow	1	2

407 Does the homestead (land and buildings) belong to the household?

Yes	1
No	2

408 If no, who does it belong to?

_____

409 The main building material used for the residence/structures where people live. (Mark only one)

BUILDING MATERIAL	CODE
Bricks/concrete blocks	1
Wood	2
Corrugated iron	3
Wood and mud (traditional)	4
Asbestos	5
Plastic	6
Other (specify):	7

410 Do you have access to land for agriculture?

AGRICULTURAL ACTIVITY	YES	NO
1. Crop production	1	2

2. Grazing for livestock	1	2

411 If yes to 1, what crops do you grow?

_____

412 If yes to 2, what livestock do you keep?

_____

413 Do you grow any fruit or vegetables at the homestead?

HORTICULTURAL ACTIVITY	YES	NO
1. Fruit	1	2
2. Vegetables	1	2

414 If yes to 1, what fruits do you grow?

_____

415 If yes to 2, what vegetables do you grow?

_____

416 Is any member of the household involved in a community garden?

Yes	1
No	2

417 If yes, who is involved and in which community garden/where is the community garden?

WHO	GARDEN

418 Is any member of the household involved in a community project?

Yes	1
No	2

419 If yes, who is involved and in which community project?

WHO	PROJECT

500 SERVICES AND INFRASTRUCTURE

501 What is the main source of water for this homestead? (Mark One Only)

MAIN WATER SOURCE	CODE
Piped water in dwelling	1
Piped water in yard	2
Piped water, public tap	3

Borehole	4
River/ stream/ well	5
Protected spring	6
Other (specify): (e.g. water kiosk, tanker, from nearby house):	7

What type of sanitation (toilet facility) is available on the site of this homestead? (Mark One Only)

TYPE OF SANITATION	CODE
Full waterborne flush toilet (off-site disposal)	1
Septic tank (on-site disposal)	2
Ventilated Improved Pit Latrine (VIP)	3
Basic Pit Latrine	4
Chemical Toilet	5
No facility	6
Other (Specify):	7

503 Do you have access to electricity at this homestead?

Yes	1
No	2

504 What energy source is mostly used at this homestead for cooking? (Mark only one)

ENERGY SOURCE FOR COOKING	CODE
Electricity (Eskom or Local Authority)	1
Electricity (Solar)	2
Electricity (Generator)	3
Gas	4
Paraffin	5
Wood	6
Coal	7
Dung	8
Other (specify):	9

505 What energy source is mostly used at this homestead for lighting? (Mark only one)

ENERGY SOURCE FOR LIGHTING	CODE
Electricity (Eskom or Local Authority)	1
Electricity (Solar)	2
Electricity (Generator)	3
Gas	4
Paraffin	5
Candles	6
Other (specify):	7

506 How do you dispose of refuse or rubbish at this homestead? (Mark One Only)

TYPE OF REFUSE REMOVAL	CODE
Refuse bags removed from the house by local authority at least once a week	1
Refuse bags removed from the house by the local authority, less often than once a week	2
Removal by local authority from a community refuse container	3
Placed on communal refuse dump but not collected by local authority	4
Placed on refuse dump but not collected by local authority	5
Burnt in a pit / buried in vicinity of property	6
No refuse removal	7

Other (specify):	8

507 What is the main means of transport used by the members of this household? (Mark One Only)

MODE OF TRANSPORT	CODE
Own car	1
Taxi	2
Bus	3
Bicycle	4
Walk	5
Other (specify):	6

600 HEALTH

Member number (refer to page 3 for names)	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
601 How would you describe the general health of each household member at present? 1. excellent 2. good 3. average 4. poor 5. don't know (do not read 6. refused (do not read)	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6
602…Is any member of the household covered by a medical aid or medical benefit scheme? 1. yes 2. no 3. don't know 4. refused	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □	□ 1 □ 2 □ 3 □ 4
603…Is any member of the household currently ill/injured or was ill/injured during the last month? 1. yes 2. no 3. don't know 4. refused	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4	□ 1 □ 2 □ 3 □ 4
604…If the answer to Q603 was yes for any household member, give a brief indication of the nature of the illness/injury for each.															

