# The role of churches in tackling HIV stigma in eastern Zimbabwe

### **MERCY NETSAI NHAMO**

Submitted for the Doctorate Degree in Social Psychology London School of Economics and Political Science Houghton Street, London WC2A 2AE, England UK September, 2011

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ABSTRACT

#### ABSTRACT

Much has been written about the need to involve communities in efforts to reduce HIV stigma. However less is known about the psycho-social pathways between participation and stigma reduction or the most appropriate strategies for ensuring such participation. Drawing on Campbell's social psychological conceptualisation of social capital and the 'HIV competent community', this study explores how community groups in eastern Zimbabwe, and in particular churches--the most established formal social network in the area--tackle HIV stigma, drawing on data collected between 2005 and 2009. The thesis explores four issues: the effect of participation in community groups on stigmatizing attitudes; the extent to which church groups perpetuate or reduce stigma; possible differences between the role played by the Protestant, Apostolic and Catholic churches in relation to stigma and the potential for using the 'community conversations' (CCs) approach to develop more effective responses to stigma amongst the three churches. The quantitative analysis from over 15,000 respondents used multivariable logistic regression modelling to explore relationships between participation and stigmatizing attitudes. Fewer of the individuals who participated in community groups than those who did not were found to report stigmatising attitudes towards people living with HIV (PLHIV). The qualitative research involved a total of 30 individual interviews and 24 CCs and explored how church groups respond to PLHIV. Participants discussed the strategies to combat HIV stigma and suggested that the church facilitated unhelpful attitudes, as well as helpful attitudes and actions. CCs workshops provided participants with opportunities to formulate a range of creative plans to tackle stigma in their communities. However over time it emerged that various obstacles stood in the way of putting these plans into action in their lives beyond the context of workshop discussions. I conclude that CCs have an important role to play in promoting reflection and action planning amongst participants. However, external constraints limit the extent to which people are able to turn this reflection and planning into action. To address these constraints I argue for the need to create sustainable bridges with external support agencies.

**Key words:** churches, community conversations, participation, social capital, HIV competent communities, HIV and AIDS, stigma, Zimbabwe

I dedicate this thesis to my beloved son Ike- Akatendeka Murire.

### ACKNOWLEDGEMENTS

Writing this thesis was not easy but it was worth it, and it would not have happened without enormous support from many people. I am indebted to my supervisors Professor Cathy Campbell and Professor Simon Gregson, for motivating and giving me constructive feedback. My supervisors have been the best source of support that one could ever hope for. Their insightful comments and intellectual influence is recognised throughout my work. Words can never express how grateful I am. Academically Cathy and Simon offered me this opportunity to undertake PhD studies. I am extremely thankful for all of their support, seeing and believing in my potential when I never saw any of that in myself.

I would also like to thank the study communities in Manicaland that participated in this study. It was an honour to be received by participants who committed themselves to this project without expecting anything in return. I would like to acknowledge the support I received from Biomedical Research and Training Institute (B.R.T.I) in Zimbabwe in undertaking my research and for the past six years I have worked for the organisation. I am thankful for all the research support from Claudius Madanhire. I thank Dr Andy Wells and Kerry Scott for their constructive feedback and comments. I give thanks to the Lord Almighty for enabling me to achieve all I have achieved.

Lastly, I would like to thank my husband Stanley Murire for his patience, support and love throughout my work. To Mum I thank you for your love, words of encouragement and reminding me that I have to work hard each time we spoke.

Finally, this work has been financially supported by Wellcome Trust, I am so grateful for the generous funding.

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### Acronyms

AFM	Apostolic Faith Mission	
AIDS	Acquired immunodeficiency syndrome	
ART	Anti-retroviral Therapy	
ARV	Anti- retroviral	
BRTI	Biomedical Research and Training Institute	
CCs	Community Conversations	
CHW	Community Health Worker	
HIV	Human immunodeficiency virus	
IDI	In-depth Interviews	
MoHCW	Ministry of Health and child welfare	
NIHR	National Institute of Health Research	
NIHR PLA	National Institute of Health Research Participatory Learning and Action	
PLA	Participatory Learning and Action	
PLA PLWHA	Participatory Learning and Action People/Person living with HIV/AIDS	
PLA PLWHA PLHIV	Participatory Learning and Action People/Person living with HIV/AIDS People living with HIV	
PLA PLWHA PLHIV PMTCT	Participatory Learning and Action People/Person living with HIV/AIDS People living with HIV Prevention of Mother to Child Transmission	
PLA PLWHA PLHIV PMTCT SSA	Participatory Learning and Action People/Person living with HIV/AIDS People living with HIV Prevention of Mother to Child Transmission subw1s-Saharan Africa	
PLA PLWHA PLHIV PMTCT SSA STIS	Participatory Learning and Action People/Person living with HIV/AIDS People living with HIV Prevention of Mother to Child Transmission subw1s-Saharan Africa Sexual Transmitted Infections	

#### THESIS OVERVIEW

Each chapter of the thesis begins with a chapter overview, which provides a brief summary of the chapter's contents. These chapter overviews are presented below to orient the reader to what is to follow.

#### **Chapter 1: Context of study**

The purpose of this first chapter is to contextualise my study and review literature on social capital and AIDS. First I examine the scale of the HIV and AIDS epidemic in Africa, Zimbabwe and Manicaland Province. Thereafter I justify my interest in churches in Africa, Zimbabwe and Manicaland, before turning to discuss the wider Manicaland Project, within which my research is nested. I provide an overview of the existing academic literature on HIV and AIDS stigma as well as outlining existing empirical research on the church and AIDS in Africa and Zimbabwe. I conclude with a review of how group members use social capital available to them to address HIV and AIDS.

