A COMPARATIVE ANALYSIS OF QUALITY OF LIFE AND STIGMA EXPERIENCED BY PEOPLE LIVING WITH HIV RECEIVING ANTIRETROVIRAL THERAPY IN A HOME-BASED CARE PROJECT IN MALEMA AND RIBAUE DISTRICTS, MOZAMBIQUE

by

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DEDICATION

This dissertation is dedicated to:

- my beloved partner, Vanusa de Castro Raposo who always believed in me and made it all possible
- my mother, Céline Veilleux,
- my father Reynald Massicotte and
- my brothers Nicolas and Frédéric who created such a loving and stimulating environment and who are still a source of peace for me. For this you have my eternal gratitude.

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Finally, my admiration goes to the HBC volunteers all over Africa who work so hard to make a difference and offer hope to the members of their communities and their families who are living with HIV. Thank you for proving that having almost no material resources is not an excuse for despair and inaction.

DECLARATION

I, ALEXANDRE RAYNALD CLAUDE MASSICOTTE, declare that **A COMPARATIVE ANALYSIS OF QUALITY OF LIFE AND STIGMA EXPERIENCED BY PEOPLE LIVING WITH HIV RECEIVING ANTIRETROVIRAL THERAPY IN A HOME-BASED CARE PROJECT IN MALEMA AND RIBAUE DISTRICTS, MOZAMBIQUE** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references. The thesis has not been submitted for the award of any degree to any other university.

ALEXANDRE RAYNALD CLAUDE MASSICOTTE DATE

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SUMMARY

Stigma is broadly considered as an important obstacle in HIV prevention and treatment. In Mozambique, more PLWHIV have access to treatment than ever. ART increased their QoL and created a new context for stigma production.

This cross-sectional study conducted in Northern Mozambique explored a possible association between stigma and QoL. The Berger Stigma Scale and WHOQOL-BREF were used to measure levels of HIV-related stigma and perceived QoL in two groups of PLWHIV receiving ARV, with participation in a HBC programme as the independent variable.

The study uncovered a weak to moderate negative correlation between stigma and QoL scores. Statistically significant differences were discovered between the groups' scores on the Berger Stigma Scale and a higher perceived QoL for PLWHIV in the HBC group on three WHOQOL-BREF subscales and on the overall score. The scores on the social relationships subscale indicated lower perceived QoL for PLWHIV in the HBC group.

KEY WORDS

AIDS, HIV, HIV-related stigma, home-based care, Mozambique, quality of life.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ACRONYMS AND ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
ANOVA	Analysis of variance
ARV	Antiretrovirals
ART	Antiretroviral treatment
CD4	Glycoprotein expressed on the surface of helper T lymphocytes which serves as a receptor for human immunodeficiency virus
COCAMO	Canada Mozambique Cooperation
DHL	Deutsche Post DHL
HAT –QOL	HIV/AIDS-targeted quality of life
HBC	Home-based care
HIV	Human immunodeficiency virus
MA	Master of Arts
MOS-SF-36	Medical Outcome Study Short Form 36 item health survey
MQOL-HIV	Multidimensional Quality of Life Questionnaire for Persons with HIV/AIDS
NGO	Non-governmental organisation
PLWA	People living with AIDS
PLWHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission
PWRD	Primate's World Relief Development Fund
QoL	Quality of life

UNISA	University of South Africa
US$	American dollar
USAID	United States Agency for International Development
VCT	Voluntary counselling and testing facility
WHO	World Health Organisation
WHOQOL-BREF	World Health Organisation Quality of Life Assessment

« *… stigma is less a barrier to providing AIDS care as it is the reflection of a complete lack of decent health care for the poor. Stigma is a symptom of this grotesque failure but it is often used as an excuse for further inaction* ».

Paul Farmer (2006), American anthropologist and physician

CHAPTER 1 : SITUATING THE RESEARCH PROBLEM

1.1 INTRODUCTION

With over 16.1% of its 15- to 49- year old population currently living with HIV, Mozambique is ranked 8th in Africa in terms of highest HIV prevalence rates (Joint United Nations Programme on HIV/AIDS 2008a; Population Reference Bureau 2006: 7). Overall, more than 1.8 million people are living with HIV in Mozambique (United Nations Joint Programme on HIV/AIDS 2006: 412). The number of people living with HIV (PLWHIV) in need of antiretroviral therapy (ART) exceeds the actual response by the Ministry of Health. In fact, as of December 1st 2007, 78,236 PLWHIV were receiving ART in Mozambique out of 233,954 in need of treatment as estimated in October of 2005 (Global Fund 2007:2; Government of Mozambique 2006: 21).

Most Mozambicans, especially in rural areas, have to face many difficulties such as low levels of educational attainment, a weak public health care system, widespread poverty, unequal gender relations and food production which is dependant on rain-fed crops (African Union 2004: 1; Hardon, Davey, Gerrits, Hodgkin, Irunde, Kgatlwane, Kinsman, Nakiyemba, & Laing 2006: 1; Kessides 2005: 1; Kim & Watts 2005: 769; Marston & de Cock 2004: 80; Organisation for Economic Co-operation and Development 2002: 226; Smit & Pilifosova 2001: 903; United Nations Educational, Scientific and Cultural Organisation 2005).

PLWHIV in rural areas not only face these problems, but have to deal with aggravating circumstances that further lower their life expectancy and quality of life (QoL). In the context of the study, rurality is an issue, as people living in rural areas have limited access to ART, low access to prevention of mother-to-child transmission (PMTCT), increased expenses in order to adhere to treatment and high levels of HIV and AIDS-related stigma (Hardon *et al.* 2006: 7; McCoy 2003:

31; Rosen, Sanne, Collier & Simon 2005: 1098; World Health Organisation 2007: 5). These conditions form some of the barriers preventing PLWHIV in rural areas from enjoying a good quality of life.

1.2 THE RESEARCH PROBLEM

The targeted communities of the study, that is, residents in the Malema and Ribáuè Districts, are located in the Province of Nampula in Northern Mozambique (see Figure 3.1). Salama, a local non-government organisation (NGO), has been implementing a home-based care (HBC) programme for PLWHIV since 2006, first in Ribáuè and then in the Malema District in 2007. Before the completion of the current study, it had been impossible to measure QoL and HIV and AIDS-related stigma levels in Salama's HBC programme. By analysing the relationship between these variables, this study filled a knowledge gap relevant to the work conducted by the NGO as the reduction of HIV and AIDS-related stigma and the improvement of the quality of life of PLWHIV in the above mentioned communities is an objective of Salama's HBC programme (Salama 2006:5).

Research by Major and O´Brien (2005) has established that stigma affects people's mental and physical health, and can be associated to a reduction in access to health care services. Also, a study by Remor (2002) has shown that there is a link between social support and ART adherence. Even though it is not a stated objective of home-based care by the Ministry of Health (Mozambique, Ministry of Health 2003: 4), anecdotal evidence gathered from programme staff and volunteers suggests that there is a relationship between the presence of a home-based care programme and reduced levels of HIV and AIDS-related stigma as well as an increase in the perceived quality of life for the PLWHIV benefiting from the programme. Based on this, the central research focus of this study was to compare perceived quality of life and experiences of HIV and AIDS-related stigma for PLWHIV in two groups: one consisting of PLWHIV on ART receiving HBC services, and another of PLWHIV on ART not receiving HBC services.

Thus, this study is an attempt to comprehensively describe the conditions for PLWHIV in the Malema and Ribáuè Districts, to ascertain their quality of life and experiences of HIV and AIDS-related stigma and to examine the relationship between these two concepts.

1.3 THE METHODOLOGICAL ORIENTATION

The study measured quality of life and HIV and AIDS-related stigma levels in two groups: one group composed of PLWHIV on ART receiving HBC services and another composed of PLWHIV on ART not receiving HBC services.

A variety of separate quantitative instruments were employed within the same interview session to measure the perceived quality of life and HIV and AIDS-related stigma levels experienced by the research participants. The Berger stigma scale (Berger, Ferrans & Lashley 2001), a tool designed to measure the levels of HIV and AIDS-related stigma experienced by PLWHIV, was used to review the levels of stigma experienced by each group and then compare levels between groups. In addition, an instrument based on the Portuguese, abbreviated version of the World Health Organisation Quality of Life Assessment (WHOQOL-BREF) was used to measure the quality of life in both groups (Canavarro, Simões, Vaz Serra, Pereira, Rijo, & Quartilho 2008; World Health Organisation 2004).

1.4 THE PURPOSE OF THE STUDY

The purpose of the study is to explore whether or not receiving HBC services is linked to quality of life and level of HIV and AIDS-related stigma experienced by PLWHIV on ART. Should a link be discovered, the nature of the interaction is to be discussed. As it would be premature to look for a causal effect of HBC programmes on HIV and AIDS-related stigma scores and QoL measurements in PLWHIV before examining if a difference between PLWHIV in a HBC programme versus PLWHIV not in a HBC programme exist, the current study looked at correlation between those variables instead.

The reason for choosing HBC as a research focus is that HIV and AIDS-related stigma reduction is considered to be an objective of HBC programmes (Waterman, Griffiths, Gellard, O'Keefe, Olang, Ayuyo, Obwanda, Ogwethe & Ondiege 2007:1037). However, the scientific literature available does not provide clear evidence that HBC services actually play a role in decreasing stigma in communities where they are implemented (Young & Busgeeth 2010).

From the start, it was decided to focus on people accessing ART. This orientation was taken by the researcher because PLWHIV on ART have a confirmed HIV status and have disclosed at least to one health provider when they were tested for HIV. Also, because PLWHIV on ART have to fetch their medicines regularly at the local VCT (voluntary counselling and testing) facilities, they could be contacted to take part in the study without the researcher having to identify PLWHIV on ART in the general population, a process that would have entailed all kinds of ethical and methodological problems.

1.5 THE RESEARCH OBJECTIVES

The objectives of the study were to find answers to the following questions:

1. Is there a difference in the level of HIV and AIDS-related stigma experienced by PLWHIV on ART receiving HBC services and the level experienced by PLWHIV on ART not receiving HBC services?

2. Is there a difference in the self-reported quality of life scores for PLWHIV on ART receiving HBC services and the scores for PLWHIV on ART not receiving HBC services?
3. Is there a correlation between HIV and AIDS-related stigma and self-reported quality of life?

1.6 DEFINITIONS OF KEY TERMS

1.6.1 HIV and AIDS

HIV means "human immunodeficiency virus" and consists of two different subtypes: HIV-1 and HIV-2. It was discovered in 1983 by two teams of scientists, one led by Luc Montagnier in France and the other conducted by Robert Gallo (Van Dyk 2005: 4).

AIDS stands for "Acquired immune-deficiency syndrome". AIDS was identified in 1981 after a cluster of men in the United States became ill with a rare form of pneumonia. HIV was found to be the causal agent for AIDS. (Evian 2003: 3).

1.6.2 HIV and AIDS-related stigma

To the ancient Greeks, the word stigma referred to a mark, such as a tattoo, that could serve a decorative or religious function. Also, burning, scarring and otherwise permanently marking a slave could indicate ownership. It is important to note that the notion of stigma did not necessarily carry a pejorative meaning to the Greeks, as some marks were related to military wounds and were hence considered to be proof of hardships endured (Simon 1992: 30).

The sociologist Erving Goffman (1963: preface) explained that "*Stigma is the situation of the individual who is disqualified from full social acceptance".* More specifically, HIV and AIDS-related stigma means *"prejudice, discounting,* *discrediting and discrimination that are directed at people perceived as having HIV or AIDS, and at individuals, groups and communities with which they are associated"* (Herek, Mitnick, Burris, Chesney, Devine, Fullilove, Fullilove, Gunther, Levi, Michaels, Novick, Pryor, Snyder & Sweeney 1998:36).

According to Berger *et al.* (2001: 519) who designed the instrument used to measure perceived stigma in PLWHIV in this study, stigma evolves from what a person perceives to be the attitudes of society in relation to people living with HIV and one's actual knowledge of living with HIV. Furthermore, *"The central concept - perceived stigma- is conceptualized as the person with HIV's awareness of HIV-related actual or potential social disqualification (less than full social acceptance, social rejection), denial or limitation of opportunity (for example, in housing, jobs, or dental services), and negative change in social identity (how others see him/her)"* (Berger *et al.* 2001: 519).

1.6.3 Quality of life (QoL)

The concept of quality of life is constructed by different perspectives in sociological literature. One perspective focuses on the relation between quality of life and health; definitions emerging from that vantage point *"… range from those with a holistic emphasis on the social, emotional, and physical well-being of patients after treatment to those that describe the impact of a person's health on his or her ability to lead a fulfilling life"* (Carr, Gibson & Robinson 2001: 1240). On the other hand, quality of life can be defined by so-called "objective" measures such as life expectancy, literacy rates and economic growth indices (Costanza, Fisher, Ali, Beer, Bond, Boumans, Danigelis, Dickinson, Elliott, Farley, Gayer, Glenn, Hudspeth, Mahoney, McCahill, McIntosh, Reed, Rizvi, Rizzo, Simpatico & Snapp 2008: 12).

One of the features of quality of life research is that it is a multidimensional, complex and culture-bound concept that has different meanings depending on the individual, the society, the period in time and many other factors. In that context, Skevington (2002: 135) has come to the conclusion that each study has its own definition of quality of life.

The World Health Organisation suggested a general definition as a guideline for the development of the WHOQOL-BREF, the instrument used to measure quality of life in the current study. The organisation: *"… defines Quality of Life as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. [It is] affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment"* (World Health Organisation 1997: 1).

Similarly, the definition proposed by Costanza *et al.* (2008: 12) establishes the level of attainment of human needs as the essence of the concept of quality of life. This definition converges with the one proposed by the World Health Organisation in the sense that social interactions, mental and physical health and autonomy reflect basic needs that could be perceived as being fulfilled or not for an individual. The level of satisfaction conveyed by the perception of fulfilment is, in fact, perceived quality of life. This perception can be measured objectively with an instrument such as WHOQOL-BREF, or can be appraised with qualitative indicators. In this study, quantitative data have been used to provide quality of life measurements.

1.6.4 Home-based care (HBC)

The World Health Organisation (2002: 6) defines community home-based care as *"…as any form of care given to ill people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities*. [Its goal] *is to provide hope through high-quality and appropriate care that helps ill people and families* *to maintain their independence and achieve the best possible quality of life*". This definition matches the reality of the HBC programme investigated in this study, as it included all the components of care mentioned above.

1.6.5 Antiretroviral treatment (ART)

ART is a combination of antiretroviral drugs that suppresses HIV and puts a halt to the progression of AIDS. ART has a number of side-effects, as well as toxicities and interactions with other drugs. (Habib 2006: 287; World Health Organisation 2009)

1.7 CONCLUSION

This chapter introduced the context in which the study was conducted. Background information about Mozambique and the barriers to health for PLWHIV were discussed. Next, the research problem was circumscribed and the methodological orientation outlined the quantitative methods used in the study. The purpose of the research followed, in which the focus on people living with HIV on ART was explained. The next section covered the three research objectives of the study. Finally, definitions for HIV and AIDS, HIV and AIDS-related stigma, quality of life, home-based care and antiretroviral treatment were provided.

In the next chapter, the relevant available literature for the study will be explored, including a description of the social context of HIV and AIDS in Mozambique, the nature of HIV and AIDS-related stigma and the concept of home-based care. A short presentation of Salama, the organisation through which the study was conducted, is also provided.

In the third chapter, the methodology of the study is analysed, with specific sections on research design, sampling methods, measurement of variables, data collection procedures, data analyses and ethical considerations.

The fourth chapter exposes the findings of the study and the characteristics of the sample. This will precede the discussion in which the results will be analysed and interpreted.

The fifth chapter proposes a conclusion composed of the limitations of the study, suggestions for further research and recommendations for policy and practice.

The list of references and the annexes are provided at the end of the study.

CHAPTER 2 : LITERATURE REVIEW

2.1 INTRODUCTION

In this chapter, the researcher examines the interrelatedness of HIV and AIDS-related stigma and quality of life for PLWHIV in the Mozambican context based on a review of existing data and theories. These ideas are expanded to consider HBC, ART and the relevance of this in addressing HIV and AIDS-related stigma. Also, the work of Salama, a national NGO involved in providing HBC services to PLWHIV in Malema and Ribáuè, is described. Finally, the theoretical point of departure of the study is outlined and a model integrating HIV and AIDS-related stigma and quality of life is proposed.

2.2 THE SOCIAL CONTEXT OF HIV AND AIDS IN MOZAMBIQUE

When news of AIDS became known around the world, well into the 1980s, Mozambique was less than ten years removed from its political independence (Cliff, Kanji & Muller 1986: 7). At that time, many experts did not believe that HIV-infection would spread heterosexually on a large scale. When evidence to the contrary started to mount, researchers from developed countries thought that the heterosexual transmission of HIV represented a new subtype and branded it *"African AIDS"* (Kallings 2008: 228). That labelling probably contributed to the social construction of the concept of HIV and AIDS in both developed and developing countries, as societies assumed they had correctly identified the so-called vectors for the spread of the disease, such as homosexuals or Haitians in North America, then started to blame them (Farmer 1992: 234).

According to the official institution in charge of the national response to HIV and AIDS in Mozambique, the National Council, the first diagnosis of AIDS was made in the Northern Province of Cabo Delgado, in 1986. Interestingly, this first patient was defined as a foreigner of Haitian origin working as a medical doctor. In his thesis about the HIV and AIDS response in Mozambique, Matsinhe (2006: 37) argues that by insisting that this first case was already infected with HIV before entering Mozambique, the National Council against HIV and AIDS showed a glimpse of the *"…mixture of references and representations, often contradictory, stereotyped, that subtly nurture a system of negation, accusation and discrimination, with the sponsorship of the official discourse…"* that would contribute to the social representation of HIV and AIDS in the country.

In Mozambique, the social meaning of HIV and AIDS was influenced by political and historical aspects. Conspiracy theories considering AIDS to be a weapon developed by the Western world were often mentioned by the Soviets during the first years of the epidemic (Goodwin, Kozlova, Kwiatkowska, Nguyen-Luu, Nizharadzee, Realo, Külvet & Rämmer 2003: 1379). The fact that the pre-1985 Soviet Union Government deemed AIDS to be a decadent Western disease, borne out of the capitalist lifestyle, paved the way to an association of HIV and AIDS with immorality (Kallings 2008: 232; Williams 1994: 92). As Mozambique maintained close social and cultural ties to the Soviet Union at that time, it can be argued that this interpretation of HIV and AIDS was, at least initially and in part, integrated into the local social construct of the disease.

The process of acknowledgement that HIV and AIDS was a health problem in Mozambique has been, according to Matsinhe (2006), largely dependent on the support of the World Health Organisation (WHO). This, along with mostly foreign technical support and educational materials, contributed to the creation of the first Mozambican response to HIV and AIDS. As was the case in other African countries most affected by the HIV pandemic at the time, Mozambique's health system was not prepared to deal with such a challenging threat (Fredland 1998: 551). Matsinhe (2006: 38) argues that the most important aspect of this phase is the *"…humble and clear acknowledgement of the incompetence and ignorance of the country in the face of a new and emergent problem*".

In 2000, the Mozambican government established a multi-sector HIV and AIDS Council and published its first national strategic plan to combat HIV and AIDS. Shortly after, in 2001, the health ministry introduced voluntary testing and counselling services in the public sector. During the same year, the parliament passed a law against the discrimination of PLWHIV in the workplace (World Health Organisation 2005: 1). Despite an apparent interest in defending the rights of PLWHIV, no study has been found in which HIV and AIDS-related stigma levels, or QoL of PLWHIV, have been measured in Mozambique. The extent and prevalence of HIV and AIDS-related stigma perceptions and experiences of Mozambicans living with HIV is thus unknown.

Until 2001, the Mozambican government was, in congruence with the World Bank, the United States Agency for International Development (USAID), the European Union and other major donors, against the introduction of ART in the country. It justified its decision by referencing high costs, lack of laboratory facilities and human resources. Government authorities also believed that Mozambicans would not be able to maintain the necessary adherence to treatment required to make it effective (Matsinhe 2006: 132).

After the idea of the introduction of ART in Mozambique finally made it to mainstream politics, the approach was still a very cautious one. Matsinhe (2006: 135) believes it was due to two different factors, one behavioural and the other historical. Some health decision-makers thought that introducing ART could signal the end of the lethal threat posed by HIV infection, and as a consequence people would adhere less to prevention measures against HIV infection. The other factor is that because at first antiretrovirals (ARVs) were made available only to civil servants (considered the 'elite'), it would be seen as an act reminiscent of post-independence socialism when the same 'elite' could purchase goods in relatively well-stocked shops while the remainder of the population had to form long queues in shops where nothing worthwhile could be bought (Matsinhe 2006: 135). The lack of initial commitment towards access to treatment could be seen as a way for the Mozambican government to avoid taking policy routes that could have been interpreted as a promotion of unequal access to treatment in favour of the “elite”.

Nevertheless, ARV roll-out was implemented at a very rapid pace after 2001. Data show that in March 2004, only 7,000 people in the country were accessing ART. By the end of 2007, 90,000 people were receiving the treatment (Joint United Nations Programme on HIV/AIDS 2008b: 12).

The marked increase in the number of people accessing ART in that period could be interpreted as being the result of a new era of strong leadership and commitment on the part of the government in ensuring universal access to ART to all its citizens. This interpretation however is debated. For example Nattrass (2008) compared antiretroviral coverage to predicted antiretroviral coverage as an indicator of AIDS leadership in countries all over the world. Out of 38 African countries studied, Mozambique came out as the fourth worst in terms of antiretroviral coverage in 2006 compared with what would be expected considering its gross domestic product per capita, external support, the scale of the epidemic, health-related demands and politico-institutional capacity. The variables chosen for the analysis could be argued with, but the study indicates that despite the rapid pace of the introduction of ART in Mozambique, the Ministry of Health was slower than its African counterparts in providing ART to its population. The situation, however, could have changed since 2006, as Mozambique has further accelerated its antiretroviral roll-out after that year (Joint United Nations Programme on HIV/AIDS 2008b: 12), and in September of 2009, 161,381 Mozambicans were treated with ARV. Among them, 8,409 were living in the Nampula Province (Republic of Mozambique, Ministry of Health 2009).

In Mozambique, access to ART continues to be a challenge, especially in rural areas. The lack of sufficient human resources has, in particular, been a problem. Van Damme, Kober & Kegels (2008) calculated that in order to reach the 2008 target of 132,000 people on ART, the delivery system would have required 264 of the current 360 medical doctors in Mozambique to work solely on implementing the ART programme. The authors of the study conclude that Mozambique, just like Malawi, Zambia, Rwanda and Tanzania, lacks the human resources needed to further expand their ART programme (Van Damme *et al.* 2008: 2110). However, research continues to suggest that ART in Africa is effective for those who have access to treatment (Boulle & Ford 2007: 503).

In the next section, we will look at how stigma related to HIV and AIDS is produced and what are its consequences.

2.3 HIV AND AIDS-RELATED STIGMA

For many researchers, HIV and AIDS-related stigma is considered one of the most important obstacles in HIV prevention and treatment interventions, preventing PLWHIV from enjoying an acceptable health level (Campbell, Foulis, Maimane & Sibiya 2005: 808; Kalichman, Simbayi, Jooste, Toefy, Cain, Cherry & Kagee 2005: 135; Valdiserri 2002: 341). HIV infection carries a high level of social consequences. Thus, it is crucial to pay attention to the social aspects related to it, such as HIV and AIDS-related stigma (Green & Platt 1997: 90).

The search for a unified conceptual framework to explain stigma is rendered complex by the fact that sociologists, psychologists, philosophers, health specialists and others have probed their disciplines to define it. As Deacon (2006: 419) puts it, the quest is *“suffering from conceptual inflation”*, and the typology used and the variety of competing theories can be overwhelming. In this study, some models for HIV and AIDS-related stigma are introduced. However, the following discussion is not an exhaustive review of the scientific literature on the topic. In fact, the models presented here have been selected for their ability to provide a framework grounded in a socio-cognitive approach, pioneered by work from Goffman (1963), and later explored by social psychologists (Mahajan, Sayles, Patel, Remien, Sawires, Ortiz, Szekeres & Coates 2008: S70). This approach focuses mostly on perceptions of PLWHIV and the impact of these perceptions.

Although stigma is considered to be universal (Burris 2008: 473; Keusch, Wilentz & Kleinman 2006: 527; Murthy 2002: 28), other researchers specify that what is stigmatised in a particular context at a particular time might not be considered as such in another context (Heatherton, Kleck, Hebl & Hull 2003: 65). Furthermore, not every disease has a potential for stigmatisation. According to Herek (1999: 1109), HIV and AIDS possess four characteristics that contribute to the high level of stigmatisation related to it, namely:

1) In HIV infection, the bearer is perceived to be responsible for the condition, as the behaviours leading to infection are understood to be avoidable and voluntary. As HIV is mostly transmitted through sexual contact in Africa, HIV and AIDS-related stigma is often related to the lethal potential of the infection intertwined with connotations of sexual deviancy (Carr & Gramling 2004: 31).
2) There is still no cure to AIDS, and the disease is still thought of as a fatal, even if ART can prolong life.
3) Infectious diseases have a higher potential for stigmatisation as they are perceived as a risk that can cause harm to others.
4) Diseases such as AIDS cause the bearer to have visible signs and symptoms. These create more stigmatisation because they can disrupt social interactions.

Merely understanding how general characteristics create a favourable context for stigmatisation is not enough, as stigma can exist outside of these conditions. Culturally-bound representations of disease, like witchcraft or a spiritual system involving fate, for example, can add layers of significance for local populations, and play an important part in shaping stigmatisation. This can lead to a very complex web of behaviours and attitudes interacting with and responding to the situation of PLWHIV within the community (Liddell, Barrett & Bydawell 2005: 693). Relations of power, gender inequality, political and economic conditions can also influence how stigma is created, maintained or avoided in the socio-cultural context (Abadía-Barrero & Castro 2006: 1221; Link & Phelan 2001: 367; Ogden & Nyblade 2005: 38; Parker, Aggleton, Attawell, Pulerwitz & Brown 2002: 9; Reidpath & Chan 2005: 425). In the next section, the context in which these conditions interact with each other in the process of stigma production will be outlined.

2.3.1 The stigma production process

As major contributors to research in the field of stigma, Link and Phelan (2001) have designed a theoretical framework exposing the various steps in the elaboration of stigma. The researchers' model contains five components:

1. Labelling and distinguishing a difference
2. Linking people who bear the difference with negative connotations
3. Creating a distinction between "us" and "them"
4. Causing a loss of status for the bearers of the difference by discriminating against them
5. Allowing the social, economic and political powers to maintain the four other components

In the first step, PLWHIV are differentiated from people not living with HIV. As only HIV testing can permit a definite differentiation between the two groups, there are a number of strategies employed to discover HIV status by means of proxy markers, such as physical appearance, behaviour or discourse. (Suarez & Miller 2001: 292). This strategy is called "*faulty heuristics*" by the researchers because it is based on unscientific or illogical beliefs. Guessing someone's HIV status using proxy markers is more easily achieved when the person has reached the full-blown AIDS stage, as signs of disease progression are then more obvious. For example, visible signs of later stage AIDS, such as facial lipoatrophy can cause people to involuntarily disclose their condition (Kavouni, Catalan, Brown, Mandalia & Barton 2008: 485). The differentiation can also occur when the person living with HIV displays specific behaviour linked to an HIV positive status, as shown in a study about an HIV treatment project in the Kibera slum in Kenya (Unge, Johansson, Zachariah, Some, Van Engelgem & Ekstrom 2008:148). In that study, researchers noted that access to ARV was conditional to disclosure of one’s status to a treatment buddy. This amounted to compulsory disclosure, as patients were forced to tell a friend or their partner of their HIV status to get enrolled in the ART scheme. This condition was abandoned after the study showed that it led to stigma and threats from family members when they became aware that the patient had HIV.

In the second step, a link is established between an HIV positive status and negative behaviour or attitudes, while preconceived ideas and stereotypes are constructed to create meaning (Skinner & Mfecane 2004: 158). As HIV can be sexually transmitted, some people might erroneously conclude that PLWHIV are unfaithful, sexual deviants, homosexuals or prostitutes (Bond, Chase & Aggleton 2002: 348; Schatz 2005: 489; Ulasi, Preko, Baidoo, Bayard, Ehiri, Jolly, & Jolly 2009: 256). This process can also be indirect, as when the media, without realising it, cause unnecessary stigma. For example, Lean and Lee (2008: 181) report a television broadcast in the United Kingdom that portrayed haemophiliacs living with HIV “through no fault of their own”. This presentation inadvertently presented them as “innocent victims”, implying that there were other “not so innocent victims” undeserving of the same sympathy.

The third step consists in making clear there is a difference between the stigmatiser and the stigmatised. In essence, the stigmatiser makes an attempt at providing evidence confirming the existence of a gap between his/her behaviours, attitudes or conditions and those believed to be the ones possessed by PLWHIV. This can be achieved by increasing the existing body of preconceived ideas and generalisations toward PLWHIV, thus substantiating the perceived differences between the two groups. In this regard, Wang (1992) in her study on the production of stigma in injury prevention campaigns, points out that the slogans and images that portray disabled people as victims and that instil fear in others, involuntarily produce stigma.

In the fourth step, the stigmatisers take on an active role in denying social status to the stigmatised. This removal of privileges is based on the belief that PLWHIV do not deserve to be treated equally.

The stigma produced in the four initial steps could be of local significance only, with a few individuals affected. For it to transform into an "epidemic of stigma" (Herek & Glunt 1988), a facilitating social, economical and political environment has to be in place, which is the fifth and final step in the framework proposed by Link and Phelan.

2.3.2 Types of stigma

Stigma encompasses multiple dimensions (Green & Platt 1997: 90) that can be categorised in two subtypes: external and internal.

External and internal stigma result in PLWHIV becoming distressed and living in fear of being stigmatised. HBC service providers may also suffer from stigma and discrimination because of their daily contact with PLWHIV (Lindsey, Hirschfeld & Tlou 2003; Orner 2006).

