Title: Family dynamics in Home-based Care Settings of Zimbabwe’s Eastern Highlands in Mutasa North Rural District

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ACRONYMS AND DEFINITION OF TERMS

AIDS    Acquired Immune Deficiency Syndrome
ART    Antiretroviral Therapy
ARV    Antiretroviral (drugs)
CBO    Community-Based Organisation
HBC    (Community) Home-Based Care
HIV    Human Immune Virus
MDG    Millennium Development Goals
MHCW    Ministry of Health and Child Welfare
NGO    Non-Governmental Organisation
PAR    Participatory Action Research
SPSS    Statistical Package for Social Scientists
STI    Sexually-transmitted Infections
UNICEF    United Nations Children’s Fund

DEFINITIONS OF TERMS

1. AIDS – a condition by which the human body’s immune system collapses and gives in to opportunistic infections of various kinds, impairing an individual’s ability to respond to treatment, leading to rapid weight loss, general health deterioration and subsequently death, especially if antiretroviral therapy is not taken or delayed (UNAIDS, 2002: 2).

2. Chronic illness (or ‘chronically ill’) – a persistent condition of severe poor health that impairs an individual’s ability to do physically demanding tasks such as moving about, eating properly and, in extreme conditions, talking (UNAIDS, 2002: 2–3). For this research’s operational purposes, chronic illness was marked by one’s prolonged stay in bed, receiving support from others to perform tasks they could otherwise have done for themselves.

3. (Community) Home-based care (HBC) – the physical care, emotional support and disease treatment that other people in a community, including family members, do for chronically ill patients on voluntary terms with technical advice from qualified health professionals serving at local clinics and hospitals. HBC is a measure that Zimbabwe Ministry of Health and Child...
Welfare took after the number of HIV patients admitted in major hospitals and clinics outstripped the capacity of available beds (Government of Zimbabwe, 2003).

4. HBC settings – households in which at least one person was diagnosed to be infected with HIV and is receiving home-based care (researcher’s definition for operational purposes of this study only).

5. Family – a collective term for people sharing a number of essential entitlements such as a name or identity, resources, belongingness, values and social support. Members of a family are socialized into certain power relations, values and responsibilities. Some theories attach certain functional principles to the family and view it as an absolute social institution to which ‘normal’ people should belong (Morgan, 1996). This research attempts to enrich existing definitions and contest family theories that reinforce the notion that certain characteristics define what a ‘normal’ family should be.

6. Nuclear family – a family comprising two heterosexual spouses or parents who are tied together by a marriage and residing in the same household with their biological children (Researcher’s inference based on Sunde and Bozalek, 1995).

7. Families – a term being used to systematically replace the reference to “the family” as an absolute social institution out of the realization of diversity in family dynamics across the divides of race, gender, social class, cultural and generational differentials, which are “embedded in complex interactive power dynamics” (Sunde and Bozalek, 1995).

8. Household – a collection of people who are identified by a common residential location or, more specifically, house, where they share a number of physical resources such as living space (for example, kitchen, lounge, etc), utilities such as toilets, stoves and responsibilities such as paying rates (Zimbabwe Central Statistical Office and Measure DHS, OPS Macro, USAID, CSO., 2006). Members of a household can be, but are not always, members of one family.

9. Familism – an ideology that emphasizes the naturalness of ‘the family’ as a unit, thereby creating context-limited perceptions of family (Sunde and Bozalek, 1995).

10. Family dynamics – the ways (activities and strategies) through which families organize or reorganize themselves to better cope with changing social realities, which, in the context of this study, are the effects of HIV and AIDS, including but not limited to the chronic illness or
death of a family member, increase in the number of orphans and post-bereavement conflict within families (Researcher’s definition for operational purposes of this research).

11. Feminism – a movement that challenges patriarchal dominance in families and advocates for equitable power sharing between men and women as well as revision of theories, practices and policies that undervalue the contributions of the female gender to society (Perry-Jenkins, 1994)

12. (Structural) Functionalism – a theory that contends that people are organized beings living within rule-governed institutions or structures that serve specific functions productively and for the common good (Morgan, 1985). Under this theory, a family is therefore a structure that serves such functions as reproduction, child care, breadwinning and so forth.

13. Gender – the socially constructed roles of men and women ascribed to them on the basis of their sex, which is one’s fixed, hormone–determined and/or natural biological processes and physical characteristics (Pietila, 2002). Gender is reproduced in the realm of material practices such as the distribution of resources, wealth, work, decision making and political power. In turn gender influences the outcomes of these material practices, where, subject to cultural differences, men or women end up disproportionately enjoying certain entitlements within their families and communities (United Nations, 1999b).

14. HIV – the virus that attacks and destroys one’s immune system, causing the person to be vulnerable to disease infections (UNAIDS, 2002: 2).

15. Postmodernism – a perspective that seeks to reconstruct the concept of family by advocating for an unbiased and open view of families (as opposed to ‘the family’) that accommodates the influence of socioeconomic forces, human migration, cultural values, historical developments and other dynamics affecting families.
ABSTRACT

Ever since United Nations’ declaration of 1994 as the Year of the Family, the study and understanding of families has taken center stage, albeit with constant references to ‘normal’ versus ‘deviant’ families based on structural functionalism theory’s rigid definitions of what a ‘normal’ family should be. On the other hand HIV/AIDS has attracted much attention too because of its life threatening traits, especially in Sub-Saharan Africa where Zimbabwe lies. Efforts to fight the epidemic have seen the mushrooming of innovative programs, which include home–based care (HBC) services for those infected with HIV. However, although HIV and AIDS has clearly had adverse impacts on families, it is rarely discussed within perspectives that integrate family dynamics. To fill this gap this study has explored how HBC, as a response to HIV and AIDS, may change our understanding of families. Research data was gathered within the participatory action research design through methods such as focus group discussions by 35 HBC volunteers and patients, interviews of 26 of these, review of relevant family policies and other interactive participatory exercises by which research participants expressed their opinions through drawings. The evaluation showed that households were not always synonymous with families, although a thin line divided the two. Further, survival considerations are the leading priority why people find themselves in families within HBC settings. However, survival options available to women are exploitative and this has kept those in HBC settings reeling under the burden of demanding but unrewarded care work and domestic household jobs. The study teaches that families cannot be understood in aggregated terms and that individuals dictate what families become, not the other way round. The research essentially recommends policy revisions to reflect unique realities found in HBC settings, and among female HBC volunteers. This should be coupled with awareness campaigns in communities and further research on families.
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Chapter One

Introductory background

This research sought to explore conceptions of families within settings where home-based care (HBC) is provided to chronically-ill patients diagnosed through an HIV test to be infected with HIV and suffering from a disease related thereto. The study thus omitted bed-ridden patients suffering from other diseases unrelated to HIV. It was carried out in Zimbabwe’s Eastern Highlands region of Mutasa North Rural District, which lies along Zimbabwe’s eastern border shared with Mozambique where people living with HIV organized themselves into a support group to collectively address their shared socioeconomic, medical and emotional needs.

1.1. Background to the study

Zimbabwe has ten provinces demarcated largely along lines of ethnicity. Accordingly, most provinces are named after the languages that resident people speak (for example, Matabeleland North and South Provinces harbor Ndebele-speaking people while Shona-speakers are found in Mashonaland East, West and Central Provinces and Manyika-speakers occupy Manicaland). Harare, Bulawayo, Midlands and Masvingo Provinces are the only ones with ethnically-neutral names. Although ethnicity seems to be the defining characteristic of Zimbabwe’s provinces, their geographical demarcation coincidentally follows climatic lines as well. Matabeleland provinces and Masvingo are characterized by low rainfalls, high temperatures and limited natural life while Mashonaland ones receive moderate to high rainfalls amid good temperatures and diverse natural life. Midlands Province, which lies in the middle of Zimbabwe, experiences average conditions while Harare and Bulawayo are urban provinces, the former being the country’s capital and the latter its second largest city. Provinces are subdivided into districts, then administrative wards and, ultimately, villages.

The focus of this study, Mutasa North District’s Eastern Highlands, lies in Manicaland Province – a mountainous, densely vegetated and sparsely populated region that enjoys Zimbabwe’s heaviest summer rainfalls and coolest winter temperatures. These conditions favor crop farming, and one can almost infer that poverty levels are generally low among people in this province.
given that agriculture is the mainstay of livelihoods for the majority of rural Zimbabweans. This impression sounds sensible considering that Manicaland Province is in fact home to most of Zimbabwe’s largest farming estates that produce and process the bulk of its tea, coffee, all kinds of fruits, vegetables, flowers, canned foods and grain. However, these large estates are owned by a few rich moguls who employ the predominantly poor local people, including children, as cheap labor. One Tanganda Tea Estate was at one point the subject of much debate on children’s rights following its ‘earn and learn program’ by which it employed children from poor families and paid them paltry wages in exchange of free education (Bourdillon, et al, 2010: 127).

The Eastern Highlands of Mutasa North District comprise several villages dotted along Zimbabwe’s eastern border shared with Mozambique where cross-border movements for informal trade and labor exchange busily occupy the local people. Most of these locals have dual citizenships to enable them to switch over to the country with the better living conditions at any given time. This makes for interesting shifts in family practices. For example, when in 2008 inflation in Zimbabwe reached astronomical levels and pre-election violence between supporters of rival political parties heated up, many villagers on the Zimbabwean side crossed over to Mozambique, which had a stronger currency and more stable political environment. That was a reverse of what happened in the mid 1980’s when there was civil war in Mozambique.

For informal traders in this area, Mozambique offers a lucrative export market for manufactured commodities such as agrochemicals because of its less developed industry while its proximity to the sea makes it a cheap source of sea food, which is on high demand in Zimbabwe. In November 2005 Zimbabwe experienced a minor tremor that exposed diamond deposits in Chiadzwa region of Manicaland’s Marange District, which local people mined for about three years before the government formalized and took over the mines. During that time illegal diamond mining and smuggling increased human traffic across the border, raising concern over the likelihood of negative shifts in living arrangements among families and transference of epidemics, especially HIV and AIDS.

Today, as most Zimbabwean families are becoming more economically desperate, emigration to other countries is getting increasingly more feminized due to shifts in gender roles vis-à-vis
generating family income and sharing family labor responsibilities. Massive emigrations of women and girls into Mozambique have raised the potential for wide ranging cross-border sexual partnerships that have been associated with increases in teen pregnancies and early marriages. The number of families with at least an individual suffering from a chronic HIV-related illness is similarly on the increase in the Eastern Highlands where a network of home-based caregivers has naturally expanded. This has increased the complexity of families and the urgency of the need to understand family dynamics in contexts where HIV is highly endemic and it coincides with high rates of poverty and busy cross-border human traffic.

1.2. Statement of the problem

HIV and AIDS have adversely affected economies and social life in the world, especially the sub-Saharan African region where Zimbabwe is situated. It is one of the leading fuels of the country’s mortality rates. UNICEF acknowledges that “the burden of widespread chronic illness and a tragically early mortality associated with HIV/AIDS is placing increasing strain on the fabric of everyday life, undermining traditional support structures and established family patterns of coping with diversity” (2001: 81). It further hints that “the consequences of the AIDS epidemic are far reaching in all families in Zimbabwe,” suggesting a strong connection between the effects of the epidemic and the way families operate. However, despite the attention that HIV and AIDS has attracted, emphasis has been placed more heavily on searches for a cure and preventing the further spread of HIV than on its influence on how families organize themselves to cope with its effects. This is in spite of research evidence showing that some families now exclusively consist of orphaned children caring for each other and that grandparents are caring for orphans from several households because of AIDS (UNICEF, 2004).

Home-based care is the Zimbabwe government’s answer to the incapacity of its health facilities to cope with swelling numbers of HIV-infected patients. Zimbabwe’s Home-Based Care Policy acknowledges that a significant proportion of “…the population in Zimbabwe is…HIV positive with 2,000 new infections every week..., which impacts heavily on the already overstretched health delivery system.” (2001: 3). The policy proceeds to advise that “the future prospective
health care delivery has to move from hospitals to home care, in partnership with the community.” However, the policy mentions terms like ‘home’ and ‘community’ without defining the scope of using these terms and does not define what a family is in spite of using the term in many of its texts. This implies either or both of the following underlying assumptions:

a. Everyone automatically understands the terms ‘family’, ‘home’ and ‘community’ from the same perspective regardless of differences in social contexts and;
b. Families and households have readily and freely available caregivers among their members on whom the government can fall back for the care of the chronically ill.

Caring for the sick within family settings now seems to demand more than just emotional bonds, which had been strongly viewed as the glue of relationships in families according to conventional definitions of family. The chronic nature and intensity of HIV-related illnesses, allied with the delicacy of care that they require, mean that palliative care now demands professionalism more strongly than ever before. In Zimbabwe this has seen homed-based caregivers in communities receiving prior training in a broad range of health and social skills while home-based caregivers are increasingly contesting the idea of serving as volunteers. Because of “lack of kits and incentives…,” laments Zimbabwe’s Ministry of Health and Child Welfare (2008), “volunteerism has been ineffective, as most caregivers can no longer forego their income-generating activities for voluntary work in a depressed economy”.

On the other hand attention to ‘the family’ has ever increased since the United Nations declared 1994 as the year of the family. However, references to stable versus volatile families, ideal versus abnormal families and related contrasts have remained too widespread in family discourses to go unnoticed. Although family types vary widely across different socio-cultural settings and have changed even within single cultures as a result of historical, socioeconomic, political and other developments, the idea that certain characteristics distinguish ‘ideal’ from ‘deviant’ families is still widely entertained. This is based on familism – an ideology that conceptualizes ‘the family’ around gender or age-specific roles that individual members should perform, but in the process portrays the western middle-class nuclear family type as the absolute and ideal order. This research intends to explore family diversities inherent in rural settings...
where chronically-ill HIV-infected patients receive care at home to contest these rigid familist perspectives of families. The study intends to reconstruct the way families are viewed and promote pluralism in family discourses, especially considering that dominant social constructions flavor the contents of national family policies. For example, Zimbabwe’s birth registration policies require proof of a child’s maternity and paternity prerequisite to acquiring a birth certificate, obviously basing on familist presumptions that all children live in a family with a mother and a father.