# Chapter 2: Constructing a theoretical framework for investigating how church groups tackle HIV and AIDS stigma

This chapter highlights the limitations of biomedical health approaches and models for designing HIV and AIDS interventions and the need for greater understandings of the social psychological pathways through which social capital impacts on health. I provide an overview of the concept of HIV competence (defined in terms of the concepts of social capital, social identities and dialogue, social representations and stigma, empowerment and critical consciousness, power in the context of social capital and social change), which frames this thesis. Finally problems encountered in addressing HIV/AIDS stigma in churches will be discussed with particular attention to social capital.

#### **Chapter 3: Methods**

To explore the research questions, I employed three methods: (i) a secondary analysis of cross sectional survey data; (ii) individual in-depth interviews and (iii) community conversations. This outline is followed by a discussion of public accountability as the most appropriate quality indicator of qualitative research. Finally I discuss the role of cross- sectional surveys as a secondary source of data for the quantitative research.

# Chapter 4: Exploring if social group membership reduces stigmatising attitudes (Quantitative research)

This chapter examines whether social group membership reduces stigmatising attitudes towards PLWHA. I begin by presenting my research question; thereafter, I report on my analysis, results and conclusions. The analysis is based on quantitative data and is designed to investigate the first research question outlined in the introduction to this thesis, i.e. whether being in a social group reduces stigmatising attitudes and, if so, which types of groups help to reduce stigmatising attitudes. Although church groups are the most popular form of social participation (i.e. 4 163 out of 15 672), I have used social groups because the sample size of being church members is small considering the huge sample size. This secondary analysis was conducted using data from a large-scale cross-sectional population survey of 15 672 people in Manicaland, eastern Zimbabwe.

# Chapter 5: How church groups are responding to AIDS and building AIDS competence (Qualitative research, part I)

This chapter examines how churches are responding to HIV/AIDS by means of a thematic network analysis of individual in-depth interviews conducted with 30 church leaders and members in 2008 and 2009. I begin by presenting my thematic analysis of the interviews, using Attride-Stirling's (2001) thematic network analysis method. Thereafter I present my findings arranged in seven sections, each of which reflects a theme arising from the analysis.

# Chapter 6: If and how community conversations can contribute to stigma reduction (Qualitative research, part II)

This chapter focuses on the potential contribution of grassroots community groupings to the reduction of HIV stigma. Three rounds of community conversations were held with members of the Apostolic, Anglican and Catholic sects. Participants met three times (May 2008, September 2008 and January 2009) in three groups of approximately 10 people to discuss HIV stigma. While the same participants were sought for each round of community conversations only 80% attended all three

rounds. Approximately 5% attended only one and 15% only two of the three sessions. New participants were invited to join sessions when original participants did not show up in order to maintain a minimum of eight people in each community conversation. This chapter presents my analysis of participants' discussions of possible ways of tackling stigma and their accounts of factors that might facilitate or hinder putting these strategies into action.

## Chapter 7: Creating social spaces for positive church responses to HIV and AIDS: A proposed social psychological perspective

In this chapter I outline three social psychological models which have been supported by my research into the potential impacts of community group memberships on stigma. The first (Figure 22) maps out the six stages through which organic social capital is mobilised within community groups. The second model (Figure 23) illustrates how lack of effective dialogical spaces might lead to the perpetuation rather than reduction of stigma by community group members. The final model (Figure 24) synthesises my own empirical findings with work from 'the social psychology of participation' to highlight the psycho-social mediators between group memberships and stigma reduction. I conclude the chapter by making some remarks about the implications of my findings for policy and practice.

#### **Chapter 8: Thesis conclusion and implications**

This chapter discusses the research process and the effects of the research project on me, the researcher, and the participants. I highlight the contributions that this thesis makes to the existing research literatures within the community health field. My recommendations for future research include the need for longitudinal analysis of the association between community groups and stigmatising attitudes. Other ideas for future research include more exploration of the HIV competence framework within church groups, the need to look at the potential for other social settings (e.g. the workplace) to generate HIV competence, and the need for more research into the way in which bridging social capital might facilitate the CC process

### INTRODUCTION

#### **Research Aims**

Framed within the social psychology of participation, the aims of this research project are:

- To examine whether social group membership reduces or facilitates stigmatising attitudes towards PLWHA.
- II) To explore possible differences in the ways in which three religious denominations (Anglican, Catholic and Apostolic) tackle HIV stigma.
- III) To report on an action research study that used community conversations to promote stigma reduction in church groups.

In tackling these goals, I will seek to use a social psychology of participation model to explore the potential role of the church in effective prevention, care and treatment for HIV and AIDS through attention to the following questions:

- How do groups respond to stigma?
- What are the various levels of stigmatising attitudes in different groups?
- To what extent do church groups perpetuate stigma? To what extent do they reduce stigma?
- Are there differences between the role played by the Protestant, Apostolic and Catholic churches in relation to stigma? If so, what are they?
- Can the community conversations approach be used to develop more effective responses to stigma amongst members of the three churches?

These research questions will be discussed in the three empirical chapters respectively:

- <u>Chapter 4</u>: Does social group membership reduce stigmatising attitudes? (Quantitative)
- <u>Chapter 5</u>: In what ways are churches responding helpfully and unhelpfully to HIV? (Qualitative, part I)
- <u>Chapter 6</u>: What, if and how community conversations contribute to stigma reduction? (Qualitative, part II)

INTRODUCTION

#### The research study

HIV/AIDS is a serious problem in Zimbabwe and the challenge of promoting effective prevention, care and treatment is an urgent priority. Stigma is a key impediment to effective HIV/AIDS management (Parker & Aggleton, 2003; Valdiserri, 2002).

There is a growing interest (Campbell, 2003; Gregson et al, 2004) in the role played by local community groups in perpetuating or challenging HIV and AIDS stigma. Against this background, this study focuses on the potential role of the church, the most organised and significant social network in many HIV affected communities, for playing a greater role in stigma reduction efforts.