2.3.2.1 External/enacted stigma

External stigma (also named enacted stigma) refers to *"… experiences of PLHA [people living with AIDS, see PLWHIV] being* *treated unfairly and differently to everyone else".* (Futures Group 2006: 6). An example of enacted stigma can be found in the testimony of Ana Maria Muhai, a woman living with HIV in Maputo, Mozambique: "*Sabem, quando fiquei doente e sem força, já ninguém comprava na banquinha de verduras e bebidas que tinha montado perto de casa. Todos me apontavam com o dedo e não compravam os meus produtos por medo de se infectarem. Os meus filhos, e isto me doía mesmo muito, não podiam assistir televisão em casa de ninguém, porque tinham uma mãe seropositiva. A discriminação que os meus filhos sofreram foi a minha dor maior*" ("*You know, when I got ill and without strength, no one was buying at my vegetable and drinks stall I had installed near my house. Everybody was pointing a finger at me and they wouldn't buy my products in fear of getting infected. My children, and that was really painful, couldn't watch TV in anyone's house, because they had an HIV-positive mother. The discrimination my children suffered was my greatest pain*") (Muhai 2006, translation made by the researcher from the original version in Portuguese).

According to her verbatim, Ana Maria was treated badly by her community because she was ill and people thought that she was HIV-positive. The stigma extended to her children as they were also ostracised by family and friends. It can be hypothesised that neighbours and friends lacked knowledge about HIV and AIDS in general, and HIV transmission vectors in particular. This was a major factor in the maintenance of stigmatising attitudes, a situation consistent with research by Hamra, Ross, Karuri, Orrs & D'Agostino (2005: 912) which associated HIV and AIDS knowledge with less expressed stigma.

2.3.2.2 Internal/felt/imagined stigma

Internal stigma (also known as felt or imagined stigma) refers to *"…the way a person feels about themselves"* (Futures Group 2006: 6) and is expressed as feelings of shame or fear, especially in reaction to, or anticipation of, enacted stigma (Baskind & Birbeck 2005: 69; Mawar, Sahay, Pandit & Mahajan 2005: 474). In their study of women living with HIV, Carr and Gramling (2004) found that some PLWHIV change the way they see themselves because of their infection. Whatever their personal identity was before being diagnosed, they could not see themselves as anything else but as women living with HIV after they received the diagnosis. One of the interviewees in the study described the lingering self-stigma process she dealt with thus: "*When I look in the mirror, I no longer see Sonya. I see a woman with HIV disease. It is the first thing I think about when I wake up in the morning and the last when I go to sleep at nigh*t" (Carr & Gramling 2004:32).

In a study about stigma in the United States, Lee, Kochman & Sikkema (2002: 315) found that most PLWHIV experience internalised HIV and AIDS-related stigma. The authors, however, advise not to generalise this conclusion to every person living with HIV as some do not feel stigmatised at all, as discussed in the next section

2.3.3 The consequences of stigma

Stigma can trigger a myriad of consequences for the person living with HIV, their family, the community and the nation as a whole. One of them is the negative effect on emotional health of PLWHIV (Fife & Wright 2000: 51).

Not every stigmatised person, however, places the same importance on the stigmatising condition. This is what Crocker and Major (1989: 620) call the "centrality of the stigmatising condition in the self-concept of the individual". Although the focus can shift over time, for some people, HIV status can become a central aspect of their identity, while for others, it is considered as a peripheral attribute (Baumgartner 2007: 922).

Even before knowing one's HIV status, the fear or being stigmatised if the result is positive can lead to delays in HIV testing (Chesney & Smith 1999: 1162). When a person does get tested for HIV and the result is positive, the reaction can be to stop working or to try to find a new place to live (Wig, Lekshmi, Pal, Ahuja, Mittal & Agarwal 2006: 4), either out of fear of being stigmatised or because of actual stigma.

Among the individual consequences of stigma, fear of being stigmatised which leads to non-disclosure of HIV status is considered to be a barrier to health (Carr & Gramling 2004: 37). Disclosing one's HIV status is an important step for a person living with HIV, but some studies have shown that many opt not to disclose their status, even to medical providers at ART sites, until they become symptomatic or cannot care for themselves anymore (Jeffe, Khan, Meredith, Schlesinger, Fraser & Mundy 2000: 39). The fact that PLWHIV not on ART do not always disclose their HIV status to a health service provider is the reason why PLWHIV on ART have been chosen for the current study. PLWHIV on ART have disclosed their HIV status to the local counsellor at the VCT and are readily available as participants in a study as they have to maintain regular contact with the counsellor in order to access their medicine.

In a rural context such as that in Malema and Ribáuè Districts, ART is usually initiated when the signs and symptoms, together with a positive HIV test result, indicate that such treatment is necessary in order to address opportunistic infections or to stave off the onset of full-blown AIDS. These signs and symptoms have often been noticed by family members for some time before the person seeks help and treatment. In Salama's HBC programme, the onset of AIDS-related symptoms is often the initial step leading to HIV testing and, later, to the inclusion in the HBC programme.

Serovich (2001:356) sheds some light on the different theories related to HIV disclosure: on one hand, there is the popular belief that more noticeable symptoms lead to increasing difficulty in keeping the condition secret and that this is the reason why PLWHIV eventually disclose their status. This is called the ""progression of HIV infection theory". The author has found, however, that the "consequence theory of disclosure", according to which *"...the relationship between disease progression and disclosure is moderated by the consequences one anticipates resulting from the disclosure*", could better explain why people disclose their HIV status. Based on her study, it seems as if people fear fewer consequences to disclose when there are measures taken in the health, legal and social systems, as well as steps taken to reduce stigma, discrimination and violence against PLWHIV. By understanding better how stigma and quality of life interact with the HBC services based on the conclusions of this study, it is possible that HBC service providers will be able to provide PLWHIV with scientific evidence of what to expect from disclosure of HIV status, in terms of social consequences and QoL.

Related to non-disclosure, in some cases PLWHIV refuse to go for treatment or to use HIV services because they are afraid that the visits and the pill-taking rituals will expose their HIV status (Schuster, Collins, Cunningham, Morton, Zierler, Wong, Tu & Kanouse 2005: 807). This attitude can delay the onset of care and further complicate treatment as the person waits until symptoms are apparent and CD4 levels are very low (Chesney & Smith (1999: 1167). Also, failure to disclose can also mean fewer adherences to treatment, as PLWHIV who don't tell anyone of their HIV status cut themselves off from potential "treatment buddies" or family members who could remind them to take their medicine and support them with the secondary effects they experience.

Other consequences of stigma might include higher unemployment, avoidance of social contact leading to a weakened financial situation, deteriorating health, lack of productivity, more time spent in medical consultation and gradual isolation, all of which further erode quality of life (Fife & Wright 2000: 51; Wig *et al.* 2006: 4).

Finally, not all individuals react the same way to stigma. Wang (1992: 1093) for example, citing a study of former mental patients and people with disabilities conducted by Anspach, found out that some patients get involved in advocacy work as a response to being stigmatised. This would be one of the very few indirect, positive consequences of stigma, which demonstrates the potential for resilience amongst PLWHIV. In fact, Salama's HBC programme includes volunteers who are living with HIV. These volunteers use their personal experience to increase acceptance of PLWHIV, and to help people recently diagnosed with HIV to cope with their new situation (Salama 2008: 9).

As discussed above, the consequences of HIV and AIDS-related stigma are serious and can mean the difference between life and death for many PLWHIV. Because of this, the links between HIV and AIDS-related stigma and QoL of PLWHIV warrant a closer analysis. This study's research questions have been chosen based on the importance of the impacts of stigma on the lives of PLWHIV, in the hope that a better understanding of the relation between HIV and AIDS-related stigma and QoL could help HBC programme developers to design interventions that could significantly reduce the impacts of stigma on PLWHIV.

2.3.4 Interventions in the field of stigma and evidence-based approaches

For years, reduction of stigma has been considered as an essential element to the HIV/AIDS response in many sub-Saharan Africa's countries (Republic of

Uganda. 2000: xxxvi; Republic of Zambia 2006:13; Tanzania Commission for HIV/AIDS 2003: 30). In Mozambique, public interventions in the area of HIV and AIDS-related stigma are outlined in the *Plano Estratégico Nacional de Combate ao HIV/SIDA* (National Strategic Plan for the Fight Against HIV/AIDS). The Mozambican government has identified six main objectives in its HIV and AIDS-related stigma reduction strategy (Republic of Mozambique 2004: 23).

The first objective is to promote a greater visibility of PLWHIV. Promoting the active presence of PLWHIV in public debate, such as participating in conferences, giving speeches and, in general, shifting AIDS from an abstract concept to a personal encounter, are activities known to achieve stigma reduction (Klein, Karchner & O'Connell 2002: 51; Nyblade, Stangl, Weiss & Ashburn 2009: 15). The idea that empowering people is a condition for any successful policy-making which aims to reduce stigma is central to the work of Morrison (2006: 9) (See Figure 2.1). Participation in a group of PLWHIV is also an activity that is known to provide social support and stimulate empowerment (Brown, Macintyre & Trujillo 2003: 53; Ribble 1989: 54).

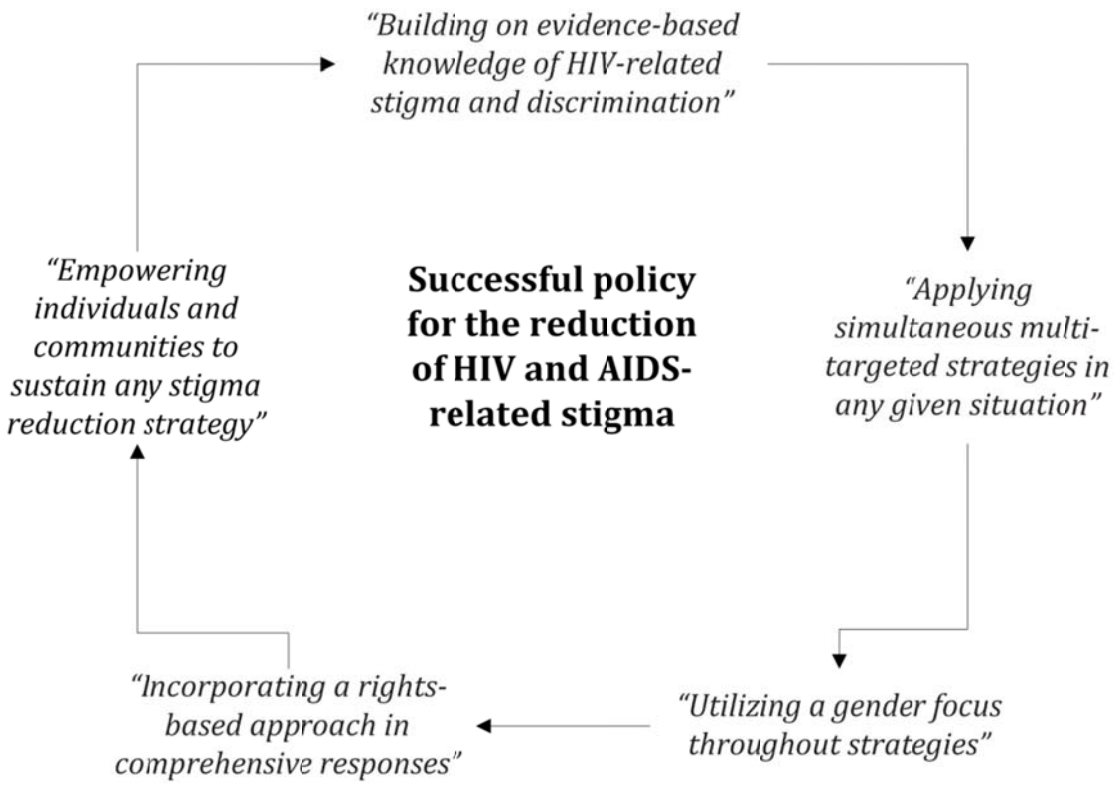
Using a human rights approach to ensure that the rights of PLWHIV are respected is the second objective of the National Strategic Plan. For Chopra & Ford (2005:386), the human rights approach in the field of HIV and AIDS aims at enhancing "… *the relationship between claims holders (community members) and duty bearers (people in authority, either from government or development agencies) so that ordinary people can realize their right to survival, health and development, and those in authority can fulfil their responsibility to govern effectively*". According to Castro & Farmer (2005:53), most practitioners in the field of HIV and AIDS consider stigma to be, in fact, a violation of human rights. Maluwa, Aggleton & Parker (2002: 13) also insist on the necessity of the human rights approach as a HIV and AIDS-related stigma reduction strategy.

The third objective of the Strategic Plan is ensuring access to health care and treatment for all. Limited accessibility to a decent level of health care and provision of sub-par health services are inadequate responses to the problem, and the symptom of these failures is stigma, according to Farmer (2006: xiii).

The fourth objective concerns the health workers. According to the Plan, they are the first agents of change when it comes to stigma reduction. In that aspect, the Mozambican strategic plan is parting ways with strategies which are considered to be evidence-based by Nyblade *et al.* (2005: 15). In the opinion of these authors, the involvement of the entire staff in a health care setting is necessary, especially in the area of training and policy-making. The authors suggest that putting the onus of stigma reduction on health professionals could be detrimental, as it reduces the feeling of ownership in the response to stigma for other workers at the health care facility, such as administrative and security staff.

The Strategic Plan also considers the involvement of religious communities in the fight against HIV and AIDS-related stigma. Finally, it states that the debate on HIV and AIDS-related stigma has to be public and that every chance to discuss the matter should be seized.

Figure 2.1: Elements needed for a successful policy in the field of HIV and AIDS-related stigma (Morrison 2006: 9)



2.3.5 Measurement of stigma

In order to adequately measure the perceptions of stigma and its effects on PLWHIV, a validated and objective instrument is needed. A review of the existing literature revealed the existence various instruments designed at measuring HIV and AIDS-related stigma. In this section, we are presenting three of the most cited instruments: the Berger Stigma Scale, the Sowell Stigma scale and Kalichman's AIDS-related stigma scale.

One of the earliest such instruments is the **Berger HIV Stigma Scale**, proposed by Berger *et al.* (2001). As no conceptual model specific to HIV and AIDS-related stigma was available when the Berger Stigma Scale was developed, the authors conducted a large literature review and proposed a two-factor model: *"… the individual's perceptions of societal attitudes toward people living with HIV and his or her personal knowledge of being infected with HIV*" (Berger *et al.* 2001: 519-520). This explanation of the genesis of HIV and AIDS-related stigma is in line with Goffman's views, according to which stigmatised people expect adverse reactions and are acutely aware that they possess a characteristic that contravene to social norms (Goffman 1963: 14). The instrument was first tested in the United States and consists of 40 items, encompassing four subscales: personalised stigma, disclosure, negative self-image and public attitudes. Since its design, it has been used in many studies, such as Wright, Naar-King, Lam, Templin & Frey (2008), Buseh, Kelber, Stevens & Park (2008) and Mahendra, Mudoi, Oinam, Pakkela, Sarna, Panda, Rau, Singh & Rutenberg (2007). Translations have been shown to be valid in different cultural contexts (Franke, Muñoz, Finnegan, Zeladita, Sebastian, Bayona & Shin 2008). A study by Bunn, Solomon, Miller & Forehand (2007: 205) has concluded that the HIV Stigma Scale is valid and reliable.

Another scale available is the **Sowell Stigma Scale**. It consists of 13 items with a 4 point Likert scale. The scale was designed in the late nineties from research conducted with HIV-positive women in South-eastern United States (Emlet 2005: 293).

The **AIDS-Related Stigma Scale** designed by Kalichman *et al.* (2005) is an instrument designed in South Africa. It consists of 9 items, measures a wide scope of stigmatising beliefs and is based mostly on Goffman's theory. The scale shows strong reliability and validity and has been tested on a diverse range of African men and women.

While some researchers have hypothesised that stigma measurement tools must be tailor-made for every specific and local context, this would mean that no stigma scale could be used outside the area where it was designed (Weiss, Ramakrishna & Somma 2006: 284) which is not helpful for the progression of worldwide sociological studies. However other researchers believe that stigma experienced in varied contexts can be measured by a comparable scale, even in countries both developed and developing (Van Brakel 2006: 329).

A valid and reliable instrument that could be used across different cultural contexts is very useful, and this is the view taken by this study and by the choice of the Berger Stigma Scale as its main instrument for measuring HIV and AIDS-related stigma. In the context of this study, the precursors of HIV and AIDS-related stigma proposed by Berger *et al.* (2001: 519-520), that is individual perceptions of prevalent attitudes toward PLWHIV in the community and personal experience of being infected with HIV, are a component of the theoretical framework presented in Figure 2.3.

2.4 QUALITY OF LIFE AND HIV

Quality of life is now considered as a significant outcome in the continuum of health care provision (Hickey, Bury, O'Boyle, Bradley, O'Kelly & Shannon 1996: 29). According to Hays, Cunningham, Sherbourne, Wilson, Wu, Cleary, McCaffrey, Fleishman, Crystal, Collins, Eggan, Shapiro & Bozzette (2000: 714), "*Health-related quality of life refers to how well a person functions and to his or her perceptions of well-being in the physical, mental, and social domains of life*". The concept of health-related QoL has been explored widely in scientific literature since 1980 and made necessary as a result of an increase in the number of chronic diseases that accompany longer life expectancy in many countries (Murdaugh 1997: NS41).

A review of the available literature reveals a scarcity of research about HIV and AIDS-related quality of life in sub-Saharan Africa. Such a situation is problematic since an accurate assessment of QoL of PLWHIV could be used to examine the impacts of ARV treatment both in terms of health improvement and effectiveness of invested resources (Hays *et al.* 2000: 714). One of the earliest studies in an African setting, published by O'Keefe and Wood (1996: 275), examined if HIV and AIDS impacted QoL in South Africans. The study concluded that QoL was impacted by HIV for people of every racial origin, without any significant difference between ethnic groups. Another more recent research studied the military in Nigeria and showed that PLWHIV had lower QoL scores and reported more post-traumatic stress disorder than seronegative colleagues (Olley & Bolajoko 2008: 94). In South Africa again, Jelsma, MacLean, Hughes, Tinise & Darder. (2005: 579) found that ART has a positive impact on QoL levels but that the secondary effects of the medicine have no significant influence on QoL scores. Furthermore, Greeff, Uys, Wantland, Makoae, Chirwa, Dlamini, Kohi, Mullan, Naidoo, Cuca & Holzemer (2009) concluded from a study covering five African countries that over time, ARV treatment seems to have a positive effect on perceived QoL.

Quality of life can be influenced by the source of health care. This is especially relevant in the African context where health care is available (or not) from sources across the spectrum such as home-based care, traditional medicine and western medicine. In a study in Zimbabwe, Taylor, Dolezal, Tross & Holmes (2008) have found that people who have been treated at a traditional African site show a greater improvement in their perceived QoL after one month than people who have been treated at a western medicine site. This is an important discovery that could further underline the potential effects of HBC on Qol in a programme such as the one developed by Salama, as traditional doctors are actively involved in the referral and treatment phase of PLWHIV in tandem with ART provision.

2.4.1 Quality of life and HIV and AIDS-related stigma

Until recently, very few studies had established a link between HIV and AIDS-related stigma and QoL. A study by Dos Santos, Franca & Lopes (2007), based on a sample of 365 PLWHIV in Brazil, noted that the QoL levels for signifiers based on physical and psychological health were higher than those of people with another diagnosis, but that the signifiers referring to relationships were lower. They hypothesised that the difference was due to the impact of stigma, although no evidence was provided on this account.

The latest studies on the subject revealed that QoL is negatively affected by stigma, so that for every increase in perceived stigma levels, there is a drop in life satisfaction levels (Greeff *et al.* 2009; Suit 2005:82). A study by Holzemer based on a sample of 726 PLWHIV in 14 sites in Africa, Porto-Rico and the United States demonstrated that 5.3% of the explained variance in the QoL scores was due to stigma. Important limitations of this study were the convenience sampling technique used to recruit participants and the use of self-reported instruments to gather data (Holzemer, Human, Arudo, Rosa, Hamilton, Corless, Robinson, Nicholas, Wantland, Moezzi, Willard, Kirksey, Portillo, Sefcik, Rivero-Méndez & Maryland 2009: 162). But Holzemer does produce evidence to argue that internalised HIV stigma seems to produce a negative impact on the QoL of men and women (Lee *et al.* 2002: 318).

2.4.2 Measurements of quality of life

Various tools and instruments have been designed by researchers to measure quality of life. Some of them are generic, such as the Medical Outcome Study Short Form 36 item health survey (MOS-SF-36), and can be applied in measuring QoL in people living with cancer, chronic diseases, physical disability or HIV (Ware & Sherbourne 1992). Using a generic tool has the advantage of allowing comparisons between different diagnostic groups (Robinson 2004: 15S; Wiebe, Guyatt, Weaver, Matijevic & Sidwell 2003: 52). However, people being tested with a generic instrument can dislike the general questions and have the feeling that they are being disconnected from their own experience of the disease. Also, they are considered less accurate when changes in clinical condition occur (Skevington & O'Connell 2003: 332). One of the most widely used generic quality of life instruments available is the WHOQOL-BREF. The instrument was designed by the World Health Organisation and has been used in various studies throughout different settings such as Brazil, Taiwan, Rwanda, India and Nigeria (Dos Santos *et al.* 2007; Fang, Chang, Hsu, Twu, Chen, Chen, Huang, Hwang & Wang 2007; Mutimura, Stewart, Crowther, Yarasheski & Cade 2008; Nirmal, Divya, Dorairaj & Venkateswaran 2008; Ola, Adewuya, Ajayib, Akintomide, Oginni & Ologun 2006).

Since the end of the nineteen eighties, a range of instruments has been designed to specifically measure the quality of life of PLWHIV (Remple, Hilton, Ratner & Burdge 2004: 947). A review by Robinson (2004) identified six such instruments. Here are two of the most used HIV and AIDS-related QoL instruments:

The Multidimensional Quality of Life Questionnaire for Persons with HIV/AIDS (MQOL-HIV) is a 40-item questionnaire encompassing ten domains: mental health, physical functioning, physical health, social support, social functioning, cognitive functioning, financial status, partner intimacy, sexual functioning and medical care. It has been validated for use in male and female populations (Remple *et al.* 2004: 948). So far the instrument has been used mostly in developed countries such as Spain, the United States and Japan (Carballo, Cadarso-Suarez, Carrera, Fraga, De la Fuente, Ocampo & Ojea 2004; Osowiecki, Cohen, Morrow, Paul, Carpenter, Flanigan & Boland 2000; Watanabe, Ishihara, Nishimura & Oka 2000).

The HIV/AIDS-targeted quality of life (HAT-QOL) is a self-report instrument designed to measure QoL in PLWHIV and people who have AIDS. It is considered valid (Taylor *et al.* 2008: 553). Studies using the HAT-QOL were first conducted in the United States on a sample of mostly male and homosexual/bisexual PLWHIV (Holmes & Shea 1998), then Brazilian women (Galvão, Cerqueira & Marcondes-Machado 2004) and more recently on patients in American health centres (Kudel, Farber, Mrus, Leonard, Sherman & Tsevat 2006).

In the current study, a generic instrument, the WHOQOL-BREF has been chosen to measure QoL. The reason for this choice is that very few studies have used the MQOL-HIV or the HAT-QOL presented above, and choosing these instruments would have limited the potential for comparison between studies.

2.5 HBC SERVICES FOR PEOPLE LIVING WITH HIV

HBC is a model of health care and support delivery. It usually includes physical, psychological, social, palliative, and spiritual elements (World Health Organisation 2002). Management of opportunistic infections, referral, counselling, support for carers, training, nutritional and treatment adherence advice are some of the most common activities implemented within HBC programmes. Furthermore, in relation to HIV and AIDS-related stigma, HBC services have to provide more than "empathy inducement" measures, as this has proved to be ineffective (Maluwa *et al.* 2002: 12).

The provision of HBC services has many advantages in a setting where hospital care is often inaccessible and/or expensive (Nsutebu, Walley, Mataka & Simon 2001: 240). For example, direct support from HBC programme volunteers can help women and girls (who usually provide most of the care giving), allowing them to gather resources for the family and continue their education (Opiyo, Yamano & Jayne 2008). It can also reduce nosocomial transmission of tuberculosis from PLWHIV to other patients and vice-versa (Nsutebu *et al.* 2001: 240). Another positive effect of community health worker programmes is their success with ARV treatment implementation (Tolle 2009: 669).

Home-based care service provision as a strategy for PLWHIV in Africa is now implemented in countries such as Zimbabwe, Zambia, Malawi, Uganda, Botswana and Mozambique. These initiatives started to emerge in the late eighties (Blinkhoff, Bukanga, Syamalevwe & Williams 1999: 9; Bowie, Kalilani, Marsh, Misiri, Cleary & Bowie 2005; Floriano 2007; Ngwenya & Kgathi 2006; Nsutebu *et al.* 2001: 240; Weidle, Wamai, Solberg, Liechty, Sendagala, Were, Mermin, Buchacz, Behumbiize, Ransom & Bunnell 2006).

2.5.1 The socio-economic context of HBC services

In order to understand the importance of HBC services for PLWHIV in Africa, the socio-economic context of families affected by HIV must be taken into account. Compared to the situation in developed countries, African families cannot count on the State to take care of their ill. Therefore economic factors play a significant role in the type of care that can be provided to people and their families affected by HIV and AIDS.

The micro-economic impacts of HIV and AIDS in Africa are the most visible, as they affect the very fabric of communities and cause changes in the behaviour of individuals and families. One of the most immediate impacts of HIV and AIDS is to reduce the income of affected households (Whiteside 2001: 80, Casale & Whiteside 2006: 5). Because AIDS-related illnesses threaten the productive members of the household, there is a risk that family income might fall below the poverty line (Isaksen, Songstad & Spissoy 2002: 11). In Botswana for example, the poorest quartile of households affected by HIV and AIDS saw their per capita household income drop by 13%, and income-earners having to care for four more dependents as a direct result of a family member living with HIV and AIDS. (Casale 2006: 5).

For households caring for someone who is ill with AIDS, this drop in income is often accompanied by increased expenditures (Casale & Whiteside 2006: 5; Whiteside 2001: 80). In order to cope with the immediate needs of the person with AIDS, households might divert resources to AIDS care, which can amount to up to 1/3 of household income (Casale & Whiteside 2006: 6; Whiteside 2001: 85). To illustrate this, a study in Rwanda showed that households with an AIDS patient spend 20 times more on average on health care than households without an AIDS patient. (Isaksen *et al.* 2002: 11). Other households embark upon the sale of productive assets (livestock, tools) to meet short term needs, frustrating income generation for the future and perhaps leading to the need to rely on borrowed funds to survive. (Casale & Whiteside 2006: 8).

The diversion of household resources from long-term assets to short term needs has many economic impacts because it influences household savings and modifies investment decisions (Casale & Whiteside 2006: 7). Initially the reallocation of resources means lower household savings as the decrease in household consumption achieved by the family is nevertheless not equal to the reduction of household income brought by the inability of the ill family member to work. (Booysen, Geldenhuys & Marinkov 2003: 5). Fewer savings can mean, for instance, that a family cannot buy or maintain the productive assets it needs to cultivate the land, make long term investments in housing or create a safety buffer to protect itself from reduced agricultural yields due to weather cycles or pests.

Hard choices have to be made between tending the fields and taking care of the ill family members (Whiteside 2001: 80). In many cases, this means lower productivity in subsistence labour (Casale & Whiteside 2006: 5). To illustrate this, a study in Tanzania reports that a woman with an ill husband spends 60% less time on agricultural activities than she would normally do. (Isaksen *et al.* 2002: 11). In Zimbabwe, there is evidence that households that had lost a member because of AIDS experience a reduction of 40% to 60% of their crops as a result. (Isaksen *et al.* 2002: 77).

As more and more people are infected, get ill and die, the costs of funerals can quickly become a major problem (Whiteside 2001: 81, Casale & Whiteside 2006: 5). For example, a study in Kagera in Tanzania reported that an AIDS-related death in the household spent on average 50% more on funerals than on medical care (Isaksen *et al.* 2002: 11).

As the affected families sell productive assets and cultivate less land, the availability of food is affected (Casale & Whiteside 2006: 6). Some countries are expected to lose as much as 25% of their agricultural workforce by 2020 (Schneider & Moodie 2002: 5). When family members can't help in the fields because they are too ill, especially during crucial periods of planting or harvesting, this can cause a significant reduction in the size of the harvest (Bollinger and Stover 1999: 5).Simultaneously, households try to cope with this reduced production by reducing their consumption, which leads to a drop in quantity and quality of their food intake (Isaksen *et al.* 2002: 11).

When a family member is affected by AIDS-related illnesses, other members of the household may not be allowed to go to school or might work less so they can provide care. Daughters and wives are usually the ones having to miss school or work (Bollinger & Stover 1999: 4). As a result of HIV and AIDS affecting mostly adults, this transfer from dependency on productive middle generations to dependency on children and the elderly to provide welfare and care is creating a cascade of consequences. (Casale & Whiteside 2006: 8). What is more, fewer resources like time, money and care directed towards children's development and preparation for the future (Casale & Whiteside 2006: 7), means bleak prospects for the next generation's ability to pull itself out of poverty.

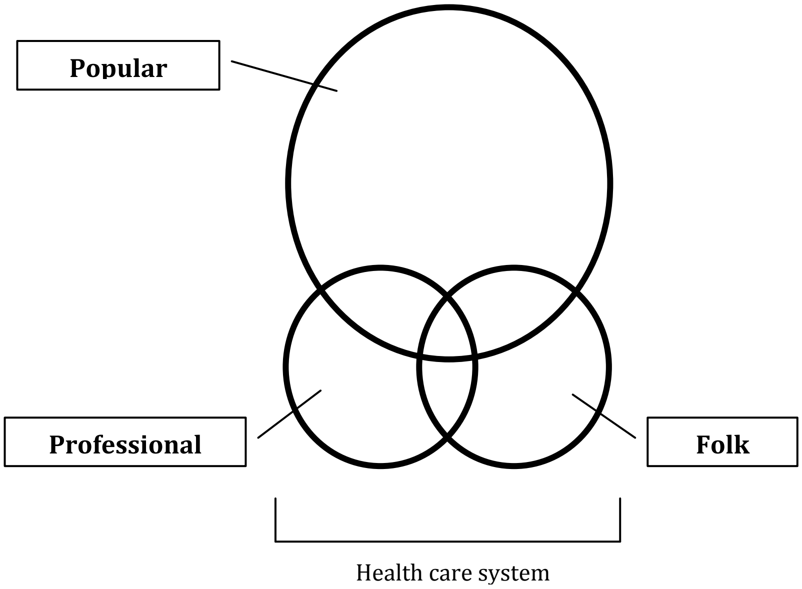
There is hope, however. The provision of antiretroviral therapy might mean a recuperation of human capital, as Thirumurthy, Graff Zivin & Goldstein (2005: 27) discovered. In their study, they uncovered evidence showing that child labour decreases after parents embark on ARV treatment. This could translate into children being relieved of their duty as income generators and being able to return to school.