Member number	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
605 If the answer to Q603 was yes, were medical expenses paid as a result of the illness															
1. yes	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1
2. no	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2
3. don't know	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3
4. refused	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4
606 Is any member of the household currently in hospital or in a care facility or has been, in the last month?															
1. yes															
2. no	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1
3. don't know	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2
4. refused	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3
	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4
607 If the answer to Q606 was yes, provide the name or a brief description of the facility.															
608 If the answer to Q606 was yes, were medical expenses paid as a result of the stay in hospital/ other facility?															
1. yes															
2. no	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1
3. don't know	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2
4. refused	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3
	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4

Member number	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
609 Is any ill/injured member of the household currently being taken care of at home?															
1. yes	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1
2. no	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2
3. don't know	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3
4. refused	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4
610 Did any member of the household visit/consult with any of the following in the last three months? (you can mark more than one for a hh member)															
1. clinic (public)															
2. doctor/specialist	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1
3. hospital (public)	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2
4. hospital (private)	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3
5. pharmacist/chemist	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4
6. dentist	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5	□ 5
7. traditional healer	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6	□ 6
8. spiritual healer	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7	□ 7
9. community health worker	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8	□ 8
10. any other health care provider	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9	□ 9
	□ 10	□ 10	□ 10	□ 10	□ 10	□ 10	□ 10	□ 10	□ 10	□ 10	□ 10	□ 10	□ 10	□ 10	□ 10
611 Did you have to pay for the service?															
1. yes	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1
2. no	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2
3. don't know	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3
4. refused	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4
612 Is any member of the household currently using medication to treat an illness?															
1. yes	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1	□ 1
2. no	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2	□ 2
3. don't know	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3	□ 3
4. refused	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4	□ 4

613 If you did not visit a clinic during the last three months, why not? (can mark more than one)

REASON	CODE
Too expensive	1
Too far	2
Not necessary	3
Don't know	4
Other reason, specify:	5

614 Did you experience any of the following the last time you visited a clinic? (Can mark more than one)

EXPERIENCE	CODE
Long waiting time	1
Opening times not convenient	2
Staff rude	3
Medication needed not available	4
Incorrect diagnosis	5
Other reason, specify:	6

615 What is the name of the public clinic nearest to your homestead?

616 How far is the clinic from the homestead?

Less than 500m	501m to 2km	3 to 5 km	More than 5km

617 Did any member(s) of your household pass away during the last year?

Yes	1
No	2

618 If the answer to Q617 was yes, provide the following details on each deceased member.

NAME	*GENDER	AGE	*RELATION TO HEAD	REASON

*** use code from household roster**

Ask the respondent if there is anything else they would like to add!

Thank the respondent!

Summary

In non-urban KwaZulu-Natal, South Africa, very few households escape the impacts of HIV and AIDS, either the direct impacts as a result of illness and death, or the indirect impacts through providing care and support to family, friends and neighbours. HIV and AIDS becomes part of the context or situation within which households arrange their lives, generate livelihoods and arrange and provide care. The differential impacts of HIV and AIDS on male and female members of different ages within households is poorly documented and understood. How people arrange care, especially for household members who are chronically ill, while generating livelihoods at the same time, is even less clear in the context of HIV and AIDS. This research assessed household living and care arrangements and livelihood generation in non-urban Mbonambi in the KwaZulu-Natal province of South Africa, in the context of HIV and AIDS. The study used a combined approach of quantitative and qualitative methodologies.

Demographic, socio-economic and health data were collected at the level of the household by means of a survey and results were verified and clarified by means of focus group discussions. For the survey, two research locations were selected, one close to town, with a high population density and fairly good infrastructure and the other further from town and with poorer infrastructure. In the latter location, lack of access to electricity and clean water close to the home adds to the burden of domestic work. In addition, this location also has fewer individuals who are working, with many of those who are working, employed in low paying elementary occupations or working as unskilled labourers. Households at this location also have lower household incomes, are more dependent on state grants and own fewer assets that can be converted to cash if need be.