This study is framed within wider debates about the impact of social capital on health, with particular attention to the role of community participation on health, and how community groups can enable such participation. I hope to make novel contributions to existing understandings in three ways. First, to date, little research has been done focusing on the links between social capital and HIV. Second, much remains to be learned about the psycho-social processes through which social capital might impact on health in general, and HIV in particular. Lastly, little is known about the potential role that community groups, and particularly church groups (the most prevalent type of group in Zimbabwe and sub-Saharan Africa), can play in anti-stigma interventions to facilitate more effective HIV management.

This thesis has eight chapters. In this introduction I provide a thumbnail overview of my research questions and highlight the original contributions I seek to make to the existing AIDS literature. In chapter one I give a brief account of the general background of the research, both in relation to the HIV and AIDS epidemic in Africa and Zimbabwe, as well as the presence and role of Christian churches in Africa, specifically Zimbabwe.

In chapter two I (i) provide an outline of the theoretical framework that informs the research, with particular reference to the psycho-social processes mediating between social capital and health; (ii) provide an examination of the empirical literature on churches in Africa, then in Zimbabwe with particular reference to the role of churches in facilitating or hindering AIDS stigma.

Chapter three provides an outline of the methodological rationale of the study. I introduce the notion of community conversations, individual interviews and cross-

sectional surveys and justify why they are the most appropriate approach to pursue my research questions.

I also provide an outline of the three stages of the study, giving details of my research informants as well as the methods I have used for my data collection and analysis.

Chapter four presents my secondary analysis of the quantitative survey data exploring if social group membership reduces stigmatising attitudes. Chapter five presents an analysis of my 30 in-depth, individual interviews with church members and leaders, discussing the helpful and unhelpful ways in which the Anglican, Apostolic and Catholic churches are responding to HIV. Chapter six presents the findings from the community conversations I conducted with church members and more broadly discusses the potential of the community conversations technique as a community-based stigma reduction intervention.

Community conversations are group discussions facilitated by an external agent (in this case myself or a research assistant) that not only seek to understand community perspectives on salient social issues but also seek to bring about positive change. Unlike focus groups, which explore how issues and relationships are seen by community members, community conversations have an intervention focus, seeking to engage participants in critical thinking and strategising about how they can work to make things better. The external change agent does not attempt to teach or advise community members; instead, the facilitator's role is to bring out pre-existing community understandings and strengths and encouraging the community to analyse and solve their own problems. Thus, while the interviews presented in chapter five sought to determine the current state of individual perceptions of the church and HIV, the community conversations presented in chapter six sought to bring about community change. The interviews focused on descriptions of church members' and leaders' activities and approaches while the community conversations focused on creating a social space for challenging perceptions, exploring new ways of understanding, and developing strategies to reduce stigma that participants could attempt to enact in the broader community.

People who lack the power to shape their life course in important ways, such as those struggling with poverty and lack of opportunities in Manicaland, are less likely to believe that they can take control of their health, and thus less likely to engage in health promoting attitudes and behaviours (Bandura, 1996). Not only do the poor suffer but they are also more likely to have their suffering silenced (Farmer 1997, p. 280). Moreover, lack of material and symbolic resources undermines peoples' access to health related knowledge, which is believed to be one driver of stigma, though not the only one (Campbell & Deacon, 2006; Nhamo, Campbell, & Gregson, 2010; Richard Parker & Peter Aggleton, 2003). By examining how church groups in Manicaland affect health knowledge and agency, my research seeks to explore the potential for church groups to reduce HIV stigma in marginalised communities.

Goffman (1963b) defines stigma as an undesirable or discrediting attribute possessed by an individual or group which results in the reduction of that individual's status in the eyes of society. Drawing attention to the links between stigma and social inequalities, Parker and Aggleton (2003) describe stigma as a social process that produces relations of power and control (based on varying combinations of devalued social markers such as gender, age, sexual orientation, class, race or ethnicity as well as the particular negative marker in question, in this respect, HIV and AIDS). Such relations of power and control create space for some groups to devalue others based on these differences.

The term stigma originates from Greek, referring to "tattoo marks branded on the skin of an individual as a result of some incriminating action," (Crawford, 1996), identifying the person as someone to be avoided. Heatherton, et al. (2003a) characterise stigma to include affective (for example feelings or emotions), cognitive (such as knowledge perception, awareness and reasoning), and behavioural responses (for example the responses or actions of a person). The primacy of each factor results from variable interactions between the nature of stigma, the context in which it is encountered and individual differences. The presence of stigma within a society depends both on the extent to which individuals hold and express stigmatising attitudes and the extent to which individuals holding the devalued markers internalise these views (Link & Phelan, 2001). In this thesis I will use the definition of stigma by Campbell et al., (2007), considering stigma to be those negative thoughts, feelings or actions towards people bearing some devalued marker. In chapter 7 I outline three social psychological models which have been supported by my research into the potential impacts of community group memberships on stigma. Focus is on creating enabling spaces for positive church responses to HIV and AIDS. Chapter 8 presents thesis conclusion and implications.

#### **Chapter overview**

The purpose of this first chapter is to contextualise my study and review literature on social capital and AIDS. First I examine the scale of the HIV and AIDS epidemic in Africa, Zimbabwe and Manicaland Province. Thereafter I justify my interest in churches in Africa, Zimbabwe and Manicaland, before turning to discuss the wider Manicaland Project, within which my research is nested. I provide an overview of the existing academic literature on HIV and AIDS stigma as well as outlining existing empirical research on the church and AIDS in Africa and Zimbabwe. I conclude with a review of how group members use social capital available to them to address HIV and AIDS.