1.3. Rationale of the study

This study comes at the right time and is well placed to contribute towards filling the gaps in available knowledge about families. First, it was conducted in a third world country’s poor rural community along the border where economically-inspired human migration is rampant. Most available information on families is based on studies on middle class urban families from developed countries or students from various socioeconomic backgrounds (for example, Sunde and Bozalek, 1995). There is still very little family research data that is informed by poor rural communities from the developing world. Zimbabwe is an interesting developing country because its poor rural families still vividly reflect the damages of its decade-long period of political turmoil, famine and socioeconomic collapse (i.e., 1999 to 2009).

Second, the study focuses on three topical social issues, namely HIV and AIDS, families and human migration. Human migration or population movement is an age old problem because it is associated with distortions of social life in source and host countries and has forced governments to alter their immigration regulations from time to time, sometimes leading to mass deportations. Studying this phenomenon from various dimensions diversifies knowledge for making relevant policy decisions. Much study on human migration is limited to long-term migration of professionals (for example, IOM, 2009) while there is still very little data on temporary migrations of poor people in search of a means for survival, let alone research studies that link migration to family practices or HIV and AIDS. Even though many research publications identify human migration as one of many developments that change the shape and purpose of families over time and space (Sassen, 1998), more research work needs to be done to link
specific migratory practices to the definitions of families. This study sought to understand families and households affected by HIV and AIDS within the context of survival strategies that are anchored in highly migratory economic ventures. The study employed a participatory approach that enabled the people experiencing various family dynamics to share their stories in their own terms.

HIV and AIDS, the study’s central focus, count among the world’s leading disasters. It has decimated many families and workplaces, forcing nations and world regions to shift their macroeconomic priorities in order to alleviate its impact. This epidemic has been so serious that the United Nations convened a series of conferences that culminated in what are now known as the Millennium Development Goals (MDGs). These are global human development targets to guide individual nations in planning, setting targets for and evaluating their own human development programs and policies. They comprise eight goals including one to combat HIV/AIDS, malaria and other diseases. Therefore, any study that additionally informs strategies of combating HIV and AIDS, especially the pursuit of the MDGs related to the epidemic, is highly desired. In Zimbabwe, although people infected with HIV are found everywhere, there are now geographical and social spots that are peculiarly known to be zones with the highest risk of contracting HIV. Border points, which this study targeted, are among these.

This study uses realities of families in which people living with HIV in a highly endemic and migratory community are cared for within their homes to contest theories that idealize static family arrangements, calling any others that divert from these ‘abnormal’, ‘problematic’, ‘deviant’ or other anthologizing terms. As much as HIV and AIDS is one of the most extensively studied subjects, most researches have placed heavy emphasis on HIV prevalence, evaluation of responsive programs, HIV knowledge and awareness levels, behavior patterns and related matters at the expense of assessing the relationship between the epidemic and families.

1.4. Research questions

This research’s questions were formulated in line with the study’s objectives. The first set of questions solicits information on the composition of and relationships shared within families.
The second set comprised exploratory questions seeking a deep understanding of realities that care giving and receiving entailed. The role of migration to HIV patient care was similarly explored. The final set of questions sought suggestions of policies and programs for improved HIV patient care. The specific key questions of the research were as follows:

i. How many and what types of individuals constitute households and/or families in which HBC is provided? How do people in HBC settings define a family and what characteristics do they associate with members of one family?

ii. What relationships are shared between members of households where HIV–infected patients are receiving HBC and what roles or tasks do men/boys and women/girls perform to fulfill family needs?

iii. Are members of one’s family the only or most important people in their circle of relationships? If not, what other important relationships exist outside families and what purposes do these serve?

iv. What does care involve within HBC settings and is this care a reserve of one’s family?

v. Are Zimbabwe’s community development programs and policies that affect families or regulate the delivery of HBC suited to the realities of today’s families in the Eastern Highlands?

vi. What are the respondents’ or groups’ recommendations for making HBC more effective?

1.5. **Aims and objectives of the study**

This study set out to explore the conceptions of family relationships, living arrangements, dependency relationships, compositions and other emerging attributes of families where chronically-ill HIV-infected patients are cared for in their homes within a highly migratory community through the following specific objectives:

i. To describe the compositions of families and households in HBC settings and their members’ relationships

ii. To describe socioeconomic dynamics in Eastern Highlands region of Mutasa North District and their relationship with the composition of families and households in HBC settings
iii. To explore and describe emerging family relationships, including caring and dependency relationships, between members of households where HBC is taking place

iv. To explore the conceptions of family within HBC settings, especially how these are influenced by dynamics related to HBC

v. To explain the relationship between HIV/AIDS and family processes implied in objectives i, ii and iii above

The objectives above are informed by and will further inform the researcher’s contestation of familist ideals and identification of social behaviors, national policies and government practices that have a familist influence. On that basis the research will recommend ways of better embracing situational diversity in the understanding of families’ mechanisms of coping with the effects of HIV and AIDS.

1.6. Significance of the study

This research is conceptually and practically significant. Conceptually, it will provide data on practical and lived experiences of today’s families to substantiate and/or validate existing family theories. The study chose to explore the realities of families in a setting that differs from those which informed such early theories as structural functionalism and ideologies such as familism and familialism. These early theories and ideologies based their conclusions largely on middle class families in developed countries of Europe and America around the era of the industrial revolution. With time these theories have been challenged on the evidence of emerging realities of modern families. This study offers fresh evidence informed by families from a poor rural and migrant community in a developing country.

Postmodernism, which provides some of the strongest arguments against functionalism, familism and familialism, recommends that any definition of the family should be based on people’s lived experiences – the very alternative that this study offers.

The study notes that attention to the family has increased ever since 1994 was declared the year of the family. Following that declaration many projects and programs that target families have
mushroomed in different parts of the world including Africa, especially in South Africa where the Department of Social Development takes the lead. However, these initiatives took off before the term ‘family’ was deeply explored. This research modestly attempts to address that shortcoming in order that future family-focused programs and projects can be more relevant to realities of modern families.

Most politicians seemingly pin their hopes for garnering maximum support by making statements that demonstrate sensitivity to ‘stable family’ life, with some of them parading their wives and children before their supporters during their election campaigns to prove a point (for example, reference to Tony Blair’s campaigns by which he paraded his smiling family members his rallies in Sunde and Bozalek, 1995). Encouragingly, what this implies is that families make up a powerful interest group that politicians cannot ignore and good leadership can be marked by a government’s sensitivity to the needs of families. However, it seems that most politicians, policy makers, media houses and other powerful drivers of public opinion still seem to understand a family in the familist way – one characterized by a breadwinning father, housekeeping mother and their dependent biological children. Other family arrangements continue to be viewed as symptoms of broken down, abnormal, deviant, and unstable families. Rather than acknowledging, embracing and involving them in national development, families that are not nuclear are counted among the society’s worst misfits and therefore excluded from programs meant to benefit what has become known as ‘the family’. HIV and AIDS is among the leading epidemics in history to have changed families around. Ironically, it has claimed many lives of breadwinning husbands or fathers who in familist thinking are considered to be the pillars of families. This study will broaden the definition of families within the context of a social problem that has forced many governments to review their priorities and redirect their resources. If its findings are taken seriously, policies that are more responsive to emerging realities of marginalized families can be expected.

Zimbabwe still does not have a distinct family policy, although most of its policy and legislative documents that have a bearing on families (for example, the National Orphan Care Policy) mention the family without clearly defining the term. This research will therefore correct some
misinformed positions of viewing families and provide data that can direct discussions in Zimbabwe of either a distinct family policy or revisions of existing policies that affect families.

1.7. Layout of the thesis

Chapter 2 of this report builds on the discussion in this chapter by reviewing available literature on families, HIV and AIDS, human migration and home–based or other forms of care. This literature is based on theory and research to place this study into the conceptual framework in which the term family will be used in forthcoming chapters. Chapter 3 describes and justifies the methods by which information for the research was collected and analysed, beginning with the chosen study design. The research’s findings are presented and discussed in Chapter 4 to inform the recommendations and conclusions in Chapter 5.
Chapter Two

Literature Review

2.1. Introduction

The United Nations declared 1994 as the year of the family after its decades–long experience of supporting various welfare programs and policies had shown that families were among the leading social facets around which human life revolved. This declaration legitimized increased family–specific discussions, program planning and policy formulation. It came nine years after the discovery of Africa’s first HIV infection case in Uganda. Now, given the way HIV and AIDS have decimated many families, especially in Sub–Saharan Africa, any attempt to discuss or plan families without considering factors related to the epidemic cannot yield the desired results. The same holds true for attempting to discuss HIV and AIDS outside the context or without a polished understanding of how families cope with diverse realities.

UNICEF echoes this view in its educational material for Advanced level and college students by arguing that “the burden of widespread chronic illness and a tragically early mortality associated with HIV/AIDS is placing increasing strain on the fabric of everyday life, undermining traditional support structures and established family patterns of coping with diversity” (2001: 81). It further hints that “the consequences of the AIDS epidemic are far reaching in all families in Zimbabwe,” with statistics showing that 38 million people, including 2.1 million children in the world, are now infected with HIV (UNAIDS, 2004). Of these, 66% are from Sub–Saharan Africa alone, and these include 1.9 million children. This means that Sub–Saharan Africa harbors 90% the world’s HIV–infected children. In Zimbabwe there are 1.8 million people officially known to be living with HIV, 165,000 or 9.2% of them children. This represents 7.2% of the population living with HIV in Sub–Saharan Africa.

Further demonstrating that HIV and AIDS imposed wide diversities in living arrangements and caring relationships in families, UNICEF (2004) showed, for example, that female headed households did more care giving work for HIV–infected patients (two thirds of the households) than male–headed ones. In addition, 27% of households were found to be headed by
grandparents who permanently lived with their orphaned grandchildren, which illustrates the necessity to treat families and HIV/AIDS as inseparable and important subjects of human development.

2.2. Relationships between HIV/AIDS and families

HIV and AIDS has been extensively studied and widely documented, albeit with heavier emphasis on its medical implications (for example, searches for a cure) than on its relationship with how families organize themselves or can be strengthened to more effectively cope with its effects. It is therefore not surprising that not much progress has been made to more deeply understand twenty-first century families vis-à-vis HIV/AIDS and, in Zimbabwe, family policies have not been changed to accommodate new realities that the epidemic has imposed. For example, a child is still expected to prove its paternity and maternity prerequisite to securing a birth certificate, although some families now consist of children only as a result of HIV and AIDS. This is in spite of Zimbabwe’s progress report on implementing the Millennium Development Goals (MDG) noting a rapid increase in the number of AIDS orphans and calling it a ‘cause for concern’ (pp47), cautioning that it may cause social disintegration and increase pressure on policy makers. The document proceeds to recommend improved quality of care, with HBC settings being prescribed to be part of this drive. People living with HIV should receive home-based care with institutional support, according to this report, which adds that children and young people affected by the epidemic need community-based protection towards respectful and dignified growth.

In many ways HIV and AIDS has distorted African families in the 21st century, although the study of families has remained a neglected priority on the continent. Similarly, caring relationships in families are no longer top-down, where adults care for children, but new instances are emerging in Zimbabwe where children are caring for their sick HIV–infected parents and each other (NAC, 2006). Grandparents in families, especially female ones, are fast becoming less dependent on remittances from urban employed people, but more relevant as givers of care to many orphans left behind by the urban folk (27% households in 21 Zimbabwean households had this characteristic according to UNICEF, 2004). A UNAIDS study in Uganda
reports of a Rebecca Nakabazzi, an AIDS widow, who lived with her mother, son, siblings and lots of children, making a total of 13 people in a small rural dwelling. This reality contrasts the traditional belief that such a big number of children can only be found under the care of a breadwinning father and home making mother.

Zimbabwe’s Home-Based Care Policy acknowledges this reality, stating that “...20% of the population in Zimbabwe is...HIV positive with 2,000 new cases being reported every week..., which impacts heavily on the already overstretched health delivery system.” (2001: 3). The policy therefore advises that “the future prospective health care delivery has to move from hospitals to home care, in partnership with the community,” which makes sense if terms like ‘home’ and ‘community’ are defined and the dominant role of women in home-based care is acknowledged.

The widely documented feminization of poverty and HIV/AIDS (for example, Zimbabwe Human Development Report, 2006), unfair division of patient care labor and unequal sexual relations between married or casual heterosexual partners whereby men manipulate their superior age, physique, education and social status to impose their ideas, exposing women and girls to HIV and AIDS, invites more thorough gender analysis in the understanding of today’s families. The way patient care labor is divided between men and women is now being challenged more strongly than ever before. Unequal gender relations in families have further meant that marriage alone is no longer, if it ever was, a protective factor against HIV infection for married women. This is because of men’s frequent extra-marital sexual relationships which are fueled by economically motivated migrations, resistance of condom use among married couples, men’s reluctance to disclose their HIV status, as well as their unwillingness to take HIV tests in the first place, and such cultural practices as bereaved wife inheritance (NAC, 2006: 17). Unlike in the past when married women were less prone to sexually transmitted infections than sexually active singles, wives are currently more vulnerable to HIV and have less control over their protection than today’s sexually active singles, who enjoy the convenience of using condoms during their sexual encounters without risking verbal abuse (WHO, 2007).
Finally, caring for the sick now demands more than just emotional bonds, which had been strongly viewed as the glue of family relationships in familist definitions of family. The chronic nature and intensity of HIV-related illnesses, allied with the inconveniences they bring, mean that palliative care now demands professionalism more strongly than ever before. This explains why homed-based caregivers in communities now receive prior training in a broad range of health and social skills and also why they now contest the idea of serving on a voluntary basis. Because of “lack of kits and incentives…,” laments Zimbabwe’s Ministry of Health and Child Welfare (2008: 12), “volunteerism has been ineffective, as most caregivers can no longer forego their income-generating activities for voluntary work in a depressed economy”.