Female-headed households proved to be bigger than male-headed ones, having significantly more demographic and effective dependents residing at their homesteads. Female heads are significantly older than their male counterparts, the majority of them widows relying on state old-age pensions as the main source of household income. Female-headed households have significantly lower average incomes and fewer assets than male-headed households. All the households in the survey sample were categorised based on whether and how they were afflicted and/or affected by HIV/AIDS and/or TB, where TB was used as a proxy indicator for HIV infection. Households were allocated to four clusters. Households in Cluster 1 did not experience any impacts attributed to AIDS and included just more than half of all the households. Afflicted households in Cluster 2 had at least one ill member diagnosed with HIV or TB and requiring some care, but did not experience any deaths and were not taking care of orphans. Affected households in Cluster 3 had no ill members, but took care of orphans and/or experienced deaths, while households in Cluster 4 were both afflicted and affected by HIV and AIDS.

Progression from Cluster 1 to Cluster 4 showed a significant difference in household size, with households in Cluster 4 having on average two more members than households in Cluster 1. Households in Clusters 3 and 4 had significantly more demographic dependents than those in Clusters 1 and 2, while the households hosting orphans in Clusters 2 and 4 had significantly more effective dependents than the households in the other clusters. Although not significant, households in Clusters 2, 3 and 4 had lower household incomes and fewer assets. Of all the households it is clearly visible that households in Cluster 4 that host ill persons and orphans, and experienced deaths, are in all regards worse off than the households in the other clusters, and are extremely vulnerable to livelihood insecurity. Considering that these households have more

dependents they will be more severely affected by the lower household income that has to be shared by more persons. Having fewer assets also mean that they do not have anything they can sell when they need money to cover household expenses or to pay for transport or a funeral.

Case study households were selected from each cluster for further study of their living arrangements and livelihoods. This was done by means of interviews and observations, and each household was visited at least two times over a period of six months. This revealed that the majority of households experienced changes in their living arrangements, regardless of whether and how they were affected by HIV and AIDS. It was especially young people and children who were mobile and individuals were leaving or joining households for a variety of reasons. Young women with or without their children were leaving to look for work, get married or provide care. Mobile children moved between the homesteads of unmarried mothers and biological fathers. The case study households included several households where unmarried mothers were living with their children at the homesteads of their frequently unmarried or widowed mothers.

Although changes in living arrangements can be caused by many factors other than morbidity and mortality, the majority of cases described experienced changes as a direct result of TB and/or AIDS-related illness and death. The time frame of inter-household movements varies from a few months to several years. The variation in cases presented illustrates that when movements between homesteads take place, the impact of HIV/AIDS-related morbidity and mortality on the livelihood and resources extends beyond the single household.

It is clearly visible that the majority of households depend on social transfers, either grants from government or private grants, as their only or main source of income, emphasizing the strategic importance of grants in coping with poverty. The financial situation of households may even improve when children receiving grants join a household and are 'accompanied' by their grants. But when such children move, the gain of income in one household will translate into a loss for another. Furthermore, some cases show that accessing grants for children is difficult when the status of the child changes and/or the foster parent does not have the required papers. The role of maternal parents or grandparents becomes clear when looking at intra-household cooperation to arrange health care or take care of vulnerable or orphaned children.

All the households are visited regularly by paid Community Health Workers and/or volunteer Home Based Caregivers, all of them female. These people are well-trained and work closely with the local public health clinic to assist households with care activities, caregivers with emotional support and patients with nutritional advice and traditional treatments to maintain health and relief symptoms. This is very important, as none of the HIV-positive persons in this small sample were on antiretroviral (ARV) treatment at the time of the research. Although treatment is free, to access it means regular blood tests and frequent hospital visits, which translates into indirect costs.

The cases clearly reveal that women are still the main providers of health- and childcare. When the demand on their time to provide care increases, they have less time to devote to income generating and community activities, which means less time to invest in social networks. This will cause already poor households with weak safety nets 'to fall through' the vulnerability threshold. All case households reveal the significance of social capital, the network of kin in particular, as a source of material and immaterial support. Relatives may take in a child to relieve the household's burden, may send money, or may provide emotional and practical support. When no relatives are living nearby, the neighbours provide the latter kind of support. At the same time, the cases also show 'missing' partners and parents who have opted out and whose whereabouts are sometimes not even known.

Although the majority of children in the case study households manage to stay in school, they are absent from school more often due to HIV/AIDS-related morbidity and mortality. As a result they fall behind and are at risk of eventually dropping out. Some children choose to stay at the homestead of their late parents, with or without adult supervision rather than moving in with grandparents or other relatives, in an attempt to retain their parents' homestead and land. This may make children vulnerable to exploitation. Child migration as a strategy to cope with HIV/AIDS-related morbidity was employed by some of the households. Although migration in search of employment has long been common in Southern Africa, migration of ill persons and children seeking care is a much more recent phenomenon.