#### 1.1 The African epidemic

According to UNAIDS's most recent figures (2010), globally 33.3 million people are infected with HIV. In 2009 a total of 2.6 million people were newly infected and 1.8 million AIDS related deaths were recorded. The annual number of incidence has slightly declined due to the high uptake of antiretroviral therapy (UNAIDS, 2010, Avert, 2011). Inadequate access to HIV prevention and treatment services has been cited as the cause of new infection and high death rates (Barnett & Whiteside, 2006; Shapiro & Benatar, 2005). The HIV/AIDS pandemic has been cited as the most serious of infectious disease challenges to public health (UNAIDS, 2009), although this is controversial, and some would say that malaria is worse (Global Health Council, 2009). Sub-Saharan Africa (SSA) remains the most seriously affected region, accounting for 71% of all new HIV infections, 67% of all people living with HIV and nearly three quarters (72%) of AIDS related deaths in 2008 (Avert, 2010).

UNAIDS data (2009) suggests that an estimated 1.9 million people were newly infected with HIV in sub-Saharan Africa in 2008, resulting in 22.5 million people with HIV living there. In 2008, more than 14 million children in sub-Saharan Africa had lost one or both parents to AIDS (Avert, 2010). Adult prevalence (15 years and above) was 14.3% according to the National HIV Estimates of 2010 (UNAIDS, 2009). The HIV prevalence rate has been declining in sub-Saharan Africa, from 23.7% in 2001 to 18.4% in 2005 with a further decline to 14.3% in 2009 (UNAIDS, 2009). While this decline offers hope, the rate of change and current high prevalence rate illustrates

the tremendous long term challenge that lies ahead for provision of treatment and prevention services.

AIDS is erasing decades of progress in extending life expectancy in many African settings. Millions of adults are dying from AIDS while they are still young. The average life expectancy in sub-Saharan Africa is now 47 years while it is estimated that it would have been 67 years without AIDS (Avert, 2010). The HIV/AIDS epidemic is putting a strain on the already challenged health sectors in AIDS-afflicted African countries. There is growing evidence that HIV prevention efforts can be effective, based on research studies of successful programmes in some of the most heavily affected countries (Campbell and Cornish, 2011; Cornish, 2006; Merson, Dayton, & O'Reilly, 2000). For example, in Uganda, strong government leadership, broad-based partnerships and effective public education campaigns have all contributed to the decline in HIV prevalence from 29% in 1986 to 6.5% in 2010. However, it is feared that HIV prevalence may be rising again in Uganda (Avert, 2011). Moreover, the challenge of 'scaling up' programmes that have been successful in particular settings remains huge (Fauci, 2007). Overall a massive expansion in sustainable prevention efforts is needed.

Zimbabwe is experiencing one of the harshest AIDS epidemics in sub-Saharan Africa (Avert, 2011). One in seven adults---13.7% of the adult population—are living with HIV and an estimated 565 adults and children become infected every day in Zimbabwe (UNAIDS, 2009). Zimbabwe has a higher number of orphans in proportion to its population than any other country in the world according to UNICEF (Avert, 2010; UNAIDS, 2009). In spite of optimism following the formation of Government of National Unity (GNU) in late 2008, the tense political and social climate in Zimbabwe has made it difficult to respond to the crisis. The government of Zimbabwe has been widely criticised by the international community for its political and economic policies, leading to increasing isolation, both politically and economically.

When HIV/AIDS first emerged in Zimbabwe, the government was slow to acknowledge the problem and take appropriate action (Avert, 2010). Whilst the government founded the National AIDS Council (NAC) in 1999, its response to HIV/AIDS has been compromised by the numerous other political and social crises that have dominated political attention and have overshadowed the implementation of the national AIDS policy. The situation has been worsened by poor organisation in implementing HIV/AIDS programs and a lack of resources for HIV sufferers (Avert,

2010). Zimbabwe has attracted intense international criticism in recent years for corruption, human rights abuses and media repression (see for example: Chingono, 2010). All these factors have negatively impacted on the AIDS epidemic.

The scarcity of both human and material resources in Zimbabwe has resulted in the discharge of increasing numbers of AIDS patients to be cared for in their homes (Gwatirisa & Manderson, 2009). For patients in Zimbabwe, 'home care' often means 'home neglect' (Jackson & Mhambi, 1992). Antiretroviral drugs (ARVs) are available free of charge to HIV-infected members of the public within specific hospitals. However many people have trouble obtaining the drugs (Avert, 2010). Most people cannot afford to pay for their transport to access the drugs, particularly in conditions of poverty that have been exacerbated by the country's economic challenges (Rosen et al., 2005). Between 6000 and 7000 children die per year as a result of HIV and in most cases the children would have failed to access ART (Herald, 2011).

Zimbabweans who reside in rural areas find it particularly difficult to obtain ARVs (Avert, 2010). Rural household incomes tend to be low and rural women often rely upon the irregular incomes of husbands working in urban areas for financial support. Zimbabwe's average life expectancy for women with HIV is 34 – among the lowest in the world (UNAIDS, 2009). HIV prevalence is thought to have declined in Zimbabwe from 23.7% in 2001 to 14.3% in 2010 (Zimbabwe Ministry of Health and Child Welfare, 2009). However, caution should be taken when interpreting the data, since it is not known whether the trend is a sign of long term change or merely a temporary movement (Avert, 2011).

Declining prevalence has also been observed in rural Manicaland (Gregson et al., 2006). Mathematical modelling suggests that the decline in HIV prevalence could not be attributed solely to the natural evolution of Zimbabwe's epidemic but is in part due to behaviour change (Hallet et al., 2007; Gregson et al., 2010). Gregson and Hallett's Manicaland findings suggest that over the last ten years women and men have increasingly avoided sex with non-regular partners, and that consistent condom use with non-regular partners increased for women (from 26% in 1998-2000 to 37% in 2001-2003) though not for men (Gregson, et al., 2006).

However, even with such reductions, massively expanded prevention and treatment care efforts will be needed to sustain these positive changes and in their absence, the AIDS death toll in Manicaland is expected to continue to rise.