2.3. An overview of the problem of HIV and AIDS in Zimbabwe

Zimbabwe is among Africa’s countries most heavily burdened with HIV, with life expectancy having fallen from an average of 55 years in the 1970’s to 33 years by 2002, according to the 2002 population census. Infant mortality rose from 50 per 1,000 in 1987 to 60 per 1,000 by 2003 (UNGASS, 2008). Although Zimbabwe’s Ministry of Health and Child Welfare (2008) reported a decrease in HIV prevalence from 24% in the late 1990’s to 15.6% by 2007 following a presidential declaration in 2001 that the epidemic was a national disaster, the country’s formal health delivery system is still struggling to cope with volumes of HIV patients. For instance, 342,000 adults and 72,000 children living with HIV were diagnosed to be in need of antiretroviral therapy (ART) in 2004, but only 18,000 adults and 2,097 children were accessing it in 2005. However, there has been an encouraging increase in the number of ART sites from 18 in 2004 to 50 by 2006 and access to these services is improving, especially in areas where there are strong community–led programs of disseminating information about services related to HIV and AIDS. HBC is so far the most vibrant community–led response to HIV and AIDS, which is firmly anchored on the way families are organised and linked to the wider community. This makes the study of how families organize themselves to cope with their challenges within the context of HIV and AIDS an interesting and critical arena.

However, although the declaration of 1994 as the year of the family and HIV/AIDS as a national disaster in Zimbabwe in 2001 stimulated increased attention to families and HIV/AIDS...
respectively, the discussions of these two critical themes have never really been harmonized, but have always run parallel to each other. This is partly because HIV and AIDS has been treated as a purely medical matter with no relation whatsoever to any social phenomenon for a considerable time. On the other hand, dominant views about families around 1994 were flavored by ideologies and theories such as structural functionalism, the systems theory, familism and familialism, which treated families as fixed social institutions that are barely affected by happenings in the world outside.

2.4. An overview of family theories and a critique of traditional family theories

Family theories have substantially influenced social workers’, psychologists’ and psychiatrists’ approaches of handling behavioral disorders and delivering family therapy as well as government policies, with popular education, media, political rhetoric and consumerism being used as vehicles to assert dominant ideals of family (Chambers, 2000). Structural functionalism is one of the theories to pioneer the study of families, having emerged during the industrial revolution in Europe when patriarchal male-headed nuclear families were not just the norm, but a living arrangement that favored the labor requirements of industrialists of the time. With a system of male-headed nuclear families, men could work in industries for long hours without their wives complaining while the idea of supporting a small family comprising one’s wife and biological children only would reduce the number or burden of dependents per breadwinner and minimize the threat of industrial action.

Structural functionalism has taken center stage in family theory debates over the years, being one of the schools to draw theoretical attention to the collectivized study of families (and other social institutions). Its overarching goal is to describe and advise social activity that supports harmony, stability or equilibrium, which directly contrasts the thrust of the critical school, namely to deepen the understanding of conflict and power relations in families. Structural functionalism therefore holds social disharmony as a deviation from the norm, which has given rise to such ideologies as familism, which dominant members of society have manipulated to sustain the social order that favors them. Familism is the view that a family has to be defined by a marriage, a father and mother figure, biological children and gender-specific roles of caring within the
home (done by the mother or wife) and breadwinning outside the home (father or husband). Familism portrays ‘normal’ women as being natural caregivers of children, the aged, terminally ill and other dependent family members. As a result Bozalek (1999) argue that many governments claim that the care of differentially abled members of families is left in the hands of the community, although in reality the term community is used in an amorphous way. In truth, it is women who provide this care on a voluntary basis and they are not compensated in any structured way. Bozalek (2004: 160–162) describes in reference to family profiles of her Social Work students how functionalism influenced rigid ideas about the family course by which an individual is expected to go through distinct life phases until the stage of starting their own family. She observes that families were commonly perceived to be originating from one heterosexual man and woman who “fall in love” and bear biological children together. The suitability of potential daughters–in–law is measured in terms of their capacity to care for a husband and bear children for him. Coupled with men’s obligation to pay lobola for a woman, which is tantamount to buying a wife, this system weakens women’s social position and unfairly privileges men. Popular family discourses and policies in Africa and elsewhere have been strongly flavored by these social systems.

According to structural functionalists, people are organized beings that live within institutions or structures governed by some rules to serve specific functions productively and for the common good. A family, for example, is seen as a structure that serves such functions as reproduction, child care, breadwinning, child education, moral development and so forth. According to this theory, no structure can function properly if there is no equilibrium or if it is in a state of ‘dysfunction’ or ‘pathology’. Rules and norms always have to be in place within the institutions or structures to prevent dysfunctional occurrences, which manifest in the form of symptoms. The systems theory was postulated to explain how structures operate to maintain harmony. The theory argues that systems need to be in place to define roles, relationships and identify the ideal constituents of a structure to keep it intact. The malfunctioning of a component of the structure can only be understood in the context of its relationships with other components and addressing this problem mends the system.

A major functionalist contribution to the systems theory is its emphasis on wholes and parts,
where the former take prominence over the latter. Morgan (1985) sums it up by saying the systems theory consolidated the perception that “the whole is greater than the sum of its parts.” According to the theory, behaviors of individuals cannot be understood outside the context of their family members or background. For instance, a family member who becomes asthmatic has to be in that condition just because his/her father, mother or sibling had a similar problem. The behaviors of constituent parts are understood in terms of their fulfillment of the functions of the whole structure, not their personal motives, struggles (for example, HIV and AIDS) or other individual drives. This has strongly flavored the thinking and therapeutic practice in the ‘psy’ functions, where some developmental psychologists even attempt to trace juvenile delinquency to a youth’s relationship with his/her mother at childhood, ignoring the influence of their peer relationships or personal aspirations. It is in these contentions that the major contributions of functionalism can be accurately located.

Single parent, child-headed, migrant and extended families exist outside the functionalist definition of family. As a result, legal, educational, religious and political institutions refer to heterosexual nuclear models where men control the stakes whenever they talk about families. These institutions have in many ways been used to reinforce ideals about family that consolidate the power of men over women and adults over children. They exclude other diverse types despite Bozalek’s (1999) observation that 72% of a class of social work students had been raised in extended families and only 26% in nuclear ones. Corrective advice from some media, religious or other sources of popular thinking are seemingly deliberately ignored. For example, the Bible, which is the basis of the Christian faith and one of the most ancient sources of religious doctrine, offers many examples to the effect that God Himself commissions a flexible approach to understanding situations, people and, specifically, families. A passage from the book of Joshua 17:3–4 relates an incident in which daughters received rights to land ownership. It says: “But Zelophehad... had no sons, but only daughters. And they came near before Eleazar the priest, before Joshua the son of Nun, and before the rulers, saying, “The Lord commanded Moses to give us an inheritance among our brothers.” Therefore, according to the commandment of the Lord, he gave them an inheritance among their father’s brothers.”

1 ‘Psy’ professions are disciplines such as psychology and psychiatry, which are defined by their focus on and concern for human mental, emotional, cognitive and behavioral attributes.
Functionalism also gave birth to familialism – the idea that there are family boundaries that separate a family from other institutions, occurrences and networks and that the family is so powerful an institution to an individual’s life that other relationships hardly matter (Sewpaul, 2005). The theory’s solution to individual people’s problems is to simply correct relationships within their family, not outside. If relationships outside the family are considered, emphasis has to be on how family systems process that ‘external input’ to sustain its own equilibrium. Within the family, relationships between members are circular not linear, whereby one member affects the other causing him/her to affect another through a ripple effect (Morgan, 1985). In all this, nonetheless, the theory does not accommodate any spill over to other people outside the family.

This has invited a fair amount of criticism and drawn attention to wider dimensions of relationships, with some questioning the attention given to family relationships and others the patterns of relationships – whether they are circular or linear, open to outside influences or closed to family boundaries and so forth. Others have opted to think outside family confines and focus on the roles of time, change and history in and outside the family. For instance, Roseneil (2004) observes that many changes are taking place even in the west where nuclear and cyclic family types were considered normal, with increases in births to young and unmarried mothers, cohabitation, divorce and single parenthood by choice emerging as new diversities in family arrangements. Commenting on this observation, Coleman (200: 241) says “the continuing adherence to a notion of traditional family will not help young people who are already much more accepting of different forms of family.” Weeks et al (2001) makes reference to the “chosen family”, referring to how networks of friendship offer an alternative for young family members to escape or engage with threats and anxieties of their own lives.

HIV–dictated realities have increased the evidence that ‘the family’ can no longer be the solitary source of its HIV-infected members’ palliative care. The high volumes of HIV patients and congestion of public health facilities, high service fees and shortage of family labor to care for patients has invited other trained people from the community to care for their HIV-infected neighbors. NGOs, churches and related institutions have become more prominent partners to families in caring for their sick. A UNAIDS study in Uganda concurs that NGOs have taken
over some roles traditionally considered to be family-specific (2005: 26-27). The report relates the story of a Jajja Home of children, which is essentially a philanthropic grandmother’s residence that was converted into a day care center for the sole purpose of relieving “families that struggle with the extra burden” of caring for orphans and chronically ill patients.

The restricted scope of functionalism has contributed to children’s and women’s struggles to be conflated as ‘family issues’ (for example, child abuse or women abuse is construed as ‘family violence’). Bozalek (1999) notes that this practice underplays the need to cushion individual victims (for example, abused wives, children, and so forth), against the evils of these occurrences, especially in view of realities that HIV and AIDS have introduced. For example, although it is known that some men willfully transmit HIV to unsuspecting women, there is still no legal mechanism to prosecute and punish them, as HIV testing has remained voluntary, all because such matters are treated as aftermaths of intimacy within a family. Women dominate care giving work in their families, but the government has maintained the stance that HBC should rely on community resources in the view that care work is a ‘family’ responsibility even when evidence suggests that these resources have been stretched to the limit (Home Based Care Policy of Zimbabwe, 2001: 3).

Functionalist has been so powerful in shaping early thinking about family that even critical theorists simply questioned the power and control dynamics implied in the theory, but barely questioned the very categorization of processes and objects into functions and structures respectively. Morgan notes how some feminists subsequently referred to Marxism as ‘Marxist functionalism’. This perception of families as ends in themselves eliminates other networks such as friendships, professional networks, church fellowships, non–governmental organisations (NGO) and others to which members of some families belong and are gaining increased relevance in the face of the damaging effects of HIV and AIDS.

This research therefore concurs with Russell’s (1995) position that late nineteenth century industrial European ideals of one employed male breadwinner with a dependent wife and minor children merely represent a transient historical oddity rather than any benchmark for universal domestic normality. Feminist theories have challenged the silence of structural functionalism on
power relations in families, contending that power has to be more equitably shared and women’s position in families and society more seriously acknowledged. Postmodern theories advocate open and pluralistic thinking in analyzing families on a case by case basis. The call now is to deconstruct the family and challenge the patriarchal assumptions thereof, especially the entrenched notion that ‘normal’ families are defined by what they are, should be or by roles that their members should play (Robinson, 2001). HIV and AIDS, which the government of Zimbabwe had by 2001 pronounced a natural disaster, deserves special attention in the study of families that it has affected so much.

2.5. Care giving, receiving and family relationships

Morgan (1996) offers a comprehensive review of the notion of caring in which he observes difficulties in drawing lines between paid and unpaid care work or care in the private and public spheres. He notices that the study of care cannot be separated from that of gender because of women’s dominant involvement in care work and society’s treatment of care as a natural defining feature of femininity. Morgan makes a further distinction between caring for and caring about others, where the former relates to care as a form of work and the latter as a form of love–inspired emotions. Tronto (2008) expands the discussion to view care as a phased process that begins with ‘caring about’ someone before ‘caring for’ them. She adds that ‘caring for’ others prompts ‘care giving’, which is the act of meeting the physical and emotional needs of others, and ‘care receiving’ – the position of benefiting from one’s care, which the care receiver can evaluate in terms of whether the care was sufficient or not. Because of the loose connection between caring for and caring about, Morgan argues, ‘care’ and family are bracketed together in social science analysis, ideological and policy statements without specifying who really provides or receives most care, although ample research evidence point to the heavy involvement of women as caregivers and men as care recipients. We therefore need to question the correctness or naturalness of caring responsibilities in families before gender–insensitive ideologies cement their place in national legislations to worsen what is probably already a sorry situation. Besides women’s involvement in care giving, HIV/AIDS has further dictated children’s participation as caregivers for terminally ill adults or fellow orphaned children.
2.5.1. Care work and gender

Overwhelming evidence, including Tronto (2008) suggests that woman are more heavily involved in care work in and outside the home as well as formal and informal settings because prevailing constructions of motherhood attach care work to women. This is the case whether one is caring for or caring about others. If men increasingly involve themselves in care giving, the question that remains is whether their masculinity will be perceived in the same way as those who do not. To this end, caring can be empowering, fulfilling, disrupting or be either combined with one’s career or classified as part of one’s life. There are many perspectives of analyzing care, but the scope of so doing should be extended beyond gender, caregivers and families and include the following dimensions, according to Morgan (1996):

- The role of age, class, race and ethnicity to care work
- Focus on (caring and power relationships between) both the caregiver and care recipient
- Focus on care within and outside families
- The place of emotional labor versus rationality involved in giving and receiving care

2.6. Conceptual framework of the study

In line with the arguments discussed in this chapter this research’s conceptual framework was the Continuum of Care model, which is illustrated in Fig 1 below.
According to Fig 1 above, the Continuum of Care concept represents a step forward in advancing the care and support for people living with HIV. The World Health Organisation is strongly promoting the Continuum of Care Concept among institutions that provide any form of care and support for disadvantaged members of their communities. The central argument of the concept is that no single entity can provide people living with HIV the entire range of care and support services that they need and no single perspective can provide the true picture of what HIV and AIDS are all about. Fig 1 shows that while provincial and district hospitals provide medical remedies to HIV, faith–based organisations focus on spiritual dimensions and schools, community–based initiatives address the social aspects of the epidemic. None of these dimensions is mutually exclusive. Although the concept has not been fully tested in practice because of resource constraints, it is believed to be the best way to generate the most effective solutions to a problem.