Inter-household movements are likely to occur when a household affected by AIDS-related morbidity and mortality does not have the capacity to meet the additional demand for care. Moving of ill persons or vulnerable or orphaned children across household boundaries may make for more efficient use of human, material and financial resources. The cases show a continuous adaptation of living arrangements in response to illness and death. While the homestead and the kinship network still function as important anchors for people's lives, at the same time HIV and AIDS induce flux and instability, changes dependency relations between homesteads, makes 'holes' in safety nets, and undermines relations between partners, in particular those that are not sanctioned by traditional marriage, turning their children into de facto orphans. The homestead also seems to be losing its unified and patriarchal character, though more analysis is needed to prove this, and the supportive role and authority of grandmothers and maternal relatives is increasing. Care is not only morally grounded, it can also add to moral authority.

The government should look into ways to facilitate better access to ARV treatment, because this would not only improve and prolong the life of people living with HIV, but also contribute to a better quality of life for household members. Streamlining access to foster care grants will prevent households taking care of orphans or orphans living on their own from living in extreme poverty. Increasing the number of well-trained paid community health workers, liaising with formal health care and social workers, will enhance the much need support required by households living with the burden of HIV/AIDS-related morbidity and mortality.

Although consisting of a very small sample of households studied over a relatively short period of time, this study shows significant HIV/AIDS-induced changes in living arrangements, the variation in the timeframe of these changes, and the impact of these changes on the livelihoods of households and their potential to arrange health- and childcare, thus revealing the mechanisms of micro-level social change induced by the AIDS epidemic. It demonstrates the importance of qualitative research to complement cross-sectional survey research. More qualitative and longitudinal research is needed to know whether in the wake of the epidemic the cultural and social landscape of rural KwaZulu-Natal is fundamentally changing.

Samenvatting

In ruraal KwaZulu-Natal, Zuid-Afrika, ontsnappen slechts weinig huishoudens aan de gevolgen van HIV en AIDS. Zij ervaren directe gevolgen in de vorm van ziekte of dood, of indirecte gevolgen doordat zij zorg en steun verlenen aan familie, vrienden en buren. HIV en AIDS maken deel uit van de context waarbinnen huishoudens hun leven organiseren, in hun levensonderhoud voorzien en zorg organiseren en bieden. De verschillende gevolgen van HIV en AIDS voor mannen en vrouwen van verschillende leeftijdsgroepen zijn tot nu toe gebrekkig gedocumenteerd en weinig inzichtelijk. Nog minder duidelijk is hoe mensen zorg arrangeren in de context van HIV en AIDS, in het bijzonder voor de chronisch zieke leden van het huishouden, terwijl zij tegelijkertijd in hun levensonderhoud moeten voorzien. Dit onderzoek bestudeerde woon- en zorgarrangementen en de wijze waarop huishoudens middelen van bestaan genereren in ruraal Mbonambi in de provincie KwalZulu-Natal, Zuid-Afrika, in de context van HIV en AIDS. De studie gebruikte een combinatie van kwantitatieve en kwalitatieve methoden.

Demografische, sociaaleconomische en gezondheidsdata werden verzameld op het niveau van huishoudens door middel van een huishoudsurvey; vervolgens werden de resultaten geverifieerd en verder verduidelijkt door middel van focusgroep discussies. Voor de survey werden twee onderzoek locaties geselecteerd: één dichtbij de stad, met een hoge bevolkingsdichtheid en een betrekkelijk goede infrastructuur; de andere verder van de stad met een meer gebrekkige infrastructuur. Op deze tweede locatie betekende de gebrekkige toegang tot elektriciteit en schoon water dichtbij huis een extra belasting voor het huishoudelijk werk. Bovendien telde deze locatie minder mensen met een baan, terwijl veel mensen die een baan hadden werkten in laagbetaalde, eenvoudige beroepen of als ongeschoolde arbeiders. Huishoudens op deze locatie hadden lagere inkomens, waren meer afhankelijk van overheidsuitkeringen en bezaten minder duurzame gebruiksgoederen die, indien nodig, in geld kunnen worden omgezet.