Efforts to prevent the spread of HIV in Zimbabwe have been spearheaded by the National AIDS Council (NAC), non-governmental organisations (NGOs) and some more progressive religious and academic organisations. However, the messages promoted by different prevention programmes have often conflicted. Some religious sects have discouraged the use of condoms and placed emphasis on abstinence, contrasting with the strategies of other organisations such as progressive NGOs that advocate condoms. There is disagreement amongst concerned groupings on how best to prevent HIV infection.

#### **1.2 Context: Manicaland**

This study is located in the province of Manicaland, in the eastern part of Zimbabwe. This is a predominantly rural area, on the border of Mozambique and Zimbabwe. Because of their geographical isolation and limited access to health services and employment compared to urban Zimbabweans, members of these rural communities are considered marginalised. Many people in these communities lack the material (such as money and transportation) and/or symbolic (such as education and respect) resources to control key aspects of their lives such as access to good quality health care, educational opportunities for their children and opportunities for a secure income.

#### **1.3 The Manicaland Project**

I chose Manicaland, Zimbabwe as my research site because I am Zimbabwean and have worked for five years as a qualitative researcher for Biomedical Research and Training Institute (BRTI), an NGO that does extensive work in the area. The Manicaland Project is housed within BRTI in Harare. The organisation is a joint venture between UK based Imperial College Faculty of Medicine and three Zimbabwe groupings: BRTI, the National Institute of Health Research (NIHR) and the Ministry of Health and Child Welfare (MoHCW).

The Manicaland Project has two main aims. First it aims to study how HIV spreads by looking at which groups are already infected and which are becoming newly infected. Second it aims to develop a population based sample to study the biomedical, behavioural and social determinants of behaviour change, treatment and care programmes. My own participation as one of the project researchers has focused on

examining the role of social capital in prevention and care (the 'Social Capital Project') which falls under the second aim of the organisation.

The Social Capital Project draws on the social psychology of behaviour change with particular emphasis on the need to move beyond simply targeting individuals with biomedical or behavioural programmes. Rather, the project seeks to understand how best to create community contexts that enable and support the possibility of change, through maximising grassroots participation in the implementation of activities.

I became interested in the role of churches in facilitating or hindering the creation of community contexts for change while working on the Social Capital Project. In many sub-Saharan African settings, the church is the most established social network and as such serves as a vital community resource, especially in settings with limited access to health and welfare support services (Ogden & Nyblade, 2005). However the church plays a complex and contradictory role in responding to HIV and AIDS, particularly given its disapproval of both sexual relationships outside of monogamous marriage and for some church groups the use of condoms. In addition, many churches are committed to male-dominated relationships (Agadjanian & Sen, 2007; Marshall & Taylor, 2006), with men taking most key leadership positions in the church and women taught that they should defer all decision-making to their husbands. A detailed discussion of this contradictory role is presented later in this chapter under section 1.7. I next present background information on churches in first Zimbabwe and then Manicaland.

#### 1.4 Churches in Zimbabwe

The most common church groups in Zimbabwe are Mission, Pentecostal and Spiritual churches. Mission churches were the first to be established during the colonial times though they are sometimes referred to as the main churches. These are the Roman Catholic, Methodist and Anglican churches. Roman Catholics are led by the pope and are known for implementing their Catholicism in cultures where their churches are established. The Methodist, Anglican and Baptist churches are more charismatic (favoured by grace) in recent years.

Pentecostal churches have a growing number of local churches that branched from the mainline Christian churches. The two most common Pentecostal church groups are Zimbabwe Assembly of God church (ZAOGA) and Apostolic Faith Mission (AFM). Spiritual churches comprises of many different Apostolic and Zionist churches established in Africa that came from local Pentecostal churches. Most spiritual churches in particular the Apostolic base their teachings on prophecy, inspiration and revelation from the Holy Spirit believing to hear directly from God (Engelke, 2007). What makes them so distinct is their resistant to western Christian practises taking pride in maintaining African traditions and rituals (Bourdillon, 1991). Spiritual churches are known to have strict rules and regulations making members to be liable to punishments if seen not adhering closely to these rules (Gregson et al., 1999).

The table below presents the percentages of different religious institutions in Zimbabwe. 68% of the total population are Christians (Zimbabwe Council of churches, 2009).

Religious affiliation	Percentage
Christians	68
Traditional	30
Other	2
Total	100

#### Table 1: Churches in Zimbabwe

Churches have an important place in Zimbabwe society. Below, the 68% of Christians is broken down into specific religious sects.

Religious sect	Percentage
Protestant	13.7
Catholic	8.2
Anglican	2.6
Apostolic	6.8
Independent and other sectors	36.7
Total	68.0

#### Table 2: Percentage of affiliation to Christian religious sects in Zimbabwe

#### 1.5 Why I chose to focus on three church groupings in particular

The reason I chose to focus on the Catholic, Anglican and Apostolic churches is because they are the biggest groups in Manicaland. Whilst no firm statistics exist, having lived and worked there for five years myself, I observed that the majority of people are Apostolic followed by Roman Catholic and Anglican. In addition to being the three churches with the largest membership in Manicaland, I also chose to study them because they differ in interesting ways. In relation to HIV/AIDS, Catholicism has drawn a lot of controversy due to its resistance to any artificial form of birth control. When the Pope visited Cameroon on March the 17<sup>th</sup>, 2009, for example, he said that the battle of AIDS could not be resolved with the distribution of condoms and that only 'responsible' and 'moral' attitudes toward sex would help fight the disease (BBC, 2009). This attitude has a long history. For example, in 2003, the late cardinal Alfonso Lopez Trujillo made headlines saying that condoms may spread AIDS through providing a false sense of security, claiming that they were not effective in blocking transmission of the virus (BBC, 2003).

However, many Africans within the Catholic Church oppose these views. In South Africa, 14 nuns who work with AIDS victims formed the network Sisters for Justice. They advocated for the use of condoms to protect against HIV. Many bishops in southern Africa have recommended the use of condoms by married couples, as research suggests that married women are particularly vulnerable to contracting HIV (Dominican Sisters, 2008). In light of the complexity of Catholics' responses, my research seeks to contribute to the development of a better understanding of the role of Catholics in tackling or perpetuating HIV and AIDS stigma in Manicaland, Zimbabwe.