The next chapter describes the methods that the research employed to gather data on family processes within HBC settings according to frameworks provided in this chapter.
Chapter Three

Research Methodology

This chapter describes the design, methods and tools that the study employed to gather information. It further justifies the researcher’s choices of approaches to establish grounds for relying on the study’s results for various purposes.

3.1. Study design

The study’s data was collected and analyzed within the participatory action research (PAR) design (Babbie and Mouton, 2008) in keeping with the critical theory, which emphasizes the importance of using research to empower people by actively, genuinely and influentially involving them in its processes with the ultimate aim of inspiring remedial action for addressing the research problem. To achieve this, the researcher engaged members of the community that provided the data in planning for the exercise and explained the importance of the study to the community, which was represented by members of a support group of people living with HIV and a traditional leader. This enabled local people to own the process of the research. When collecting data interactive techniques were used, which locals easily identified with and enjoyed taking part in (such as using drawings, poetry and proverbial language to communicate their views). Within this design, triangulation – the “practice of asking different questions, seeking different sources and using different methods” (Babbie and Mouton, 2008: 277) in order to overcome “personal biases that stem from single methodologies” (Denzin, 1989: 236) or lone researchers – was applied to obtain good quality data. To this end the research used different orthodox and unorthodox research methods to gather qualitative and quantitative data.

3.2. Study population and sampling procedures

The study population comprised HIV patients and caregivers2 belonging to a support group of people living with HIV and their uninfected partners in rural households of the Eastern

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2 Caregivers are volunteers chosen by community members and their leaders to receive training from the Ministry of Health and Child Welfare and work in liaison with local health centers and non-governmental organisations, with the responsibility of caring for HIV-infected patients on HBC.
Highlands of Manicaland province along Zimbabwe’s eastern border shared with Mozambique where chronically-ill HIV-infected patients are cared for within their homes. These were purposively sampled, with treatment buddies\(^3\) of HIV-infected patients being asked to direct the research to households where HBC for these patients was taking place. The key advantage of purposive sampling is that it isolated the most relevant segment of the population. Field workers of Africa Community Development and Research Center (ACDRC) – a Zimbabwean research institution operating in the study area facilitated the researcher’s entry into the community and, together with treatment buddies, assisted in mapping relevant households. The households that took part in the research were systematically selected from a list of HBC patients, where every third–appearing individual on the list would be visited. Households with bed-ridden patients on the list who suffered from diseases unrelated to HIV were omitted. Twenty–six households, of caregivers and care recipients were randomly picked from six villages that constitute one administrative ward. From these, 14 HBC patients, nine HBC volunteers or caregivers and three people infected with HIV who also provided HBC to others were interviewed, making a total of 26 respondents. These and an additional nine members of families of HBC patients – a total of 35 participants – were allocated to three groups of 12 or 11 members before being engaged in focus group discussions and other interactive exercises of the research. People from the same geographical location were placed into the same discussion group because they experienced similar circumstances.

### 3.3. Data collection procedures

The research collected household and community-level data through household interviews and a focus group discussion involving caregivers and patients on HBC respectively. Household interviews were used to capture information that applied to individual families or households while the focus group discussion informed shared experiences and facilitated debate for exchange learning and, where divergent opinions existed, consensus building. This process was educating and empowering. All 35 participants that the research sampled partook in the focus group discussion to share their experiences of living arrangements, caring relationships, family

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\(^3\) Treatment buddies are individuals who health centers assign to help HIV-infected patients on ART to adhere to their treatment routines. These are the people in whom HIV-infected patients confide regarding their HIV status and personal health.
compositions and their understanding of families in view of the need to care for chronically-ill HIV patients. To do this they were asked to break into smaller discussion groups of 12 members (or slightly less) each to discuss issues and sketch diagrams according the Part C of the Composite Participatory Data Collection Tool in Annex 1.

One-on-one interviews were held per household with one HIV-infected patient who was found willing and able to talk as well as the patient’s caregiver. The interviews focused on what people considered to be key definitive aspects of a family, who they counted as family, why they needed a family, if they needed support from outside the family, if they perceived any changes to their families and how they related giving or receiving HIV-related care to their understanding of family. To place the primary data gathered through these methods into the national policy context, a documentary analysis of policy documents such as the Community Home Based Care Policy of Zimbabwe, National Orphan Care Policy and related others was done to evaluate, through guided content analysis, the inclusiveness of Zimbabwe’s HIV/AIDS and family policies. Before participating, all HBC volunteers and patients were informed about the research, its purpose and they discussed ways of how they could maximize their benefits by participating in the research before those willing to participate signed consent forms agreeing to participate in the research study and expressing their willingness to have their information used for academic purposes.

3.4. Ethical statement

For ethical accountability the research kept the identities of its informants confidential. Local experts, the ACDRC field officers who better understand local people and values, advised the study’s data collection strategy. At the outset, community input was accommodated through an inception meeting of the researcher and ACDRC staff and selected community representatives, including the local chief, at which the former committed himself to give feedback to the community on outcomes of the research. By this the researcher showed respect for local people’s expertise and values. Involving ACDRC in planning the study made the research part of that organization’s ongoing work and increased its social relevance to the study area while the engagement of the local chief before fieldwork was crucial given that locals participate more
comfortably in programs that have the backing of their traditional leaders. HBC volunteers and patients partook in the research willingly, exercising their right to withdraw at any point if they so wished. All the people who agreed to partake in the research were asked to complete a Consent Form (Annex 1) that clearly explained to them what the study was about so that they could commit themselves to it from an informed perspective. To avert possible harm on the respondents, especially critically ill HBC patients, only those strong enough to talk were interviewed. Food hampers were provided to all participants of the study upon the request of the local chief, although the researcher reminded them not to expect food hampers from every other researcher who may require their participation in future.

3.5. Data collection instruments

A semi-structured dialogue guide and focus group discussion thematic guide were used as checklists of the research’s themes and possible probing questions to guide questioning during household interviews and facilitation of the focus group discussion. In addition, the research collected data through the following Participatory Learning and Action\(^4\) (PLA) tools from a menu of 100 available in the International HIV/AIDS Alliance PLA Manual (2006):

3.5.1. **Social networks/relationships diagrams** – sketches that guided participants to locate the family and other social relations that are (un)available to HIV-infected patients and to specify how, if at all, each of them was beneficial

3.5.2. **Daily routine diagrams** – profiles of routine daily activities that take place at each HBC setting from the time of waking up to that of retiring to bed, including possible instances when it becomes necessary to wake up during the night to assist a patient. This tool was combined with the **Division of labor chart**, which identified the gender, age and relationship to the patient of the persons responsible for each task on the daily routine diagram

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\(^4\) Participatory Learning and Action is the approach for conducting research or other activities in given communities by which the people affected by a research problem actively take part in analyzing the situation affecting their well being, exploring solutions for their problems, planning action steps, evaluating the outcomes of the process and taking useful lessons together. The researcher’s role in this is to facilitate a process for mutual learning and joint action planning.
3.5.3. **Resource mapping diagrams** – participants’ sketches of their maps of human, material, financial, technical and other resources within and outside the family that are available to their communities with HIV–related services

3.5.4. **Life story telling** – study participants were asked to tell stories of the lives to exemplify their special experiences with families within HBC settings. They were asked to use proverbial language such as poetry, familiar proverbs or riddles to express themselves.

3.6. **Mechanisms for reliability and trustworthiness**

Triangulation – the practice of employing various study methods and consulting several sources to validate the outcomes of one method or source with data from others – was used to enhance the study’s reliability. This allows a researcher to enjoy the strengths of different methods. Further, the study findings in Chapter 4 are not generalized to all settings, but carefully contextualized to the socioeconomic dynamics of the area and time of the research.

3.7. **Data analysis methods**

Qualitative data was analysed using the grounded theory (Wasserman, et al, 2009) which entails inferring new ideas from research data gathered rather than manipulating the data collection tools and process to support a given idea or theory. Glaser (2002) emphasizes that the grounded theory is a qualitative data analysis tool. “It is essentially a process of coding data (collected) and then grouping those codes into concepts in an increasing hierarchical fashion… Unlike typical hypothesis testing, which begins with the development of hypotheses that are tested with subsequently collected data, in grounded theory everything begins with the data.” (Wasserman, et al, 2009). The grounded theory data analysis methods best suits researches meant for generating knowledge, not testing hypotheses. This research developed research themes or concepts from the diagrams that participants sketched to exemplify their various situations during focus group discussions. These diagrams were scanned and annexed at the end of this report (Annex 2), but neatly reproduced using computer graphical simulations. Similarly, catchy statements through which group discussants expressed their opinions were translated into English and quoted verbatim as life stories. Content analysis of secondary data from policy
documents that the research reviewed was employed to place the research’s primary data into the context of Zimbabwe’s policies.

3.8. Study limitations and assumptions

The study focused on a limited range of comparable scenarios. By targeting a rural setting it missed comparative information on dynamics that characterize urban families caring for HIV–infected clients. Its emphasis on HIV–infection meant excluding other terminal illnesses that are unrelated to HIV, but likely to affect the way families reorganize themselves to cope. However, it made up for this by clearly defining the social context of the findings and assuming that such clarity would guide the design of follow up studies in different settings. The research’s emphasis on HIV may narrow its focus, but undoubtedly the choice to focus on the epidemic is strategic given the severity of its negative impacts on Zimbabwe’s economy and social life.

3.9. Conclusion

The research’s methodology applied an open approach its investigations, where several methods were triangulated within a participatory framework to accommodate multiple possibilities in line with the arguments in Chapter 2, which basically suggest that single or rigid view points or approaches can never provide an objective picture of reality. It is therefore hoped that any possible shortfalls of the research methods that were used can be compensated for by its strength in reflecting the lived experiences of local people and their active involvement in defining their everyday realities. Chapter 4 presents and discusses the findings that were obtained by applying the methods described in this chapter.
Chapter Four

Research Findings and Discussion

The findings presented and discussed in this chapter are based on the opinions and experiences of 26 respondents of household interviews and nine focus group discussants from Wards 1 and 29 of Mutasa North District of Manicaland Province. This number makes up a total sample of 35 research participants, including 25 women and 10 men. However, all statistical data presented in this chapter were derived from the 26 respondents of household interviews. These administrative wards are situated around Katiyo Tea Estate in the Eastern Highlands region of Mutasa North District where Africa Community Development and Research Center (ACDRC) – a Zimbabwean NGO – works with people living with HIV on programs to alleviate the effects of HIV and AIDS. Table 4.1 below shows the distribution of the sampled population by gender.

<table>
<thead>
<tr>
<th>Category of respondent</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>HBC volunteers without HIV</td>
<td>1</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>HBC patients</td>
<td>6</td>
<td>8</td>
<td>14</td>
</tr>
<tr>
<td>HBC volunteers with HIV</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>8</strong></td>
<td><strong>18</strong></td>
<td><strong>26</strong></td>
</tr>
</tbody>
</table>

As can be seen in Table 4.1 above, 69% of the interview respondents were women. Of the 26 respondents, 14 were HIV–infected patients receiving HBC, including eight women and six men. Nine respondents were HBC volunteers not infected with HIV and three were HIV–infected HBC volunteers. Therefore 14 HBC patients or clients and 12 HBC volunteers provided the opinions that are elaborated on in this chapter.

The research’s findings will in this chapter be presented and discussed under five themes as follows:

a. Compositions of households and families in HBC settings
b. Purposes and priorities of families in HBC settings
c. Relationships of family members within HBC settings
d. Organisation of HBC and interdependences between families in HBC settings

e. Cross–cutting themes

4.1. Compositions of households and families in HBC settings

Some 26 people who informed this research resided in the farm compound of the government–managed Katiyo Tea Estate and the other nine came from the rural villages surrounding the tea estate. Families and households in these two settlements had different compositions because their households served different purposes. In rural villages where people owned the land and had established their houses to meet the needs of their children and close relatives, families were found living in the same households whereas households in farm compounds harbored people who had no family ties at all because land belonged to the tea estate and their houses were specifically for labor accommodation. Accordingly, it was quite common in the tea estate compound to find a married couple with three or so children occupying half of a four–roomed house shared with a single young man or woman. In this sense it is clear that land and property ownership rights of given families can be key determinants of whether or not a household would be the central place in which to find a family. On this evidence it is more likely to find a family living in the same household if they own the land and/or residential property than if accommodation is rented or provided by a private employer exclusively for its employees.

However, when asked about compositions of their households during interviews, respondents listed members of what they called ‘family’ only and they ignored those with whom they shared accommodation. One of the reason for this is that there was very little else apart from a common residential space that people sharing accommodation at the tea estate’s compound had in common, with some mentioning that they preferred to use different entry doors into the shared houses and could spend days without talking to their housemates. One group of discussants observed that “the major criterion for sharing accommodation in the compound was not our interests or relations, but the estate management’s views of what could maximize production”. Nevertheless, group discussants overwhelmingly believed that in most shared houses, especially where married couples lived together with single young adults, sneaky intimate relationships were rife between a married spouse and a housemate or neighbor of the opposite sex. These
relationships and their role in accelerating the spread of HIV increased the salience of intimacy issues in the discussions about families and households. In addition, this finding affirmed the view that marriage is no longer a “protective factor” or safe place for hiding from HIV–infection (ZNASP, 2006). It is surprising that while familism holds that marriage ties distinguish ‘normal’ from ‘abnormal’ or ‘deviant’ families, it remains silent on intimacy issues in spite of their power to keep marriages intact, protect spouses from HIV–infection and prevent what functionalists prefer to call ‘family break up” or “pathology”. The issues of intimacy associated with living arrangements in households within the compounds that caught the attention of group discussants are expressed in the terms quoted from selected groups as follows:

- “Many married women do not get sexual satisfaction from their marriages but cannot express their true feelings to their husbands for fear of being labeled prostitutes, so if they live together with attractive and sexually available young singles they go for them.”