Huishoudens geleid door vrouwen bleken groter te zijn dan huishoudens met een man aan het hoofd, telden significant meer afhankelijke leden, en hadden een lager gemiddeld inkomen en minder bezit. Vrouwelijke hoofden van huishoudens bleken significant ouder dan mannelijke. De meerderheid van hen was weduwe, afhankelijk van een overheidsuitkering (oudedagsvoorziening) als belangrijkste bron van inkomen.

De huishoudens in de steekproef werden ingedeeld naar de mate waarin zij direct (*afflicted*) of indirect (*affected*) waren getroffen door HIV/AIDS en/of tuberculose, waarbij TBC werd gebruikt als indicator voor HIV infectie. Er werden vier clusters onderscheiden. De huishoudens in Cluster I, iets meer dan de helft van alle huishoudens, ondervonden in het geheel geen effecten die toegeschreven konden worden aan AIDS. De huishoudens in Cluster 2 hadden tenminste één lid gediagnostiseerd met HIV of TBC en hadden enige zorg nodig, maar telden geen AIDS-doden en hadden ook geen AIDS-wezen onder hun hoede. De huishoudens in Cluster 3 hadden geen zieke leden, maar zorgden voor AIDS-wezen en/of hadden AIDS-doden te betreuren. De huishoudens in Cluster 4 combineerden de kenmerken van de huishoudens in Cluster 2 en 3.

Gaande van Cluster 1 naar Cluster 4 zien we een significant verschil in huishoud grootte, waarbij huishoudens in Cluster 4 gemiddeld twee leden meer telden dan die in Cluster 1. Huishoudens in Cluster 3 en 4 telden meer afhankelijke leden dan die in Cluster 1 en 2, vooral de huishoudens die onderdak boden aan AIDS-wezen. Hoewel niet significant, hadden de huishoudens in Cluster 2, 3 en 4 lagere inkomens per huishouden en bezaten minder duurzame gebruiksgoederen. Duidelijk werd dat de huishoudens in Cluster 4, die onderdak boden aan zieken en wezen en ook nog doden te betreuren hadden, in alle opzichten slechter af waren dan de huishoudens in de andere clusters. Deze huishoudens

bleken extreem kwetsbaar te zijn voor bestaansonzekerheid. Vanwege de hoge afhankelijkheidsratio van deze huishoudens zullen zij ernstiger getroffen worden door een lager inkomen, dat gedeeld moet worden met meer mensen. Het hebben van minder gebruiksgoederen betekent ook dat zij niets te verkopen hebben wanneer zij geld nodig hebben om huishoudelijke uitgaven te dekken en transport of een begrafenis te betalen.

Uit ieder cluster werd een aantal casestudy huishoudens geselecteerd voor verdere analyse van woonarrangementen en de wijze waarop deze huishoudens voorzagen in hun bestaan. Deze analyses waren gebaseerd op interviews en observatie. Elk huishouden werd ten minste twee keer bezocht in een periode van zes maanden. De analyse onthulde dat in de meerderheid van de huishoudens veranderingen plaatsvonden in de woonsituatie, ongeacht of en in welke mate zij getroffen waren door HIV en AIDS. Het waren vooral jonge mensen en kinderen die mobiel bleken te zijn. Zij verlieten een huishouden, of traden juist tot een huishouden toe, om een aantal verschillende redenen. Jonge vrouwen met of zonder hun kinderen vertrokken om werk te zoeken, te trouwen of om elders zorg te verlenen. Kinderen bewogen zich tussen de *homesteads* (woonerven) van hun (ongetrouwde) moeders en biologische vaders. De casestudy huishoudens telden ook enkele huishoudens die bestonden uit ongetrouwde moeders met hun kinderen die woonden in de *homestead* van hun veelal ongetrouwde of verweduwde moeder.

Hoewel veranderingen in woonarrangementen veroorzaakt kunnen zijn door andere factoren dan ziekte of sterfte, beschreef toch de meerderheid van de respondenten de ervaren veranderingen als een direct gevolg van TBC- en/of AIDS-gerelateerde ziekte en sterfte. De tijdsspanne van de verhuizingen tussen huishoudens varieerde van een paar maanden tot enkele jaren. De gepresenteerde cases illustreren dat de invloed van AIDS-gerelateerde ziekte en sterfte op het dagelijks bestaan en de beschikbare hulpbronnen de grenzen van het enkele huishouden overschrijdt, in het bijzonder wanneer er verhuizingen tussen verschillende *homesteads* plaatsvinden.