The Apostolic sect in Manicaland was founded in the region and a huge proportion of Zimbabwe's Apostolics reside there (Bennetta, 1975; Gregson et al., 1999; Mapostori, 2009). This group is also particularly interesting in relation to HIV/AIDS because some Apostolic sects support polygamy, which has created a lot of controversy. My research aims to further our understanding of how the Apostolics perpetuate and or challenge HIV/AIDS stigma. The difference between Apostolics and Pentecostals, another fairly common Christian denomination in sub-Saharan Africa, is that the Apostolics do not believe in the trinity that is the father, spirit and son. They believe in spiritual healing considering the church to be an alternative health care in the provision of respite from chronic and debilitating health conditions

(Mpofu et al., 2011). In my research I take Apostolic to mean all spirit type Christian groups. My quantitative data in chapter 4 disaggregates Apostolics and Pentecostals.

Finally, the Anglican Church is also of particular interest because the Anglicans have taken the most progressive and pragmatic approach to the use of condoms in Zimbabwe.

#### 1.6 Evidence linking social capital, group membership and AIDS

Social capital is defined by Berkman and Kawachi (2000, p. 15) as, "those features of social structures—such as levels of interpersonal trust and norms of reciprocity and mutual aid—which acts as resources for individuals and facilitate collective action". The role of social capital in promoting health is currently widely debated within international public health. Portes (1998) states that social capital can equally function in both a socially exclusive and an inclusive way, having positive welfare effects for some and negative for others. For example Campbell, Williams and Gilgen (2002), investigating the effectiveness of an HIV peer-education program in rural South Africa, reported that social capital was strongly related to health behaviours, although it did not always promoted positive health behaviours. Pronyk et al. (2008) suggest that high levels of social capital and community cohesion might be protective and facilitate more effective collective responses to the epidemic. Other studies (Campbell et al., 2002), which I will discuss later, have argued that group membership has been a risk factor for HIV infection especially among intravenous drug users (Kral et al., 2001).

There are a number of mechanisms through which social capital might affect the prevalence and distribution of HIV in populations (Berkman & Kawachi, 2000; Campbell & Macphail, 2002; Campbell et al., 2002; Gregson, et al., 2004). Well-functioning community networks may protect community members from engaging in risky sexual behaviour. Strong social networks have been found to exert social or cultural pressure on members in ways that deter high risk sexual activity. These networks facilitate the exchange of information between peers who may be able to discuss issues on safe sexual health. In addition to information exchange, these networks may shape community norms around gender relations, communication and sexual negotiation (Pronyk, Harpman, et al., 2008b).

Despite the growing popularity of linking social capital and health, little research has been done in Africa and more specifically in Zimbabwe on social capital and how group membership affects members' risk of HIV and attitudes towards HIV/AIDS.

Campbell et al. (2002) focus on the impact of social capital on health issues in a South African mining community, and Gregson et al. (2004) examine links between social capital and HIV avoidance in Zimbabwe. Both studies suggest that group memberships have a significant link with HIV avoidance or vulnerability. Campbell et al. (2002) found that some groups (e.g. women's' groups, youth groups) protect people against HIV, but others (e.g. stokvels, unions) make it more likely that people will be HIV positive. Thus their findings suggest that some groups have properties that protect members from high risk sexual activity while others endanger members by creating environments conducive to risky sex.

In Nigeria, Gruber and Caffrey (2005) argue that mobilizing social capital (in their paper referred to as community human resources) is a core strategy on which successful HIV prevention initiatives have been built. Gruber and Caffrey (2005) illustrate that community conflicts erupt when community gate keepers—individuals who have high amounts of respect and control over change within a community—and the wider community were not accorded the opportunity to participate in the process of prioritising needs, defining interventions, monitoring programs and evaluating outcomes. Hence they highlight the need to develop HIV/AIDS interventions that are genuinely responsive to different socio-cultural contexts to avoid community conflict and break down.

Disclosure of HIV status often has important positive implications for HIV prevention and treatment in communities with high HIV rates. HIV/AIDS-related policies and interventions often recommend the promotion of openness about HIV status as a vital aspect of effective HIV and AIDS management. There is evidence that women's efforts to participate in prevention of mother to child transmission (PMTCT) programs, adhere to infant feeding guidelines and prevent unintended pregnancies are difficult without the knowledge and support of other trusted people in their communities (Brou et al., 2007; Buskens, Jaffe, & Mkhatshwa, 2007; Medley et al., 2004). Hence there is an urgent call to encourage and enhance opportunities to support disclosure, with community groupings being seen to constitute a vital arena for support and assistance to those who disclose (Takyi, 2003).

Gittens (2000) states that AIDS-afflicted people are often victims of stigma and prejudice at work, in the community, and at home. They often lack the support mechanisms available to sufferers of most other fatal disease. The Sonagachi Project, a community-based HIV intervention in the red light district of Kolkata, is an example of a successful effort to address HIV stigma through building social capital. The Project was able to foster increased community organization by female sex workers, leading to the women gaining more information about HIV, adding more value and acceptability to HIV prevention efforts (Jana et al., 2004) as well as enabling women there to challenge the stigmatisation of commercial sex work (Cornish, 2006).

There is a need for Zimbabwe as a nation to confront the escalating health, social and economic challenges caused by HIV, including building the capacity of existing community organisations to support those in need. This study seeks to build our understandings of how churches might offer fertile spaces in which stigma can be challenged by and amongst people who are spiritually and emotionally supported.

#### 1.7 Research on HIV stigma and social capital

Barnett and Whiteside (2002) argue that both prevention and impact mitigation programs in Africa have to date been half hearted and inadequate. The epidemic exacerbates poverty and perpetuates inequality at the individual, household and community levels. HIV and AIDS stigma has been cited as one of the key drivers to effective HIV prevention (Ogden & Nyblade, 2005). This section provides a review of the academic literature on HIV stigma and social capital.