- “Many men are sexually unavailable to their wives because either they spend many days away from home working or trading in Mozambique where they will probably be sexually active or they work as night guards, which keeps them away from their spouses at the most critical time.”

- “The combination of sharing accommodation with someone who is intimately available and the wide popularity of sexually–explicit audiovisual materials such as pornography in the compound increase the convenience of multiple concurrent sexual partnerships wherever accommodation is shared and/or crowded.”

- “In spite of the clear evidence of multiple concurrent sexual partnerships in the compound, men do not take kindly a proposal from their wives to use condoms.”

The above statements clearly show that there is so much more to a household’s or family’s composition than mere numbers of occupants. This research proved that people are quick to think about the people who share such family resources as food, blankets and finances – the people they count as family – when asked about members of their households, although a lot of other things are shared wherever accommodation is communal. An exploration of a wide spectrum of dynamics in settings where people share living space, evidently, can open up discussions about how household compositions can be a source of conflict between families. This indicates that community problems such as HIV and AIDS are better understood once the
term household is broadened to include not just people sharing living space, but a range of social
dynamics that emerge from people’s strategies of solving their personal struggles within various
household arrangements. Indeed, in Katiyo Tea Estates, one of the leading activities of HBC
volunteers is to raise awareness of the dangers of multiple concurrent sexual partnerships that are
fueled by the sharing of accommodation. This cannot happen if the terms ‘family’ and
‘household’ continue to be treated as two sides of the same coin.

The compositions of families emerged to be somewhat more straightforward, and respondents
identified members of their families as those who depended on and supported each other for
labor, financial needs, emotional needs and material needs. The research showed that the marital
status of senior adults or heads of households and families is still a dominant variable for
defining families, where references to ‘single parent families’, ‘step parent families’ and so forth
holds true even for families that informed this research. However, the study showed that today’s
families, especially in HBC settings, are not always, if at all, made up of married parents and
their biological children because of HIV and AIDS, which has increased the population of
orphans, widows and, to a very slight extent, widowers. The chart below shows that although
most families in HBCC settings were founded on marriages, other arrangements existed and
were feasible.

![Fig 4.1: Marital status of interview respondents](chart.png)

According to Fig 4.1 above, 14 out of 26 respondents were married. Seven respondents had been
widowed, mostly by HIV and AIDS, and four had divorced or been separated. One woman was
single.
These figures present a strong challenge to the centrality that marriages occupy in conventional definitions of ‘the family’ that are based on structural functionalism. First, 11 of the 26 respondents who were previously married had adopted a new status through widowhood and divorce or separation, but were coping as heads of their families. Interestingly, 10 of these were women, with all six widows identifying HIV–related illnesses as the cause of their husbands’ deaths. This pattern tallies with the preamble to the Zimbabwe National AIDS Strategic Plan 2006–2010 (NAC, 2006), which states that the epidemic has claimed lives of male breadwinners in many families, leaving economically vulnerable widows burdened with the guardianship of many orphans. This raises serious questions about the idea of continuing to associate men with breadwinning in families and women with economic dependency. Further analysis showed that two of the four divorcees in the sample had left their husbands after disclosing their positive HIV status while the only single woman in the respondents’ sample was 31 years old and she was coping with singleness even at an age that society in Zimbabwe widely regards to be ideally ripe for one to be firmly settled in a marriage. She was remaining single because she was living with HIV and avoiding being sexually active for the sake of her health.

In addition, although biological children of adults interviewed in this research made up the largest fraction of most families and households, not all these children financially depended on their parents entirely. Economic challenges that face families where terminally ill people are cared for in the home have meant that every family member had to partake in a profitable economic activity even when attending school. For example, a child can carry some fruit for sale to school, which has meant that most members contribute towards family or household income. Table 4.2 below shows that members of households and families of the 26 sampled HBC patients and volunteers did not entirely depend on one breadwinner, but were enterprising in many ways.

<table>
<thead>
<tr>
<th>Family members’ preoccupation</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formally employed</td>
<td>8</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>Self employed</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Piece – work</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Farming</td>
<td>5</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>School going</td>
<td>20</td>
<td>23</td>
<td>43</td>
</tr>
<tr>
<td>Job seeking</td>
<td>8</td>
<td>0</td>
<td>8</td>
</tr>
</tbody>
</table>
Table 4.2: Economic activities of family members

<table>
<thead>
<tr>
<th>Family members’ preoccupation</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Household laborer</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Minor (preschool age)</td>
<td>6</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Home making spouse</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>School drop out</td>
<td>0</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Terminally ill</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>51</td>
<td>46</td>
<td>97</td>
</tr>
</tbody>
</table>

Dependents per household head 4

Table 4.2 above indicates that 12 members of the respondents’ families and households were formally employed, although only half of these were female. Men’s domination of formal employment was evident in that all the eight people who were job-seeking were men. Equal numbers of men and women added up to the 10 who were farmers. The actual dependents included two terminally ill members, 43 school goers and seven minors of preschool age. It is noteworthy that female household and family members continued to lag behind in participation in economically empowering ventures, where all three family workers, all four school drop outs and the only home making spouse (otherwise termed fulltime housewife) were women. Although these four school drop outs were orphans, it is surprising that all male orphans were attending school! Given the sample size of 26 respondents who were heads of their families and households that were made up of 97 members, the average dependency ratio in all represented families was 1 family head to 4 dependents, although the dependency relationship was not necessarily financial. In many families the people who earned an income contributed part of their earnings towards the common family pool of income to meet the household’s needs such as food while they used the rest to procure personal belongings such as clothes, toiletries and related utilities. In few unique cases some family members assisted the head of the family to meet the expenses of educating younger members. This contradicts familist ideals where a single male breadwinner lives with a trail of economic dependents.

Each of the 35 families represented at focus group discussions included at least one paternal, maternal or absolute orphan. As a result of higher paternal mortality in the Eastern Highlands

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5 A paternal orphan is a child whose father died while a maternal orphan refers to a child who lost its mother and an absolute orphan is the one without both parents.
as evidenced by the sizeable number of widows in Fig 4.1 on page 32, there were more paternal orphans in the respondents’ families and households than maternal and absolute orphans. The existence of orphans made relationships between step parents and step children a critical issue for discussion concerning HBC settings, with discussants reporting that orphans, especially maternal ones, were victims of emotional abuse from step mothers. They quoted a proverb in the local language that says “nherera inoguta musi wafa mai”, which when laterally translated means that “an orphan eats his/her last decent meal on the day that his/her mother dies”. The table below deeply explores realities of living arrangements that faced different types of orphans.

<table>
<thead>
<tr>
<th>Orphan type</th>
<th>Type of alternative family</th>
<th>Commonest challenges faced</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal orphan</td>
<td>Step–parent headed family if father remarry, or grandparent family if father abandons children to live with a lover, who happens to hate the children</td>
<td>The threat of emotional and physical abuse from some step mothers is high. Common forms thereof are constant reminders of the children’s deceased mothers, deprivation of food and denial of opportunities to spend time with fathers. In the worst circumstances children run away to work for other families or to live with their grandparents, who however are normally too old to work and earn enough income for decent livelihoods as explained below.</td>
</tr>
<tr>
<td>Paternal orphan</td>
<td>Grandparent–headed family (if mother emigrates to a different location in search of income opportunities) or single female parent–headed family</td>
<td>Orphans who remain with their mother who previously was economically dependent on her husband can live in poverty but they continue to receive love. Greedy male in–laws may loot properties of the deceased to leave the family destitute. Grandparents are normally too aged and poor to work, so they assign most work to the orphans at the expense of their studies. Grandparents normally care for many orphans at a time, which reduces the share of food per child. Female orphans can be forced to abandon school and hope to get married at a young age.</td>
</tr>
<tr>
<td>Absolute orphans (or abandoned children)</td>
<td>Child–headed family or grandparent–headed family</td>
<td>Child–headed families are most burdensome to the oldest child who has to sacrifice a lot of his/her personal needs, including play time, for the well being of younger siblings. Children staying alone are at high risk of sexual abuse during the nights and have limited sources of psychosocial support. They receive some supplies of food from the chief, well wishers and NGOs. Girls marry early or resort to prostitution to survive.</td>
</tr>
</tbody>
</table>
From the above table it is clear that:

- Biological parents are not always the central ingredient for family ‘functionality’ because the extended family and community offers some safety nets.

- Children have the capacity to cope with the loss of parents either to death or through abandonment, although they face various challenges. Such losses are not as disastrous as implied in functionalist terms.

- Shelter, food and clothing seem to be the things of value around which families organise themselves. Relationships remain the glue that keeps families intact, but it does not matter who relates with who, and life without parents is very much manageable.

4.2. Purposes and priorities of families in HBC settings

This study showed that the priorities and purposes for which people join new families or remain in old ones is an important theme for analyzing HBC settings. The findings on family and household compositions above and their discussion show that families do not serve a given set of rigidly defined functions, but people create or join families for their individual purposes and priorities. Therefore the purposes of families in various settings should be defined by the members thereof. According to this study, HIV and AIDS caused or worsened poverty in the households that it affected, yet all the families that informed this research were severely affected. As a result survival became the topmost priority of families, whereby individual members’ convergence was primarily to make sure that food would be available on the table and there would be a roof above everyone’s head. For example, survival needs had seen four girls from some families of the 26 respondents being forced out of school in order to add more hands to their families’ teams of hired labor. Group discussants identified the following practices as common symptoms of how basic survival is the top priority within HBC settings:

- *Multiple concurrent sexual partnerships between married men or women and opposite sex singles or married people*: marriage does not restrict women, including those living with HIV, from indulging in concurrent sexual partnerships with other men if these can support them financially, especially with the widely known assurance that condoms can prevent the further spread of HIV. These are common among spouses who found themselves in
unhappy marriages (for example, those forced into marriages, those in polygamous marriages, and so forth).

- The pledging of girls from poor families to become wives of wealthier men who could be married to other women – a system called ‘Kuzvarira’ in the local Shona language: families can survive on the marriage of young girls to wealthy men when these young girls exploit their intimate closeness to their new found husbands to manipulate them into sending money and groceries to their siblings and parents. Six of the 25 female participants of group discussions had been married under these circumstances, two of them at the ages of 14 and 16 years respectively, four at between 18 and 19 years and all of them at the expense of their personal endeavors including education. In such marriages intimacy and reproduction are not as important priorities as they are portrayed in functionalist theories. The life story of Dede (pseudonym) in Box 1 below exemplifies the extremity of some survival–inspired decisions involving the marriage of young girls.

**Box 1: A life story**

**Dede and her almost stolen dreams**

My name is Dede (pseudonym). I witnessed in shock the divorce of my parents when I was only 14 years old. Neither my father nor my mother was keen to accommodate me because my father was determined to remarry, and his lover did not want anything to do with his past, least of all me. My mother on the other hand did not want me around her in case she too would find a lover of her own, so I was sent to stay with my grandmother who could not afford my educational expenses. I had to abandon school and join a certain family as their domestic laborer, earning very little. I did not care about the remuneration because at least I had a place to stay and be fed. Later on, my elder sister invited me to stay with her and on one of my days there her husband raped me. My sister forbade me from reporting the matter to the police because she would lose her husband’s financial support if he got arrested. In agreement with her husband, she encouraged me to become the second wife of her husband to which I consented after shedding off the bitterness that was heavy in my heart. When I discovered through an HIV test that the rape had exposed me to HIV I could not contain my hatred for my husband and yet I was not ready to disclose my HIV–positive status to him, fearing to hurt my sister. I also considered the likelihood that she could believe that I was the one who had infected her husband, not the other way round. As a result I quietly walked out of the marriage and started a new life at the
tea estate. I joined the support group of people living with HIV, which today has helped me to be strong. The support group has been like a family to me, I should say. I have attended many seminars that have exposed me to more knowledge of keeping myself healthy. I think I am making it, now at 40. The man who raped me is now late, but I long forgave him. My experience taught me that not all HIV–infected people are sexually immoral, but they can be victims of desperate situations because of poverty like me. So they need to be loved. As a result I do not care about being infected with HIV myself and have chosen to serve as a HBC volunteer. I am enjoying it all!

The above practices and Dede’s life story demonstrate that survival priorities have forced other human values down the rank order. One such value that discussants identified as having been sacrificed for personal survival is love. “Everyone in a family, whether by birth or by circumstances such as poverty, wants to be loved”, said one respondent, “but poverty places you into a position where you say ‘I do not care even if they treat me like a dog, so long as I have food on my table at the end of the day’”. To ever talk about ‘family functions’ or ‘family values’ becomes misplaced here when individuals in families evidently set and regard their own priorities and dictate what families should do for them, not the other way round. In HBC settings survival is apparently the primary motivation why people remain in or join new families. Dede’s story shows how an individual can switch from one family to another in search of their priorities as opposed to enduring hardships in their families of birth just in order to maintain family values or the family structure intact.