HBC services are thus provided in a context of poverty, and the decisions made by families are often not based on a wide range of choices, but on limited alternatives dictated mostly by economic considerations. These choices are made not only to provide care to the family member affected by HIV and AIDS but also to ensure the survival of the whole group.

2.5.2 HBC services within the local health system

In Mozambique, health care is the responsibility of the Ministry of Health. In many communities, and especially in rural areas, the resources available from the local health system are scarce. In these communities, the State cannot reach the population with the whole scope of services theoretically available to all Mozambicans, and the provision of public health services is actually minimal. In this context, health options are not confined to the mainstream public health system offered by the Ministry of Health, but also include other possibilities of care. Kleinman (1980: 50-51), as shown in the Figure 2.2, has suggested a framework consisting of three areas of health care: the popular, folk and professional sectors.

Figure 2.2: Local health care systems: Internal structure (Kleinman 1980: 50)



The ***popular sector*** is considered by Kleinman as being the entrance point of health care, and the one in which most care is given. Popular health care can be provided by the ill person itself, according to prevalent cultural beliefs. The family can help to validate the state of the person, to effectively label it as “illness” or, alternatively, identify it as “normal” and not worth paying attention to. Based on the results of this investigation process undertaken with family, friends, neighbours or advisors, the person can decide to move on to another level of health care, and seek either folk or professional care providers. Also, the author points out that the role of popular health care is not only related to the concept of illness, but also is closely linked to the maintenance of a good health. Therefore, traditional principles and beliefs concerning health and how to remain healthy can be included in the popular sector of health care (Kleinman 1980: 50-53).

According to Kleinman’s theory, the ***folk sector*** consists of a heterogeneous group of non-professional health practitioners with or without religious affiliation

(Stollberg 1993: 239). In Mozambique, traditional healers, called *curandeiros* or *médicos tradicionais*, are the most prominent members of this group.

Finally, the ***professional sector*** includes the scientific practitioners of health care, like doctors, nurses and other professionals trained in schools and universities (Kleinman 1978: 87).

There are many types of HBC programmes encountered in the field. Some are provided only by health workers from the professional sector. In Mozambique however, as is the case with Salama, the organisation implementing the HBC programme that is the target of this study, the three sectors often overlap. Care providers are family members, community health workers, traditional healers and, of course, nurses at the health post. In this model, each component of the health care continuum has a specific and unique role to play, and the success of the endeavour lies on the collaborative effort of all.

2.5.3 HBC services in Mozambique

In 2004, former president of Mozambique, Joaquim Chissano, declared HIV and AIDS to be a "national emergency" (African Presidential Archives and Research Center 2004: 81). However, total expenditure on health as a percentage of gross domestic product has remained low, at 4.7% (United Nations 2006: 182). This translates into a per capita expenditure on health care (in USD$ at average exchange rates) of between $7.78 and $12 (United Nations 2006: 188; United Nations Population Fund 2005: 74). This is much lower than what is considered to be the minimum recommended investment in health care for developing countries. The Commission of Macroeconomics and Health, an institution created by the World Health Organisation in 2000 which includes some of the world's most influential economists and policy makers, "…*estimates that $30-40 per capita per year is the minimum required for essential health interventions in low-income countries. Much of this expenditure requires public funding* *particularly to provide services for the poor*" (United Nations Population Fund 2005: 74).

The low level of funding in health care is relevant to this study as financial resources are limited for these communities, and because there is an increasing number of PLWHIV in Mozambique: growing from 1.1 million in 2004 to 1.8 million in 2006 (International Labour Organisation 2004: 11; United Nations Joint Programme on HIV/AIDS 2006: 412). In this context, lower-cost alternatives to institutional care are actively sought to ensure available resources are used not only for treatment and care of PLWHIV, but also for HIV prevention. However, before committing financial, human and material resources to any alternative, governments and civil society organisations need to be convinced that the intervention is cost efficient and effective.

Increasingly, HBC programmes for PLWHIV are viewed around the world as a viable alternative to institutional care provided in hospitals (Arambam 2002; Chandler, Decker & Nziyige 2004; Sekirassa, Grosskurth, Mayala, Mayaud, Laukamm-Josten & Le Jacq 1993). HBC services have several advantages over conventional, institutional care like hospitalisation. Lower cost is the most obvious; in resource-poor settings, similar to those found in rural Mozambique, it is often the only way to deliver services to PLWHIV (Nam 2005: 5). For this reason, HBC services have been a crucial care and support intervention in Uganda (Walker, Aceng, Tindyebwa, Nabyonga, Ogwang & Kiiza 2003: 2).

Faced with limited resources and a burden of care created by increasing numbers of PLWHIV, the Ministry of Health of Mozambique has decided to get more involved in community HBC programmes as a way of delivering health services to PLWHIV (Republic of Mozambique 2004: 91).

Acknowledging its importance and outreach, the Ministry of Health has a publicised objective to extend the network of HBC programmes with the support of local NGOs, religious organisations, family members of PLWHIV and activists. This strategic decision was made because the Ministry believes that the home is the most practical and convenient place for the ill to get better quickly and also calculates this will result in lesser hospitalisation expenses (Republic of Mozambique 2002:6). However, PLWHIV and those who are AIDS-ill, as with any other chronic diseases, experience relapses and uncertain recoveries, a reality that might clash with the Ministry's vision of the ill being able to quickly improve their health status at home.

2.5.4 HBC services and HIV and AIDS-related stigma

Most of the research on HBC and HIV and AIDS-related stigma has concentrated its efforts on the stigma and discrimination from the carers' point of view, not the PLWHIV they care for (Campbell & Foulis 2004, Mwinituo & Mill 2006).

So far, few studies have looked specifically at the link between HBC service provision and the reduction of HIV and AIDS-related stigma. In their study undertaken in 1987-1990 in rural Zambia, Chela, Siankanga, Bailey & Mwilu (1991) uncovered the essential role played by HBC services in the reduction of stigma associated with AIDS. The study concluded that physical, psychological, social and spiritual needs of PLWHIV are better catered for in a home environment than in a hospital, provided a network of support is in place.

In a study with families supporting PLWHIV in Kenya, the researchers found that there is a relationship of unidentified directionality between improved care and knowledge of available support acquired through educational interventions on the one hand and expressed stigma on the other. In turn, decreased stigma will improve the quality of support by changing the care provider's perceptions about the quality and intensity of care and support required by PLWHIV (Hamra *et al.* 2005: 921).

In Zambia, one quasi-experimental study with young peer educators, reported qualitative changes between the baseline and the end-of-project in fear reduction, interest in caring for PLWHIV and acceptance (Esu-Williams, Geibel, Motsepe & Schenk 2003: 7). Another study (Letamo 2003: 347), found that *"the more tolerant attitudes towards a family member with HIV/AIDS appeared to be promoted by the fact that family members have been and continue to care for their ill members through a government project called Community Home-based Care aiming at relieving public hospitals of their HIV/AIDS patients".*

The literature review could not yield any specific study looking at a relation between HBC programmes versus HIV and AIDS-related stigma in Mozambique. By comparing mean HIV and AIDS-related and QoL scores between a group of PLWHIV on ART participating in a HBC programme and a a group of PLWHIV on ART not participating in a HBC programme, this study's purpose was to fill that research gap.

2.6 PROFILE OF THE ORGANIZATION THAT HAS DEVELOPED AND IMPLEMENTED THE HBC PROGRAMME FOR PEOPLE LIVING WITH HIV

2.6.1 General presentation of Salama and origins of the HBC programme

Based in Northern Mozambique, Salama is a national, non-profit, community health organisation founded in 1995. It was formed by a group of local health workers when a project led by the Canada-Mozambique Cooperation (COCAMO) was phased out. It undertakes activities in Ribáuè, Malema and Mecuburi Districts and currently is involved in community health, HIV prevention and HBC services for PLWHIV. At a local level, Salama works with *parteiras* (traditional midwives), *curandeiros* (healers), *activistas* (community health workers) and community leaders (Salama 2004: 3).

In 2005, Olinda Sebastião Magaia, a nurse managing Salama's community health programme, noticed an increase in the number of people staying at home because of a chronic illness. At that time, HIV testing was virtually unknown in the rural areas covered by the programme. After involving local leaders, community health workers and healers in a survey, the nurse realised that a significant number of people living with a chronic illness were showing signs in accordance with the clinical framework of AIDS-related treatment. Nurse Magaia decided to create a community home-based programme aiming at assisting PLWHIV and secured funding from COCAMO, PWRDF (Primate's World Relief Development Fund) and Trôcaire, all international development NGOs working in Mozambique. In the first year, 2006, more than 100 people benefited from the programme and received material, logistical and spiritual support.

2.6.2 Objectives of Salama's HBC programme

Salama's HBC programme has three objectives:

1) Provide home-based support to 500 ill people or people with symptoms in accordance with the clinical framework of AIDS and secure continued health care by their primary carers (family members at home)
2) Contribute to the nutritional improvement of 500 PLWHIV
3) Raise awareness in the community and promote the involvement of people and community groups in the support and integration of PLWHIV in the active life of the community (Salama 2005: 5).

2.6.3 Elements of Salama's HBC programme

The World Health Organisation (2002) has identified the necessary core elements of any HBC programme. In Table 2.1, the activities included in each element are described. The third column shows which of these activities are implemented by Salama in its HBC programme.

Table 2.1: Core HBC programme activities (World Health Organisation 2002)

Core Elements	Core Activities	Activities implemented by Salama
Provision of care (Service package)	Basic physical care	**YES**
	Palliative care	**NO**
	Psychosocial support and counselling	**YES**
	Treatment of tuberculosis and opportunistic infections	**YES**
	Food supplementation	**Very occasionally**
Administration	Network of services and resources	**YES**
	Ensuring access to referral services	**YES**
	• Transportation to referral services	**Very occasionally**
	• Payment waivers (ability to pay)	**YES**
	Coordination with facilities	
	• Discharge planning	**YES**
	• Written referral	**YES**
	Benefits to families: cash allowances, care-giver compensation (in-kind, honorarium)	**YES**
	Supply and storage of HBC kits, necessary drugs and commodities, and equipment	**YES**
	Staffing: supervision, recruitment, staff rotation between HBC and community clinic to avoid burn-out	**YES**
	Budget and financial management including income-generating activities	**YES**
	Monitoring and evaluation	
	• Quality assurance	**YES**
	• Monitoring and supervision	**YES**
	• Evaluation	**YES**
Education/Training (Target groups: PLWHA, family members, community health workers, community volunteers, administrative staff)	Curriculum development	**YES**
	Educational management and curriculum delivery	**NO**
	Outreach activities	**YES**
	Education to reduce stigma	**YES**
	Mass media involvement	**NO**
	Evaluation of education	**NO**

2.6.4 Results obtained by the programme

As of October 2008 about 465 people living with HIV, many of whom were undergoing ARV treatment, were enrolled in the HBC programme in the districts of Malema and Ribáuè. According to the annual report produced in 2008, before the start of the programme, the community considered taking care of a person living with HIV as taboo, and most people did not want to receive ARV treatment. As a result of Salama's work, some PLWHIV are now getting involved and being trained in HBC services themselves. They want to act as agents of change by talking about their own experience of living with HIV (Salama 2008: 9).

2.6.5 Challenges for the future

In informal discussions with the manager and volunteers from the programme, it became clear to the researcher of the current study that the issue of stigma experienced by the beneficiaries is important. The HBC volunteers can identify instances where PLWHIV suffering from stigma and discrimination have, after receiving support from the programme, seen their psychosocial situation greatly improve and felt integrated once again in their own communities and families.

2.7 THEORETICAL POINT OF DEPARTURE

The following synthesis was used as a theoretical point of departure for this study.

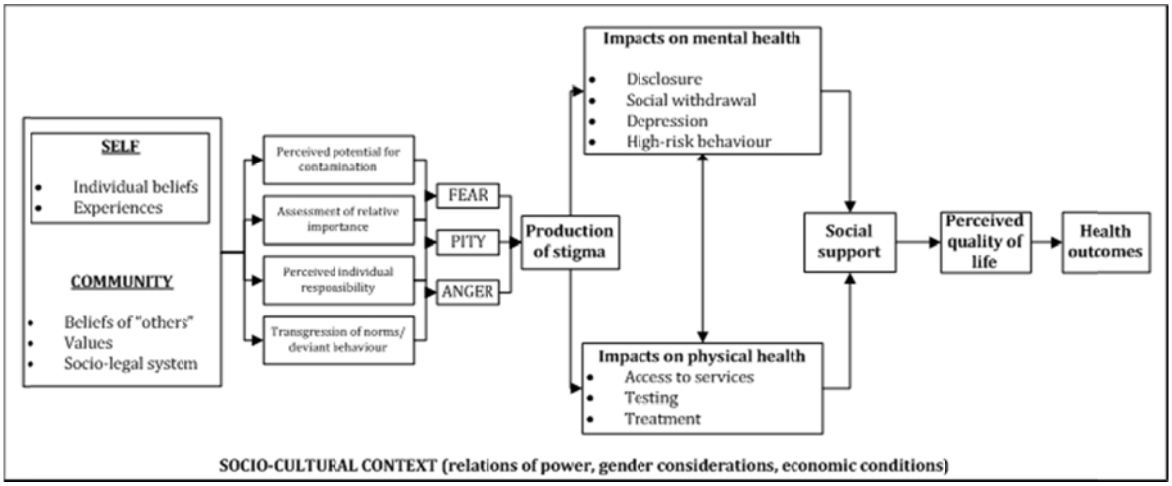
Drawing on the work of Rintamaki, Davis, Skripkauskas, Bennett & Wolf (2006: 360) and their sociocognitive model, as well as Bos, Schaalma and Pryor (cited in Stutterheim 2008: 10) with their cognitive-emotional model, it is proposed to use a conceptual framework for the study which encompasses the relations between stigma and QoL (See Figure 2.3).

The social-cognitive theory (SCT) focusses on a dynamic, three-way, continuous and reciprocal relationship between personal, environmental and behavioural factors (Redding, Rossi, Rossi, Velicer & Prochaska 2000: 185). According to this theory, each factor constantly influences the other two. In the proposed framework for this study, individual beliefs and social values can influence the behaviour of the individual and vice-versa. For example, when a PLWHIV believes that HIV is the consequence of a sin, and the society puts a premium on following religious principles, the behaviour of the PLWHIV could be to withdraw from social interactions and refrain from disclosing his or her HIV status.

Albert Bandura, a Canadian psychologist, is a major tenet of the social cognitive theory. According to Bandura (2002: 269), there are three types of actions that human beings can put in motion in a context of development and adaptation to change. The first one is individual action. In the conceptual framework presented in Figure 2.3, an example of this type of action would be when a person decides to stop seeing a friend who has HIV because he believes he is at risk of being infected. The second type of action is achieved by using a proxy, meaning that the individual will influence others to realise the action in order to attain a certain desired outcome. This could be illustrated when parents complain to the school principal that a pupil has HIV, believing that this child will put their own children at risk of HIV infection. The third type is collective action and can be defined as an action undertaken by a group of people working together to reach a common goal. When PLWHIV are beaten or isolated by groups of people, a collective action described by Bandura is a consequence of the stigmatisation process and creates the impacts on mental health and physical health shown in Figure 2.3.

The cognitive-emotional model described by Bos, Schaalma & Pryor (2008) examines the relationship between cognitive, emotional and behavioural factors that shape up reactions to PLWHIV. The authors divide the attitudes towards PLWHIV in two different types: instrumental and symbolic, in which “*… instrumental attitudes involve a concern about the potential consequences of interacting with a person with HIV and are related to the contagious and serious nature of HIV*” and “…. *symbolic attitudes involve a concern about what HIV symbolizes*” (Bos *et al*. 2008: 453). In the integrated model presented in Figure 2.3, the instrumental attitudes are linked to “perceived potential for contamination” and “assessment of relative importance”. For example, a person with a cognitive process that leads her to believe that her relationship with a PLWHIV is highly risky in terms of HIV infection can develop fear and withdraw from the social interaction. The symbolic attitudes are related to the “transgression of norms/deviant behaviour”. In that case, some people might start to project the negative attitudes they have about drug-use or commercial sex on PLWHIV themselves, in a symbolic transfer.

Figure 2.3: Conceptual framework for the integration of stigma and quality of life



The integrated framework proposed above attempts to describe the process in which stigma is created from individual, environmental and behavioural factors and how these factors interact with emotional responses. In this study, the production of stigma is explained in chapter 3 through a review of literature. The impacts of stigma on mental and physical health of PLWHIV are measured with the Berger Stigma Scale and the WHOQOL-BREF is used to evaluate the QoL of PLWHIV on ART, both inside and outside the HBC programme. The views of PLWHIV in the study are created by the socio-cognitive dynamics of their own experience, producing a vision of themselves (the “Self” section in the conceptual framework) which interacts with the beliefs, values and socio-legal systems of the society (the “community” section in the conceptual framework).

In addition, any conceptual framework for stigma would benefit from acknowledging the emic/etic dichotomy, in which emic is defined by the field corresponding to the “insiders’ perspective” within a certain cultural group and etic to the “outsiders’ perspective”, characterised by professionals or scientific observers (Weiss, Doongaji, Siddhartha, Wypij, Pathare, Bhatawdekar, Bhavem Sheth & Fernandes 1992: 820).

In this study, the “emic” perspective meant that the views expressed by PLWHIV were used as primary data. It has been collected from an “emic” position as it is a reflection of thoughts and feelings of “insiders” who are part of the socio-cultural context being studied.The “etic” perspective was provided by the literature on HIV and AIDS stigma. The analysis of this data is conducted from an “etic” perspective as the researcher does not come from the same socio-cultural context as the participants in the study.

2.8 CONCLUSION

The links between HBC services, HIV and AIDS-related stigma, and QoL in PLWHIV are complex and multidimensional. There is a large quantity of literature on each of these components but little research has been done to integrate them all, especially in sub-Saharan Africa. An HBC programme such as the one implemented by Salama is an ideal opportunity to examine how PLWHIV undergoing ARV treatment in Northern Mozambique perceive their QoL and how they experience stigma in their day-to-day activities.

In the next chapter, we will look at the methodology used to conduct the current study, including an overview of the research design, sampling design and the measurement of variables.

CHAPTER 3 : METHODOLOGY

3.1 INTRODUCTION

The third chapter discusses the methodological considerations of the study. The research design is introduced, including the type of study, data and sources used. The research hypotheses are outlined. The key variables and the instruments used for data-gathering are described. Finally, ethical considerations are discussed.

3.2 THE CHOSEN RESEARCH DESIGN

3.2.1 Type of study

The study is a cross-sectional, quantitative investigation. It was designed to test if there are differences in the mean scores for HIV and AIDS-related stigma and QoL measurements for PLWHIV on ART in Ribáuè and Malema, whether they are receiving HBC services or not. The design was chosen based on a number of considerations. The first is related to the resources available to conduct the study. The design of the study had to take into account the limited resources available to the researcher, both in terms of time and financial inputs. The time factor made a longitudinal study unrealistic as the data needed to be collected within a short time frame as it was a requirement for the completion of a graduate programme. Also, the researcher had limited financial resources which did not allow for an expensive study design.

The design was also selected because the study is not looking for causality, but for a possible correlation between the key variables: participation in a HBC programme as an independent variable and stigma/QoL levels as a dependent variable. In that context, correlationality can be defined as a *“… systematic association between different aspects of two phenomena. […] Correlation does* *not imply that a phenomenon is the cause of the other*" (Gauthier 1986: 515). The design chosen is the most effective way to find preliminary evidence of a difference between the two groups studied, so that other studies could move ahead to a more specific study examining a potential causal relationship between participation in a HBC programme on one hand and QoL and stigma levels on the other. In other words, it would not be scientific to look for a causal effect of HBC programmes on HIV and AIDS-related stigma scores and QoL measurements in PLWHIV, when no evidence of a difference between PLWHIV in the HBC programme versus PLWHIV not in the HBC programme had yet been found.

3.2.2 Type of data and sources used

The study gathered and analysed quantitative data related to HIV and AIDS-related stigma and QoL. Using quantitative data permitted comparisons with other studies about HIV and AIDS-related stigma that used the same survey tools.

Data were collected via face-to-face interviews with PLWHIV on ART in the Malema and Ribáuè districts who also receive HBC services from the HBC programme implemented by Salama. The data were also collected in face-to-face interviews with PLWHIV on ART in the Malema and Ribáuè districts who do not receive assistance from the HBC programme, because they resided in a section of town outside the designated programme area.

As the HBC intervention was already ongoing at the time of the commencement of the study, it was not possible to create a sample of randomly selected research participants from amongst PLWHIV receiving ART in Malema and Ribáuè. Also, the researcher could not assign cases of ART recipients in these areas in an experimental and a control group as one might desire to do for a randomised trial because detailed lists of ART recipients could not be accessed.

It was assumed, however that the study design would not create a significant selection bias as most PLWHIV on ART in Malema and Ribáuè districts were included in the sample.

3.3 RESEARCH HYPOTHESES

In the study, the independent variable is participation in the HBC programme, and the dependent variables are the level of HIV and AIDS-related stigma and QoL in PLWHIV on ART. The three objectives of the study (see Chapter 1) were tested based on the hypotheses described in this section.

3.3.1 Hypothesis related to objective 1

The first objective of the study was to answer the following question: *Is there a difference in the level of HIV and AIDS-related stigma experienced by PLWHIV on ART receiving HBC services and the level experienced by PLWHIV on ART but not receiving HBC services?*

The null hypothesis for objective 1 is:
$H_0 : \mu_1 = \mu_2$
μ_1 = Mean scores for HIV and AIDS-related stigma of PLWHIV on ART receiving HBC services in Ribáuè and Malema.
μ_2 = Mean scores for HIV and AIDS-related stigma of PLWHIV on ART not receiving HBC services in Ribáuè and Malema.

The alternative hypothesis for objective 1 is:
$H_1 : \mu_1 \neq \mu_2$
μ_1 = Mean scores for HIV and AIDS-related stigma of PLWHIV on ART receiving HBC services in Ribáuè and Malema.

μ_2 = Mean scores for HIV and AIDS-related stigma of PLWHIV on ART not receiving HBC services in Ribáuè and Malema.

3.3.2 Hypothesis related to objective 2

The second objective of the study was expressed in the following question: *Is there a difference in the self-reported QoL scores for PLWHIV on ART receiving HBC services and the scores for PLWHIV on ART not receiving HBC?*

The null hypothesis for objective 2 is:
$H_0 : \mu_1 = \mu_2$
H_0 = the null hypothesis
μ_1 = Mean scores for quality of life of PLWHIV on ART receiving HBC services in Ribáuè and Malema.
μ_2 = Mean scores for quality of life of PLWHIV on ART receiving HBC services in Ribáuè and Malema

The alternative hypothesis for objective 1 is:
$H_1 : \mu_1 \neq \mu_2$
μ_1 = Mean scores for quality of life of PLWHIV on ART receiving HBC services in Ribáuè and Malema.
μ_2 = Mean scores for quality of life of PLWHIV on ART not receiving HBC services in Ribáuè and Malema

3.3.3 Hypothesis related to objective 3

The third objective of the study was to answer the following question: *Is there a correlation between stigma and self-reported QoL?*

The null hypothesis for objective 3 is:
H_0 : There is no correlation between the variables at α=0.01

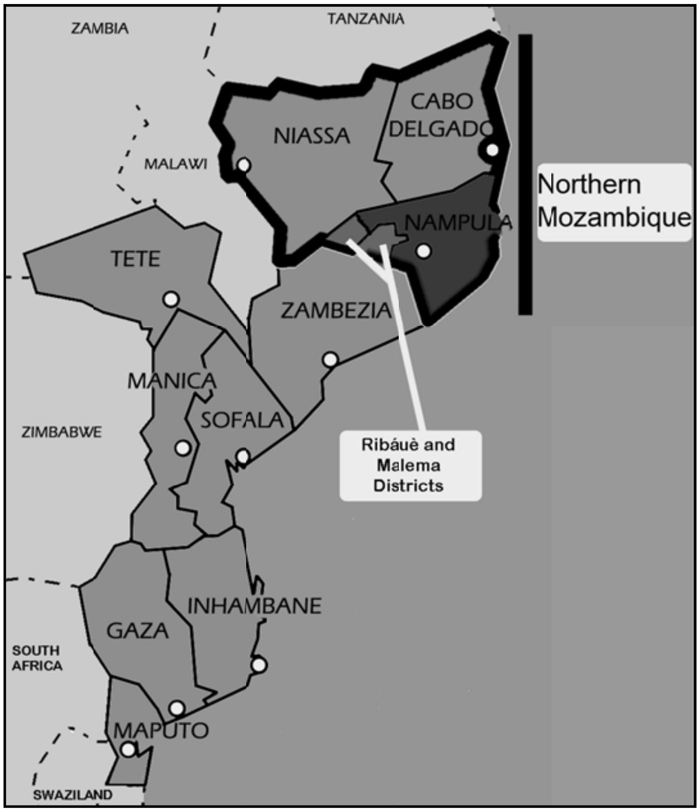
The alternative hypothesis for objective 3 is:

H_1: There is a correlation between the variables at α=0.01

3.4 RESEARCH SITES

The data collection took place in two geographic areas, namely the Malema and Ribáuè districts. Both districts are located in the Province of Nampula, in Northern Mozambique. These two districts were chosen as they are the target sites for Salama's HBC programme. Figure 3.1 shows the geographic location of Nampula within the country, and more specifically the two districts studied, Malema and Ribáuè.

Figure 3.1: Localisation of Ribáuè and Malema Districts, Nampula Province in Mozambique



(Adapted by author from International Labour Organisation 2009)

The districts' inhabitants share similar socio-cultural characteristics, as there is only one ethnic group, the Makua, and one local language, Emakua (Republic of Mozambique 2005a: 12; Republic of Mozambique 2005b: 12).

In the following table, socio-demographic indicators for both districts are presented:

Table 3.1: Socio-demographic indicators for Ribáuè and Malema districts (Republic of Mozambique 2005a; Republic of Mozambique 2005b)

	Ribáuè	Malema
Population (2005)	153,794	149,782
Percentage of the population under 15 years old	48%	46%
Urbanisation rate	12%	26%
Health installations (hospital, health posts)	One per 19,000 people	One per 20,000 people
Professional health technicians	One per 2,600 people	One per 4,500 people
Religion:		
Muslims	46.0%	41.8%
Catholics	27.0%	24.7%
Evangelicals	18.3%	18.4%
Animists:	10.2%	-
Other	11.1%	15.1%
Illiteracy percentage (1997)		
Men	63.0%	58.9%
Women	87.3%	83.7%
Total	75.3%	71.5%

The information presented in Table 3.1 shows that the two districts are similar in terms of socio-demographic indicators, except for the urbanisation rate, which is twice as high in Malema as in Ribáuè

3.5 SAMPLING DESIGN AND PROCEDURES

The HBC programme which was studied is implemented by Salama, a local NGO. As of October 2008, about 465 PLWHIV, many of whom are also undergoing ART, were enrolled in the HBC component of the programme in the districts of Malema and Ribáuè. The following tables, provided by the districts'

Health Departments to Salama's head nurse (Olinda Magaia, October 2008, personal communication) show the number of PLWHIV in Ribáuè and Malema. In bold typeface are the numbers of PLWHIV that formed the universe of potential participants for the study:

Table 3.2: Number of PLWHIV in Malema district in October 2008 (Olinda Magaia, October 2008, personal communication)

			Men	**Women**
PLWHIV (according to data collected by the VCT facility)	On antiretroviral treatment	On Salama's HBC programme	**50**	**109**
		Outside Salama's HBC programme	**7**	**-**
	Not on antiretroviral treatment	On Salama's HBC programme	25	192
		Outside Salama's HBC programme	297	637
		TOTAL	***379***	***938***

Table 3.3: Number of PLWHIV in Ribáuè District in October 2008 (Olinda Magaia, October 2008, personal communication)

			Men	**Women**
PLWHIV (according to data collected by the VCT facility)	On antiretroviral treatment	On Salama's HBC programme	**7**	**9**
		Outside Salama's HBC programme	**150**	**144**
	Not on antiretroviral treatment	On Salama's HBC programme	31	42
		Outside Salama's HBC programme	90	158
		TOTAL	***278***	***353***

The universe for the study was thus composed of 476 PLWHIV, comprising of 175 patients benefiting from the HBC programme and 301 not involved in the programme. Of the 175 PLWHIV on ART in the HBC programme either in Ribáuè or Malema, 120 were sampled using a method describe below and 119 valid questionnaires were collected. Using the data shown in Table 3.2 and 3.3, 119 PLWHIV on ART from Ribáuè and Malema who were not in Salama's HBC programme were sampled out of 301 potential participants, producing a total of 118 valid questionnaires from that sample. It was thus possible to interview 239

PLWHIV on ART and obtain 237 completed questionnaires, corresponding to 49.8% of the potential respondents.

As we have seen in chapter 2, the extent and prevalence of HIV and AIDS-related stigma perceptions and experiences in Mozambicans living with HIV has not been measured yet in a study. Considering an unknown difference (u1 – u2) between the HIV and AIDS-related stigma levels between the groups studied, a power of 80% and an error level of 5%, a large enough sample in each group was needed in order to detect an eventual difference. In addition, the sample had to be sufficient to compute a regression model including various explicative variables (age, gender, education level, number of people living in the patient's house, number of months since HIV diagnosis, membership/attendance of support groups, marital status and religious affiliation). The regression model allowed the researcher to observe the differences between the groups studied and to determine if they were statistically significant.

In the case of this study, no comparable data from other research existed that could have helped in defining the standard deviation of the variable between the groups. Sample size also had to take into account the limited financial, human and time resources available to the researcher. Concerning the minimal sample size needed to conduct a study such as this one, it was stated by MacCallum, Widaman, Zhang & Hong (1999: 96) that the minimal number of participants in a study depends on the variables used and the design of the study, rendering general guiding principles "*not valid or useful*". Also, given a normal distribution, central limit theorem applies to samples of over 30 individuals (Norman & Streiner 2008: 32). In this study, a sample of 120 PLWHIV on ART receiving HBC services and 120 PLWHIV on ART not receiving HBC services, for a total of 240 research participants, was planned. However, due to the rejection of two questionnaires because two respondents were under 18 years of age and a miscalculation of the number of completed questionnaires in the non-HBC programme group, the final number of valid questionnaires was 119 in the HBC programme group and 118 in the non-HBC programme group, for a total of 237 completed questionnaires. The two groups studied were sampled from the universe of potential participants described above.