HIV is often viewed as a shameful disease. In Zimbabwe, HIV is strongly associated with promiscuity to the extent that the terms are interchangeable (Gregson et al., 2007). Fear, suspicion and victim blaming has been the norm in most families. Research in many sub-Saharan African countries have found high levels of HIV stigma. Most people do not want to associate or share anything with an AIDS sufferer (Duffy, 2005). People with HIV and AIDS are often shunned and treated with contempt and described as immoral (Parker & Aggleton, 2003). Even in situations where a handful of people living with HIV and AIDS (PLWHAs) are open about their condition, stigma remains and tends to prevent PLWHAs from receiving adequate care and treatment (Haddad, 2002). The situation is often worse in rural areas where

community leaders and tribal authorities make discriminatory statements during funeral orations of people who have died from AIDS.

Newman et al. (2008) studied how Black Canadian women perceive HIV risk and prevention. Their findings suggest that stigma, cultural disconnection, lack of engagement of black religious institutions and multiple intersecting forms of discrimination serve as potent barriers to existing HIV preventive interventions. They cite how current models of HIV preventive intervention require individuals to combat powerful structural forces such as sexism, racism and HIV/AIDS stigma, and to circumvent social pressures emerging from cultural institutions such as the church and the family.

They further state that, "HIV prevention strategies that require individuals to protect themselves at the cost of alienation from traditional bastions of support seem ill conceived and unlikely to be effective" (Newman, et al., 2008). Traditional bastions of social support, such as families, churches and schools, need to play a central role in supporting people with HIV and AIDS. My research seeks to investigate the role of churches in Zimbabwe as traditional bastions of support for communities and how the churches in turn reinforce or challenge HIV-stigma reduction.

Chiu et al.'s (2008) study in a South African township found that social capital, measured in terms of components including empowerment, trust and group membership, significantly predicted levels of stigma above and beyond demographic covariates (e.g. age, gender, marital status) and whether the participant knew someone with HIV. They found that people with a higher sense of empowerment to make changes in their lives had less stigmatizing attitudes. Individuals who felt trust and safety in their community were less likely to think that others in their community held stigmatizing attitudes.

Sivaram et al. (2009) examined links between social capital and HIV stigma among commercial female sex workers and men who frequent beer halls in Chennai, India. They found that, among men and women, membership in formal community groups was associated with reduced fear of HIV transmission, reduced shame, blame and judgement, and reduced personal support for discriminatory actions against PLHIV. In addition, a sense of trustworthiness and the ability to rely on others for financial help were strongly associated with lower levels of stigma. In South Africa, HIV infected and affected individuals were found not to be passive victims, but as active

survivors who attained ownership and acceptance of one's status (Squire, 2007) Overall, the literature on links between social capital and stigma tends to be qualitative in nature, often using small samples. There is an urgent need for an integration of both qualitative and quantitative studies.

In Africa, HIV and AIDS stigma is rampant. In 2008, Member of Parliament in Swaziland, Timothy Myeni, suggested that those who have tested positive for HIV be marked on their buttocks with a special insignia to warn possible lovers of their status. He said that this would assist possible sexual partners in verifying the status of the other person prior to engaging in intercourse (Mail and Guardian online, 2009). In South Africa, on the 12<sup>th</sup> of December in 1998, Gugu Dhlamini a HIV positive activist was stoned and stabbed to death after she disclosed on a local radio station that she was HIV positive (South African Government Information, 1998).

Bond and Nyblade (2006) illustrate how in Zambia tuberculosis (TB) and HIV have become intertwined in the social reality of people living in high settings with HIV prevalence. They argue that TB, the most common and serious of HIV's opportunistic infections in sub- Saharan Africa, has become progressively more stigmatized through its growing association with HIV.

The psychological mechanism of creating a boundary between 'us,' the morally upright, normal, uninfected people, and 'them,' the 'other,' immoral, deviant and infected people, is one strategy people use to protect their positive sense of identities (Ogden & Nyblade, 2005). This strategy has been repeated in many societies as a response to the HIV epidemic (Joffe, 1999; Parker & Aggleton, 2003). Bond and Nyblade (2006) report how women are particularly susceptible to this type of judgement.

Similarly, a study conducted by Ogden and Nyblade (2005) in Zambia and Vietnam highlight the tendency to link HIV and morality. They argue how associating illness with immoral behaviour has been a major feature in contributing to HIV and AIDS related stigma. In most African societies, stigma has been worsened by the serious condition of the illness and its association with behaviours that are socially sensitive such as sex and prostitution. Given the traditional intolerance of the church to behaviours such as prostitution and infidelity, this research examines the possibilities and limitations of using church groups as spaces for critical dialogue about myths and misconceptions about HIV/AIDS that resonate within churches and communities.

This thesis takes up Ogden and Nyblade's concern about church perpetuation of stigma by exploring the potential of a community engagement intervention to reduce stigma among church members.

Despite vague references to the importance of mobilising social networks for stigma reduction (Maluwa, Aggleton, & Parker, 2002) much remains to be learned about the potential role of grassroots social networks such as local church groups in addressing this challenge. Stigmatising attitudes towards people living with HIV and AIDS (PLHIV) have long been one of the major problems facing infected individuals and hampering attempts to control HIV epidemics in Zimbabwe (Gittens, 2008) and elsewhere (Bond & Nyblade, 2006).

Low Beer and Stoneburner (2004) argue that relatively high levels of communication about HIV and AIDS in Uganda may have served as one of the factors for positive behaviour change in Uganda in the 1990s. Their findings suggest that significantly more Ugandans had heard about HIV and AIDS from people they know, rather than an impersonal source such as the media, as compared to countries such as Zimbabwe. The authors suggest that communication in face to face networks reduce levels of stigma, making people more likely make optimal use of HIV prevention and AIDS care information and services.