4.3. Emerging relationships in families within HBC settings

Relationships within HBC settings, according to this study, go well beyond one’s immediate family of parents, guardians, siblings and close relations to include several networks outside households within the continuum of care framework described and illustrated in on page 21. To understand these relationships, participants of focus group discussions were asked to sketch a map showing places in their communities where they accessed their most important survival needs, especially considering that personal survival was identified as the leading priority of being in a family. Three maps with varying amounts of detail were sketched and are in Annex 2 while
their combined impressions were synthesized into one map on the computer. From the maps, the following are inescapable relationships outside family ties that are important to HBC settings:

4.3.1. Support groups and ‘treatment buddies’ – Dede referred her support group as her family after she had been betrayed by a sister’s husband and this sister had protected him from prosecution. Respondents of this research described support groups as sources of peer counseling and a platform for sharing their problems and exploring solutions. In these support groups each person living with HIV was paired with someone they really trusted with whom they discussed their deepest felt concerns about life and shared reminders of when to take routine medication. These buddies became closer than a spouse to most female HBC patients, especially when they were considering whether, when and how to disclose their HIV status to their spouses as well as to encourage them to take the HIV test themselves. Support groups also served as a front for HBC patients to pool resources and generate income for personal survival. On Wednesdays, which are traditionally reserved for people in the area to rest from their agricultural work, support group members visit communities to raise awareness about various HIV and AIDS matters. Part of the awareness initiative is to educate members of HBC patients’ families on how to provide follow up care in between the visits of HBC volunteers. Intriguingly, HBC volunteers claimed that HBC patients experienced worst forms of discrimination and stigma from their close relatives or family members, which is contrary to functionalist view that caring for the sick is an automatic family responsibility. It is during these visits that HBC volunteers extend counseling services, spiritual support and palliative care to bed–ridden HBC patients. Child–headed families are given material support in the form of food packs during these visits.

4.3.2. Support groups, the local clinic and the district hospital – support groups receive further education on how to manage HIV from their nearest clinic at Katiyo Tea Estate. They now share a very personalized relationship with the nursing sister who it is running the clinic. HIV tests are done at this clinic and those diagnosed with HIV receive initial counseling and are referred to the district hospital for CD4 count – a blood test that gauges the concentration of the HIV virus in one’s blood to determine whether they are due for ART or opportunistic infections (OI) treatment. However, the hospital is 20
kilometers away from the community of the study’s respondents, which makes its services expensive as much as they are critical. The clinic is the meeting place for support groups, members of which take turns to maintain hygiene by cleaning its premises. People suspecting that they could be infected with HIV become closer to the nurse at the clinic than to their spouses, visiting her secretly to receive preliminary counseling before getting HIV tested.

- **NGOs** – informants of this study identified Farm Orphan Support Trust (FOST), World Vision, Africare and Plan International as key NGO partners that distributed relief food packs to families affected by HIV and AIDS as well as HBC health kits that HBC volunteers use in providing palliative care to patients. Family AIDS and Counseling Trust (FACT), New–Life and Arise were acknowledged for their counseling services while ACDRC and the Biomedical Research Institute were mentioned for their involvement of communities in public health, social and HIV and AIDS research.

- **Local leaders and the National AIDS Council** – the chiefs of the area have a system of reserving part of the common land available to them for growing crops that are dedicated to the food security of orphans, widows and other poor members of society. The National AIDS Council (NAC) is the coordinating body of all responses to HIV and AIDS. Support groups report the progress of their activities and challenges to this body every month via District AIDS Action Committees to which they are members.

4.3.3. **Katiyo Tea Estate** – this is the employer and provider of accommodation to 26 of the group discussants of this study. At the time of collecting research data the farming estate was bankrupt and its employees were experiencing severe economic challenges, having not been paid for six months prior to the study. This could be one reason why survival was identified as the leading reason for one’s subscription to a given family arrangement. On the other hand, though, it was the estate that established the clinic that improved local people’s access to health services.

Fig 4.2 overleaf shows essential community resources that support HBC settings.
According to Fig 4.2 above, health facilities, shopping centers, a school, the tea estate, villages and farm compounds were the readily retrievable features of the support network outside one’s family that was available to HBC settings. Interestingly, one group strongly emphasized the limited sources of ‘unprotected water’ in their community, including at the clinic. Fig 4.2 therefore shows that facilities and circumstances in one’s physical environment can dictate the place that families occupy in one’s life. It also shows that families have no social boundaries from other institutions, but are woven smoothly into their immediate environments.

4.4. Organisation of HBC and interdependences between families in HBC settings

The research explored how families organised themselves in HBC settings to attend to their own and HBC patients’ needs at the same time. Interview respondents were asked to account for their hourly and daily activities, which were then consolidated into Daily activity schedules below.
The above table was developed by shading the hours during which most respondents reportedly performed specific activities. As shown above, the way roles were shared between people in various capacities and health conditions in HBC settings was key to defining what families affected with HIV occupied themselves with. HBC volunteers’ visits to HBC patients normally consumed six hours between 1400 and 1800, especially on Wednesdays – the day that local chiefs reserved for rest from farming activities. Agricultural work, which occupied almost every household, took place during mornings from 0300 to around 1000, as farmers sought to avoid excessive sun heat, and this routine was applied by families that owned adequate agricultural equipment and draught power. Poorer households extended their daily agricultural times to around 1200 because they first had to work as hired labor on other families’ fields for several hours before turning to their own later in the morning. Thereafter, farmers would rest before resuming work in the fields from 1500 to 1800. Two types of formally employed labor stood out: those who worked on day shifts and those who served during the night (for example, guards). Night guards worked longer hours from 1800 to 0600 the next day, but afforded very little time to sleep because they also practiced agriculture to complement their incomes. This meant that they would sleep from 0700 to 1100 after which they would spend the rest of their days farming. Women in these jobs experienced worse stress because they had to carry out domestic chores of cooking, dish washing, laundry and cleaning in addition to agricultural work. In fact in all cases women and girls assumed all domestic tasks in their homes and usually men and boys would be relaxing during the times when women carried out these tasks, which

Table 4.4: Schedule of commonest daily activities in HBC settings

<table>
<thead>
<tr>
<th>Key activities</th>
<th>0500–0800</th>
<th>0900–1400</th>
<th>1500–2000</th>
<th>2100–0400</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agricultural activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visits to HBC patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Formal employment – day</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Formal employment – night</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Domestic chores, for example, cooking</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income – generating activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relaxation/resting – men and boys</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relaxation/resting – women and girls</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleeping</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
occupied about three hours around meal times. The table below shows the activities that each type of person in HBC settings performed.

**Table 4.5: Individual family members’ daily activity schedule**

<table>
<thead>
<tr>
<th>Category of household member</th>
<th>0500–0800</th>
<th>0900–1400</th>
<th>1500–2000</th>
<th>2100–0400</th>
</tr>
</thead>
<tbody>
<tr>
<td>Terminally ill HBC patients–both sexes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stable HBC patients – male</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stable HBC patients – female</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed HBC volunteers (night shift)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed HBC volunteers – male (day)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed HBC volunteers–female (day)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HBC Volunteers – farmers – female</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HBC Volunteers – farmers – male</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School going boys</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School going girls</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male school leavers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female school leavers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preschool aged boys</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preschool aged girls</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Key: Agricultural work, Household chores, Relaxation, School, Formal employment, Sleeping

As indicated above, productive activities of agriculture and formal employment dominated activities of all adult family members regardless of their health or HIV status, although the terminally ill HBC patients had more resting time. That is thanks to educational sessions that they attend at the local clinics, which has emphasized to them that they are better off preserving their health than straining themselves by working too hard. In general men and boys have more resting time than women and girls because boys are customarily exempted from household chores while female family members are considered to be custodians of that business. This has implications on gender equality that are discussed in detail in section 4.5 of this report.

**4.5. Cross cutting themes**

The major themes that cut across the research’s findings presented and discussed in this chapter include gender in HBC settings, the distribution of privilege or vulnerability in families and the salience of family policies in HBC settings.
4.5.1. Gender dynamics in HBC settings

Age differences between married men and their spouses can be a strong foundation for contestations of decision making processes among married couples, according to this study. Ages of the married respondents of this research ranged between 22 years and 69 years, with married women being generally younger than married men. The most senior of all married women who informed this research was 45 years old, which is two years less than the average age of married men. Apart from one man who was 22 years old, ages of married men ranged between 47 and 69 years. Married women’s average age was 34 years and men’s 47. This could be coincidental and specific to the study’s sample but, according to group discussants, these age gaps mirrored the reality in most marriages, especially in the Eastern Highlands where girls from poor families are commonly forced into marriages to men who are twice as old as them. The existence of huge age gaps between men and women whether in families or at meetings such as this research’s focus group discussions can easily give men an advantage over women to impose unfavorable decisions and justify them on grounds of their seniority. Gender and seniority therefore combine to give men unfair privileges over women.

Participants of focus group discussions concurred that women generally married husbands who were by far older than them just so as to fulfill societal expectations, but that created generation gaps too wide to accommodate fruitful communication between wives and their husbands. This resulted in women finding themselves compelled to accept all their husbands’ decisions even if they disagreed, especially if these age gaps coincided with women’s economic dependency on their husbands. Now, most if not all married women who informed this research were economically dependent on their husbands, with some having been forced into polygamous marriages to men of their fathers’ ages at the expense of their education because of poverty. As shown in the table below, women were generally less educated than men.

<table>
<thead>
<tr>
<th>Highest education level reached</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never attended school</td>
<td>1</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Primary education before Grade 7</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Grade 7</td>
<td>4</td>
<td>3</td>
<td>7</td>
</tr>
</tbody>
</table>
Table 4.6: Respondents’ educational status

<table>
<thead>
<tr>
<th>Highest education level reached</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Form 2</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Form 3</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Form 4</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
<td>18</td>
<td>26</td>
</tr>
</tbody>
</table>

As Table 4.3 indicates, eight out of the nine respondents who had never attended school were women. Further enquiry showed that three of these eight were married and they reported that their illiteracy placed them at a disadvantage during negotiations for decision making. Three of four respondents who had attended primary school and abandoned school before sitting for Grade 7 Certificate examinations were all married women. The study did not collect data on the educational status of each woman’s spouse, but interview respondents and group discussants confirmed that all women who partook in the research were far less educated and much younger than their husbands and that created communication problems.

As discussed in section 4.1 of this chapter, the inability of women to communicate their intimate feelings to their husbands, which is typical among couples that are separated by wide age margins or generation gaps has seen some women seeking sexual gratification outside their marriages from younger men who are more inclined to listen to their views and feelings. In the same way women’s difficulties of communicating their feelings to their older husbands inhibited them from insisting on using condoms for sexual intercourse even as multiple concurrent sexual partnerships are known to be highly prevalent. This sustains the rapid and circular spread of HIV and, given the frequent temporary emigrations of local people into Mozambique, this unfortunate trend occurred on either side of the border dividing the two countries.

HBC volunteers extended the subject to mention that most local married men used the privileged position of their seniority and economic power over women to turn down not only their wives’ advice to use condoms for sex, but also to resist calls to take HIV tests. The nine HBC volunteers who informed the evaluation cared for 68 patients, 10 of them children. Of the 58 adult HBC patients, only 17 were men while 41 were women. This illustrates better health–seeking behavior among the latter than the former. It is therefore not surprising why the ratio of widows to widowers in the sample of respondents was 8 widows to 1 widower. “Women in our
community take awareness campaigns seriously and they take HIV tests in order to take early
treatment and live positively with HIV for longer,” one HIV–infected HBC volunteer explained.
“Men (on the other hand) do not want to take HIV tests because they expect a positive result
given that most of them indulge in unprotected extra–marital sexual relationships.” The table
below, which was extracted from records of the Katiyo Estate private clinic, shows statistics of
the HIV tests that were carried out in November 2010.

<table>
<thead>
<tr>
<th>Table 4.7: Gender and uptake of HIV tests</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV status of tested clients</td>
</tr>
<tr>
<td>--------------------------------</td>
</tr>
<tr>
<td>HIV–tested – HIV-negative</td>
</tr>
<tr>
<td>HIV–tested – HIV-positive</td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
</tbody>
</table>

Table 4.4 above shows that 15 women and 11 men were tested for HIV, and that none of the
tested men was diagnosed with HIV while three women tested positive. This was interpreted by
the nurse at the clinic as evidence that the few men who took HIV tests were those who had the
confidence that they were free from HIV on account of their safe sexual practices. “In contrast,
women take HIV tests once they feel unwell for a long time and they do not fear the possibility of
being HIV–infected. As a result women in the study area live longer with HIV than men,
according to the nurse who further said, “I wonder why most men still cannot face an HIV test
result when there is evidence that only one person on treatment has died in the last five years”.

This explains why male HBC volunteers are fewer than female ones. This study is indicative of
low male participation as well, with only 10 of the 35 focus group discussants and 8 of the 26
interview respondents being men. When probed further as to why male participation on a matter
that is so serious to human life was low, group discussants said that men generally considered all
care giving work to be a women’s domain and those who actively partook as HBC volunteers
were viewed as inadequately masculine. “People actually laugh at us and say that we are only
short of putting on women’s dresses”, a male HBC volunteers reported. However, the few male
HBC volunteers dominate leadership positions of support groups – a sign that patriarchal ways of
doing things still inhibits women’s social progress to decision making position even in circles
where they have the numbers.
The final gender issue that concerned HBC volunteers was the unrewarding nature of care work, especially they noticed that staff of NGOs that supported them were handsomely paid. “After spending the day visiting the sick,” one woman complained, “I am the one who is expected at my home to prepare food for the family.” These gender dimensions are more exhaustively explored among policy issues below.

4.5.2. Family policies and programs versus realities in HBC settings

Key family policies, especially those influenced by new realities of HIV and AIDS, were reviewed to assess their responsiveness and application to various situations in which families affected by HIV and AIDS find themselves in. These include the National Orphan Care Policy of Zimbabwe, Birth and Death Registration Act, ZNASP 2006–2010, Inheritance laws and the Home–Based Care Policy. The National Orphan Care Policy essentially offers six alternatives of caring for an orphaned child. Its major strength is that it applies to all orphans irrespective of the causes of their parent(s) death. However, the policy prescribes that a child should grow within an ideal ‘family environment’ without clearly defining this environment, although subsequent texts mention the presence in that family environment of a father and mother figure. Accordingly, children’s homes or childcare centers in Zimbabwe have officers whose job titles are ‘mothers’, ‘fathers’, ‘uncles’ and ‘aunts’. Whether children in these embrace these people as their real blood relatives when they see them retiring home after 4pm, leaving them alone is a contestable point.