PLWHIV on ART have to attend a VCT facility every month in order to receive their medication. Those not involved in the HBC programme were asked by the VCT counsellor if they had an interest in participating in the study. The request was made at the end of a normal counselling session. The purpose of the study was explained and it was made clear that participation was voluntary, unpaid and that refusal to participate would not have any negative consequences. After agreeing to participate, a separate appointment was made for the volunteers outside normal clinic hours so that the interview would not replace normal counselling being given to the patient. The VCT staff's collaboration and commitment to the study were essential. The first 120 PLWHIV using ARV and not involved in the HBC programme who agreed to take part duly signed the informed consent form and were enrolled in the study.

As explained, a specific time was planned for the interview, at a moment that did not influence normal clinic activities and the counsellor made sure patients understood that the study interview was an event separate from counselling, and that normal counselling would continue as usual. The interviewer, in this case the VCT counsellor, used pre-prepared forms for the study and did not communicate names of the respondents to anyone. In some cases, and in order to ensure conformity between the interviews which were undertaken by two different counsellors, the head nurse of the HBC programme participated in the interview as an observer. This was done only after securing the patient's agreement to this arrangement. If the patient did not agree to the presence of the head nurse, but agreed to the interview with the counsellor, the head nurse did not participate as an observer and the interview was conducted with the counsellor as the only other person present.

Respondents on ART and receiving HBC services were selected randomly by the nurse supervising the programme. The selected respondents were contacted by a programme volunteer or the head nurse and introduced to the research. They read (or someone did the reading for them) the informed consent form. A specific date and time was decided for the interview. The head nurse conducted the interviews, in the presence of a programme volunteer who helped to make the participants feel at ease. The beneficiaries of the HBC programme were told that this was a separate visit from the normal HBC visits and that these would continue as planned, without interference by the study interview. The true names of the respondents were known to the head nurse, but no names were revealed to the researcher, thus preserving the confidentiality of the respondents.

The following table shows the sampling frame and criteria for inclusion in the study:

Table 3.4: Sampling decisions

	Group 1 - PLWHIV on ART receiving HBC services in Salama's HBC programme	**Group 2- PLWHIV on ART not receiving HBC services in Salama's HBC programme**
Number of participants	120 (out of 175 potential participants)	120 (out of 301 potential participants)
Criteria for inclusion	• 18 years old or older • Living with HIV • Receiving ART from local testing and counselling facility in Malema or Ribáuè • Receiving support from Salama's HBC programme (for at least the previous 3 months) • Received thorough explanation of the purpose of the study, their rights as participant and signed the informed consent form	• 18 years old or older • Living with HIV • Receiving ART from local testing and counselling facility in Malema or Ribáuè • Had never received support from Salama's HBC programme • Received thorough explanation of the purpose of the study, their rights as participant and signed the informed consent form
Interviewer	HBC programme nurse and a local programme volunteer as an observer	Counsellor at the local VTC and HBC programme nurse (if agreed to by the participant) as an observer

	Group 1 - PLWHIV on ART receiving HBC services in Salama's HBC programme	Group 2- PLWHIV on ART not receiving HBC services in Salama's HBC programme
Sampling technique	• A list of all the PLWHIV receiving ART who were beneficiaries of the HBC programme was produced by the head nurse of the programme. Each person was assigned a number and 120 numbers were randomly selected during a draw. The head nurse noted the 120 names. • Potential participants were approached by the head nurse of the HBC programme, and were given an explanation of the purpose of the study. If interested, each potential participant consented verbally and then signed the informed consent form.	• A list of all the PLWHIV receiving ART who were not beneficiaries of the HBC programme was produced by the counsellor at the VCT. Each person was assigned a number and 120 numbers were randomly selected during a draw. The counsellor noted the 120 names. • Potential participants were approached at the end of a routine meeting with their usual counsellor at the VCT, and were given an explanation of the purpose of the study. If interested, each potential participant consented verbally and then signed the informed consent form.

3.6 ACCESS, AUTHORISATION AND CLEARANCE

Clearance was sought and secured by the researcher from the Department of Sociology's Ethics Committee at the University of South Africa (UNISA). Since the researcher was not present in Mozambique when data was gathered, the Ministry of Health officials at district level were informed of the process by Salama's head nurse, on behalf of the researcher. This is standard procedure for activities involving Salama, used for example when the organisation collects baseline data to evaluate its HIV/AIDS or community health programmes. The district officials received verbal information related to the study and provided the necessary authorisation for the study to proceed. Other verbal authorisations were granted from local leaders from the communities concerned during informal meetings held by Salama's head nurse.

3.7 INSTRUMENTATION

In order to gather data on HIV and AIDS-related stigma and QoL, a selection of quantitative instruments was assembled. Quantitative data was collected using the tools described below.

3.7.1 The Berger Stigma Scale

Berger's Stigma Scale consists of 40 items and is a standardized instrument designed to measure stigma (Berger *et al.* 2001). It examines stigma experienced on the following subscales: Personalised stigma, disclosure, negative self-image and public attitudes. Berger *et al.* (2001: 526) claim that the tool is *"reliable and valid with a large, diverse sample of people with HIV"*. The Berger Stigma Scale has been chosen because it is a multiple item questionnaire specifically designed for measuring various aspects of stigma. As Kalichman *et al.* (2005: 135) point out, "… *multiple item measures have several advantages over single item measures, including increased reliability, greater variability, better sensitivity to change, and greater construct representation*".

3.7.2 WHOQOL-BREF

This is the World Health Organisation's generic tool to measure quality of life (Canavarro, Simões, Pereira & Pintassilgo 2005; World Health Organisation 1996). The 26-item instrument collects data in four different domains: Physical health, psychological health, social relationships and the environment. Each domain contains facets of life describing the situation of the person. In the context of this study, the WHOQOL-BREF was selected as the QoL instrument as it has been used previously in Africa and proved reliable and valid in different settings (Dos Santos *et al.* 2007; Fang *et al.* 2007; Mutimura *et al.* 2008; Nirmal *et al.* 2008; Ola *et al.* 2006). As it is a generic instrument, it allows comparisons with other studies which could prove to be useful in future research (Robinson 2004: 15S; Wiebe *et al.* 2003: 52).

3.7.3 Translation of the questionnaires

The questionnaire was produced in two versions: Portuguese and the local language, Emakua. The questionnaire was translated into Portuguese by the researcher and double-checked by Salama's head nurse, who is a native speaker. The questionnaire in Emakua was translated by a committee consisting of Salama's staff members, under the direct supervision of the researcher who spent two days in February of 2008 with the staff members to do the translation. The involvement of local staff members in the translation of the instruments used was considered an essential step so that questions would be "*unambiguous and culturally shared*" (Bowling 2005: 419) a method suggested by the author to ensure proper cultural equivalence. The staff members were explained the purpose of the work and were told that the questionnaires would be used in a study conducted by the researcher as a requirement for a Master's degree. The staff members were paid by the researcher for the work done on the questionnaires. The researcher's role in the translation phase was to explain the meaning of the questions in the various questionnaires to make sure the translation was based on the right interpretation of the Portuguese version. The Emakua questionnaire was back-translated into Portuguese by one of Salama's HIV/AIDS programme manager, who was paid by the researcher from his personal money to check for consistency.

3.7.4 Training of the interviewers

The questionnaires were introduced to the head nurse of Salama's HBC programme and the counsellors from the VCTs in Ribáuè and Malema. These people were selected by the researcher because they were able to speak the local language, Emakua and were already known by the PLWHIV in the communities. For their work as interviewers, they were paid by the researcher's own money. The researcher trained the head nurse over the phone on the use of the study's questionnaires and carefully explained how to conduct the interviews. As the researcher had previously worked with Salama's head nurse in data-collecting events, ethical issues related to community surveys and precautions needed to avoid introducing bias while conducting the interviews had already been explained and integrated. The head nurse then trained the two VCT counsellors on the use of the questionnaire and was asked to refine the interview techniques. The training was conducted in July of 2009 after the researcher's supervisor at UNISA gave her authorisation to proceed with the interviews. Every question was reviewed and the head nurse gave explanations when needed. The main objective was to make sure that all the interviewers would ask the same questions in the same way and write down the answers in a consistent and coherent manner. Linguistic issues regarding the questionnaires which had been translated into Emakua were addressed, to ensure that the meaning of Portuguese expressions was accurately conveyed in Emakua.

3.7.5 Pre-testing of the instruments

The first step of the pre-testing phase was to make a list of all the PLWHIV on ART and enrolled in the HBC programme. The list was provided by the head nurse as it already existed in the HBC programme database. The sampling procedures were designed by the researcher (See Table 3.4) then explained to the head nurse. For practical reasons, as the researcher was not physically present when the sampling was done, the head nurse wrote the names from the list on pieces of paper and put them in a bag. The first 10 names randomly picked were assigned to the group of "pre-test" and the next 120 names were assigned to the "study" group, in accordance with the sampling framework of the study. The names selected for each group were put on a separate sheet of paper, and kept only by the head nurse in charge of the programme to preserve the anonymity of the participants. The remaining pieces of paper were destroyed.

For the next group, PLWHIV on ART but not participating in the HBC programme, the first 10 PLWHIV who went to the VCT for their monthly visits and agreed to sign the consent form for the study were asked by the counsellor to answer the questionnaires as a way to pre-test the questionnaires. The criteria used to select the participants were the same as the study's criteria, as shown in Table 3.4. For their participation in the pre-test phase, the 20 PLWHIV were reimbursed the cost of a meal (2$US), an amount that was paid by the researcher with his personal money.

Before they tested the questionnaires, the VCT counsellors were trained by Salama's head nurse to use the tools consistently. Starting in July of 2009, the questionnaires to be used in the study were formally tested in the districts of Malema and Ribáuè in Northern Mozambique. After a first round of tests with 20 PLWHIV (10 from the PLWHIV in the HBC programme and 10 PLWHIV not in the HBC programme), the VCT counsellors met with the head nurse and discussed administering the questionnaires. Suggestions to improve quality were formulated and changes were made by the researcher to the questionnaires to improve clarity. Changes included adding the word "resources" to the question 12 in the WHOQOL-BREF questionnaires to adapt to the fact that very few people in the rural area manipulate paper money, but use resources such as food and other goods instead of money to evaluate their economic status. The question 13 of the same questionnaire had to be changed also, because it measured the level of information that PLWHIV can have access in their everyday life. That question made little sense to the people interviewed, so the researcher decided to add some examples of the types of information that could be needed, such as health-related or information about rights. Finally, question 11 in the Berger Stigma Scale had to be changed by the researcher because the counsellors reported that it was puzzling to the PLWHIV interviewed in the test phase. The original question was labelled "*It is easier to avoid new friendships than worry about telling someone that I have HIV*" (Berger *et al.* 2001). After discussion with the head nurse, the researcher re-labelled the question to "*I prefer not to make friends because I am afraid I will have to tell them I have HIV*" which was more easily understood by the PLWHIV.

During the testing phase, the staff noted that administering each questionnaire took between one hour and one hour and forty-five minutes. This proved to be difficult for some of the participants who became tired after forty-five minutes. To make sure that participants were able to answer questions to the best of their ability, the interviewing team had to break up the interview into two parts to allow participants some time to rest.

Also, as the Emakua language is prone to local interpretations, the use of a local volunteer during the interview helped the participants to feel at ease. The introduction of a local volunteer, to which the participants agreed, was a way to double-check the accuracy of the answers and make sure that the answer written on the form reflected the opinion of the participant.

After the testing rounds, an updated version of the instrument was produced and final reviews were made by the interviewers to make sure that all problems had been resolved. Another training session was held to explain the changes made to the questionnaires and to fine-tune interview techniques.

The supervisors of the study (Dr. Gretchen du Plessis and Mr. Leon Roets) were informed of the results of the testing and granted final authorisation for the main data collection to begin.

3.8 DATA COLLECTION PROCEDURES

The interviews with PLWHIV included in the HBC programme were conducted by Salama's head nurse, accompanied by a local volunteer in the HBC programme. PLWHIV not included in the HBC programme were interviewed by the HIV/AIDS counsellor at the HIV testing and counselling facility over a three month period. Both the head nurse and the counsellors at the VCT were paid by the researcher's own money, but the programme volunteers were not paid. As they had to spend a few hours with the interviewer, participants were reimbursed the cost of a meal (2$US), an amount that was paid by the researcher with his personal money.

The data collected was coded, checked and computerised in an Excel spreadsheet. After checking, two questionnaires had to be eliminated from the analysis because the ages of the respondents were younger than 18 years. One of the questionnaires rejected was of a PLWHIV in the HBC programme (case #127) and the other was of a PLWHIV not in the HBC programme (case #246). The data in the spreadsheet was analysed using SPSS statistical software.

3.9 DATA ANALYSES

Data was collected about socio-demographic variables such as age, gender, education level, number of people in the research participant's household, number of months since HIV diagnosis, membership/attendance of support groups, marital status, employment status and religious affiliation. The information gathered was then processed by an analysis of variance (ANOVA) in order to understand the relationship between the variables and to extract significant differences between the two groups. Differences between these findings and existing literature are discussed and compared in chapter 4. Data in that chapter is presented using graphs and tables which clearly show the strength of the relationship between the different variables.

3.10 LIMITATIONS OF THE STUDY

The study has various limitations. In this section, they are described and discussed.

3.10.1 External validity

Based on the study design and limited sample, the conclusions of the study cannot be generalised to refer to every PLWHIV in Mozambique, or indeed elsewhere. The data collection was conducted using a sample of PLWHIV on ART in Ribáuè and Malema, so it would be imprudent to reach the conclusion that the current study would be applicable even to the situation of PLWHIV in Maputo, for example. Further research will be needed to verify if similar results could be uncovered in different settings.

3.10.2 Value of self-reported measurements

One of the issues that could be viewed as contentious is the value of self-reported measurements in the field of HIV and AIDS-related stigma QoL. The main questions in this regard are: a) Were the participants able to understand the questions and provide the information asked and b) Were they honest in their answers?

The ability to understand the question was given much attention in the testing phase of the questionnaires. Because the interviewers reported some respondents had difficulties in answering some questions, modifications were made to the problematic sentences to increase the interviewees' comprehension. However, given that HIV itself can impair judgement when it attacks the neurological system (Owe-Larsson, Säll, Salamon & Allgulander 2009: 116), partial loss of cognitive capabilities such as memory and self-awareness could have prevented some participants from fully understanding the questions asked. Assessing whether or not a participant was suffering from neurological impairments would have been a massive undertaking that was not contemplated for this study, given the level of clinical observation needed to diagnose patients and the limited scope of the study. The prevalence of neurological complications for a general population of PLWHIV in Africa is not known, but a study of 5000 homosexual men in the United States place it at about 15% (McArthur, Brew & Nath 2005: 543). However, it is known that ART can reduce the incidence of neurological problems and even reverse their effects for at least 50% of PLWHIV (McArthur *et al.* 2005: 543). All the respondents of the study were on ART when they were interviewed, which possibly contributed to reduce the impact of neurological impairments on the answers given.

The question of honesty in the answers given is important because of the context of the study. Personal observations made by the researcher tend to support the hypothesis that some people might give answers in a way they think will lead them to acquire more services or resources, a process know as "*strategic answering*" (Macours 2002: 2). In some cases, reporting worse health could be interpreted by the respondent as a way to attract the attention of carers or programme donors. The effects of this were considered to be equal for both groups, but it might be argued that the participants in the study coming from the group not benefiting from the HBC programme might be more tempted to answer in a strategic way to attract the services that they cannot currently access. More research would be needed to confirm or deny this hypothesis.

3.10.3 Social desirability effect

Another issue of note is the fact that interviews were conducted in a face to face situation with an interviewer. This method was chosen because literacy rates are low in the region studied, at 28% in the District of Malema and 25% in the District or Ribáuè (Republic of Mozambique 2005a: 13; Republic of Mozambique 2005b: 16). In such a context, written questionnaires might have severely limited the number of respondents. The downside of this is that face to face interviews might have affected the answers given because of the social desirability effect. As Muldoon, Barger, Flory & Manuck (1998: 544) point out, "… *some people have response biases that lead them to give the answers they think are most socially* *acceptable or cast them in a favourable light*". To reduce the effect of social desirability, a neutral attitude for interviewers at all times while conducting interviews was promoted, and the confidential nature of the answers was given emphasis.

3.10.4 Study design

In order to thoroughly examine the differences between the two groups studied, a longitudinal study would have yielded the largest amount of information. A randomized, controlled trial would also have been a design of choice as it would have allowed measuring the impact of the HBC programme on QoL and stigma levels in PLWHIV on ART. In the context of the study and given the resources available, a cross-sectional study was considered to be an adequate alternative. The main disadvantage of the cross-sectional design of the current study is that it does not allow the establishment of a causal link between the involvement in a HBC programme and HIV and AIDS-related stigma and QoL. However, it provides sufficient information to point out differences between the groups and suggest avenues for future research.

Also, the sampling methods used in the study were not completely random. The reason for the non-random sampling of the participants is that there was no list available to identify PLWHIV not in the HBC programme. The selection of the participants had to be conducted as PLWHIV were fetching their medicine at the local VCT, resulting in a "first come, first to have a probability of participating in the study" sampling method for that specific group. On the other hand, the presence of a list of PLWHIV in the HBC programme allowed for a randomized sample in that group, meaning that every PLWHIV on ART in the HBC programme had the same probability of being selected as a participant in the study.

3.10.5 Variables not measured

Significant and potentially confounding factors based on objective health status measures such as CD4 count and weight, were not collected nor measured. A specific instrument to measure health status was not available and health-related information such as HIV diagnosis date and occurrences of previous opportunistic infections was self-reported. The emphasis of the study was put on a subjective, self-reported assessment of QoL and HIV and AIDS-related stigma, and validation of the respondent's perception against objective measurements of health was not in the scope of the study.

3.10.6 Use of instruments not validated in the specific socio-cultural context

Finally, the quantitative instruments that were used have not been tested in the socio-cultural context of Northern Mozambique, and do not have a standardized Portuguese or Emakua version. Extra attention was paid to the way the questionnaires were translated and adapted to ensure they were well understood by the respondents and that items corresponded to their socio-cultural reality.

3.11 STRENGTHS OF THE STUDY

3.11.1 Internal validity

Studies looking at interaction between two phenomena, such as the presence or absence of participation in the HBC programme versus levels of stigma and QoL scores, need to establish internal validity (Fortin 1996: 132). Internal validity is defined as the relationship between the programme and the observed outcome (Bernard 2000: 108). In the case of this study, there was no intention of proving causality between the HBC programme and the stigma and QoL scores. It was necessary, however, to have relatively high confidence that any potential difference between the two groups would not be biased because of the existence of a concurrent HBC programme or similar intervention with the group of people not involved in Salama's HBC programme.

In the case of Malema District, few interventions in the field of HIV/AIDS have been conducted by other organizations. In Ribáuè, HIV/AIDS interventions outside Salama's HBC programme were exclusively of a preventive nature, and no other HBC programme had been implemented at the time of the study.

Another threat to validity would have been a difference between the two groups. The first group consisted of PLWHIV on ART receiving HBC services, and the second of PLWHIV on ART not receiving HBC services. Apart from their participation in the HBC programme, both groups were considered to be similar.

3.11.2 Selection of participants

A large percentage of known PLWHIV was included in the study and according to the counsellors at the VCT and Salama's head nurse who conducted the interviews, no one refused to take part in the study which reduces the effects of selection bias. However, in two cases in Ribáuè and three in Malema, PLWHIV selected to participate in the study lost their lives before they could be interviewed. These participants were substituted the same way they were selected in the first place. The sample of PLWHIV not participating in the HBC programme was formed of patients taken from outside the HBC catchment area, not of PLWHIV who lived in the catchment area but did not want to be included in the HBC programme.

3.12 ETHICAL CONSIDERATIONS

In 2007, UNISA published ethical guidelines for the research conducted by its students (University of South Africa 2007). The document established four "*moral* *principles*", namely: autonomy, beneficence, non-maleficence and justice. As a complement to these principles, the guidelines stated ten "*general ethical principles*". In this section, those principles will be reviewed and a description of what has been done to ensure they were respected during the preparation and implementation of the current study will be provided.

3.12.1 "Essentiality and relevance"

The study includes a review of the existing literature on the topic of HIV and AIDS-related stigma, QoL and their relation to home-based care for PLWHIV. No other study exploring these concepts was found to be comparable to the current study. This study explores the subject in a way that could uncover new evidence and yield positive benefits for programmes designed for PLWHIV.

3.12.2 "Maximisation of public interest and of social justice"

Any findings relevant to the population studied will be communicated to Salama's staff so they can be integrated into the HBC programme. The results of the research will be shared with interested parties, including stakeholders and policy-makers involved in HBC services in Mozambique. Original research documents and articles will be provided on request.

3.12.3 "Competence, ability and commitment to research"

The researcher had already completed all necessary requirements to obtain the MA degree (except the production of the dissertation), and is committed to the field of study.

3.12.4 “Respect for and protection of participants’ rights”

The notion of confidentiality was explained to the participants, as well as the purpose and time needed for the interview. Data collected during the interview was not shared with other people, and only the researcher and the interviewers handled the completed questionnaires.

Training of Salama’s head nurse on the use of the study’s questionnaires was done over the phone as the researcher was in Canada at the time. The researcher made a comprehensive review of how the interview would have to be conducted with Salama’s head nurse. The researcher had previously trained Salama’s head nurse during successful community data-collecting events between 2002 and 2005, so ethical issues related to community surveys and precautions needed to avoid introducing bias while conducting the interviews had already been explained and integrated. Salama’s head nurse proceeded to train the two VCT counsellors on the use of the questionnaire and was asked to refine their interview techniques. Every question was read and discussed, and further explanations were given by the head nurse when needed. This was done to ensure that the interviewers would ask the same questions consistently and register the answers coherently without interfering or introducing bias.

During data collection, each questionnaire was identified with a number in order to make it impossible to connect the questionnaires with a specific participant. Only socio-demographic characteristics were noted. After all the questionnaires were collected by Salama’s head nurse, they were packed and sent to the researcher in Canada through DHL, a courier company. The completed questionnaires were kept by the researcher in a locked file cabinet, and will be destroyed upon the completion of the dissertation.

3.12.5 “Informed and non-coerced consent”

The interviewers explained the purpose of the study and stated clearly the rights of the participant (see informed consent form in annex). Participants gave their consent verbally and were presented with an informed consent form for them to sign. They kept one form and the other remained with the interviewer. After signing the form, a date and time was set up for the interview.

3.12.6 “Respect for cultural differences”

The researcher provided questionnaires in the language of the participants and used the help of local informers and interviewers to ensure the cultural relevancy and sensitiveness of the instruments used. Permission to visit PLWHIV at home was granted by the local authorities before the start of data collection.

3.12.7 “Justice, fairness and objectivity”

The participants in the study were selected based on objective criteria and were not burdened with repetitive interviews and tests.

3.12.8 “Integrity, transparency and accountability”

The research was conducted in a spirit of intellectual honesty and openness. The limitations of the study were clearly thought-through and contributions acknowledged. The researcher achieved no personal gain from the process, apart from the conclusion of the academic degree.

3.12.9 “Risk minimisation”

In the case of PLWHIV participating in the HBC programme, the interviews were delivered in the participants’ homes; as they already received visits from the programme volunteers, this was considered the best approach to minimise discomfort from travelling. The PLWHIV not participating in the HBC programme were interviewed at the Salama facility by their normal counsellor, so their identity would remain secret. This ensured that the participants clearly understood that the study interview was different from the usual services they received at the VCT. Salama's facility is a quiet and secluded setting and provided ideal conditions for confidentiality. The participants were provided with names of counsellors working in nearby VCT facilities in case the interview left the participant with questions or feelings of stress. As the interview did not include physical examination, there were no possibilities of physical harm. However, if the respondent felt tired during the course of the interview, it was possible to stop and start again at a more convenient time. Also, breaks to take medicine or go to the bathroom were accommodated by the interviewer.

3.12.10 "Non exploitation"

No community member was exploited during the completion of this study. Salama's head nurse, the questionnaire translators and the VCT counsellors who helped with the collection of data were paid by the researcher, so their time was compensated. PLWHIV are vulnerable people and all precautions were taken to guarantee their protection from harm. Also, the conclusions of the study will be used to improve the current HBC programme, so the participants and the local communities will benefit from the knowledge uncovered as a result of the study.

3.13 CONCLUSION

In the preceding chapter, the methodological aspects of the study were described. This included sections on research design, research hypotheses and respondent selection. The quantitative instruments used in the study were described. The last section of the chapter was dedicated to the ethical considerations that guided every step of the research process.

The next chapter will be dedicated to the research findings, including a description of the research sample.

CHAPTER 4 : FINDINGS

4.1 INTRODUCTION

This chapter comprises a presentation and discussion of the findings of the study, based on the data gathered in the Ribáuè and Malema districts. As mentioned in Chapter 1, the questions that guided the study were:

1) Is there a difference in the level of HIV and AIDS-related stigma experienced by PLWHIV on ART receiving HBC services and the level experienced by PLWHIV on ART not receiving HBC services?
2) Is there a difference in the self-reported QoL scores for PLWHIV on ART receiving HBC services and the scores for PLWHIV on ART not receiving HBC services?
3) Is there a correlation between stigma and self-reported QoL?

Before testing these hypotheses, the characteristics of the sample are presented. This is followed by a report on the collated score analyses for the stigma scale and QoL scale for the sample. In the third section of this chapter, the three hypotheses are tested.

4.2 CHARACTERISTICS OF THE SAMPLE

The data collection process was conducted between July and November 2009. 237 valid questionnaires out of the 239 originally issued were collected by the interviewers.

Table 4.1 shows the distribution of the respondents between the HBC group and the non-HBC group. It shows that 119 valid questionnaires were collected in the HBC group, and 118 in the non-HBC group, amounting to 99.2% realisation of the expected sample.

Table 4.1: Distribution of respondents in the HBC and non-HBC groups

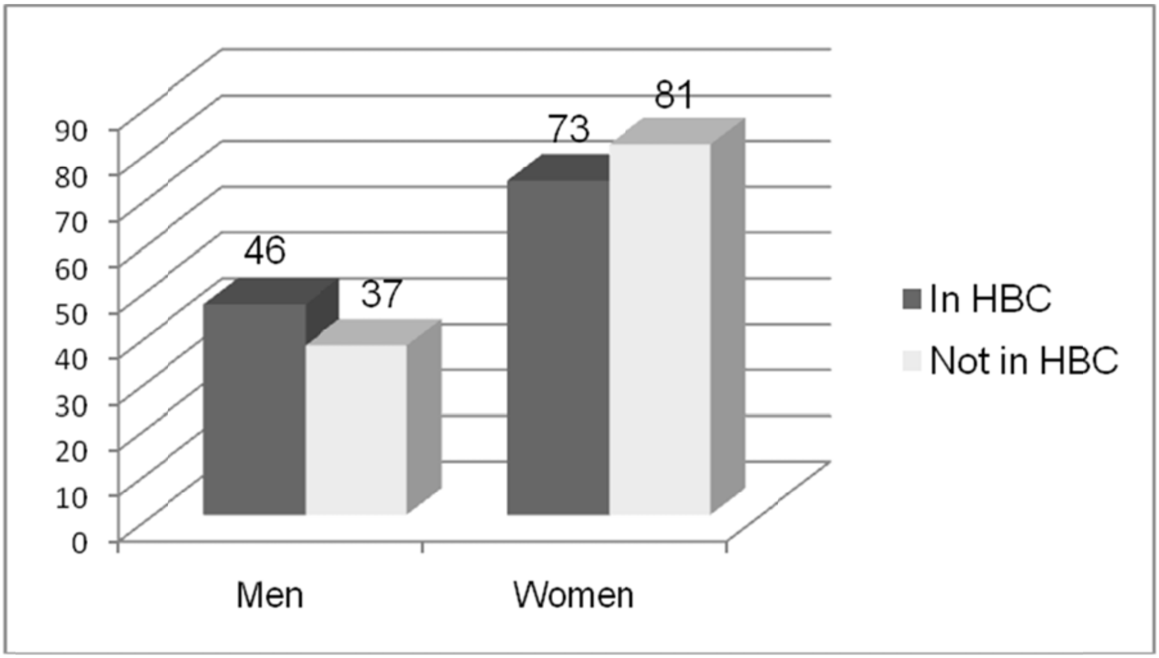
Group	Frequency	%
In HBC	119	50.2
Not in HBC	118	49.8
Total	**237**	**100.0**

Figure 4.1 shows the distribution of respondents according to gender. 65% of the respondents interviewed in the study were women (154/237), while the universe of potential respondents for the study had a gender breakdown of 55% women (262/476) and 45% men. Further analysis of the data shows that the gender imbalance was present in both the HBC and the non-HBC groups, with the number of men in the HBC group being slightly higher than in the non-HBC group (38.7% vs. 31.4% respectively). This is congruent with other home-based care studies undertaken in Africa, such as Apondi, Bunnell, Awor, Wamai, Bikaako-Kajura, Solberg, Stall, Coutinho & Mermin (2007: 71) in which 72% of respondents were women. Amuron, Coutinho, Grosskurth, Nabiryo, Birungi, Namara, Levin, Smith & Jaffar (2007: 26) also noted that in Uganda more women than men access ART.

A higher percentage of women in the study is also coherent with the notion of feminisation of the epidemic, according to which women are more likely to become infected with HIV (Himmelgreen, Romero-Daza, Turkon, Watson, Okello-Uma & Sellen 2010: 404). In Mozambique, according to data published by the Joint United Nations Programme on HIV/AIDS (2008a: 4), about 54% of people living with HIV are women.

Gender differences between the HBC and non-HBC, however, were not found to be statistically significant $\chi^2(1, N = 237) = 1{,}39, p > .05$.

Figure 4.1: Distribution of the respondents by gender



In Table 4.2, the mean ages of the respondents in the two groups are shown. The selection criteria demanded that all of the respondents be adults. Just more than half (59.7%) of the respondents in the HBC group were below 35 years of age whereas 75.2% of the non-HBC respondents were below the age of 35 years. One respondent in the "not in HBC" group did not state his age and was left out of the analysis for the variable. This explains the discrepancy between the data presented in Table 4.1 and Table 4.2 in terms of respondents in the "not in HBC group". There was a slight difference of 2,2 years in the mean ages of the two groups, with the mean age in the HBC group being older. Based on an ANOVA, there was a statically significant difference between the mean ages of the two groups, *F* (1,234) = 4,820, *p* < .05.

Table 4.2: Mean age of the respondents

	N	Minimum	Maximum	Mean	Std. Deviation
In HBC	119	18	49	32.4	7.9
Not in HBC	117	18	55	30.2	7.7

In terms of place of residence (See Table 4.3), the respondents were evenly distributed between Malema and Ribáuè, the two districts studied. 117 respondents were interviewed in Malema (59 in the HBC group and 58 in the non-HBC group) and 120 in Ribáuè (60 in the HBC group and 60 in the non-HBC group).