Het onderzoek maakt duidelijk dat de meerderheid van de huishoudens afhankelijk is van sociale voorzieningen, zowel overheidsuitkeringen als privé bijdragen, als hun enige, of voornaamste, bron van inkomsten. Hieruit blijkt hoe belangrijk dergelijke uitkeringen zijn om armoede de baas te kunnen. De financiële situatie van huishoudens kan zelfs verbeteren wanneer kinderen die een uitkering ontvangen zich bij een huishouden aansluiten met medeneming van hun uitkering. Maar wanneer zulke kinderen verhuizen, zal de inkomensvermeerdering in het ene huishouden leiden tot een inkomensdaling in het andere. Echter in sommige gevallen wordt de toegang van kinderen tot uitkeringen bemoeilijkt, namelijk wanneer de status van het kind verandert of wanneer de pleegouders niet de benodigde papieren hebben. De rol van (groot)moeders wordt duidelijk als wij kijken naar samenwerking binnen huishoudens om verpleging van zieken en de zorg voor kwetsbare en verweesde kinderen te organiseren.

Alle huishoudens worden regelmatig bezocht door betaalde gezondheidswerkers en/of vrijwilligers. Deze vrouwen – het zijn allemaal vrouwen – zijn goed opgeleid en werken nauw samen met het lokale gezondheidscentrum om huishoudens bij te staan met zorgactiviteiten, om mantelzorgers emotionele ondersteuning te bieden en patiënten te helpen met voedingsadviezen en traditionele behandelmethoden om hun symptomen te verlichten. Dit laatste is heel belangrijk, aangezien geen van de HIV-positieve personen in de steekproef tijdens het onderzoek met antivirale middelen werd behandeld. Hoewel gratis, brengt deze behandeling indirecte kosten met zich mee vanwege de vereiste regelmatige bloedonderzoeken en ziekenhuisbezoeken.

De casestudies onthullen dat vrouwen nog steeds de belangrijkste zorgverleners zijn. Wanneer de aanslag op hun tijd om zorg te verlenen toeneemt, hebben ze minder tijd om zich te wijden aan inkomen genererende en sociale activiteiten, en dus ook minder tijd om te investeren in sociale netwerken. Het gevolg hiervan is dat huishoudens die al arm zijn en over zwakke sociale vangnetten beschikken, onder het bestaansminimum zakken.

Alle casestudy huishoudens toonden het belang van sociaal kapitaal – in het bijzonder het netwerk van familieleden – als bron van materiële en immateriële steun. Familieleden kunnen de zorg voor een kind op zich nemen om de last van een huishouden te verlichten, ze sturen soms geld, of ze verlenen emotionele of praktische steun. Wanneer er geen familieleden dichtbij wonen, dan verlenen buren vaak die laatste vorm van ondersteuning. Tegelijkertijd laten de cases ook zien dat er partners vaak afwezig zijn en dat er ouders zijn die zich aan hun verantwoordelijkheid onttrekken en waarvan soms zelfs de verblijfplaats onbekend is.

Hoewel de meerderheid van de kinderen in de casestudy huishoudens het klaarspeelde om naar school te blijven gaan, bleken zij vaker afwezig te zijn door HIV/AIDS-gerelateerde ziekte of sterfte. Als gevolg daarvan lopen zij achter en riskeren het om uiteindelijk de school niet af te maken. Sommige kinderen kozen ervoor op de *homestead* van hun overleden ouders te blijven, met of zonder supervisie van een volwassene, liever dan in te trekken bij hun grootouders of andere verwanten. Op deze wijze proberen zij de *homestead* en het land van hun ouders te behouden. In een dergelijke situatie zijn deze kinderen kwetsbaar voor exploitatie. Migratie van kinderen werd door sommige huishoudens ingezet als strategie om HIV/AIDS-gerelateerde ziekte het hoofd te bieden. In Zuid-Afrika is arbeidsmigratie al heel lang gebruikelijk; de migratie van zieke personen en kinderen op zoek naar zorg is echter een veel recenter verschijnsel.