Policies for birth and death registration have not been reviewed for a long time and are based on familist ideals of ‘the family’ because a child is still expected to prove their paternity and maternity in order to secure their birth certificates. This study’s respondents and discussants reported that widows, single mothers and grandparents in their communities who cared for orphans were experiencing serious challenges in registering the births of these as a result. That aside, although birth certificate is every child’s passport for writing major school examinations and security other citizenship or identity and travel documents, home affairs offices that process these documents are found at major shopping centers, which are a distance away for most rural communities. One widow thus said: “securing a child’s birth certificate is like a major project
that one has to endure sleepless nights to plan because a lot of money is needed in bus fares, but there is no guarantee of getting it because of long queues and long lists of prerequisites.”

ZNASP 2006–2010 was developed out of the 199 AIDS Policy into a guiding document for action by all sectors of the society. Its development was the work of a wide spectrum of various HIV and AIDS activists and practitioners. The document is in effect for five years at a time, which allows room for review to address situational changes.

Inheritance laws still have a lot of loopholes because they legitimize extra marital relationships by acknowledging both customary and certified marriages. Some men take advantage of this by marrying one wife officially and secretly marrying several more the customary way. Women cannot do the same, as extra marital affairs are obviously convenient for men and shameful if entered into by women. Deaths of men who were secretly polygamous have been sources of serious conflict involving the surviving wives and their children, with those married customarily acceptable channels usually emerging the victims.

HBC volunteers further challenged the national budget formulation process, especially for totally ignoring HBC work, and not reserving finances for remunerating or supporting it (for example, by replenishing health kits, funding further training, and so on). They expressed dissatisfaction in the government’s continued treatment of this kind of work as an obligation for women in communities and assuming that these have resources, time and energy to carry it out for free.

4.5.3. The place of privilege and vulnerability in family discourses

Through evidence of HBC patients and volunteers in this study generally demonstrated that the behavior and experiences of people are neither always nor entirely explicable in terms of the structure or make up of their families, but what each individual is able to be and to do. Further, people in families seem to accept or take comfort the existing status quo (for example, men’s domination of decision making in families) not because they agree but constructions of gender and generation in families have become internalized through the workings of power dynamics inherent in people's everyday courses of coping with emerging challenges such as the need to
care for the sick. The life story of Dede in Box 1, especially her resolve to rather cohabit with a rapist as her husband than report him to the police, can be explained in similar terms. This study’s focus group discussions offered this kind of platform and enabled people to reconsider what they termed household or family members and to broaden their scopes of discussing the various living arrangements vis-à-vis HIV and AIDS. Dede’s life story further illustrates how a young girl forced into a polygamous marriage made a breakthrough in life at the very moment that she decided to pull out of an unsatisfying relationship without consulting her parents and still managed to cope. In fact the story demonstrates that what are commonly referred to as ‘family decisions’ do not reflect the opinion of anyone else in the family except the parents. There could therefore be called parental decisions. Such decisions can be highly exploitative if, as in the case of Dede they, are made without the input of subject.

4.6. Conclusions

This study’s findings show that the relationship between families and HIV/AIDS is cyclical, where on one hand the spread of HIV in the study area was fueled by the way families organised themselves within local cultural or traditional values and on the other hand families’ attempts to respond to the epidemic forced them to rearrange their ways of living. This rearranging has meant diverse relationships between families and households where patients have received care from members of other families and the act of care giving surpassed such simple emotional requirements as love to demand high level technical proficiency and costly material resources. Gender and generation emerged defining factors of caring relationships between caregivers and care receivers, where women found themselves predominantly more on the care giving than the care receiving end and vice versa. In the process, gender defined which community members enjoyed which privileges at whose expense. Women, without protection from culture, dominant social norms, national policies and legislation, experienced diverse vulnerabilities and men: numerous privileges. The next chapter discusses in detail the implications of these findings.
Chapter Five

Conclusions and Recommendations

5.1. Overview of the research findings

The research collected information from 35 participants, 26 of them including bed-ridden patients receiving HBC and caregivers. Its inclusion of nine members of families of patients on HBC enabled the study to collect information on views, attitudes and practices of people in families who may not be infected HIV or involved in the care of those infected.

This study’s findings demonstrate that people do not necessarily belong to families, but they do or act families (Morgan, 1996) as they seek to cope with various realities such as the need to secure basic needs like food after losing a breadwinning spouse or parent. Through social processes such as human migration, formal employment, marriages and divorce, people from different families can find themselves cohabiting and sharing a wide range of material and emotional resources, including intimacy, but without viewing each other as members of one family. HIV is contracted in the processes of these living arrangements and subsequent social interactions, leading to families reorganizing themselves again to share care giving responsibilities and care receiving privileges, which however, according to this study, occurred in a highly rigid gendered way. The life story of Dede, which attempted to capture various dynamics of how people contract HIV and partake in efforts to prevent its further spread within HBC settings, shows that people’s interactional trajectories in families are determined by what people can be and can do. These dynamics, which are shaped by social norms, cultural practices, policies and legislation that privileges men and increases women’s vulnerability, should form the parameters of describing various family forms that exist in different settings. The low participation of men in providing HBC services does not match their grave need for care if they contract HIV, especially given their delayed reporting for HIV tests. This counts as one of the most major gender issues within HBC settings.

On account of these findings it is not sensible to offer a blanket definition of family or, worse, to use strong terms like “the family” in a world where situations are fast changing and demanding
new ways of doing things. In addition, this study shows that households are not the absolute location where family members can be located, as several families can share one household for economic reasons, especially where labor exchange is the leading purpose of one’s residence at a particular location. The research’s findings dismiss any rigid perception of people as being organised according to specific age or gender–based categories, where, for example, children are expected to receive care and economic support from adults. Although confirming that gendered division of labor still remained, the study demonstrates that children, especially orphaned ones, are increasingly assuming active breadwinning responsibilities and even caring for their chronically ill parents at young ages because of HIV and AIDS. Care giving is seemingly turning into a technical domain with requirements that mere belongingness to a family cannot meet, resulting in the terminally ill receiving care from members of other families contrary to familist ideals.

The study exposes various forms of gender inequality in the way that women are by far dominantly engaged in voluntary care giving work while men continue to invest their energies in financially rewarding ventures. While revealing that the proportion of widows was bigger than that of widowers, which reflects the increasing necessity for women to assume breadwinning responsibilities in families, Zimbabwe’s policies still have not been adjusted to accommodate financial rewards for women–dominated care giving work.

Importantly, the research reveals that families within HBC settings are never ends in themselves and members thereof depend on other outside agencies that may include housemates and neighbors, treatment buddies within a support group, employers, social service providers such as clinics, NGOs and others for various needs. The study proved, for instance that sexually–available housemates can be viewed as sources of intimate satisfaction among households where spouses are highly migrant and living environments are crowded. Therefore, viewing families within the confines of a breadwinning husband, his dependent wife with whom he solely shares intimacy, and their biological children is too shallow to apply to the highly dynamic HBC settings or any other setting.

This position creates grounds for the study’s recommendations.
5.2. Recommendations of the research

This research recommends the following actions on the basis of the above assertions:

i. Non–governmental agencies should consider lobbying the government to make the following policy reforms in order to increase the effectiveness and efficiency of HBC networks, while rewarding volunteers involved in care work which is apparently taxing:
   a. Including allocations for HBC service requirements in the national health budget
   b. Repealing universal definitions of family in all legal and policy provisions and replacing them with context–specific ones based on wide consultations of relevant experts
   c. Establishing vibrant and accessible community structures and networks for implementing family policies, such as mobile units for registering births and deaths
   d. Strengthening legal and policy provisions of protecting women and girls from sexual exploitation by, say, increasing access of women to legal support services

ii. The government and other stakeholders that reach out to smallholder communities should, as a follow up to the above recommendation, seriously consider launching intensified policy literacy training campaigns to increase knowledge of family policies among people in hard–to–reach areas. Making friendly policies is not enough to improve the lives of the people if they are ignorant about the policies and do not know how they can benefit from them.

iii. The syllabi of humanities at Zimbabwe’s universities should be revised to include studies of families and social policies, especially within the context of HIV and AIDS. Syllabi at Zimbabwe’s universities should not remain stagnant given the rapid changes taking place in the socioeconomic and political environment. Refresher courses focused on understanding families should be developed and marketed among practicing social professionals.

iv. NGOs that work with smallholder communities should create regular platforms for community members to discuss and debate their various life or family experiences related to managing HIV and AIDS towards exploring community–driven solutions.
v. Further exploratory research on families’ mechanisms of coping with emerging social realities should be supported within various social contexts. Examples of pertinent research themes may include human migration and families (for example, marriages of convenience among that Zimbabweans overseas that are used to protect their residency there) and the impacts of some information communication technologies (for example, Facebook) on relationships in families or young people’s behavior. The latter can invite the use of internet driven research methods such as floating an electronic questionnaire to gather as much input from diverse cultures as possible.

vi. Efforts to promote HIV tests among men should be intensified along with campaigns to encourage men to partner women in the fight against HIV through various activities, including HBC voluntary services.

5.3. Conclusions

The study of families is indeed very narrowly and superficially explored in Zimbabwe and the developing world in general, with most literature coming from urban communities of developed nations. This research proves, with a single context–specific participatory study, that the effects of HIV and AIDS notably the needs for chronically ill patients to be cared for within their homes have far reaching effects on the way families can be defined. Granted that there are many more socioeconomic dynamics that affect human lives within families there remains a huge void of unexplored phenomena that should be studied to build a basis for further defining and understanding families in various contexts. Actions that arise from such studies are more likely than any information from alien contexts to inform meaningfully responsive actions that suit realities in specific geographical, socioeconomic and political contexts. Functionalism can no longer explain the fast changing orders of today’s world, although its influences are still very strong in the way families, even within HBC settings explored by this research, manage their affairs.
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45. UNAIDS, 2002: 2: Zimbabwe Epidemiological Fact Sheets on HIV and AIDS and Sexually Transmitted Infections. 2002 Update
46. UNAIDS, 2003. Stepping back from the edge: The pursuit of antiretroviral therapy in Botswana, South Africa and Uganda, Geneva
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Annex 1: Composite Participatory Data collection Tool

*Family Dynamics in Home-based Care Settings of Zimbabwe’s Mutasa North Rural District*

**Part A: Consent Form**

**Instructor Contact Information:**
Vivienne Bozalek; University of the Western Cape: vbozalek@uwc.ac.za
Nicolette Roman: University of the Western Cape: nroman@uwc.ac.za
Jules Nshimirimana: University of the Western Cape: jnshimirimana@uwc.ac.za

Dear Participant

The University of the Western Cape is conducting a research to more deeply understand families in which there is at least a patient receiving home-based care. The research is part of a larger teaching and learning project by which individual students exercise their theoretical knowledge gained at the university about children and families through field-based investigations. In this research, Mr. Kudzai Makoni is the Principal Investigator, exploring the social experiences of families where patients receive home-based care in rural Zimbabwe. His supervisor for this project, who is based at the University of Western Cape, is Professor Vivienne Bozalek whose contact details are provided above. She has been and is still involved with this teaching and learning project and wishes to share the experiences of the project with a wider audience. This information will be shared through conference presentations and by writing journal articles and book chapters on the work achieved in this project. This letter is to ask you whether you would be prepared to participate in this study and give Mr. Kudzai Makoni permission to use the information that you will provide in this research for wider sharing.

Please consider the following in your response:

1. You are requested to give permission to participate in the study.
2. It is entirely your personal decision to give or deny this permission, and your participation in this research is entirely voluntary.
3. There will be no rewards for giving this permission, as there will of course be no penalty for refusing it.
4. You have a right to withdraw your permission at a later stage, so long as it is before any publication – and we would then not include your information in the research.
5. Your information will be used for this research only and not for any other purpose.
6. You may withdraw from the research study at any time as you wish.
7. Your name and any other names you refer to will not be used, so your identity will be anonymous.
8. All information that you will provide will be strictly confidential.
9. There are no correct or incorrect answers when participating in this study. It is your opinion that the research is interested in.

Consent form

I, ________________________________ agree to participate in the study and give the person(s) mentioned above, who have been involved with the planning and implementation of this project, permission to use my information.

I understand that those involved in planning and implementing this teaching and learning project are intending to share the work generated in the module in the form of publications and conference presentations.

I also understand that:

- Whether or not to give this permission is a personal decision, and it is entirely voluntary.
- There will be no rewards for giving this permission and no penalty for refusing it.
- I have the right to withdraw my permission at a later stage, so long as it is prior to any publication – and the researcher(s) then refrain from including my story in their research.
- The researchers would use my stories/drawings and other contributions for the purpose of this study only and not for any other purpose.
- My identity or identities of any other persons included in my story will be protected.

My name above and my signature below indicate my permission to the researchers to use the material I have provided to Mr. Kudzai Makoni for this research project:

Signed at ____________________________ (Place) on ____________________________ (Date)

__________________________________________ (Name)

PLEASE NOTE:

If you have any further queries in addition to what has been explained in the attached letter or the consent form, please do not hesitate to contact the Course Instructors, whose e-mail details are given at the beginning of this letter
**Part B: Interview schedule**

This interview guide contains broad themes of the research on family dynamics in Home-based Care Settings of Zimbabwe’s Seke Rural District and probing questions for gathering detailed information around those themes. The probing questions in the right column of this schedule may not be asked verbatim or in the order they are appearing in the tool, but in the order and phrasing that matches the respondent’s answers. Creativity is required to frame open-ended questions around each broad theme that invites a response that is as detailed as possible.