Table 4.3: Distribution of respondents by residence

Group		Frequency	%
In HBC	Malema	59	49.6
	Ribáuè	60	50.4
	Total	**119**	**100.0**
Not in HBC	Malema	58	49.2
	Ribáuè	60	50.8
	Total	**118**	**100.0**

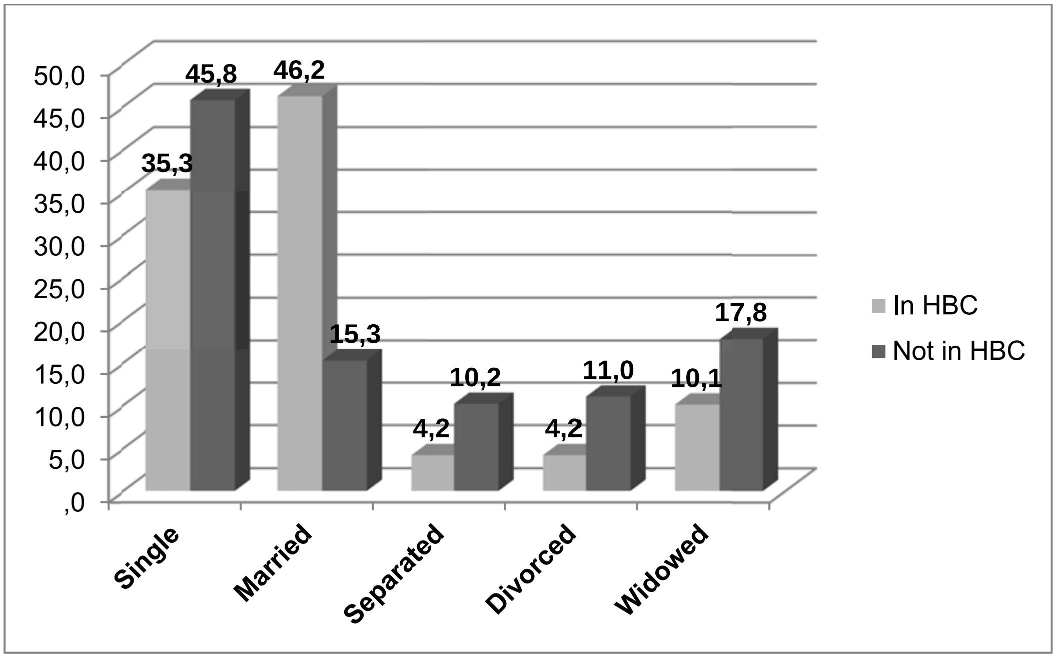
Table 4.4: Distribution of respondents by the level of formal educational attainment

Group	Level of education		Frequency	%
In HBC	No education		39	33,3
	Primary level	Grade 1-4	39	33,3
		Grade 5-6	27	23,1
	Secondary level	Grade 7-9	12	10.3
	Total for the HBC group		**117**	**100.0**
Not in HBC	No education		49	41.5
	Primary level	Grade 1-4	32	27.1
		Grade 5-6	20	16.9
	Secondary level	Grade 7-9	13	11.0
		Grade 10-12	4	3.4
	Total for the non-HBC group		**118**	**100.0**

As can be seen in Table 4.4, the group of PLWHIV not in the HBC programme had more people without any formal education than the HBC group (41.5%, and 33.3% respectively). In the HBC group, 10.3 % of the respondents had reached secondary level whereas only 14.4% of the respondents in the non-HBC had attained the same level. A Chi-square test and a Fischer Exact Test (used because 20% of the cells had a count under 5) were undertaken and revealed that there was no significant difference between the HBC and non-HBC groups, in terms of levels of education as $\chi^2(4, N = 235) = 6{,}91, p > .05$. It is important to note that two respondents in the HBC group did not provide an answer to the question about the level of education attained and were thus taken out of the analysis for the variable. This explains the discrepancy between the data presented in Table 4.1 and Table 4.4 in terms of respondents in the HBC group.

The distribution of the respondents by marital status in Figure 4.2 shows that 35.3% of the respondents in the HBC group were single compared to 45.8% in the non-HBC group. Also 46.2% (55/119) of the PLWHIV in the HBC group were married, a figure almost three times higher than in the non-HBC group where 15.3% (18/118) declared themselves to be married. These differences were found to be statistically significant, as $\chi^2(4, N = 237) = 29{,}14$, $p < .05$. The analysis of the effect of different marital status on the HBC/non HBC split is not within the scope of this study. However, it is possible that this situation might have been caused by a selection bias. Another explanation would be that PLWHIV not in the HBC programme face more stress or conflicts in their relationships because of a possible lack of psychosocial support, leading to more separations and divorces, thus reducing the number of married PLWHIV in the non-HBC group. More research would be needed on this to clarify the origins of a difference in marital status between the groups studied, especially in light of a study by Yi, Mrus, Wade, Ho, Hornung, Cotton, Peterman, Puchalski & Tsevat (2006: S23) which noted a higher depression rate in single PLWHIV compared with married PLWHIV.

Figure 4.2: Marital status distribution of study participants



In the questionnaire, various questions were posed to ascertain the respondents' experiences of HIV disclosure, diagnosis and ART. In this regard, respondents were asked to indicate the number of people to whom they had disclosed their HIV status. The results are shown in Figures 4.3 and 4.4. In the non-HBC group, no respondent had disclosed to more than 15 people. The mean number of people to whom the respondents had disclosed their HIV status was between 16-30 people for the HBC group and between 1-5 people for the non-HBC group. The differences between the two groups in the number of people to whom the respondent's HIV status had been disclosed to were statistically significant, as evidenced by a Chi-square test where $\chi^2(4, N = 237) = 130{,}18$, $p < .05$.

As shown in Figure 4.3, 94.1% of the PLWHIV in the HBC group had disclosed their HIV status to someone else whereas only 81.4% of the PLWHIV in the non-HBC group had disclosed their HIV status to someone else (See Figure 4.4).

While further research would be needed in order to understand how much the disclosure rate is a consequence of participating in the HBC programme, it is possible to postulate that respondents who agreed to be visited by HBC volunteers exposed themselves to some degree of involuntary disclosure. As the programme became well known in the communities, neighbours and friends correctly assumed that there was a good chance that the person receiving HBC visits had HIV.

A higher disclosure rate in the HBC group could additionally mean that the PLWHIV receiving HBC visits felt comfortable enough to risk telling others about their HIV status, as they would still have what some researchers (Roura, Busza, Wringe, Mbata, Urassa & Zaba 2009: 207) call a "*replacement social support network*" contributing to increased self-efficacy even if their family members reacted adversely to the news. Also, a study by Greeff, Phetlhu, Makoae, Dlamini, Holzemer, Naidoo, Kohi, Uys & Chirwa (2008: 319) showed that PLWHIV can sometimes disclose their status to people when the community as a whole expresses a need for more information about HIV and AIDS. In that context, they feel that their contribution as PLWHIV would be important to others, which gives them a reason to disclose. In the case of Salama's programme, the higher disclosure rate for PLWHIV in the HBC group could be related to this, but specific research would be needed for confirmation.

Figure 4.3: Distribution of PLWHIV in the HBC group by number of people (excluding health staff) to whom they have disclosed their HIV status

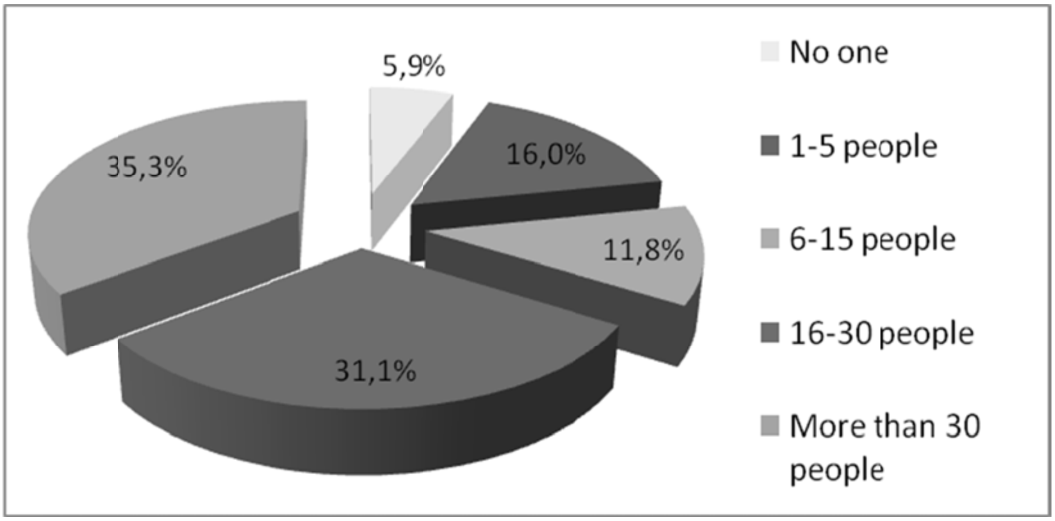
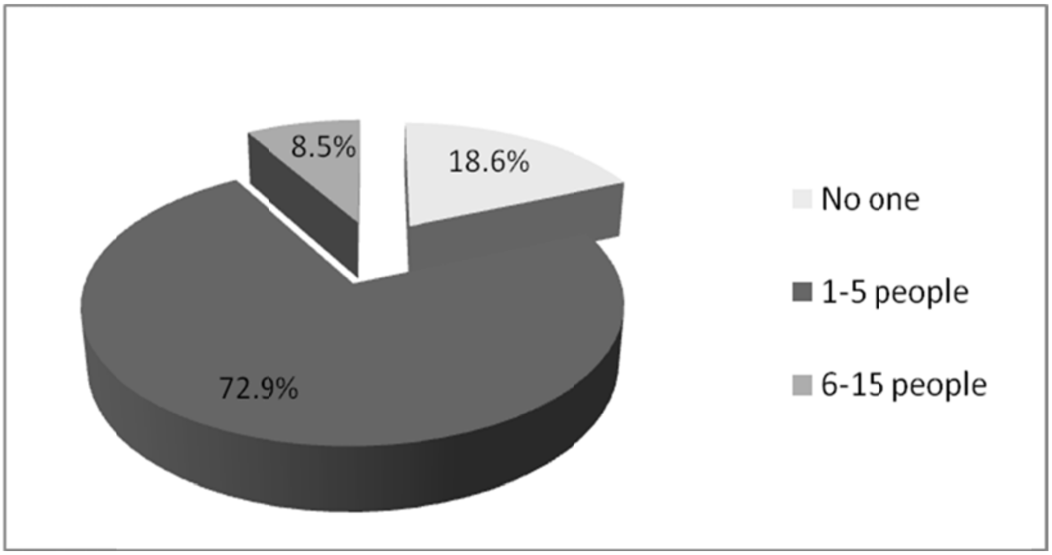


Figure 4.4: Distribution of PLWHIV in the non-HBC group by number of people (excluding health staff) to whom they have disclosed their HIV status



Respondents were asked to indicate the number of days since their HIV diagnosis. As can be seen in Table 4.5, the mean number of days since HIV diagnosis differed between the two groups. PLWHIV in the non-HBC group has been diagnosed more recently (514.6 days on average) than PLWHIV in the HBC group, who had been diagnosed for an average of 801.2 days. This was confirmed by an ANOVA, which showed that the differences between the groups were statistically significant. Because homogeneity of variance was not assumed, a Brown-Forsythe test was applied, which reached the same conclusion as the ANOVA, which is that *F* (1,234) = 61,76, *p* < .05.

Table 4.5: Mean number of days since HIV diagnosis

Group	N	Minimum	Maximum	Mean	Std. Deviation
In HBC	119	249	1345	801.2	246.4
Not in HBC	117	112	1551	514.6	310.7

As Table 4.6 shows, the mean number of days since the respondents started ART differed between the HBC and the non-HBC groups. PLWHIV in the HBC have been, on average, taking ARV for the equivalent of 683.5 days compared to 369.2 days for the PLWHIV in the non-HBC group. The difference between the groups was found to be significant based on an ANOVA, as *F* (1,233) = 96,02, *p* < .05.

The difference between the two groups could be explained by the fact that the areas where the HBC programme first started were closer to the health centres, meaning that people in those areas could have had access to information, testing and ART sooner than people outside the catchment's area of the HBC programme. There are, however, people inside the HBC programme areas who preferred not to participate in the programme, but the study did not collect data about this. Further research would be needed to know exactly how many PLWHIV not in the HBC programme would have been eligible because they resided in areas covered by the programme.

Table 4.6: Mean number of days since the respondents started ART

Group	N	Minimum	Maximum	Mean	Std. Deviation
In HBC	118	15	1219	683.5	245.2
Not in HBC	117	1	861	369.2	246.4

In the HBC group, as shown in Figure 4.5, more than two thirds (68.9%) of the respondents reported full treatment compliance, whereas less than one third (28.6%) of them declared their variable compliance. Only three respondents indicated that they were not complying with ART. The non-HBC group, as illustrated in Figure 4.6, showed 55.6% of the respondents were fully compliant, 39.3% partially compliant and six (5,1%) respondents non-compliant with ART.

Figure 4.5: ART compliance in the HBC group

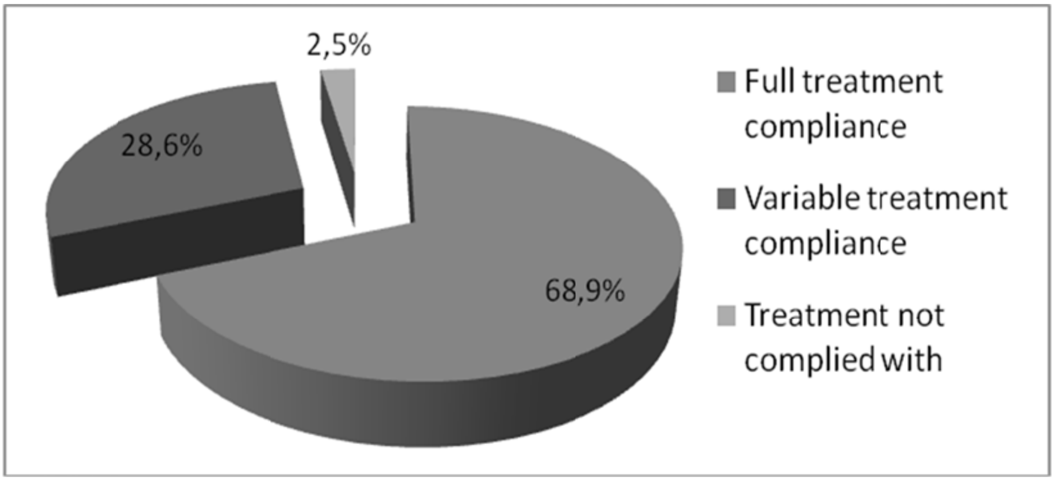
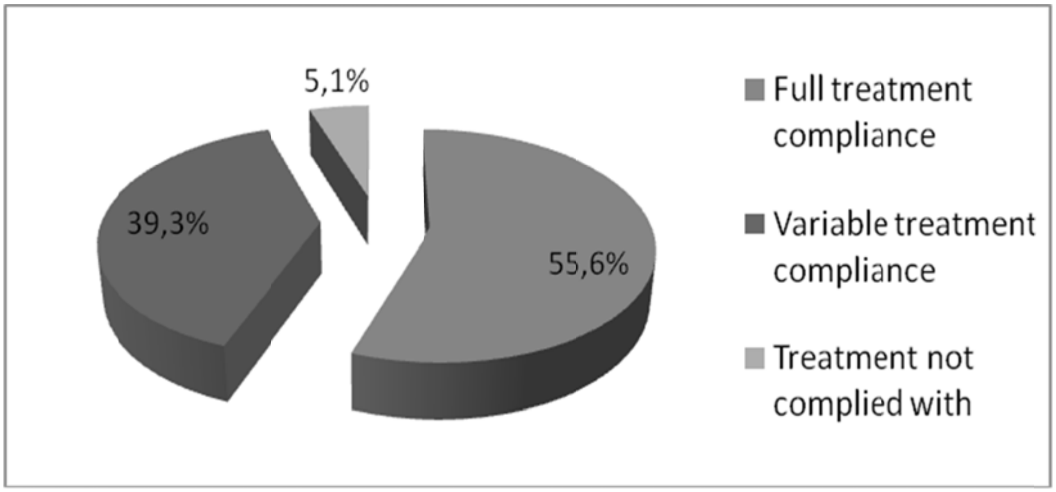


Figure 4.6: ART compliance in the non-HBC group



A chi-square test, confirmed by a Fischer Exact Test (performed as 33.3% of the cells had less than five cases), revealed that both groups were comparable in terms of ART compliance, and that this was significant: $\chi^2(2, N = 236) = 4,75$, $p > .05$.

4.3 MEASUREMENT OF INTERNAL CONSISTENCY (CRONBACH'S ALPHA)

In order to evaluate the internal consistency of the items in the Berger Stigma Scale and the WHOQOL-BREF, a simple Cronbach's alpha (α) test was conducted. The values for the tests performed from the data collected in the current study are compared to the values published by other researchers in Tables 4.7 and 4.8. It is worth mentioning that Cronbach's alpha values between 0.70 and 0.80 are considered to be acceptable (Bland & Altman 1997: 572). All the Cronbach's alpha values compiled from the data collected are above the threshold suggested by the authors, suggesting high consistency in the construction of the subscales.

Table 4.7: Reliability Coefficients for the Berger HIV Stigma Scale and Subscales

Scale	Number of items	Coefficient Alpha (n=318) in original study by Berger *et al.* (2001: 527)	Coefficient Alpha (n=237) in current study
HIV Stigma scale total score	40	.96	.97
Personalized stigma subscale	18	.93	.96
Disclosure subscale	10	.90	.95
Negative self-image subscale	13	.91	.88
Public attitudes subscale	20	.93	.96

The Cronbach's alpha values for the WHOQOL-BREF, when performed according to the specifications from the World Health Organisation, were acceptable for 3 out of the 4 subscales. In the social relationships subscale, one question (number 22) was found to be unrelated to the two other questions forming the subscale. Including question 22 in that subscale caused the Cronbach's alpha to be unacceptable at .39. It was thus decided to drop the question from the subscale, which raised the Cronbach's alpha for that subscale to a more acceptable value of .73.

Table 4.8: Reliability Coefficients for the WHOQOL-BREF

Scale	Number of items	Coefficient Alpha (n=11830)a study by Skevington, Lofty & O'Connell (2004: 304)	Coefficient Alpha (n=237) in current study
General QoL	2	Not mentioned	.88
Physical health	7	.82	.93
Psychological health	6	.81	.91
Social relationships	2	.68 (based on the 3 original items)	.73
Environment	7	.80	.90

4.4. DIFFERENCES IN HIV AND AIDS-RELATED STIGMA LEVELS BETWEEN THE HBC AND THE NON-HBC GROUP

Stigma levels measured with the Berger Stigma Scale were divided into four subscales and a general stigma score. Table 4.9 shows the results for the HBC group.

Table 4.9: Berger Stigma Scale in the HBC group

Scale	Possible Scale interval	N	Minimum	Maximum	Mean	Std. Deviation
Personalised stigma subscale	18- 72	119	19	55	32.0	6.8
Disclosure subscale	10- 40	119	11	40	18.9	5.7
Negative self-image subscale	13- 52	119	17	47	26.8	4.9
Public attitudes subscale	20- 80	119	24	64	37.9	7.4
HIV Stigma scale total score	40-160	119	50	138	77.4	15.4

Data originating from respondents in the non-HBC group is displayed in Table 4.10.

Table 4.10: Berger Stigma Scale in the non-HBC group

Scale	Possible Scale interval	N	Minimum	Maximum	Mean	Std. Deviation
Personalised stigma subscale	18- 72	118	10	62	45.6	7.5
Disclosure subscale	10- 40	118	15	36	29.5	3.2
Negative self-image subscale	13- 52	118	16	45	33.3	5.5
Public attitudes subscale	20- 80	118	32	70	53.8	7.4
HIV Stigma scale total score	40-160	118	65	134	106.6	13.5

After analysing the data presented in Table 4.9 and 4.10, statistically significant differences were found between the HBC and non-HBC groups for the four subscales and the total stigma score. The ANOVA performed on the personalized stigma subscale results in F (1,235) = 212,823, $p < .05$, which signals a statistically significant difference in the HBC and non-HBC groups for that subscale. The same conclusion can be extracted from an ANOVA conducted on the disclosure subscale (F (1,235) = 308,931, $p < .05$), the negative self-image subscale (F (1,235) = 92,552, $p < .05$), the public attitudes subscale (F (1,235) = 275,628, $p < .05$) and finally the total stigma score (F (1,235) = 241,158, $p < .05$)

4.5 DIFFERENCES IN QUALITY OF LIFE SCORES BETWEEN THE HBC AND THE NON-HBC GROUP

QoL scores calculated with the WHOQOL instrument yielded measurements in four subscales and a general QoL score. Results from the HBC group are shown in Table 4.11.

Table 4.11: WHOQOL scores in the HBC group

Scale	Possible Scale interval	N	Minimum	Maximum	Mean	Std. Deviation
Physical health	0-100	119	25	79	68.8	9.9
Psychological health	0-100	119	50	92	73.0	9.0
Social relationships	0-100	119	0	50	26.0	10.3
Environment	0-100	119	25	69	47.2	7.9
General QoL	0-100	119	25	75	63.9	12.5

Quality of life scores for the non-HBC group are shown in Table 4.12.

Table 4.12: WHOQOL scores in the non-HBC group

Scale	Possible Scale interval	N	Minimum	Maximum	Mean	Std. Deviation
Physical health	0-100	118	4	96	52.5	23.0
Psychological health	0-100	118	0	92	48.0	24.7
Social relationships	0-100	118	0	58	31.4	15.9
Environment	0-100	118	0	78	39.2	23.7
General QoL	0-100	118	0	100	53.7	26.5

In order to examine differences between the HBC and non-HBC groups presented in Table 4.11 and 4.12, a series of ANOVAs were executed. The physical health score was found to be statistically different in the two groups, as F (1,235) = 49,824, $p < .05$. All the other QoL scores were also found to differ significantly between the two groups studied; psychological health (F (1,235) = 106,704, $p < .05$), social relationships (F (1,235) = 9,731, $p < .05$), environment (F (1,235) = 12,151, $p < .05$) and the general quality of life score (F (1,235) = 14,175, $p < .05$).

4.6 HYPOTHESIS TESTING

In the next section, the three hypotheses of the study will be tested.

4.6.1 Hypothesis testing for research question 1

The first objective of the study was to answer the following question:

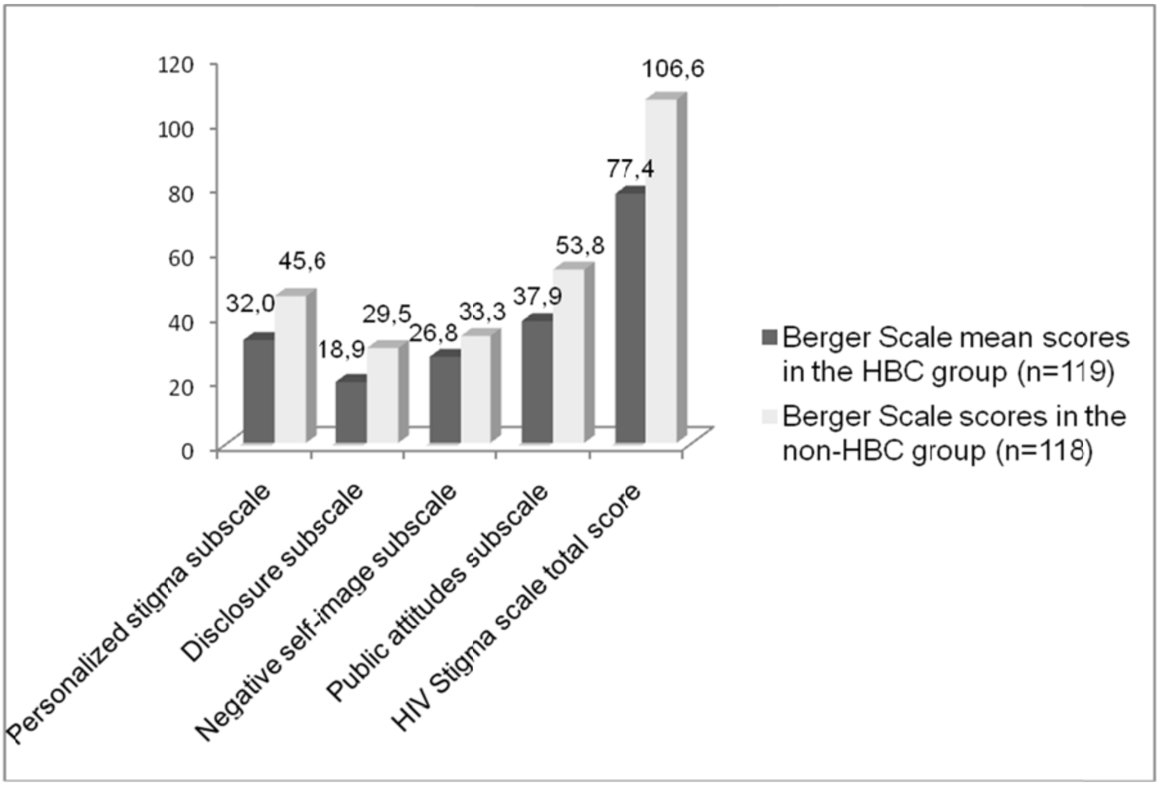
Is there a difference in the level of HIV and AIDS-related stigma experienced by PLWHIV on ART receiving HBC services and the level experienced by PLWHIV on ART who do not receive HBC services?

The null hypothesis for objective 1 was:
$H_0 : \mu_1 = \mu_2$
μ_1 = Mean scores for HIV and AIDS-related stigma of PLWHIV on ART receiving HBC services in Ribáuè and Malema.
μ_2 = Mean scores for HIV and AIDS-related stigma of PLWHIV on ART not receiving HBC services in Ribáuè and Malema.

The alternative hypothesis for objective 1 was:
$H_1 : \mu_1 \neq \mu_2$
μ_1 = Mean scores for HIV and AIDS-related stigma of PLWHIV on ART receiving HBC services in Ribáuè and Malema.
μ_2 = Mean scores for HIV and AIDS-related stigma of PLWHIV on ART not receiving HBC services in Ribáuè and Malema.

To test the hypotheses, a series of ANOVAs were executed on the mean scores for each subscale of the Berger Stigma Scale instrument, as well as for the score on the global stigma scale. Figure 4.7 shows the mean scores of the two groups on the Berger Stigma Scale.

Figure 4.7: Mean scores on the Berger Stigma Scale for the two groups studied (higher score means higher stigma)



The results show that PLWHIV in the HBC group report lower scores on all the subscales of the Berger Stigma Scale as well as on the overall score, corresponding to less perceived stigma for the HBC group than the non-HBC group. Thus, the null hypothesis for objective 1 has to be rejected.

4.6.2 Hypothesis testing for research question 2

The second objective of the study was related to the following question:

Is there a difference in the self-reported quality of life scores for PLWHIV on ART receiving HBC services and the scores for PLWHIV on ART who do not receive HBC services?

The null hypothesis for objective 2 was:

$H_0 : \mu_1 = \mu_2$

H_0 = the null hypothesis

μ_1 = Mean scores for QoL of PLWHIV on ART receiving HBC services in Ribáuè and Malema.

μ_2 = Mean scores for QoL of PLWHIV on ART not receiving HBC services in Ribáuè and Malema

The alternative hypothesis for objective 2 was:

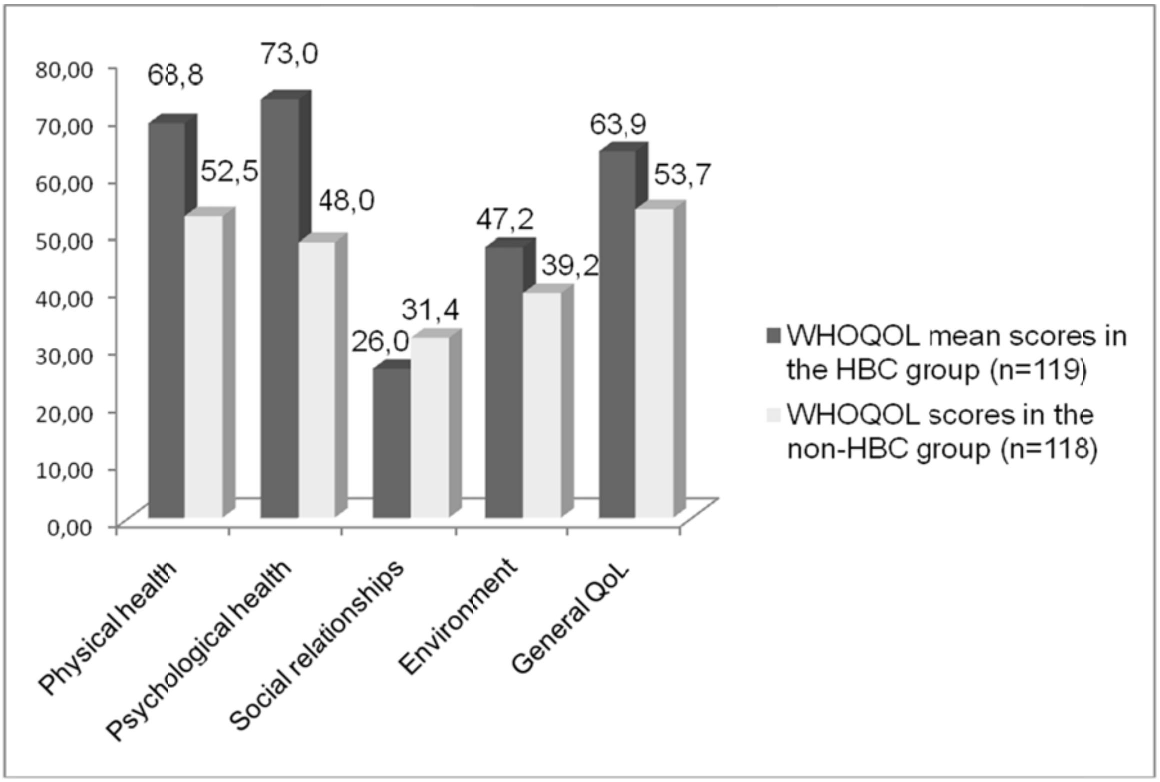
$H_1 : \mu_1 \neq \mu_2$

μ_1 = Mean scores for QoL of PLWHIV on ART receiving HBC services in Ribáuè and Malema.