Wanneer een huishouden getroffen is door AIDS-gerelateerde ziekte en sterfte en niet meer het vermogen heeft om additionele zorg te bieden, liggen verhuizingen tussen huishoudens voor de hand. Verhuizingen van zieke personen of kwetsbare of verweesde kinderen over de grenzen van huishoudens heen zouden efficiënter gebruik kunnen maken van menselijke, materiële en financiële hulpbronnen. De casestudies laten een voortdurende aanpassing van woonarrangementen zien in antwoord op ziekte en sterfte. Terwijl de *homestead* en het netwerk van verwanten nog functioneren als belangrijke ankers in het leven van mensen, veroorzaken HIV en AIDS een voortdurende beweging en instabiliteit, veranderen zij de afhankelijkheidsrelaties tussen *homesteads*, maken 'gaten' in vangnetten en ondermijnen de relaties tussen partners, in het bijzonder de relaties die niet gesanctioneerd zijn door een traditioneel huwelijk, met als gevolg dat de kinderen uit die relaties *de facto* wezen zijn. De *homestead* lijkt zijn samenbindende en patriarchale karakter te verliezen, hoewel meer onderzoek nodig is om dit te bewijzen. De ondersteunende rol en de autoriteit van grootmoeders en andere verwanten van moeders zijde neemt toe. Hieruit blijkt dat zorg heeft niet alleen een morele basis heeft, maar ook de morele autoriteit kan vergroten.

De regering zou moeten kijken naar manieren om betere toegang tot antivirale behandeling te faciliteren, omdat dit niet alleen het leven van mensen met HIV zou verbeteren en verlengen, maar ook zou bijdragen aan een betere kwaliteit van leven van andere leden van het huishouden. Stroomlijnen van de toegang tot toelagen voor pleegzorg kan extreme armoede voorkomen voor huishoudens die weeskinderen opnemen of voor wezen die zelfstandig wonen. Vergroting van het aantal goedgetrainde, betaalde lokale gezondheidswerkers, die samenwerken met de formele gezondheidszorg en het maatschappelijk werk, kan de broodnodige steun bieden aan huishoudens die leven met de last van AIDS-gerelateerde ziekte en sterfte.

Hoewel een kleine steekproef van huishoudens gedurende een betrekkelijk korte tijd is bestudeerd, laat dit onderzoek toch significante veranderingen zien die door HIV en AIDS teweeg worden gebracht: veranderingen in woonarrangementen, variatie in tijdsbestek van deze veranderingen en de impact van deze veranderingen op de bestaanszekerheid van huishoudens en hun vermogen om gezondheidszorg en kinderverzorging te organiseren. Op die manier worden de mechanismen onthuld van sociale verandering op microniveau als gevolg van de AIDS epidemie. De resultaten demonstreren het belang van kwalitatief onderzoek als aanvulling op survey onderzoek. Meer kwalitatief en longi-

tudinaal onderzoek is nodig om te weten of in het kielzog van de epidemie het culturele en maatschappelijke landschap van ruraal KwaZulu-Natal fundamenteel aan het veranderen is.

About the author

Corrie du Preez completed her B Home Economics degree at the University of Stellenbosch in 1986 after which she worked at a College of Agriculture for just over two years. In 1989 she started working as a junior lecturer in the then Department of Home Economics at the University of Zululand. She obtained a Master's degree in 'Management of Agricultural Knowledge Systems' (MSc MAKS) from Wageningen University in 2000. Corrie is currently the acting head of the Department of Consumer Sciences at the University of Zululand and lectures mainly in research methodology and community development. She also conducts and supervises undergraduate and postgraduate research and is involved in a wellness project with a local community.

Corrie's PhD research on the living and care arrangements of non-urban households in KwaZulu-Natal, South Africa, in the context of HIV and AIDS formed part of the AWLAE (African Women Leaders in Agriculture and Environment) research program on gender, food systems and HIV/AIDS in Africa. The research also produced two publications:

Du Preez, C. & A. Niehof (2010). Impacts of AIDS-related morbidity and mortality in non-urban households in KwaZulu-Natal, South Africa. In: Niehof, A., G. Rugalema & S. Gillespie (eds.), AIDS and rural livelihoods: Dynamics and Diversity in sub-Saharan Africa, pp 43-60, London: Earthscan.