<table>
<thead>
<tr>
<th>Broad theme</th>
<th>Possible probing questions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Respondent’s profile</strong></td>
<td>NB: Use the <em>Short Family Profiling Questionnaire</em> to collect this data.</td>
</tr>
<tr>
<td><strong>History of care giving work</strong></td>
<td>When did respondent start work as an HBC volunteer? Did caregiver start serving patients on own initiative? If not who initiated voluntary HBC? What were the criteria that led to respondent’s selection to serve as HBC volunteer? How many patients does respondent care for? What is involved in providing HBC? What is needed or used in providing this care? Does respondent have the resources for care giving, which ones? Are the resources enough? Where are the resources obtained from, at what cost? How is the respondent's work affected by inadequacy of caring resources? How does respondent cope with such challenges?</td>
</tr>
<tr>
<td><strong>Care giving and families</strong></td>
<td>Are the patients under caregivers' care part of his/her family? If not part of his/her family, why are not the patients' family members caring for them? Do patient's family members play a role in providing care or supporting HBC volunteers, which roles? Does care giving work affect HBC volunteer's own family, personal well being, children, profession, and so on? If caregivers' personal life is affected by care giving work, how is it affected? How do members of HBC volunteer’s family feel about his/her care giving work? What other family-specific, social, emotional, religious and economic challenges do HBC volunteers face? In general, is respondent happy with care giving work?</td>
</tr>
<tr>
<td><strong>Families and potential death in HBC contexts</strong></td>
<td>What family matters or problems can be or have been experienced in the event of death of an HBC patient regarding funeral procedures, deceased estate, fate of surviving spouse and/or orphans, and so on? What is/are the role/s of HBC volunteers in the possible event of an HBC patient’s death?</td>
</tr>
<tr>
<td><strong>Context of care giving work</strong></td>
<td>Does caregiver work on personal initiative or as part of an organized movement, for example, church, NGO, government or so? Does caregiver receive remuneration or other incentive for his/her services? If remunerated, what does remuneration include? What are caregivers' views on remuneration – its relevance, adequacy, effect on their motivation, etc? Would caregiver deliver services if there was no organization to mobilize him/her to do so or if there were no incentives for the task? How does respondent explain his/her stance on remuneration/incentives?</td>
</tr>
<tr>
<td><strong>Comments on care giving work in general</strong></td>
<td>How many other caregivers serve in respondent’s community – men, women? Are there young people or children serving as HBC volunteers, how many male/female? How many patients does each HBC volunteer serve? Do caregivers often meet to deliberate, what about? On whose initiatives and for what reasons do caregivers assemble to deliberate?</td>
</tr>
<tr>
<td><strong>Recommendations</strong></td>
<td>How should HBC be better organized for families to reap maximum benefits? These recommendations should specify the parts that government, community, NGOs, etc should play</td>
</tr>
<tr>
<td><strong>Participatory tools</strong></td>
<td>Ask respondent to complete: o a daily and weekly routine tables o a Venn diagram that shows the interconnectedness of services required to make HBC effective (respondent to concentrate on what really happens, not they expect)</td>
</tr>
</tbody>
</table>
### 2. Respondent's life history: Patient on HBC

<table>
<thead>
<tr>
<th>Theme</th>
<th>Possible probing questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondent profile</td>
<td>NB: Use the <em>Short Family Profiling Questionnaire</em> to collect this data.</td>
</tr>
<tr>
<td>History of living with HIV</td>
<td>When and how did respondent know that s/he was infected with HIV? Did knowledge of respondent’s HIV status affect his/her personal well being/family, how? To whom did the respondent disclose HIV status (ask respondent to explain in details the processes of disclosing HIV status to others – the challenges, fears, etc)? How did respondent’s family/immediate community react after knowing about respondent HIV-positive status? What is the respondent’s current phase of HIV infection (for example, opportunistic infections (OI) treatment, antiretroviral therapy (ART), etc)? What processes happened from the time the respondent was diagnosed with HIV to the time s/he was placed on HBC?</td>
</tr>
<tr>
<td>Receiving care and families</td>
<td>(How) did respondent disclose HIV test result to family and what feelings, fears, etc accompanied this disclosure? How did respondent’s family deal with his/her HIV test result? What are respondent’s special needs when chronically ill? Is HBC the best answer to these special needs? Is HBC volunteer a member of respondent’s family? If not, what is the role of respondent’s family members in HBC (respondent should specify the roles played by different family members – male/female children, siblings, spouse, etc? What does patient do for him/herself?</td>
</tr>
<tr>
<td>Context of receiving care work</td>
<td>Who is the leading influence in HBC – community, an NGO, government, etc? Does respondent belong to a support group? How is the support group linked to the HBC initiative and the respondent’s family? Can respond do without HBC, support group or any other players involved in HBC? Are there any gaps that remain in the support that respondent requires if s/he were to rely on family alone, which one(s)?</td>
</tr>
<tr>
<td>Comments on care receiving in general</td>
<td>Is the care from HBC system adequate? If inadequate, what respondents’ needs could be unmet? What are the strengths and weaknesses of HBC? What has been the impact of HBC and what are the differences between pre-HBC era and now? Is respondent's caregiver male or female? What is respondent’s opinion about whether or not gender affects the quality of care?</td>
</tr>
<tr>
<td>Recommendations</td>
<td>How should HBC be better organized for patients and their families to reap maximum benefits? These recommendations should specify the parts that government, community including HBC volunteers, NGOs, etc should play</td>
</tr>
<tr>
<td>Participatory tools</td>
<td>Ask respondent to complete: o a daily and weekly routine tables o a Venn diagram that shows the interconnectedness of services required to make HBC effective (respondent to concentrate on what really happens, not they expect)</td>
</tr>
<tr>
<td>Conceptualization of care</td>
<td>What does care mean to (a) HBC volunteer and (b) HBC patient? What major differences in focus are there between the definitions of care by HBC volunteers and definitions by HBC patients? What are the important needs of care for patients on HBC – rank them by order of importance to the patient/caregiver? For each type of care, what is the best provider (create a table with two columns, one for ‘typeof care’ and another for ‘most suitable care provider’)? Which types of care cost money and which are free? What are the differences between care needs of HBC patients and those for other people? Do young HBC patients have similar needs as older ones; if not what are the differences? What other personal and social circumstances explain the differences in care needs between different HBC patients? Do patients on HBC give care to others as well, what kind? What kinds of care are exchanged in respondent’s family?</td>
</tr>
</tbody>
</table>
**Part C: Participatory investigation tools**

1. **DAILY ROUTINE TABLE FOR RESPONDENT'S HOUSEHOLD**
   *What are respondent’s activities each hour from the time they wake up to the time they sleep?*

<table>
<thead>
<tr>
<th>Time</th>
<th>Activities for HBC patient or volunteer</th>
<th>Activities for other members of respondent’s household</th>
<th>Male Activities</th>
<th>Female Activities</th>
</tr>
</thead>
<tbody>
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<td>Adult males</td>
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</table>

2. **WEEKLY ROUTINE TABLE**
   *Concentrate on one major activity for each day (for example, housework, school, agricultural work, etc)*

<table>
<thead>
<tr>
<th>Day</th>
<th>Major activity for HBC patient or volunteer</th>
<th>Major activities for other members of respondent’s household</th>
<th>Male Activities</th>
<th>Female Activities</th>
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<tbody>
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</table>
Ask respondents to comment about daily and weekly schedules – whether busy, stressful, etc.
3. FOCUS GROUP DISCUSSION (FGD) FACILITATOR'S GUIDE

Make sure that you do the following in facilitating a focus group discussion:

i. Ask participants to introduce themselves to each other and introduce an ice-breaker to start the discussion (be flexible here)

ii. Explain the objectives and procedure of the exercise and reemphasize the group’s role in the process as well as the importance of seriousness in their participation

iii. Invite questions from participants to ensure that they fully understand what they are required to do

iv. Break the main group into two: one of HBC volunteers and another for HBC patients

v. Ask group members to choose a time keeper, chairperson to moderate each small group’s discussions, minute taker, etc, so that participants control the processes of the exercise

vi. Elaborate the questions and exercises for each group to focus on, agree on a timeframe for discussions and give them relevant stationery – writing materials, etc – as follows:

FOCUS GROUP DISCUSSION QUESTIONS/TASKS

a. Task 1: Social maps

What services are available (a) within your community and (b) outside your community to support members of your group (HBC volunteers or patients)? To answer this question, first list the services down, together with those who provide them, and then draw a social map of the services on a separate paper. The social map should have an imaginary family homestead in the middle and each of the listed services in different places relative to the family homestead, according to the way participants perceive reality. The map should show which services are near or far away from the community and devise some signs on the map that show which services cost money and which are free. Participants should be allowed the flexibility to use whatever codes they prefer to represent different images on the map. A representative of the group should then describe your map before the plenary and respond to questions of clarification that other participants will ask.

b. Task 2: Imagining exercise

Imagine the different scenarios that are possible within a family where a member is an HBC patient living with HIV or a HBC volunteer, for example, when one decides to take an HIV test and has discovered s/he is HIV positive, when one chooses to be a HBC volunteer, when one falls seriously ill, if someone dies, etc. The more scenarios you imagine the better. Imagine the dilemmas that a person goes through, challenges they face, conflicts they provoke, etc, in each scenario. For each scenario write a statement using proverbial language (for example, an idiom, a riddle, a proverb, short poem, etc) to illustrate the feelings and experiences that you went through when you encountered any or several of them. You may choose to sketch a cartoon or something to illustrate your
experience with your chosen scenarios. One member of your group can present outcomes of your discussion before the plenary and respond to questions from other participants.

c. **Task 3: Gender analysis**

In HBC, how do you compare men’s with women’s involvement? Are there differences between young people’s and adults’ involvement in HBC? How do you explain these differences? Do these differences relate to the age order in your families? How?

d. **Task 4: Suggestions for better HBC**

  o Describe characteristics of the best HBC service, one which best suits all families. How should it be organized, who should assume which roles, etc?
  o What should be done to achieve the best HBC service that you described? In discussing this, specify the roles to be played by:
    o Family members
    o Government,
    o Non-governmental organizations
    o Community leadership
    o Health centers
    o Support groups
    o Others (specify them).
FGD Enumeration Form (Each group to complete and submit form to facilitators)

Province ________________________________________________
District ________________________________________________
Name of site where FGD is held __________________________________
Name of theme group _______________________________________
Total number of participants in group ______ male _______ female ________ total

Participants register

<table>
<thead>
<tr>
<th>Name of participant (Zita renyu)</th>
<th>Sex (tick as appropriate)</th>
<th>Age (years)</th>
<th>Ward No. or name</th>
</tr>
</thead>
<tbody>
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<td>Male</td>
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</table>
2. FAMILY PROFILING FORM – HBC PATIENTS AND VOLUNTEERS

Study of family dynamics in home-based care settings of Zimbabwe’s Mutasa North rural district

Section A: General Information
1. Date ____/_______________________/2010
2. District ____________________________
3. Ward ______________________________
4. Village _______________________________
5. Site of interview(1) Respondent’s homestead (2) Clinic or hospital (3) A prearranged site (specify) ____________________________ (4) School (5) Other (specify) __________________________

Section B: Demographic Information of household
6. Type of respondent (1) HBC Volunteer (2) HBC patient
7. Sex of respondent (1) Male (2) Female
8. Marital status of respondent (1) Married (2) Single (3) Widowed (4) Divorced/Separated (5) Celibate (i.e. single because of religious beliefs or vows)
9. Age of respondent _______________ years
11. If Christian, please specify denomination (1) Roman Catholic (2) Protestant (specify denomination) ____________________________ (3) Pentecostal (specify denomination) ____________________________ (4) Other ____________________________
12. Who heads the household of the respondent (1) Respondent (2) Respondent’s spouse (3) Respondent’s father (4) Respondent’s mother (5) Respondent’s grandfather (6) Respondent’s grandmother (7) Respondent’s brother (8) Respondent’s sister (9) Respondent’s friend (10) Respondent’s other relative or associate (specify) ____________________________
13. What is the respondent’s main source of income? (1) Formal employment (2) Farming (3) Informal mining (4) Informal business (specify type) ____________________________ (5) Donations from well wishers (identify them) ____________________________ (6) Remittances from relatives in urban areas or outside Zimbabwe (7) Begging (8) Other (specify) ____________________________
14. What is the respondent’s highest educational level? (1) Primary: before Grade 7   (2) Grade 7   
(3) Form 2(4) Form 3   (5) O’ Level   (6) Form 5(7) A’ Level   (8) National certificate   
(9) National diploma   (10) Degree   (11) Other (specify) __________________________

15. How many people does respondent share living space with (i.e. the people who have been living 
and eating in respondent’s household for the past six months)?   (1) _______ males   (2) _______ females   (3) total _______

In the next table please specify details of each person in the respondent’s household from the eldest to the 
youngest.

<table>
<thead>
<tr>
<th>Member</th>
<th>Age (years)</th>
<th>Sex (M=1; F=2)</th>
<th>Economic activities (refer to key below)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td>1. School-going; 2. Formally employed; 3. Job-seeking;</td>
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<tr>
<td>3</td>
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<td>8. Other (specify)</td>
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</tbody>
</table>

16. If respondent is HBC patient, when did s/he know his/her HIV status (year)? ____________

17. What was respondent’s CD4 Count then? ____________

18. What is respondent’s latest CD4 Count? ____________

19. If HBC Volunteer, how many patients does respondent care for? Please complete table below

<table>
<thead>
<tr>
<th>Category of patients</th>
<th>Male patients</th>
<th>Female patients</th>
<th>Total patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children</td>
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<tr>
<td>Adults</td>
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<td>Total</td>
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</table>

20. Does respondent offer HBC voluntary services as part of an organisation’s program?   (1) Yes   
(2) No

21. If yes, please specify name and type of that organisation ________________________________

22. Is there a member of the respondent’s household who is infected with HIV?   (1) Yes   (2) No   
(3) Do not know

23. If yes, how many people are these?   (1) Male ______ (2) Female ______ (3) Total ______
Annex 2: Group work outcomes: Resource maps