μ_2 = Mean scores for QoL of PLWHIV on ART not receiving HBC services in Ribáuè and Malema

To test the hypotheses, a series of ANOVAs were executed on the mean scores for each subscale of the WHOQOL-BREF instrument, as well as for the score on the global QoL scale. Figure 4.8 shows the mean scores of the two groups on the WHOQOL-BREF.

Figure 4.8: Mean scores on the Berger Stigma Scale for the two groups studied (higher score means higher stigma)



The results show that PLWHIV in the HBC group report higher scores on three of the WHOQOL-BREF subscales as well as on the overall score, corresponding to a higher perceived quality of life for PLWHIV in the HBC group compared to the non-HBC group. It is revealed however that PLWHIV in the non-HBC group report a higher QoL related to social relationships than PLWHIV in the HBC group. The difference between the groups could be related to the higher HIV disclosure rate in the HBC group which could in turn reduce the number of social relationships each PLWHIV has. The results presented above mean that the null hypothesis for objective 2 has to be rejected.

4.6.3 Hypothesis testing for research question 3

The third objective of the study was related to the following question:

Is there a correlation between stigma and self-reported quality of life?

The null hypothesis for objective 3 was:
H_0 : There is no correlation between the variables at α=0.01

The alternative hypothesis for objective 3 was:
H_1: There is a correlation between the variables at α=0.01

In order to measure the correlation between the "stigma" and "quality of life" variables, Pearson Correlation's Coefficient test was conducted on the subscales and the total scores for the Berger Stigma Scale and the WHOQOL-BREF.

The interpretation of the correlation between the variables studied is based on Fox's (1999: 273) definition, which states that the threshold for strong correlation is 0.80 (or -0.80 in the case of a negative relation), 0.60 (or -0.60) for a moderate correlation and 0.40 (or -0.40) for a weak correlation. As shown in Table 4.13, no correlation could be considered to be strong between the stigma and the quality of life variables, using the 0.80 threshold.

There were, however, a number of moderate correlations between the following variables:

- WHOQOL-BREF Physical health and Berger's Personalized stigma subscale: r=-0,629(235), *p* (two-tailed) < .01.
- WHOQOL-BREF Physical health and Berger's Public attitudes subscale: r=-0,612(235), *p* (two-tailed) < .01.
- WHOQOL-BREF Psychological health and Berger's Negative self image subscale: r=-0,685(235), *p* **(**two-tailed) < .01.
- WHOQOL-BREF Psychological health and Berger's Public attitudes subscale: r=-0,704(235), *p* (two-tailed) < .01.

- WHOQOL-BREF Psychological health and Berger's total score: r=-0,685(235), *p* (two-tailed) < .01.

In relation to the testing of the hypothesis for objective 3, it is possible to reject the null hypothesis, as there seems to be a correlation between some stigma and quality of life variables. However, the results show that the correlation is moderate to weak for most variables.

Table 4.13: Pearson's Correlation Coefficient between the stigma and quality of life variables

		STIGMA SCALE - Personalised stigma subscale	**STIGMA SCALE - Disclosure subscale**	**STIGMA SCALE - Negative self-image subscale**	**STIGMA SCALE - Public attitudes subscale**	**STIGMA SCALE - TOTAL**
WHOQOL - GENERAL	Pearson Correlation	-.500	-.270	-.569	-.490	-.494
	Sig. (2-tailed)	.000	.000	.000	.000	.000
WHOQOL - PHYSICAL HEALTH	Pearson Correlation	-.629	-.374	-.605	-.612	-.597
	Sig. (2-tailed)	.000	.000	.000	.000	.000
WHOQOL - PSYCHOLOGICAL HEALTH	Pearson Correlation	-.699	-.468	-.685	-.704	-.685
	Sig. (2-tailed)	.000	.000	.000	.000	.000
WHOQOL - SOCIAL RELATIONSHIPS	Pearson Correlation	-.259	.112	-.378	-.214	-.213
	Sig. (2-tailed)	.000	.085	.000	.001	.001
WHOQOL - ENVIRONMENT	Pearson Correlation	-.524	-.189	-.560	-.505	-.488
	Sig. (2-tailed)	.000	.004	.000	.000	.000

4.7 DISCUSSION: SUMMARY AND INTERPRETATION

4.7.1 Summary

The study has found that statistically significant differences exist between the HBC and non-HBC groups for the four subscales of the Berger Stigma Scale as well as for the total stigma score.

Also, the results highlighted that PLWHIV report a higher perceived quality of life if they are in the HBC group compared to the non-HBC group on three of the WHOQOL-BREF subscales as well as on the overall score. The scores on one of the subscales, social relationships, indicated lower perceived QoL for PLWHIV in the HBC group than in the non-HBC group.

The participants in both groups were comparable in terms of gender, residence, education and compliance to ART. Statistically significant differences, however, existed between the HBC and non-HBC groups in relation to age, marital status, number of people to whom the respondents have disclosed their HIV status, mean number of days since HIV diagnosis and mean number of days since the start of ART.

Finally, a weak to moderate, negative correlation was discovered between stigma scores and QoL scores. This suggests that people with lower perceived QoL also report feeling more stigmatised than PLWHIV with a higher perceived QoL.

The next section will be dedicated to the discussion of the results.

4.7.2 Discussion of the findings

This section will compare the results of the study with the existing literature, in the context of the objectives identified in chapter 1.

4.7.2.1 Difference in the level of HIV and AIDS-related stigma experienced by PLWHIV on ART receiving HBC services and the level experienced by PLWHIV on ART not receiving HBC services

The results of the study suggest that PLWHIV on ART receiving HBC services experience less HIV and AIDS-related stigma than PLWHIV on ART who do not receive HBC services. This conclusion applies to the different aspects of stigma measured by the Berger Stigma Scale: personalised stigma, disclosure, negative self-image and public attitudes. These results are in accordance with the few studies uncovered in the literature review which focussed on this topic, such as Chela *et al.* (1991).

Some stigma subscales seem to be especially linked to HBC, such as the disclosure subscale mean scores, which are 55% higher in the non-HBC group than the HBC group, indicating more perceived stigma related to disclosure for PLWHIV not reached by a HBC programme. This could be linked to the higher number of people to whom PLWHIV in the HBC programme disclose to, either voluntarily or unvoluntarily, as data shows 78.2% of PLWHIV in the HBC have disclosed to more than five people, compared to 8.5% in the non-HBC group. It is very interesting to note that even with an increased risk of stigmatisation after disclosure, PLWHIV in the HBC group actually experienced the opposite and felt less stigma associated with disclosure than people in the non-HBC group. In the HBC group, stigma related to disclosure seems to be partially short-circuited. The results are congruent with a recent study in Mozambique (Pearson, Micek, Pfeiffer, Montoya, Matediane, Jonasse, Cunguara, Rao & Gloyd 2009) which indicated that, over a 12 month period following the start of ART, lower stigma scores were significantly associated with the disclosure of the patient’s HIV status to large numbers of people, especially friends and co-workers.

The scope of the current study was not designed to investigate what causes levels of disclosure within a group, but a study by Esu-Williams *et al.* (2003:7) has shown that HBC could help reduce fear and create a more tolerant environment in which PLWHIV learn to feel understood and protected, enabling them to be more assertive and disclose to increasing numbers of people who are not family members.

The personalised stigma subscale showed more moderate differences between the HBC and the non-HBC groups, with mean scores being 42.56% higher in the non-HBC group. This was also the conclusion of a study by Kaai, Sarna, Luchters, Geibel, Munyao, Mandaliya, Shikely, Temmerman & Rutenberg (2007:4) which revealed a decrease in personalised stigma for people that have been on ART for 12 months. As people in the HBC group have been on ART for a longer period of time than people in the non-HBC group (683 days on average for the HBC group compared to 369 days on average for the non-HBC group), it could hypothesized that a lowering personalised stigma score over time is part of the "natural history" of stigma, and that HBC might not completely explain the difference observed between the groups.

4.7.2.2 Difference in the self-reported QoL scores for PLWHIV on ART receiving HBC services and the scores for PLWHIV on ART not receiving HBC services

Overall, the results of the study show that there is a statistically significant difference between the mean QoL scores of the HBC and non-HBC groups. This is congruent with Jha, Mills, Hanson, Kumaranayake, Conteh, Kurowski, Nguyen, Cruz, Ranson, Vaz, Yu, Morton & Sachs (2002: 2038) and the World Health Organisation (2002: 9) who proposed that care and support, along with ART, can have a positive effect on the quality of life of patients. In this study, the largest difference is found in the psychological health subscale, in which the PLWHIV in the HBC group report a mean score of a perceived quality of life that is 34.19% higher than the mean score of the non-HBC group.

In terms of physical health, the mean QoL scores for PLWHIV in the HBC group are 23.6% higher than the corresponding scores in the non-HBC group. A possible explanation for this difference could be related to easier access to health services for PLWHIV in the HBC group. HBC volunteers are trained to refer their users to the local health centre as soon as the situation indicates a deterioration of health based on the observation of clinical signs. As the volunteers personally know the nurses working at the health centre and often find themselves accompanying the PLWHIV, there is reason to believe that PLWHIV in the HBC group are more likely to quickly consult and thus, are less likely to suffer physical discomforts resulting from opportunistic infections. The HBC volunteers also distribute a limited number of medicines to PLWHIV which also helps to reduce pain or infection, a service that is not available to PLWHIV in the non-HBC group unless they go to the health centre.

A moderate difference also exists between the QoL mean scores of PLWHIV in the HBC and non-HBC group in relation to satisfaction with their environment. The results of the study show that PLWHIV in the HBC group report mean QoL scores 16.86% higher than their counterparts in the non-HBC group. These results could be interpreted in the light of the activities undertaken by the HBC volunteers, which can range from helping with cleaning clothes, sweeping around the house, collecting and burning garbage, providing soap, giving advice to family members (about everything from latrine construction to nutrition) and distributing bed-nets and warm blankets. All of these activities seem to contribute to a higher perceived QoL related to the patient’s environment. It is interesting however to note that these mostly material contributions, which could be thought of as the most obvious benefit of participation in the HBC programme, do not contribute as much to a higher perceived quality of life for PLWHIV as the elements improving psychological health, as shown in the paragraph above.

The social relationship subscale, however, showed a negative difference in mean scores between PLWHIV in the HBC and the non-HBC group confirming that PLWHIV in the HBC group feel their QoL is lower in relation to that aspect than their counterparts in the non-HBC group. A possible cause for this could be linked to a reduction in the number of friends caused by disclosure. Pearson *et al.* (2009: 1193) have suggested that less social support could cause depression, which would have an impact on the perceived quality of life. This is not, however, what the results suggest in this study, as perceived QoL is higher in the HBC group, despite the lower satisfaction with social relationships. A possible explanation could be that PLWHIV in the HBC group have a lower number of friends, which is perceived as negative. On the other hand, the remaining friends are much closer which, in conjunction with the support provided by the HBC volunteers, helps to prevent the depression mentioned by Pearson *et al.* (2009: 1193). Further research would be needed to confirm this hypothesis.

4.7.2.3 Correlation between stigma and self-reported quality of life

The analysis of the correlation coefficients between stigma and self-reported QoL conducted in the current study is in accordance with the latest research reviewed in chapter 2, such as studies by Greef *et al.* (2009), Holzemer (2009, Lee *et al.* (2002) and Suit (2005: 82). In essence, there is weak to moderate, negative correlation between the two constructs.

At this point, however, it is not possible to determine what proportion of the QoL scores presented in the study is explained by stigma. Further research on the subject would be necessary to quantify the contribution of stigma to the reduction in perceived quality of life.

4.8 CONCLUSION

In Chapter 4, the findings of the study were presented and discussed. The first section was devoted to the presentation of the studied sample's characteristics. The distribution of the study's respondents was described in relation to the variables of interest: participation in the HBC programme, gender, mean age, residence, level of formal educational attainment, marital status, experiences of HIV disclosure, diagnosis and ART, number of days since HIV diagnosis, mean number of days since the start of ART, and ART compliance.

Then, the internal consistency of the items in the Berger Stigma Scale and the WHOQOL-BREF was discussed based on the results of a Cronbach's alpha (α) test conducted on the data.

Differences in HIV and AIDS-related stigma between the HBC and non-HBC groups studied were presented and significant differences were found with an ANOVA test between for the four subscales and the total stigma score. Differences between the groups in relation to Qol scores were also uncovered in four subscales and a general QoL score.

The next section tested the three research hypotheses. All of them were rejected based on the evidence gathered by the study. A discussion of the results for each research hypothesis followed and links to previous research were made.

The next chapter will be dedicated to the study's main findings and limitations. Also, recommendations for further research, policy and practice will be presented, along with a brief conclusion.

CHAPTER 5 : RECOMMENDATIONS AND CONCLUSION

5.1 INTRODUCTION

In this last chapter, the main findings and limitations of the study are discussed, followed by recommendations for further research. Also, recommendations for policy and practice are highlighted, along with a brief conclusion.

5.2 MAIN FINDINGS

The study aimed at finding an answer to three research questions. The first question was to examine if there was a difference in the level of HIV and AIDS-related stigma experienced by PLWHIV on ART receiving HBC services and the level experienced by PLWHIV on ART not receiving HBC services. After analysing the data collected from 237 PLWHIV in Malema and Ribáuè districts, it was found that statistically significant differences exist between the HBC and non-HBC groups for the four subscales of the Berger Stigma Scale as well as for the total stigma score.

The idea that a relation between stigma and HBC exist is congruent with the theoretical models which were used as a basis for this study. The "*Elements needed for a successful policy in the field of HIV and AIDS-related stigma*" described by Morrison (2006: 9) in chapter 2 have been incorporated in a large part by Salama in its HBC programme, so the results of this study can be interpreted as being logical and in-line with Morrison's model.

The results are also in accordance with the few studies uncovered in the literature review which investigated the links between HBC and stigma, such as Chela *et al.* (1991), Esu-Williams *et al.* (2003: 7), Kaai *et al.* (2007:4), Letamo (2003: 347) and Pearson *et al.* 2009.

The second research question was related to the exploration of potential differences in the self-reported QoL scores for PLWHIV on ART receiving HBC services and the scores for PLWHIV on ART who are not receiving HBC services. The results highlighted that PLWHIV report a higher perceived quality of life if they are in the HBC group compared to the non-HBC group on three of the WHOQOL-BREF subscales as well as on the overall score. The positive effect of HBC on QoL had been previously identified by the World Health Organisation (2002:9). Whilst the scope of this study was not to confirm a "cause and effect" between HBC and QoL, the results would not exclude, *a priori*, the possibility of such a relation between the variables.

The scores on the social relationships subscale, however, indicated lower perceived QoL for PLWHIV in the HBC group than in the non-HBC group. Pearson *et al.* (2009: 1193) have suggested that less social support could cause depression, which would have an impact on the perceived quality of life. This is not what the results suggest in this study, as perceived QoL is higher in the HBC group, despite the lower satisfaction with social relationships. The lower scores on the relationships subscale were also found in the study conducted by Dos Santos *et al.* (2007) and described in chapter 2.

The third question aimed at investigating the correlation between stigma and self-reported quality of life. In relation to that research question, a weak to moderate, negative correlation was discovered between stigma scores and QoL scores. This suggests that people with lower perceived QoL also report feeling more stigmatised than PLWHIV with a higher perceived QoL***.***

The analysis of the correlation coefficients between stigma and self-reported QoL conducted in the current study is in accordance with the latest research reviewed in chapter 2, such as studies by Greef *et al.* (2009), Holzemer (2009), Lee *et al.* (2002) and Suit (2005: 82).

Going back to chapter 2 and the theoretical point of departure of the study, the correlation found between stigma and self-reported quality of life can be explained by our model which proposed an integration of both concepts. Furthermore, the results of the study validate the relevance of consolidating the socio-cognitive model developed by Rintamaki et al. (2006: 360) with the socio-emotional framework used by Bos, Schaalma and Pryor (cited in Stutterheim 2008: 10) as was proposed in the study.

5.3 LIMITATIONS OF THE STUDY

The present study has certain limitations that need to be taken into account when assessing its contributions. It is important to acknowledge them so that the conclusions can be evaluated critically.

The participants in both groups were comparable in terms of gender, residence, education and compliance to ART. Statistically significant differences, however, existed between the HBC and non-HBC groups in relation to age, marital status, number of people to whom the respondents have disclosed their HIV status, mean number of days since HIV diagnosis and mean number of days since the start of ART. The fact is that these differences could be due to a selection bias constitute a threat to internal validity, meaning that any difference in QoL and HIV and AIDS-related stigma levels could be due to the characteristics of the two groups (PLWHIV receiving or not HBC services) and not related to HBC services at all (Jüni, Altman & Egger 2001:43).

Also, based on the study design and limited sample, the conclusions of the study cannot be generalised to refer to every PLWHIV in Mozambique, or indeed elsewhere. The data collection was conducted using a sample of PLWHIV receiving ART in Ribáuè and Malema, so it would be imprudent to reach the conclusion that the current study would be applicable in a different socio-cultural context.

Other limitations include the use of self-reported measurements, the possible influence of the social desirability effect on the results due to the data collection method chosen, the use of instruments which were not validated in the specific socio-cultural context of the study and the existence of potentially confounding variables which were not controlled, such as CD4 count and weight.

5.4 SUGGESTIONS FOR FURTHER RESEARCH

This section is devoted to a non-exhaustive description of research avenues that emerged as possibilities during and after the realisation of this study. Investigating these research problems could help to move forward the topics of stigma, quality of life in the context of HBC and provide answers to topics not covered by the scope of this study.

As the study has shown, the PLWHIV on ART in Salama's HBC programme have a higher perceived quality of life and lower stigma levels than PLWHIV on ART not in a HBC programme. The study, however, was not designed to determine if the HBC programme was, in fact, causing the differences in perceived QoL and stigma levels between the two groups. In other words, there are may be factors beyond HBC that may influence both quality of life and stigma. Of course, there also seems to be some correlation between quality of life and stigma that confounds the causal patterns. To be able to gauge a clearer picture of the causal links between the care-giving environment (such as HBC) and subjective experiences, a proper randomized controlled trial should be set in place before a HBC programme is implemented in a community to yield data on the impacts of HBC on stigma and QoL (Tilling, Sterne, Brookes & Peters 2005).

In this study, the situation of PLWHIV on ART was described and analysed. Further research could be conducted to find out if PLWHIV not on ART who are participating in a HBC programme are also experiencing less HIV and AIDS-related stigma and have a higher perceived QoL than PLWHIV not on ART who are not participating in a HBC programme.

Also, the study has uncovered a weak to moderate association between stigma and quality of life. Another step would be to look at how much of the QoL score could be explained by the stigma experienced by a PLWHIV, as was partially described in Suit (2005: 92).

Despite the care taken by the researcher in selecting respondents so that the two groups could be comparable based on a number of key variables, the mean scores for age, marital status, number of people to whom the respondents have disclosed their HIV status, mean number of days since HIV diagnosis and mean number of days since the start of ART between the two groups showed statistically significant differences. It would be interesting to investigate if the differences between the groups for these variables (except the age variable) could have been caused by HBC itself, and not represent the result of selection bias (Martin 2005: 147).

5.5 RECOMMENDATIONS FOR POLICY AND PRACTICE

The results of the study provide valuable information on the life of PLWHIV on ART in Mozambique. The following recommendations could be used to improve the provision of HBC services to PLWHIV in Mozambique. The first three are directly related to the study's research questions, while the next four are discoveries made possible by a closer analysis of the data collected.

5.5.1 Results related to the study's research questions

5.5.1.1 *Look for ways to increase satisfaction with social relationships in PLWHIV receiving HBC services*

The results of the study clearly indicate that PLWHIV receiving HBC services are less satisfied with the way they interact with their family and friends than PLWHIV not receiving HBC services.

In this study, the social cognitive model proposed a framework that could provide an explanation as to why PLWHIV receiving HBC services have a lower satisfaction level in relation to their social relationships. In chapter 2, the three-way relationship between personal, environmental and behavioural factors was described as being a central feature of the social cognitive model (Redding *et al.* 2000: 185). In the group of PLWHIV receiving HBC services, the environmental factors could be understood as the new context in which some members of the community are now aware that the beneficiary of HBC is infected with HIV. The community members become aware that the beneficiary of HBC is infected with HIV because the PLWHIV tells them or because they observe proxy signs such as home visits by the HBC providers or material support given by the programme (Mazzeo & Makonese 2010: 447; Wringe, Cataldo, Stevenson & Fakoya 2010: 7). The personal factors could include the feelings of the PLWHIV toward that new situation: initial shock and self-blame, fear of disclosing but at the same time hope that it will bring some much needed support, preoccupation in the face of the progression of the HIV infection, hope to get better and resume normal activities or worries about being rejected by other community members (Bernays, Rhodes & Barnett 2007; Habib & Rahman 2010: 81; Kasenga, Hurtig & Emmelin 2010: 32; Norman, Chopra & Kadiyala 2007: 1780; Monjok, Smesny, Mgbere & Essien 2010 : 26). The behavioural factors could be social withdrawal as a coping strategy or deciding to terminate old friendships in favour of new ones as disclosure of HIV status to the former friends seems too complicated (Carr & Gramling 2004: 36; Koopman, Gore-Felton, Marouf, Butler, Field, Gill, Chen, Israelski & Spiegel 2000: 664; Miller & Rubin 2007:592).

In the example above, the three components of the social cognitive model are at work to explain why some PLWHIV who have disclosed to a greater number of people can have lower satisfaction levels related to their social relationships. At this stage, this explanation is just an hypothesis that needs to be put to the test, and the factors used as an example could be different than in reality, but the basic principle remains: environmental, personal and behavioural factors in the social cognitive model can provide an explanation as to why PLWHIV receiving HBC services do not seem to enjoy their social relationships as much as PLWHIV not receiving HBV services.

Whatever the actual causes, poor social support can lead to depression (Pearson *et al* 2009: 1193), and depression can cause lower ART adherence (Starace, Ammassari, Trotta, Murri, De Longis, Izzo, Scalzini, Antonella, Wu & Antinori 2002). The results of the study do not suggest higher levels of depression nor lower levels of ART adherence in PLWHIV receiving HBC services, but then the instruments used to measure quality of life in the study could be unable to comprehensively detect clinical-level depression in the setting studied. Also, self-declared adherence measurements can be subject to recall bias and social desirability and have been shown to usually provide an overestimate of how PLWHIV adhere to their treatment (García de Olalla, Knobel, Carmona, Guelar, López-Colomés & Caylà 2002: 108; Torpey, Kabaso, Mutale, Kamanga, Mwango, Simpungwe, Suzuki & Mukadi 2008: 8).

Thus, as a precautionary measure until more is known about the causes of the lower levels of satisfaction with social relationships uncovered in the group of PLWHIV receiving HBC services, attention should be given to promotion of healthy social relationships and detection of PLWHIV who seem to have fewer social contacts. When PLWHIV suffering from isolation, social withdrawal or depression are identified, the provision of an adequate response should be a priority. Increasing community activities, support group initiatives and putting more emphasis on the importance of maintaining meaningful social and personal contacts are some of the activities known to provide social support and stimulate empowerment that need to be implemented by HBC programmes such as Salama's to help reverse the situation (Brown *et al.* 2003: 53; Ribble 1989: 54; Simbayi, Kalichman, Strebel, Cloete, Henda & Mqeketo 2007:1830).

5.5.1.2 *Involve PLWHIV in the provision of HBC services as an empowerment strategy*

At the service-delivery level, the empowerment of PLWHIV to play a bigger role in the provision of HBC, especially in the planning, delivery and evaluation phases is recommended. Garko (2007: 126) suggests that empowering PLWHIV could help them realize that their life is not over after an HIV diagnosis. In fact, the results of this study point in that direction as they show that PLWHIV on ART can attain an acceptable level of perceived QoL and positively contribute to the well-being of their families and communities. Also, empowerment is a major factor in Morrison's model, described in chapter 2, for effective policies to reduce stigma, and it has been an essential aspect of Salama's programme to date (Morrison 2006:9).

5.5.1.3 *Continue to dispense HBC services to PLWHIV even when the HBC programme has limited potential to improve their material and environmental conditions, as the potential impacts of the HBC programme on physical and psychological health of PLWHIV could be more relevant to the overall QoL levels.*

According to the data collected, the mean scores for perceived QoL related to physical and psychological health are much higher in the group of PLWHIV receiving HBC services (34,2% higher for psychological health and 23,6% higher for physical health, respectively). Also, a moderate difference also exists between perceived QoL mean scores in relation to satisfaction with their environment, with PLWHIV receiving HBC services reporting mean scores 16.86% higher than their counterparts in the non-HBC group. This reveals that although material and environmental support is important, the most important differences between the groups in terms of QoL levels are related to physical and psychological support. This is congruent with the work of Farham (2003: 690), who considers psychological support to be especially important "… *when dealing with issues such as stigmatisation, fears from other family members and multiple losses and bereavement*", which is the case with the HBC programme examined in this study. Also, a study by Gordillo, Fekete, Platteau, Antoni, Schneiderman & Nöstlinger (2009: 523) proposes "… *that emotional support is strongly associated with physical and psychological adjustment in persons living with HIV/AIDS*". The type of support provided by the volunteers in Salama's HBC programme is often more related to emotional support than on the provision of material and environmental conditions, and this could be the reason why it is more relevant to the construction of global perceived QoL.

In the context of Salama's HBC programme, which runs on very limited funds, this comes as a very relevant piece of information, as costs of providing physical and psychological support are less important than the costs of dispensing ways to change the material and environmental conditions of the PLWHIV receiving HBC services.

These results could be due to a selection bias, but they could also hint at potential effects of HBC services on PLWHIV. This conclusion is also linked to the conceptual framework used by this study, in which the social-cognitive theory proposes a three-way relationship between personal, environmental and behavioural factors in the creation of HIV and AIDS-related stigma and the development of QoL (Redding *et al.* 2000: 185). In this case, it is possible that the influence of the personal and behavioural factors is more important to PLWHIV than environmental factors in the process of acquiring and maintaing acceptable levels of QoL. If further research shows that the differences in QoL discovered in this study are due to HBC services, it could also be argued that the areas most likely to be impacted by HBC services are QoL levels related to psychological and physical health.

5.5.2 Discoveries made possible by a closer analysis of the data collected

5.5.2.1 Address the gender imbalance in the provision of HBC services

An analysis of the study's sample shows that more women than men receive HBC services, as the universe of potential respondents for the study had a gender breakdown of 55% women and 45% men. This can be due to a number of factors including a potential selection bias. However, as was discussed in chapter 4, it is increasingly clear that more women than men are now at risk of HIV infection in Southern African countries, a phenomenon called the "feminisation" of the HIV pandemic (Himmelgreen et al. 2010: 404). The percentage of men was higher in the HBC group (38,7%) compared to the non-HBC group (31,4%), indicating that perhaps a smaller number of men are reached by the HBC programme than expected.

Thus, a number of initiatives could be put in place in order to stimulate the identification and inclusion of men in the HBC programme. According to Mills, Ford & Mugyenyi (2009: 276), the promotion of support groups for men living with HIV could be a solution. In chapter 2, it was mentioned that AIDS threatens the productive members of the household and is often accompanied by a drop in income (Casale & Whiteside 2006: 5; Whiteside 2001: 80; Isaksen et al. 2002:11). Also, it was found that HBC programmes providing only “empathy inducement” measures are ineffective (Maluwa et al. 2002: 12). Acknowledging this in the creation of male support groups providing a space for sharing health information, adherence advice and support in setting up a small business, these groups specifically designed to attract men could be used to gradually introduce men to HBC services. Such as strategy could partially offset the gender imbalance in HBC programmes and generate a new momentum in the communities where HBC services are provided.

5.5.2.2 Pay attention to the causes of post-HIV diagnosis divorce/separation rates and develop strategies to reduce their impact

The data collected shows that there is statistically significant imbalance between the group of PLWHIV receiving HBC services and the group of PLWHIV not receiving HBC services in relation to marital status. In fact, 46.2% of the PLWHIV in the HBC group were married, a figure almost three times higher than in the non-HBC group where 15.3% declared themselves to be married. A closer look at the data reveals that 21,2% of the PLWHIV in the non-HBC group are either separated or divorced, compared to only 8% in the HBC group. As discussed in chapter 3, the imbalance could be due to selection bias, but this hypothesis is unlikely given the fact that PLWHIV were recruited on a neighbourhood basis and there is no evidence that people living in specific areas of the districts have a higher divorce rate than others. Also, it would be interesting to know if PLWHIV receiving HBC services remarry more than PLWHIV not receiving HBC services, which could be an alternative explanation to the higher rates of divorced PLWHIV in the non-HBC group. In retrospect, including a question in the study's questionnaire about the time of the divorce in relation to disclosure of HIV status to the partner would have been useful in pinpointing the reason for the differences between the groups.

According to Boileau, Clark, Bignami-Van Assche, Poulin, Reniers, Watkins, Kohler & Heymann (2009: i27), life transitions such as divorce and widowhood are correlated to HIV status. Another study by Murray, Haworth, Semrau, Singh, Aldrovandi, Sinkala, Thea & Bolton (2006: has found HIV status to be "…*closely associated to patterns of violence and abuse*". Furthermore, a study by Ezechi, Gab-Okafor, Onwujekwe, Adu, Amadim & Herbertson (2009: 745) with pregnant women living with HIV in Nigeria has discovered that 65.8% of them had reported abuse from a spouse, and in 74% of the cases, there was no abuse before the HIV diagnosis was made.

Why is it then that causes married PLWHIV receiving HBC services to remain in a relationship while PLWHIV not receiving HBC services are more likely to have divorced or separated? The central question here is: is counselling provided at home by HBC volunteers having an impact on the health of the relationship of married PLWHIV compared to counselling provided by a VCT counsellor to PLWHIV not receiving HBC services? This question would need a study of its own, but based on the data collected in this study, there is a difference and we can hypothesize that something in the HBC services has an influence on this. Thus, apart from recommending further research on the subject, it is also suggested that the VCT counsellor to discuss aspects related to the conjugal relationships of PLWHIV and develop a strategy to reduce post-HIV diagnosis divorces and separations.

5.5.2.3 Improve the information transfer to PLWHIV in HBC programmes so they can make informed choices

At the programmatic level, the researcher suggests the improvement of the instruments and tools used to transfer information to PLWHIV in the HBC programme, so they will become more knowledgeable about the options available to them and will make informed choices. As indicated by Hamra *et al.* (2005: 921), improved knowledge about support and care acquired through educational interventions could have an effect on expressed stigma.