Du Preez, C.J. & A. Niehof (2008). "Caring for people living with AIDS: A labour of love." Medische Antropologie 20 (1) 2008, pp 87 to 104.

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Name of the course	Department/ Institute	Year	ECTS*
I. General part			
Research methodology: designing and conducting a PhD research project	MGS (Mansholt Graduate School)	2004	3
Techniques for writing and presenting a scientific paper	WGS	2005	1.2
Time planning and project management	WGS	2004	1.5
II. Mansholt-specific part			
Mansholt Introduction course	MGS	2004	1.5
Mansholt Multidisciplinary Seminar	MGS	2007	1.0
Presented a paper at the 3rd African Conference for the Research on the Social Aspects of HIV/AIDS	Dakar, Senegal.	2005	1.0
Presented a paper at the 8th National Conference of the South African Association for Family Ecology and Consumer Sciences	Cape Town, South Africa.	2006	1.0
Presented a poster at the 8th International AIDS Impact Conference	Marseille, France	2007	1.0
Presented a paper at the Medical Anthropology Symposium	Amsterdam University	2007	1.0
Presented a paper at the 11th World Congress International Federation for Home Economics	Luzern, Switzerland	2008	1.0
III. Discipline-specific part			
Food Policy in an Era of Globalisation	MGS	2004	4
HIV/AIDS and rural livelihoods in Sub-Saharan Africa	SCH (Sociology of Consumers and Households)	2004	3
Livelihood analysis and poverty reduction strategies	CERES summer school	2004	3
Gendered impact of HIV/AIDS in Sub-Saharan Africa	SCH tutorial	2004	3
Gender, Culture and Identity (CA 2023A)	Radboud University (Nijmegen)	2004	5.7
Gender, Reproductive and Sexual Health and Fertility	Amsterdam University	2004	5
TOTAL (min. 30 ECTS)			36.9

* One ECTS = 28 hrs

AWLAE

African Women Leaders in Agriculture and the Environment

The present thesis is one of a series. It represents the fruits of a collaboration between African Women Leaders in Agriculture and the Environment (AWLAE), Winrock International (WI), and Wageningen University and Research Centre (WUR). AWLAE is a pan-African program that aims at training women professionals in the fields of agriculture and environment, to redress the existing gap between male and female representation in professions relating to these fields. AWLAE was initiated by Winrock International in 1989. Its headquarters are in Nairobi, Kenya.

Between AWLAE, WI, and WUR a project was formulated that was submitted for funding to the Minister for Development Cooperation of the Netherlands Ministry of Foreign Affairs. The goal of the project was to build a cadre of well-trained African women professionals working in agriculture, environment and related sectors to enhance their academic standing and capacity to contribute to gender-relevant research and policy-making on the role of women in food systems and the gendered impacts of HIV/AIDS on food security and rural livelihoods in sub-Saharan Africa. In April 2002 the project was granted. The Ministry agreed to fund twenty PhD scholarships at Wageningen University and the additional leadership-in-change training for twenty women from eleven African countries, ranging from East to West and Southern Africa. In June 2002 an agreement was signed between AWLAE, represented by its Regional Director, and the Director of the WUR Social Sciences Group, after which implementation of the project could start. The participating scholars were carefully selected from a large number of applications. The scholarships were widely advertised in relevant media in countries with AWLAE chapters, and the chapters concerned were actively involved in the recruitment and selection of the candidates.

The following women participate(d) in the AWLAE scholarship project:

Susana Akrofi (Ghana)
Hirut Bekele (Ethiopia)
Namizata Binaté Fofana (Ivory Coast)
Joyce Challe (Tanzania)
Fatimata Dia Sow (Senegal)
Stephanie Duku (Ghana)
Rose Fagbemissi (Benin)
Kidist Gebreselassi (Ethiopia)
Monica Karuhanga (Uganda)
Doris Kakuru (Uganda)
Mariame Maiga (Ivory Coast)
Lydia Ndirangu (Kenya)
Aifa Fatimata Ndoye Niane (Senegal)
Faith Nguthi (Kenya)
Carolyne Nombo (Tanzania)
Regina Ntumngia Nchang (Cameroon)
Daisy Onyige (Nigeria)
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Corrie du Preez (South Africa)
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