5.5.2.4 Increase the number of HBC initiatives in communities most affected by HIV to reduce stigma and improve QoL in PLWHIV

At the level of policy, the findings of this study seem to point to the value of increasing the number of community-driven, flexible, integrated and adapted HBC initiatives in the areas most affected by HIV in order to impact stigma and increase quality of life for PLWHIV (Mohammad & Gikonyo 2005: 21; Ogden, Esim & Grown 2006: 339). While more research would be needed to adequately assess the influence of HBC on HIV and AIDS-related stigma and QoL levels of PLWHIV, the differences in QoL and stigma levels between the groups of PLWHIV receiving HBC services or not discovered in this study suggest that HBC services could have an influence on these variables.

5.6 CONCLUSION

The results of the study suggest that PLWHIV on ART receiving HBC services experience less stigma and have a higher perceived QoL than PLWHIV also on ART but who are not receiving HBC services. This conclusion could be considered to be obvious to the numerous health workers involved in the provision of HBC for PLWHIV. However, backing this impression with quantitative data comes as an important step, as the absence of a difference between the groups would have meant a lesser probability of the impact of HBC programmes on stigma and perceived QoL. As mentioned earlier, it does not, however, imply that the HBC programme is actually causing the higher perceived QoL and lower stigma.

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APPENDICES

Appendix A: Consent form in English

INFORMED CONSENT FORM

Dear participant,

My name is Alexandre Massicotte and I currently completing a Master's degree in Social Behaviour Studies in HIV/AIDS at the University of South Africa (UNISA). As a requirement for the degree, I have to conduct a research study about the response to HIV and AIDS in Africa.

The purpose of the study is to better understand how people living with HIV and using antiretroviral treatment cope with their situation. For this reason, the study will measure some aspects of your life, such as quality of life, stigma and discrimination.

This is an invitation to participate in this study. If you agree to do so, you will be asked to respond to questions about you and your experience in an interview that will last about two hours. Two hundred other participants in the community will also be asked to participate in this study. Your participation is voluntary and you will not be penalised in any way should you decide not to participate. This means that whether or not you participate in the study, you will still continue to receive the services of the counsellor at the ATS. And, if you are part of the home-based care project, you will still continue to receive visits at home. However, without your kind co-operation, we cannot gather scientific data that will help people rendering ARV services to continue planning and improving these services. This is therefore an urgent appeal to you to please participate. Let me give you assurances about the extent of your participation:

- You will note that we won't ask your name during the interview. This is because nobody outside the research team has to know who answered what. After the questionnaires are completed, they will be sent to the researcher, who won't be able to ascertain the names of the participants in the study. Everything you will discuss during the interview will be kept between you and the person asking the questions. So you can feel free to answer the questions as honestly as possible without fear that someone will know what you have said. You will be asked to sign the consent form, however, and the signed forms will be kept separate from the questionnaires in a locked safe and destroyed 3 years after the study has been completed.

- Also, you can stop your participation at any time if you feel like you don't want to be part of the study anymore. If, however, you want to be part of the study, the interviewer will discuss a possible date and time for the interview and ask you to sign this document in two copies: one will remain with you and the other one will be kept by the interviewer.

If you need psychological support after answering the questions, please don't hesitate to ask for help. The person who will be able to listen and give help is your normal advisor at the testing and counselling facility, or if you are part of the HBC programme, you can contact Olinda Magaia at Salama's office.

I have read and understood this consent form, and I agree to participate in this study.

Participant's signature:	Interviewer's name:
Signature	Signature
Date	Date

Appendix B: Consent form in Portuguese

TERMO DE CONSENTIMENTO LIVRE E ESCLARECIDO

Prezado (a) participante,

Meu nome é Alexandre Massicotte e neste moment estou a concluir um mestrado em Estudos do Comportamento Social e HIV-SIDA na Universidade da Africa do Sul (UNISA). Como exigência do programa, tenho que conduzir uma pesquisa social sobre um aspecto da resposta ao HIV e SIDA em Àfrica.

O propôsito deste estudo e de conhecer melhor como diferentes pessoas vivendo com HIV recebendo antiretrovirais se adaptam a sua situação. Por esta razão, a pesquisa vai medir alguns aspectos da sua vida, como a sua qualidade de vida, o estigma e discriminação.

Este é um convite para participar na pesquisa. Se aceitar, você deverá responder à um questionário sobre si e sua experiência, numa entrevista que levará umas duas horas. Duzentas outras pessoas da comunidade serão também selecionadas para participar neste estudo. A sua participação é de livre vontade e você não será penalizado se tomar a decisão de não participar. Isso significa que, participando na pesquisa como não, você continuará à se beneficiar dos serviços do conselheiro no ATS. Se neste momento você recebe voluntários do projecto de cuidados domiciliários, você continuará à receber as visitas em casa. Portanto, sem a sua colaboração, não poderemos juntar os dados que permitirão às pessoas que providenciam serviços ligados aos antiretrovirais de continuar o planeamento e melhorar estes serviços. Este é um apelo urgente para sua participação neste estudo. Gostaria de explicar melhor o que a sua participação ao estudo implica:

- Você poderá notar que não vamos precisar de conhecer o seu nome durante a entrevista. A razão é simples: ninguém para além do grupo de pesquisadores poderá saber quem respondeu o qué. Depois de serem preenchidos, os formulários serão enviados ao pesquisador, e ele não conhecerá os nomes dos participantes da pesquisa. Tudo o que for dito durante a entrevista ficará entre você e o entrevistador. Por isso, você pode se sentir a vontade e responder honestamente às perguntas sem temer que alguém possa conhecer das suas respostas. Você deverá assinar o formulário de consentimento, e este formulário será conservado separadamente do questionário num lugar trancado e tudo será destruido 3 anos depois da conclusão do estudo.

- Também, você pode retirar a sua participação na pesquisa a qualquer momento se quiser. Portanto, se quiser participar na pesquisa, o entrevistador vai marcar uma hora e uma data para a entrevista e pedir para que você assinasse este documento em dois exemplários: uma cópia ficará com você e a outra com o pesquisador.

Se precisar de apoio psicológico depois da entrevista, não hesite em pedir ajuda. A pessoa que poderá escutar e dar apoio neste sentido é o seu conselheiro normal no ATS, ou, se você faz parte do programe de cuidados domiciliários, pode contactar Olinda Magaia no escritório da Salama.

Li e entendi este termo de consentimento, e aceito participar nesta pesquisa.

Nome do participante:	Nome do entrevistador:
Assinatura	Assinatura
Data	Data

Appendix C: Consent form in Emakua

EKANYERYO YOTTHUNA VOHIKHANYERERIHIWA NI YOLELEYA.

Namakhalela ophenteia,

N’sinanaka Alexandre Massicotte nanano va, kinmaliha ossoma makhalelo atthu vamos’a ni HIV-SIDA,Escola wulupale eri ossulu wa W’africa, eniriwa (UNISA) Ntoko vantthuneyaia muteko owo, kihana wettiha ni oholela muteko wowehaweha muhin’a watthu,enamuna womwakhula HIV ni SIDA elapo ya Wafrica. Etthwaya yossoma ela, eri ossuwela orattene, mana xeni atthu ovirikana, ekhalaka ni HIV, ni yakhelaka mirette sininkhulumula mwaxitthu olá, mota oniraya okhala ni n’xankiho olá. Tivó, yowehaweha ela enrowa ophima makhalelo khamosa khamosa, yorerela, ohiphaveliwa ni othanyiwa.

N’no, olattuliwa wi mwire n’pantta muteko ola Mwatthuna vale, nyuwo muhana wakhula sokohiwa mwa nyuwo, ntoko sinsuwelanyu yokoha enrowa okuxa iwora pili. Atthu ophiyeraka imiya pili ankomunidadeni walá anmuttettheni, anrowa othanliwa wira yire n’pantta muteko ene yola..Wira n’pantta mutekola, kahiyo wokhanyererihiwa, masí votthuna wanyu ni nyuwo khamunlamuliwa mwahitthune okhalela. Eyo enihimya wira,okhalela walá n’nari, nyuwo munotthikela wakhela miteko sa mulipa a miruku, weiwe omwaleiwa mutthu votthuna wawe..Nenla vakhala wira munniwakhela mavoluntário a mwalano wo wakhaliherya arretta, nyuwo munrowa wotoliwaka ninlelo owani. Tivó ohikhanle mukhalihero anyu, khaninwerya otakhaniha yorerela wi atthu Yale avanhe miteko sololwana ni mirette, opwahera oholo ni oreriha miteko iya. N’la, nikano nowakuveya, wira mukhalele muteko olá. Kaniphavela woleliheryani orattene okhalela wanyu muteko olá enruhelaya:

- N’yuwo munoweha wi khaninrowa ophavela osuwela n’sina nanyu okathi wa sokoha. Etthwaya tila: khavo, wahiya ale anrowa oholela muteko olá, onrowa osuwela tani akhunle exeni. Samalá olepiwa ipaphelo sinrowa ovahiwa mulupa oholela owehaweha iwo, nave owo khanrowa osuwela masina ale yirale n’pantta muteko olá. Sothene sinrowa ohinmwa okathi wokohiwa,, sinrowa okhala ni nyuwo nule onrowa okoha. Tivó, nyuwo muhana wikhalela ni wakhula vorerela sokohiwa, vohova wi okhala onrowa oswela sakhunlyanyu. Nyuwo muhana olepa epaphelo yotthuna, ni epaphelo eyo enrowa osukiwa wovalanyiwa ni epaphelo ya sokoha, ni enrowa otthukeliwa, ni sothene sinrowa ohononiwa sivinrene iyakha ttharú omalihiwene muteko olá.
- Nave nyuwo poti wikumiha, muhina wa muteko olá, okathi muntthunanyu. Tivó, mwatthuna okhalela, namakoha onrowa ohimya nihiku ni okathi onrowawe wira sokoha iyo, ni munnivekeliwa wira muhele ekanyero walá n’sina , epaphelo pili, emosa enrowa ohala ni nyuwo ekina ni mulipa owehaweha sossoma..

Mwaphavela okhaliheriwa ni miruku omanlele muteko wokohiwa, muhovelele ovekela. Mutthu onrowa wowiriyanani ni wokhaliheryani n’pantta owo, mulipanyu yole a miruku a mahiku othene, walá mwairaka n’pantta wa mutthenketjo wowakhaliherya aretta, mulume ni mai Olinda Sebastião Magaia, Osalama.

Kossoma ni kohiwa sana epaphelo ela yotthuna, ni kokupali wira n’pantta muteko owo.

N’sina na mulipa okhalela:	N’sina na mulipa ókoha:
Ekanyero	Ekanyero
Nihiku	Nihiku

Appendix D : Questionnaire in English

SOCIO-DEMOGRAPHIC QUESTIONNAIRE

The purpose of the study is to help us understand how different people living with HIV and receiving antiretroviral treatment cope with their situation. You have been randomly selected for participation in this study. Your name is not asked and will not be written down on the questionnaire. You therefore remain anonymous. 239 other people living with HIV and receiving ARV-treatment will also participate in this study. After the information has been collected, the data will be analysed together and this means that individual information will be reported together and cannot be linked to you personally. Only the research team sees the completed questionnaires. This means that all information you provide in answering these questions are confidential. You will be asked to respond to a few questions in 3 short questionnaires: one is on your personal background, the second asks questions about your quality of life and the third about stigma and discrimination. This would take about 90 minutes. I kindly ask you to help me by answering the following questions.

Please circle the answer given by the participant to the following questions or write down the information requested:

QUESTIONNAIRE NUMBER		**DATE**	
		NAME OF INTERVIEWER	

Beneficiary of Salama´s HBC programme			1
	Starting date on the programme	(MONTH, YEAR)	
Non-Beneficiary of Salama´s HBC programme			2

1	**Gender**	Male	1
		Female	2

2	**How old are you?**	**Age (years)**

3	**What is your highest level of education?**	None	1
		1-4th Grade	2
		5-6th Grade	3
		7-9th Grade	4
		10-12th Grade	5
		Post secondary school/ College/University	6

4	**What is your area of residence?**	Malema	1
		Ribáuè	2

5	**What is your current marital status?**	Single	1
		Married	2
		Separated	3
		Divorced	4
		Widowed	5

6	**Do you belong to a church?**	Yes	1
		No	2

7	**If "yes" to Question 6, please indicate to which church you currently belong. If "no" Please skip to Question 8.**	Catholic	1
		Twelve apostles	2
		Sion	3
		God's assembly	4
		Christ Evangelical	5
		Old Apostles	6
		Jehovah's witnesses	7
		Muslim	8
		Rainbow	9
		Anglican	10
		Presbyterian	11
		Other (which one?)	12

8	**How often do you go to church?**	Every day	1
		A few times a week	2
		Once a week	3
		A few times a month, but less than once a week	4
		Once a month	5
		Never	6

9	**Do you have children? (0-18 years old)**	Yes	1
		No	2

10	**If yes, how many? If no, record 00.**	

11	**How many people are living in your household?**	

12	**When have you been diagnosed with HIV? (month, year)**	Month (MM)	Year (YYYY)

13	**Have you ever been hospitalized because of HIV?**	Yes	1
		No	2

14	**Have you ever had an opportunistic infection? (Interviewer: Refer to list of opportunistic infections)**	Yes	1
		No	2
		Don't know	3

15	**Do you have an opportunistic infection at the moment? (Interviewer: Refer to list of opportunistic infections)**	Yes	1
		No	2
		Don't know	3

16	**If yes, which opportunistic infection do you have at the moment? If no, skip to Question 18.**	More than 10% body weight loss with diarrhoea or fever, intermittent or constant for at least 1 month	1
		Cryptococcal meningitis	2
		Pulmonary or extra-pulmonary tuberculosis	3
		Kaposi's sarcoma	4
		Neurological impairment that is sufficient to prevent independent daily activities, not known to be due to a condition unrelated to HIV infection (for example, trauma, or cerebrovascular accident).	5
		Oral candiasis with difficulty in swallowing.	6
		Pneumonia	7
		Invasive cervical cancer	8
		Don't know	9

17	**If yes, for how long have you been suffering from this infection (the one mentioned in Question 16)? Give the number of days, please.**	

18	**When did you start the antiretroviral treatment? (month, year)**	Month (MM)	Year (YYYY)

19	**Have you ever stopped taking your ARV medication since the first time you started?**	Yes	1
		No	2

20	**What situation among these is best describing the way you use the treatment, at the moment?**	I use them exactly as the doctor told me	1
		I use them almost as the doctor told me, because sometimes I don't take them or am late in taking them	2
		I am not using them as the doctor told me, because often I don't take them or am late in taking them	3

21	**Without counting health staff, how many other people know you have HIV?**	Nobody knows	1
		1-5 people	2
		6-15 people	3
		16-30 people	4
		More than 30 people	5

22	**Who are the people who know you are HIV positive?**	**Please mark all possibilities**	Yes	No
		Husband/wife or boyfriend/girlfriend	1	2
		Children	1	2
		My mother and/or father	1	2
		Other family members	1	2
		Friends	1	2
		Neighbours	1	2
		People who gather at the same church	1	2
		Others (who? Please specify)		

23	**Are you receiving visits from a home-based care project?**	Yes	1
		No	2

24	**If yes, how often do you receive visits from the home-based care project volunteers?**	Every day	1
		A few times a week	2
		Once a week	3
		A few times a month, but less than once a week	4
		Once a month	5
		Other (Please specify)	6

25 - Do you have any comments to make about the study?

____

____

____

____

Thanks, this is the end of the first questionnaire; we'll now start on the second one

WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, contentment and concerns. I ask that you think about your life **in the last four weeks.**

		Very poor	**Poor**	**Neither poor nor good**	**Good**	**Very good**
1 (G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	**Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things **in the last four weeks**.

		Not at all	**A little**	**A moderate amount**	**Very much**	**An extreme amount**
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4 (F11.3)	To what extent do you need any medical treatment to function in your daily life?	1	2	3	4	5
5 (F4.1)	How much do you enjoy life?	1	2	3	4	5

		Not at all	**A little**	**A moderate amount**	**Very much**	**An extreme amount**
6 (F24.2)	To what extent do you feel that your life is meaningful?	1	2	3	4	5
7 (F5.3)	How well are you able to concentrate?	1	2	3	4	5
8 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things **in the last four weeks.**

		Not at all	**A little**	**Moderately**	**Mostly**	**Completely**
10 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5

		Not at all	**A little**	**Moderately**	**Mostly**	**Completely**
12 (F18.1)	Do you have enough money/resources to meet your needs?	1	2	3	4	5
13 (F20.1)	To what extent do you have easy access to information (about your health, rights, etc)?	1	2	3	4	5
14 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18 (F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20 (F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
21 (F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22 (F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23 (F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5

		Very dissatisfied	**Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**
24 (F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25 (F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things **<u>in the last four weeks.</u>**

		<u>Never</u>	**<u>Seldom</u>**	**<u>Quite often</u>**	**<u>Very often</u>**	**<u>Always</u>**
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Do you have any comments about the assessment?

BERGER HIV STIGMA SCALE

This study asks about some of the social and emotional aspects of having HIV. For most of the questions, just circle the letters or numbers that go with your answer. There is no right or wrong answer. Feel free to write in comments as you go through the questions.

This first set of questions asks about some of your experiences, feelings, and opinions as to how people with HIV feel and how they are treated. Please do your best to answer each question.

For each item, circle your answer: Strongly disagree (SD), disagree (D), agree (A), or strongly agree (SA).

		Strongly disagree	**Disagree**	**Agree**	**Strongly agree**
1	In many areas of my life, no one knows that I have HIV	☐	☐	☐	☐
2	I feel guilty because I have HIV	☐	☐	☐	☐
3	People's attitudes about HIV make me feel worse about myself	☐	☐	☐	☐
4	Telling someone I have HIV is risky	☐	☐	☐	☐
5	People with HIV lose their jobs when their employers find out	☐	☐	☐	☐
6	I work hard to keep my HIV a secret	☐	☐	☐	☐
7	I feel I am not as good a person as others because I have HIV	☐	☐	☐	☐
8	I never feel ashamed of having HIV	☐	☐	☐	☐
9	People with HIV are treated like outcasts	☐	☐	☐	☐
10	Most people believe that a person who has HIV is dirty	☐	☐	☐	☐
11	I prefer not to make friends because I am afraid I will have to tell them I have HIV	☐	☐	☐	☐
12	Having HIV makes me feel unclean	☐	☐	☐	☐
13	Since learning I have HIV, I feel set apart and isolated from the rest of the world	☐	☐	☐	☐
14	Most people think that a person with HIV is disgusting	☐	☐	☐	☐
15	Having HIV makes me feel that I'm a bad person	☐	☐	☐	☐
16	Most people with HIV are rejected when others find out	☐	☐	☐	☐

		Strongly disagree	Disagree	Agree	Strongly agree
17	I am very careful who I tell that I have HIV	☐	☐	☐	☐
18	Some people who know I have HIV have grown more distant	☐	☐	☐	☐
19	Since learning I have HIV, I worry about people discriminating against me	☐	☐	☐	☐
20	Most people are uncomfortable around someone with HIV	☐	☐	☐	☐
21	I never feel the need to hide the fact that I have HIV	☐	☐	☐	☐
22	I worry that people may judge me when they learn I have HIV	☐	☐	☐	☐
23	Having HIV in my body is disgusting to me	☐	☐	☐	☐

Many of the items in this next section assume that you have told other people that you have HIV, or that others know. This may not be true for you. If the item refers to something that has not actually happened to you, please imagine yourself in that situation. Then give your answer ("strongly disagree," "disagree," "agree," "strongly agree") based on how you think you would feel or how you think others would react to you.

		Strongly disagree	Disagree	Agree	Strongly agree
24	I have been hurt by how people reacted to learning I have HIV	☐	☐	☐	☐
25	I worry that people who know I have HIV will tell others	☐	☐	☐	☐
26	I regret having told some people that I have HIV	☐	☐	☐	☐
27	As a rule, telling others that I have HIV has been a mistake	☐	☐	☐	☐
28	Some people avoid touching me once they know I have HIV	☐	☐	☐	☐
29	People I care about stopped calling after learning I have HIV	☐	☐	☐	☐
30	People have told me that getting HIV is what I deserve for how I lived my life	☐	☐	☐	☐
31	Some people close to me are afraid others will reject them if it becomes known that I have HIV	☐	☐	☐	☐
32	People don't want me around their children once they know I have HIV	☐	☐	☐	☐

		Strongly disagree	**Disagree**	**Agree**	**Strongly agree**
33	People have physically backed away from me when they learn I have HIV	☐	☐	☐	☐
34	Some people act as though it's my fault I have HIV	☐	☐	☐	☐
35	I have stopped socializing with some people because of their reactions to my having HIV	☐	☐	☐	☐
36	I have lost friends by telling them I have HIV	☐	☐	☐	☐
37	I have told people close to me to keep the fact that I have HIV a secret	☐	☐	☐	☐
38	People who know I have HIV tend to ignore my good points	☐	☐	☐	☐
39	People seem afraid of me once they learn I have HIV	☐	☐	☐	☐
40	When people learn you have HIV, they look for flaws in your character	☐	☐	☐	☐

Appendix E: Questionnaire in Portuguese

QUESTIONÁRIO SOCIO-DEMOGRÁFICO

O propôsito deste estudo e de conhecer melhor como diferentes pessoas vivendo com HIV recebendo antiretrovirais se adaptam a sua situação. Você foi seleccionado de maneira aleatória para participar à este estudo. Não vamos precisar de conhecer o seu nome e esta informação não aparecerá no questionário. Assim, você ficará anônimo. 239 outras pessoas vivendo com HIV e recebendo tratamento antiretroviral vão também participar neste estudo. Depois de juntar as informações, os dados serão analizados em conjunto, o que significa que a informação individual será reportada em conjunto com a informação dos outros participantes e não poderá ser ligada à você. Somente a equipa de pesquisa poderá ver os questionários preenchidos. Isso significa que toda a informação proveniente das perguntas feitas ; confidencial. Você deverá responder às perguntas contidas em três curtos questionários: um deles tem à ver com a sua situação pessoal, o segundo tem a ver com a sua qualidade de vida e o terceiro está ligado ao estigma e discriminação. O processo levará mais ou menos 90 minutos. Peço a sua ajuda respondendo à seguintes perguntas.

Por favor, assinalar a resposta dada pelo participante ou escrever a informação requirida:

NÚMERO DO QUESTIONÁRIO		**DATA**	
		Nome do entrevistador	

Beneficiário do programa de CD da Salama			1
	Data de ingresso no programa de CD da Salama	(Mês, ano):	
Não Beneficiário do programa de CD da Salama			2

1	**Gênero**	Homem	1
		Mulher	2

2	**Quantos anos tem?**	**Idade (anos)**

3	**Qual é o último nível atingido no sistema de educação?**	Nenhum	1
		1-4a classe	2
		5-6ª classe	3
		7-9ª classe	4
		10-12ª classe	5
		Nível superior (estudos pós-secundários, universidade, etc.)	6

4	**Qual é o seu local de residência?**	Malema	1
		Ribáuè	2

5	**Qual é o seu estado civil actual?**	Solteiro	1
		Casado	2
		Separado	3
		Divorciado	4
		Viúvo	5

6	**Você pertence à uma igreja?**	Sim	1
		Não	2

7	**Se "sim", qual igreja? Se não, pode avançar até a pergunta 8**	Católica	1
		Doze apóstolos	2
		Sione	3
		Assembleia de Deus	4
		Evangélica de Cristo	5
		Velhos apóstolos	6
		Testemunhos de Jeová	7
		Muçulmana	8
		Arco-Íris	9
		Anglicana	10
		Presbiteriana	11
		Outra (qual?)	12

8	**Com que frequência você frequenta a igreja?**	Todos os dias	1
		Umas vezes por semana	2
		Uma vez por semana	3
		Algumas vezes por mês, mas menos do que uma vez por semana	4
		Uma vez por mês	5
		Nunca	6

9	**Você tem crianças? (0-18 anos)**	Sim	1

			Não	2

10	**Se sim, quantas? Se não, escreve 00.**	

11	**Quantas pessoas vivem na sua casa?**	

12	**Quando é que você foi diagnisticado com HIV? (mês, ano)**	Mês (MM)	Ano (AAAA)

13	**Alguma vez você ficou hospitalizado por causa do HIV?**	Sim	1
		Não	2

14	**Alguma vez você teve uma infecção oportunista? (entrevistador: referir às infecções oportunistas mencionadas na pergunta 16)**	Sim	1
		Não	2
		Não sei	3

15	**Você tem uma infecção oportunista neste momento? (entrevistador: referir às infecções oportunistas mencionadas na pergunta 16)**	Sim	1
		Não	2
		Não sei	3

16	**Se sim, qual é a infecção oportunista que tem neste momento?.**	Mais de 10% de perca de peso com diarreia ou febre, intermitente ou constante durante pelo menos 1 mês	1
		Meningite (Criptococose)	2
		Tuberculos (pulmonária ou extra-pulmonária)	3
		Sarcoma de Kaposi	4
		Deficiência neurológica que é suficiente para impedir as actividades quotidianas, mas que não é causada por uma condição não relacionada com a infecção ao HIV (por exemplo, um acidente ou trauma cerebrovascular)	5
		Candídiase oral com dificuldade em engolir	6
		Pneumonia	7
		Cancro de colo uterino invasivo	8
		Não sei	9

17	**Você tem esta infecção oportunista há quanto tempo? (a infecção mencionada na pergunta 16)? Por favor, menciona o número de dias.**	

18	**Quando é que você começou a fazer o tratamento antiretroviral (Mês, ano)**	Mês (MM)	Ano (AAAA)

19	**Alguma vez parou o tratamento desde que o começou?**	Sim	1
		Não	2

20	**Qual é a situação que expressa melhor a maneira como você usa os medicamentos antiretrovirais, neste momento.**	Tomo correctamente como fui orientado pelo médico	1
		Tomo quase correctamente, pois às vezes deixo de tomar ou atraso o horário dos remédios	2
		Não estou à tomar correctamente, pois muitas vezes deixo de tomar ou atraso o horário dos remédios	3

21	**Sem contar os profissionais de saúde, quantas pessoas sabem que você é seropositivo(a)?**	Nenhuma	1
		1-5 pessoas	2
		6-15 pessoas	3
		16-30 pessoas	4
		Mais de 30 pessoas	5

22	**Quais são as pessoas que sabem que você é seropositivo?**	**Por favor assinalar todas as respostas mencionadas**	Yes	No
		Esposo(a) ou namorado(a)	1	2
		Meu (s) filho (s)	1	2
		Minha mãe e/ou meu pai	1	2
		Outra (s) pessoa (s) da família	1	2
		Amigo (s)	1	2
		Vizinho (s)	1	2
		Pessoas da mesma igreja	1	2
		Outros (quem?)		

23	**Você recebe visitas de um projecto de cuidados domiciliários?**	Sim	1
		Não	2

24	**Se sim, com que frequência você recebe visita dos voluntários do projecto de cuidados domiciliários?**	Todos os dias	1
		Algumas vezes por semana	2
		Uma vez por semana	3
		Algumas vezes por mês, mas menos do que uma vez por semana	4
		Uma vez por mês	5
		Outro (Por favor especifique)	6

25 - Você tem algum comentário à fazer em relação à este estudo??

____

____

Obrigado, já chegamos ao fim do primeiro questionário; agora vamos começar o segundo.

WHOQOL-BREF

Este questionário procura conhecer a sua qualidade de vida, saúde, e outras áreas da sua vida. Por favor, responda a todas as perguntas. Se não tiver a certeza da resposta a dar a uma pergunta, escolha a que lhe parecer mais apropriada. Esta pode muitas vezes ser a resposta que lhe vier primeiro à cabeça.

Por favor, tenha presente os seus padrões, expectativas, alegrias e preocupações. Pedimos-lhe que tenha em conta sua vida nas quatro últimas semanas. Por exemplo, se pensar nestas quatro últimas semanas, pode ter que responder à seguinte pergunta:

	Nada	**Pouco**	**Moderadamente**	**Bastante**	**Completamente**
Recebe das outras pessoas o tipo de apoio que necessita?	1	2	3	4	5

Deve pôr um círculo à volta do número que melhor descreve o apoio que recebeu das outras pessoas nas quatro últimas semanas. Assim, marcaria o número 4 se tivesse recebido bastante apoio, ou o número 1 se não tivesse tido nenhum apoio dos outros nas quatro últimas semanas. Por favor leia cada pergunta, veja como se sente a respeito dela, e ponha um círculo à volta do número da escala para cada pergunta que lhe parece que dá a melhor resposta.

		Muito Má	**Má**	**Nem Boa Nem Má**	**Boa**	**Muito Boa**
1 (G1)	Como avalia a sua qualidade de vida?	1	2	3	4	5

		Muito Insatisfeito	**Insatisfeito**	**Nem satisfeito nem insatisfeito**	**Satisfeito**	**Muito Satisfeito**
2 (G4)	Até que ponto está satisfeito(a) com a sua saúde?	1	2	3	4	5

As perguntas seguintes são para ver até que ponto sentiu certas coisas **<u>nas quatro últimas semanas</u>**.

		Nada	**Pouco**	**Nem muito nem pouco**	**Muito**	**Muitíssimo**
3 (F1.4)	Em que medida as suas dores (físicas) o (a) impedem de fazer o que precisa de fazer?	1	2	3	4	5

4 (F11.3)	Em que medida precisa de cuidados médicos para fazer a sua vida diária?	1	2	3	4	5
5 (F4.1)	Até que ponto gosta da vida?	1	2	3	4	5
6 (F24.2)	Em que medida sente que a sua vida tem sentido?	1	2	3	4	5

		Nada	**Pouco**	**Nem muito nem pouco**	**Muito**	**Muitíssimo**
7 (F5.3)	Até que ponto se consegue concentrar?	1	2	3	4	5
8 (F16.1)	Em que medida se sente em segurança no seu dia-a-dia?	1	2	3	4	5
9 (F22.1)	Em que medida é saudável o seu ambiente físico?	1	2	3	4	5

As seguintes perguntas são para ver até que ponto experimentou ou foi capaz de fazer certas coisas **nas quatro últimas semanas.**

		Nada	**Pouco**	**Moderada mente**	**Bastante**	**Complet amente**
10 (F2.1)	Tem energia suficiente para a sua vida diária?	1	2	3	4	5
11 (F7.1)	É capaz de aceitar a sua aparência física?	1	2	3	4	5
12 (F18.1)	Tem dinheiro/recursos suficientes para satisfazer as suas necessidades?	1	2	3	4	5
13 (F20.1)	Até que ponto tem fácil acesso às informações (sobre sua saúde, seus direitos, etc.)?	1	2	3	4	5
14 (F21.1)	Em que medida tem oportunidade para realizar actividades de lazer?	1	2	3	4	5

		Muito Má	**Má**	**Nem boa nem má**	**Boa**	**Muito Boa**
15 (F9.1)	Como avaliaria a sua mobilidade [capacidade para se movimentar e deslocar por si próprio(a)]?	1	2	3	4	5

As perguntas que se seguem destinam-se a avaliar se se sentiu bem ou satisfeito(a) em relação a vários aspectos da sua vida **<u>nas quatro últimas semanas</u>**.

		Muito Insatisfeito	**Insatisfeito**	**Nem satisfeito nem insatisfeito**	**Satisfeito**	**Muito Satisfeito**
16 (F3.3)	Até que ponto está satisfeito(a) com o seu sono?	1	2	3	4	5

		Muito Insatisfeito	**Insatisfeito**	**Nem satisfeito nem insatisfeito**	**Satisfeito**	**Muito Satisfeito**
17 (F10.3)	Até que ponto está satisfeito(a) com a sua capacidade para desempenhar as actividades do seu dia-a-dia?	1	2	3	4	5
18 (F12.4)	Até que ponto está satisfeito(a) com a sua capacidade de trabalho?	1	2	3	4	5
19 (F6.3)	Até que ponto está satisfeito(a) consigo próprio(a)?	1	2	3	4	5
20 (F13.3)	Até que ponto está satisfeito(a) com as suas relações pessoais?	1	2	3	4	5
21 (F15.3)	Até que ponto está satisfeito(a) com a sua vida sexual?	1	2	3	4	5
22 (F14.4)	Até que ponto está satisfeito(a) com o apoio que recebe dos seus amigos?	1	2	3	4	5

		Muito Insatisfeito	**Insatisfeito**	**Nem satisfeito nem insatisfeito**	**Satisfeito**	**Muito Satisfeito**
23 (F17.3)	Até que ponto está satisfeito(a) com as condições do lugar em que vive?	1	2	3	4	5
24 (F19.3)	Até que ponto está satisfeito(a) com o acesso que tem aos serviços de saúde?	1	2	3	4	5
25 (F23.3)	Até que ponto está satisfeito(a) com os transportes que utiliza?	1	2	3	4	5

As perguntas que se seguem referem-se à frequência com que sentiu ou experimentou certas coisas nas **quatro últimas semanas.**

		Nunca	**Poucas vezes**	**Algumas vezes**	**Frequentemente**	**Sempre**
26 (F8.1)	Com que frequência tem sentimentos negativos, tais como tristeza, desespero, ansiedade ou depressão?	1	2	3	4	5

Escala de Berger sobre estigmatização das pessoas vivendo com HIV

Você deve assinalar o número que corresponde melhor ao que você sente. Caso você concorde totalmente com a frase, você assinalará com um "X" o número 4, caso você discorde totalmente da frase, você assinalará o número 1. Se sua opinião é diferente dessas duas opções, marque 2 ou 3, conforme ela seja.

Não há respostas certas ou erradas. O que importa é o que você acha que combina mais com seus sentimentos. Se você quiser, sinta-se à vontade para acrescentar qualquer observação ou comentário, à medida em que for respondendo as perguntas. Por favor, esforce-se para responder cada uma das perguntas da melhor forma possível, sem deixar nenhuma em branco.

O primeiro grupo de perguntas trata das suas experiências, sensações e opiniões sobre como as pessoas com o HIV se sentem e sobre como elas são tratadas.

		Discordo Totalmente (1)	**Discordo (2)**	**Concordo (3)**	**Concordo Totalmente (4)**
1	Em muitas áreas da minha vida, ninguém sabe que eu tenho o HIV.	☐	☐	☐	☐
2	Eu me sinto culpado por ter o HIV.	☐	☐	☐	☐
3	As atitudes das pessoas em relação ao HIV fazem com que eu me sinta pior comigo mesmo.	☐	☐	☐	☐
4	Dizer a alguém que eu tenho o HIV é um risco.	☐	☐	☐	☐
5	As pessoas que têm o HIV perdem o emprego quando os patrões descobrem.	☐	☐	☐	☐
6	Eu me esforço muito para que as pessoas não saibam que eu tenho o HIV.	☐	☐	☐	☐
7	Eu não me sinto uma pessoa tão boa quanto as outras, porque eu tenho o HIV	☐	☐	☐	☐
8	Eu nunca tenho vergonha de ter o HIV.	☐	☐	☐	☐
9	Pessoas que têm o HIV são tratadas como pessoas excluídas	☐	☐	☐	☐
10	A maioria das pessoas acredita que alguém que tem o HIV tem muitos parceiros sexuais.	☐	☐	☐	☐

		Discordo Totalmente (1)	**Discordo (2)**	**Concordo (3)**	**Concordo Totalmente (4)**
11	Prefiro nao criar mais amizades porque tenho receio de contar que tenho HIV	☐	☐	☐	☐
12	Ter o HIV faz com que eu me sinta sujo (a)	☐	☐	☐	☐
13	Desde que eu soube que tinha o HIV, eu me sinto isolado(a) e excluído(a) do resto do mundo.	☐	☐	☐	☐
14	A maioria das pessoas acha que uma pessoa que tem o HIV é nojenta.	☐	☐	☐	☐
15	Ter o HIV faz com que eu me sinta uma pessoa péssima.	☐	☐	☐	☐
16	A maioria das pessoas que têm o HIV é rejeitada quando as outras pessoas descobrem.	☐	☐	☐	☐
17	Eu tomo bastante cuidado ao decidir a quem eu digo que tenho o HIV.	☐	☐	☐	☐
18	Algumas pessoas que sabem que eu tenho o HIV se distanciaram de mim.	☐	☐	☐	☐
19	Desde que eu soube que tinha o HIV, eu fico preocupado(a) se as pessoas vão me discriminar.	☐	☐	☐	☐
20	A maioria das pessoas não se sente a vontade quando está com alguém que tem o HIV.	☐	☐	☐	☐
21	Eu nunca sinto a necessidade de esconder o fato de que eu tenho o HIV.	☐	☐	☐	☐
22	Eu penso que as pessoas podem me julgar quando elas sabem que eu tenho o HIV.	☐	☐	☐	☐

		Discordo Totalmente (1)	Discordo (2)	Concordo (3)	Concordo Totalmente (4)
23	Ter o HIV em meu corpo me causa nojo.	☐	☐	☐	☐

Muitas das afirmações abaixo partem da hipótese de que você já contou a outras pessoas que você é portador (a) do HIV ou que outras pessoas já sabem disso. Pode ser que este não seja o seu caso. Mesmo assim, se a afirmação relatar fatos ou situações que não aconteceram em sua vida, pedimos que você tente se imaginar nessas situações e dê a sua opinião, baseada em como você acha que se sentiria ou como você acha que as pessoas reagiriam nas situações descritas. Lembre-se, a forma de marcação das respostas continua igual à anterior:

		Discordo Totalmente (1)	Discordo (2)	Concordo (3)	Concordo Totalmente (4)
24	Eu me sinto magoado(a) pela maneira como as pessoas reagiram quando souberam que eu tinha o HIV.	☐	☐	☐	☐

		Discordo Totalmente (1)	Discordo (2)	Concordo (3)	Concordo Totalmente (4)
25	Eu fico preocupado(a) com o fato de que as pessoas que sabem que eu tenho HIV possam contar a outras pessoas.	☐	☐	☐	☐
26	Eu me arrependo de ter contado a algumas pessoas que eu tenho o HIV.	☐	☐	☐	☐
27	De forma geral, contar a outras pessoas que eu tenho o HIV foi um erro.	☐	☐	☐	☐
28	Algumas pessoas evitam me tocar quando sabem que eu tenho o HIV.	☐	☐	☐	☐
29	As pessoas que eu considero importantes para mim pararam de me ligar depois que souberam que eu tenho o HIV.	☐	☐	☐	☐

		Discordo Totalmente (1)	Discordo (2)	Concordo (3)	Concordo Totalmente (4)
30	As pessoas me disseram que eu mereci ter adquirido o HIV por causa do modo como eu estava a viver.	☐	☐	☐	☐
31	Algumas pessoas próximas a mim têm medo de ser rejeitadas se todos ficarem a saber que eu tenho o HIV.	☐	☐	☐	☐
32	As pessoas não querem que eu tenha contato com seus filhos ou filhas depois que elas sabem que eu tenho o HIV.	☐	☐	☐	☐
33	As pessoas evitam contato físico comigo depois que sabem que eu tenho o HIV.	☐	☐	☐	☐
34	Algumas pessoas agem como se eu fosse culpado(a) por ter o HIV.	☐	☐	☐	☐
35	Eu parei de me encontrar com algumas pessoas por causa da reação delas ao fato de eu ter o HIV.	☐	☐	☐	☐
36	Eu perdi amigos quando contei para eles que eu tinha o HIV.	☐	☐	☐	☐
37	Eu pedi às pessoas próximas a mim que não contassem a ninguém que eu tenho o HIV.	☐	☐	☐	☐
38	As pessoas que sabem que eu tenho o HIV têm a tendência de ignorar minhas qualidades.	☐	☐	☐	☐
39	As pessoas sentem medo de mim quando sabem que eu tenho o HIV.	☐	☐	☐	☐
40	Quando alguém sabe que você tem o HIV, procura defeitos em seu caráter.	☐	☐	☐	☐

Appendix F: Questionnaire in Emakua

Sokohaya sa m´muttetthene

Ophaveleya wa yossoma ela, eri para osswela orattene, enamuna atthu ovirikana ekhalaka ni HIV-SIDA ni yakhelaka mirette, onikhalelaya ni muxankiho ola. N’yuwo mothanliwa wira mwire n’pamtta wa yossoma elai. Khaninnrowa ophavela osswela n’sina nanyu, ni muhupi olá khunrowa okhumela n’papheloni ya sokoha. Siso, n’yuwo munrowa ovitheya.Atthu akina ophiyeraka emiya pili ekhalaka ni HIV-SIDA ni yakhela mirette, anrowqa nawo wira n’pantta wa yossoma ela. Numalá otakanihiwa mihupi, sinrowa wululiwa ni owehiwa orattene vamosá, eyo piyo, yohimiya ya mutthu n’mosá enrowa ohinmwaka puromosa niye sakina, masi kinrowa owassani. Anrowa pahi oweha ipaphelo sa sokoha, ti makhulupale Yale ari oholo wa yossoma eyo. Eyo, enihimya wira sohimya sothene siluluwanne ni sokoha, essíri. N’uwo muhana wakhula sokohiwa sothene, mwa sokoha ttharu sokhuveya: Emosá, eluluwanne ni makhalelo awinyu, yanenli ni makhalelo a ekumi anyu, ni yaneraru eluluwanne ni ohiphaveliwa ni othanyiwa. Sokoha iya sinrowa omaliha minutu miloko mili. Kinnovekelani mukhaliheryo, mwakhulaka sokoha sinttharelana:

Por favor, assinalar a resposta dada pelo participante ou escrever a informação requirida:

MUATHELO WA SOKOHA		**Nihiku**	
		N´syna na mulipha okoha	

Mulipa okhaliheriwa ni Salama			1
	Data de ingresso no programa de CD da Salama	(Mês, ano):	
Mulipa ohikhaliheriwa ni Salama			2

1	**Mutthwene**	Mulopwana	1
		Muthiyana	2

2	**Iyakha**	

3	**Osomawawe:**	Kyiavo	1
		Yo pajerya ni yanexexe	2
		Ya nethanu namosa	3
		Ya nethanu napili ni nethanu naxexe	4
		Ya namuloko ni yanamuloko ni pili	5
		Escola etokwene	6

4	**Onkhalanyu**	Malema	1
		Ribáuè	2

5	**Mukhalelowa nyo:**	Mutchiyé	1
		Othela	2
		Nomualamuala	3
		Omualaniwa	4
		Namukweli	5

6	**Nyuwo munnetta okereja?**	Ina	1
		N´nari	2

7	**Mwira “ayo”, ekereja xen? Mwira n’nari n’pwahereke oholo ni yokoha ya nethanu na ttharu (8)**	Católica	1
		Doze apóstolos	2
		Sione	3
		Assembleia de Deus	4
		Evangélica de Cristo	5
		Velhos apóstolos	6
		Testemunhos de Jeová	7
		Muçulmana	8
		Arco-Íris	9
		Anglicana	10
		Presbiteriana	11
		Ekina (Tivil?)	12

8	**Imara kavi nyu munettanyu okereja iwó?**	Mahiko othene	1
		Mahiko vakanene va semanani	2
		Nihiko nimossa va semanani	3
		Mahiko vakani vamuerini	4
		Nihiko nimossa vamuerini	5
		N’kitonko	6

9	**Mokhalano anamuane? (0-18 anos)**	Ina	1
		N´nari	2

10	**Murino akavi? Ira hoye, muhilepe vo etthu.**	

11	**Athu akavi ankala owan´nhinho?**	

12	**Musuwenle lini wi mokhalano HIV, ovinya mweri ni eyaka mwamwaleiwanyu?**	Mweri	Eyakha

13	**Nyuwo motoko waphaxar oxipiritali muaha wa muasithu a HIV?**	Ina	1
		N´nari	2

14	**Montonko okhalano eretcha yowipunhera?**	Ina	1
		N´nari	2
		Nkisuwenle	3

15	**Nyuwo mokhalana iretta sowisokonyera nanano va? (Namakoha: Muhimye iretta sikina sotutuxerya sihinmwale ni yokoha ya namuloko ni thanu na mosa)**	Sim	1
		Não	2
		Não sei	3

16	**Mwira ayo, eretta xeni yowisokonyerya murinanyu nanano va?**	Ovukuwa olemela wanyu mwaha wa n’mirimani wala nanxekuwa, okathi tu kathi wala okathi wovalana, vophiyerya mweri n’mosa	1
		Meningite (Criptococose)	2
		Eyitica (Yannphumuni, wala n’nari)	3
		Sarcoma de Kaposi	4
		Ohimalela n’muruni ni wupuwela, muhinawerya ovara miteko sa mahikwene, vohikhala wi sitanyeriwe ni sokhumelela sovirikana ni HIV-SIDA (Ntoko ovulala, wala ovahuwa)	5
		Orutthuwiya mwanó	6
		Ephumu	7
		Ovoreiya wa n´rupo noyara	8
		Nkisuwenle	9

17	**Nyuwo murina oretta olá okhuma lini? (oretta yole ohinmwale nunmaro 16)? Xontte muhimye mahiku maka**	

18	**Nyuwo n´pajenrye lini owurya ikinino mweri xeni ni eyaka xeni? (mweri ni eyakha)**	Mweri	Eyakha

19	**Mwantoko ohiyerera owurya ikinino vapajenryanyu?**	Ayo	1
		N´nari	2

20	**Nyuwo munwurya sai ekinino?**	Kinwura ntoko sihimmawe medico	1
		Kinawura apale kitharihelaka okathi mukina kin´nahiyerera muaha wolekelela owura ikinino	2
		Hoye, nkinwura sana wi emara yintchene kinnahiya owura wala kinapissera okati wa ikinino	3

21	**Wahiya wa ale anvara muteko wa ekumi atchu akavi asuwenle wi mokhalano mwasitchu?**	Kavo kimulenlaka	1
		Mimosa na thanu atchuene	2
		Athanu namosa wala muloko nathano atchuene	3
		Muloko natchano namosa ni miloko miraru atchuene	4
		Opwaha-to miloko miraru atchuene	5

22	**Atchu osuwenle wi mokhalano mwasithchue ne yola tala:**	**Xontte, muhimye sowakhula sothene sihinmwale**	Ayo	N´nari
		Aiyaka, mwasetaka	1	2
		Annáka	1	2
		Atíti, amáma	1	2
		Akina amussyaka	1	2
		Mpuanaka	1	2
		Namuathchamananaka	1	2
		Mutchu a ekereja	1	2
		Akina ko (thani)		

23	**Nyuwo munnichekuriwa ni mutchenkeso onaweyaweya iretcha?**	Ina	1
		N´nari	2

24	**Wari ayo, imara kavi, munwakelanhu atchu a mutchenkeso enawehaweha aretcha animawani?**	Mahiko othene	1
		Mahiko vakanene va semanani	2
		Nihiko nimossa va semanani	3
		Mahiko vakani vamuerini	4
		Nihiko nimossa vamuerini	5
		Ekina (por favor especifique)	6

25 - Nhu mokhalano yohima ekinaku wopaka yosoma ela?

Koxukhuru, nophiya wokiseryani wa sokoha sopajerya. Vano ninrowa opajerya ya nenli.

WHOQOL-BREF

Muayokoha ela enassa ossuwela, murrerelo wa mukaleloanhu, ekumi nitho ekina sammapurone makina samukaleloanhu xonthe muakule sokoha sothene. Muahikalano ekekayi mua yo koha wella, muthanle munonanhu wira thirene wekekahi.

Ela podi okala yowakula yorerela ni imara sintchene muruni mwanhu. Xonthe mukaleno vavo mapatrawanho mukuweloamho, otheliwawanho, maxankihoanho, enovelekani wira mukaleno mupuelo wa okalawanho veri va isimana ixexe sokisera, n´tonhero mupuelo wo isimana sella exexe sokisera podiokalano yowakula wa yokoha ella.

	Hoye	Vakane	Vakane vakane	Vantchene	Vantechenexa
Munakela m´wa atchu akina mukavihero mutthunanyu?	1	2	3	4	5

Muhana ohela variari mwettelo m´pua mwa rota onhima sana mukalihero mwa kenlanho wa atchu akina isismana exexe sokissera. Siso mwa mukwenhenho mattelo wa nexexe mwa mukalihero munthene, wala mwattelo m´moha muaha okhaleno mukalihero n´nakala mmoha wa akina wa isimana ixexe sokissera.

Sonthe musome wakula yokoha mone mota enovoreiayani wa intchitchimiho wa yella, ni muhele n´rota mwattelo wa mpimelo veri wa kula yokoha munlikahiheranhu wi enovaha yo wakula yarerela.

		Yonanara vantchene	Yonanara	Nnakala yorera nnakala yonanara	Yorera	Yotepaxa orera
1 (G1)	Mota heni mununonelanhu mukaleloanhu?	1	2	3	4	5

		Oyitteliwaxa	Oyitteliwa	Nnakala otteliwa, nnakala oyitteliwa	Otteliwa	Otteliwa vantchene
2 (G4)	Npaka vavi mutheliwanhu nokumanho?	1	2	3	4	5

Mwa sokoha iya n´ninone n´paka vavi monnanho ittu kamosakamosa wa isimana exexe so kissera.

		Hoye	**Vakane**	**N´nakala vatchene , n´nakala vakhane**	**Vantchene**	**Vantchenexa**
3 (F1.4)	N´paka vavi oretta wa eruthuanhu onokothiyerayane ovara muttekwanhu?	1	2	3	4	5
4 (F11.3)	N´paka vavi muttunanhu wi n´nwehawehiye ekumi anyu?	1	2	3	4	5

		Hoye	**Vakane**	**N´nakala vatchene, n´nakala vakhane**	**Vantchene**	**Vantchenexa**
5 (F4.1)	N´paka vavi onosivelayani okumi?	1	2	3	4	5
6 (F24.2)	Mota heni musuwenlanhu wi okumanhu wokhalano opwanela?	1	2	3	4	5
7 (F5.3)	N´paka lini muweranhu wikhalela?	1	2	3	4	5
8 (F16.1)	N´paka lini muweranhu okhala ni n´roromelo nihiku ti nihiku?	1	2	3	4	5
9 (F22.1)	N´paka vaví munonanyu wi okhala wanyu onnirera?	1	2	3	4	5

Sokoha ikinasene iri para wonihera n´paka vavi mwereranho wala mukanlanho kamosa wa isimana ixexe sokisera**.**

		Hoye	Vakhane	Vakhane Vakhane	Vantchene	Vantchenexa
10 (F2.1)	Mokhalana ikhuru sinphiyera okhawanyu nihiku ti nihiku?	1	2	3	4	5
11 (F7.1)	Mokhala okupali okhala wa eruthu anyu?	1	2	3	4	5
12 (F18.1)	Mokhalano mussuruku/ ompihera wokhaliherani mixankihosanho ?	1	2	3	4	5
13 (F20.1)	N’pakha vavi, murinanyu okheiheriwa oleliwa (sa ekumiannyu)	1	2	3	4	5
14 (F21.1)	N´paka lini mukhanlanho okathi wa withuwa?	1	2	3	4	5

		Ohonanara vantchene	**Yonanara**	**Nnakala yorera nnakala yonanara**	**Yorera**	**Yotepaxa orera**
15 (F9.1)	Muarowa ophima sai owerya wanyu, wira mwenyenye wala mwette n´mansinyu?	1	2	3	4	5

Sokoha sintharelana sipakheliwe wiwehaweha monele orera ni mwattheliwe mwaha va makalelo ekumanhu nwa mpuwa mwa isemana ixexe.

		Oyitteliwaxa	**Oyitteliwa**	**Nnakala otteliwa, nnakala oyitteliwa**	**Otteliwa**	**Otteliwa vantchene**
16 (F3.3)	Nikove sanho mutheliwa npakhavi?	1	2	3	4	5
17 (F10.3)	N´pakha vavi, munsiveliwanyu, ni eweryelo yovara miteko sanyu, nihiku ti nihiku?	1	2	3	4	5
18 (F12.4)	Muntteliwa n´paka vavi mwaweraka ovara mitekosanho?	1	2	3	4	5
19 (F6.3)	N´phaka vavi mutteliwanho nyuwo n´mansinyu?	1	2	3	4	5
20 (F13.3)	N´pakha vavi, munsiveliwanyu, nyuwo no atchu?	1	2	3	4	5
21 (F15.3)	N´pakha vavi, munsiveliwanyu ni makhalelo a ekhapa?	1	2	3	4	5

		Oyitteliwaxa	Oyitteliwa	Nnakala otteliwa, nnakala oyitteliwa	Otteliwa	Otteliwa vantchene
22 (F14.4)	Muntteliwa n´pakhavi nimukavihero munakelanho ni apatthanianyu?	1	2	3	4	5
23 (F17.3)	N´pakha vavi muntteliwanho ni makalelo a nipuro mukalanho?	1	2	3	4	5
24 (F19.3)	N´pakha vavi, munsiveliwanyu wa miteko sinpwanelanyu sa ekumi?	1	2	3	4	5
25 (F23.3)	N´pakha vavi, munsiveliwanyu ni mukukutta onokhaliheryani?	1	2	3	4	5

Sokoha sintharelana sihima opaka nille yovorenyeni mwerere ithu ikinasene mwa isemana ixexe sokisera.

		Nkintonko	Imara vakani	Imara eimosa emosa	Imara sothene	Kata emara
26 (F8.1)	Munkhala sai ni makhalelo onanara, n´toko oripiwa murima, ohiroromela, olipelela wala, opweleya?	1	2	3	4	5

Ephimelo ya withanya mwa atthu ankhala ni mwaxitthu

N’yuwo muhana ehela ekanyeryo nunmaro ninlikana orattene ele enowereyani. Mwakhala wira munnikupali vomalela enihimyaya, munrowa ohela ekanyeryo ni “X” nunmaro na nexexe Vano vakhala wira khamunkupali yohimya eyo,, munhela ekanyeryo nunmaro nopajerya (1). Nave, yakhala wira enupuwelanyu yovirikana ni miyupuelo ia mili, muhele ekanyeryo nunmaro na nenli walá na neraru n’tokó siryaya

Kisavó sowakhuliwa orattene walá sovonyiwa.Yulupalexa tile enonanyu wira ennilolwana nllé enovoreyani.Mwatthuná mwikhalele,wira munjererye enonanyu opwanela wunjererya, walá okathi wowakhula sokoha. Xontte, mwilipiherye wira mwakhule sokoha khamosa khamosa, vanrerelaya, vohihiya n’nakhala emosá. .

N’pantta wopajerya wa sokoha, onihimya sa osuwela wanyu, othamala wanyu, ni miruku sanyu mwa atthu Yale anikhala ni HIV, makhalelo aya ni okhaliheriwa waya.

		N´kinkupalesha	N´kinkupali	Kinnikupali	Kinnicupalesha
1	Wa sovara saka mintchene sa okumi aka khavo onsuwela wi kokhalano mwasitchu	☐	☐	☐	☐
2	Miyo kottheka mwaha wo khalano mwasitchu.	☐	☐	☐	☐
3	Makhalelo atchu wa mwaha wa mwasithcu annakiruhelo miyo otepacha mwanenaka.	☐	☐	☐	☐
4	Omulela mutchu wi miyo kokhalano mwasitchu diyawopiha.	☐	☐	☐	☐
5	Atchu arinono mwasitchu annihalela muteko wakhala wi ale ananvarelaya osuwela	☐	☐	☐	☐
6	Miyo kinnailipiha vantchene wi atchu ahisuwele wi miyo kokhalano mwasitchu.	☐	☐	☐	☐
7	Miyo inkinaisona okhala mutchu orera murima nntoko akina ntakhara miyo kokhalano mwasitchu	☐	☐	☐	☐

		N´kinkupalesha	N´kinkupali	Kinnikupali	Kinnicupalesha
8	Miyo khonakulihe muru vokhalano mwasitchu.	☐	☐	☐	☐
9	Atchu arinono mwasitchu annreheriwa nntoko atchu othanyiwa	☐	☐	☐	☐
10	Atchu anchene annikupali wi mukina akhalano mwasitchu onkhala namasivelasiwa.	☐	☐	☐	☐
11	Fatari ohi n’paka opathani tho wi kihalelihe wira kokhalano mwasitchu.	☐	☐	☐	☐
12	Okhalano mwasitchu onnakipakiha miyo wupuwela wi konanara	☐	☐	☐	☐
13	Ovinyera kasuwenlaka wi kakhalano mwasitchu, miyo kinnithaliwa okwipi welapo.	☐	☐	☐	☐
14	Atchu antchene annupuwela wi mutchu mmoha orinono mwasitchu tonanara.	☐	☐	☐	☐
15	Okhalano mwasitchu onnikiruhela wi miyo mutchu mmoha owopiha.	☐	☐	☐	☐
16	Atchu antchene arinono mwasitchu tothanheya yakhala wi atchu akina amonelela.	☐	☐	☐	☐
17	Miyo kinnikasopa vantchene wowivaherera wa olé kimmulelaka wi kokhalano mwasitchu.	☐	☐	☐	☐
18	Atchu akina asuwenle wi kokhalano mwasitchu arakamelana ni mi.	☐	☐	☐	☐
19	Owinyera kisuwenlaka wi miyo kokhalano mwasitchu miyo kiri awisasasa wi atchu anasa okithamyaka.	☐	☐	☐	☐
20	Atchu antchene annisona ohikhala sana vakhala ni mutchu orino mwasitchu.	☐	☐	☐	☐

		N´kinkupalesha	N´kinkupali	Kinnikupali	Kinnicupalesha
21	Miyo n´kinona wi kivithé, mwaha wokhalana mwasitchu.	☐	☐	☐	☐
22	Miyo kinnupuwela wi atchu akhala okiphuka yakhala wi asuwela wi kokhalano mwasitchu.	☐	☐	☐	☐
23	Okhalano mwasitchu mwerutchuni mwaka onnakithanyera othanyeya.	☐	☐	☐	☐

Sohimya sintchene sa vathi, sin´natthumiha wi nyuwo muhalela atchu akina, wi nyuwo mokhalana mwasitchu, walá, atchu akina asuwela. Vakhala vohikhala vawinyu. Siso, yakhala wira sohimya sokhumelela, khasinireya mwa nyuwo, ninnivekela wira nyuwo muhana wupuwela siso, ni ovaha miruku, sinlolowana, mota warowanyu wana, walá mota sheni atchu sarowaya wonela itchu sosa salakeliwe.

Mupuwele, enamuna yohela ekanyeryo sokoha enotthikela olikana ntoko ottulí.

		N´kinkupalesha	N´kinkupali	Kinnikupali	Kinnicupalesha
24	Miyo kinnona ovoreya, mota atchu sakikhalihaya, vansuwenlaya wira kokhalana mwasitchu.	☐	☐	☐	☐
25	Miyo kiri awasasa vekekhayi wi atchu asuwenle wi kokhalano mwasitchu akhala owalelaka atchu akina.	☐	☐	☐	☐
26	Miyo kinnittharua vowalela atchu akinaku wi kokhalano mwasitchu.	☐	☐	☐	☐
27	Wa makhalelo othene walela atchu akinaku wi kokhalano mwasitchu vari yovonyeya.	☐	☐	☐	☐

		N´kinkupalesha	N´kinkupali	Kinnikupali	Kinnicupalesha
28	Atchu akina annikithanya, yasuwelaru wira kokhalano mwasitchu.	☐	☐	☐	☐
29	Atchu miyo kinaroromelaka ekekhayi ntakhara miyo ohiya okishikha vanonto asuwenlaya wi kokhalano mwasitchu.	☐	☐	☐	☐
30	Atchu akilenle wira myo kopuanela okhalana mwasitchu, mota kakhalaka ni ekumyaka.	☐	☐	☐	☐
31	Atchu akina akanttamenle, annova okottiwa yakhala wira osuwela wi myo kokhalano mwasitchu	☐	☐	☐	☐
32	Atchu akina khiattuna wira miyo kitakhanyerryane ni enaya vasuwenlaya wira miyo kokhalano mwasitchu.	☐	☐	☐	☐
33	Atchu khampavela okikwanya miyo, vasuenlaya wira miyo kokhalano mwasitchu.	☐	☐	☐	☐
34	Atchu akina anupuwela wi miyo kokhalana mulattu vanthowa wokhalano mwasitchu.	☐	☐	☐	☐
35	Miyo kohiya okumana ni atchu akina vanthowa na enamuna enkikhalihaya, vasuwenlaya wira miyo vokhalano mwasitchu.	☐	☐	☐	☐
36	Miyo akitchawa asinthamwenaka emara kalenlaka yawo wo khalano mwasitchu.	☐	☐	☐	☐

		N´kinkupalesha	N´kinkupali	Kinnikupali	Kinnicupalesha
37	Miyo kahavekela atchu akuvenle ni miyo wi ahikhale analeliwe wi kokhalano mwasitchu.	☐	☐	☐	☐
38	Atchu asuwenle wi miyo kokhalano mwasithchu akhalano werera aohishikha ekhalelo aka, ni orera waka.	☐	☐	☐	☐
39	Atchu akhalano wova wa miyo asuwenlaya wi kokhalano mwasitchu.	☐	☐	☐	☐
40	Akhala mukina osuwente wi miyo kokhalana mwasitchu onniphavela sonana sa epantte yawaó.	☐	☐	☐	☐