My research conceives of HIV risk as less a result of individual choices and more a product of social forces. Therefore HIV prevention models must be rooted in the social contexts, life experiences and perspectives of local people. This research views churches as a highly prevalent form of community institutions, and will explore, amongst other things, how church groups can address HIV and AIDS stigma.

A lot of research has been done on the need for various top-down interventions to address stigma including multi-level programmes to fight for legal protection of HIV sufferers within a human rights approach and large scale poverty relief (Parker & Aggleton, 2003).The challenge of reducing poverty and promoting human rights in sub-Saharan Africa has been long pursued with varying degrees of success by a range of actors. However, large-scale poverty reduction and human rights improvements are unlikely to be achieved in time to help millions of existing HIV sufferers. More immediate action must be pursued concurrently. Furthermore, Campbell et al. (2007) suggest that without parallel bottom up efforts to address stigma such top-down efforts may have limited success. It is in this context that I seek to explore the extent to which church groups can provide community level resources to counteract HIV and AIDS stigma.

Recent research in Zimbabwe (Genberg et al., 2008; Genberg et al., 2009) has focused on AIDS stigma. However, this research is limited to documenting stigma rather than exploring its implications for health behaviours. For instance, some studies cite how HIV stigma has obscured people from accessing health services, but do not discuss interventions to combat stigma. A notable exception is Duffy (2005) who reports on HIV stigma implications for health promotion in Zimbabwe. Duffy suggests the need for health promotion messages not to further stigmatise particular groups such as commercial sex workers and truck drivers. The limited research on the impact of HIV/AIDS stigma on HIV prevention is a major problem for Zimbabwe considering that it is experiencing high HIV prevalence levels.

In one of the few studies that do exist on HIV and AIDS stigma in Zimbabwe, Gittens (2000) found that despite high levels of awareness of HIV and AIDS in Zimbabwe, there are also high levels of stigma. One promising but little explored approach is the possibility that social capital, in the form of community group participation, might be a useful resource in challenging and reducing stigma.

Community groups are rooted in the local social contexts within which individuals form attitudes towards PLHIV and can help to reduce stigma by providing opportunities for discussion and renegotiation of previously stigmatising social norms. Community group memberships affect the formation of self-identity as well as a person's attitudes to others (Brewer & Gardner, 1996). Social capital has been found to be associated with reduced rates of HIV acquisition (Campbell et al., 2002; Gregson et al., 2011; Pronyk, Harpman, et al., 2008) and with a number of factors linked to the risk of infection including alcohol consumption (Campbell et al., 2002), intimate partner violence (Pronyk et al., 2008) and sexual behaviour (Crosby, Holtgrave et al., 2003). However, examination of the link between levels of social capital and stigma-related attitudes held by the general population towards those with a potentially stigmatizing condition (e.g. PLHIV) have not been adequately investigated. My research will contribute to fill this gap, exploring if social group memberships reduce stigmatising attitudes.

#### 1.8 Empirical research on the church and HIV in Africa and Zimbabwe

In this section I provide an overview of research on the church and HIV/AIDS in Africa and Zimbabwe. The role of the church in relation to HIV is complex and contradictory as the following sub-sections will show. First, I will look at evidence of the positive role of the church in stigma reduction, support for PLWHA and positive responses to HIV. Then I will discuss how churches perpetuate stigma and hinder positive response to HIV. Because there is very little written on this topic in Zimbabwe, I will focus more broadly on sub-Saharan Africa.

## 1.8.1 Ways churches challenge stigma and promote positive responses to HIV

Religious sectors can undoubtedly serve as a key source of support for HIV suffers in some contexts and in some countries. For instance, a recent report commissioned by UNAIDS (2008) reported that 70% of health services in the Democratic Republic of Congo (DRC) are delivered by churches and church related institutions. Half of the hospitals in the DRC are owned and managed by local churches and the Roman Catholic Church alone provides 25% of all HIV/AIDS care including home based care and support of orphans in the DRC (Haddad et al., 2008).

Indeed, in most parts of Africa, religious organisations are key providers of care and support to people living with HIV/AIDS, in spite of limited funds to their disposal (Trinitapoli & Regnerus, 2006). Miller and Rubin (2007) found that many people in Kenya disclosed their HIV positive status to church pastors. Furthermore Trinitapoli and Regnerus (2006) highlight that in rural Malawi religious leaders discussed HIV and AIDS with their congregations—a positive contribution to 'breaking the silence' that fuels stigma about HIV and AIDS.

Church groups represent traditional values of solidarity and are community based (Becker & Geissler, 2007). A study in Ghana found that the greatest contributing factor to the care and support of PLWHAs by church group members was whether respondents had heard their leader publicly speak about HIV/AIDS (Bazant & Boulay, 2007). Also Christian women are more likely to report lower levels of perceived HIV risk and higher levels of knowledge about HIV transmission than non-Christian (i.e. Muslim and traditional) counterparts. He argues that this could be due to social networking among certain groups (Takyi, 2003).

While some studies, such as those cited above, discuss Christian churches in general, others focus on specific denominations. Studies of members of Pentecostal churches suggest they may be distinctive in ways that reduce the likelihood of members from contracting HIV. In addition, Maman et al. (2009) found that Pentecostal women in the DRC relied upon their faith and turned to church leaders when they were diagnosed with HIV and prepared to disclose their HIV status with the help of church leaders. In the United States of America (USA) Szaflarski et al.(2006) created a conceptual model that explored the effects that religion had on perceptions of living with HIV /AIDS. They found that a third of their participants living with HIV felt that their lives were better after joining a religious affiliation. Church leaders were reported to be important targets for disclosure by some women.

Additionally, Dilger (2007) reports on a study of a neo-Pentecostal church in Tanzania. Neo-Pentecostal churches emphasise closeness with the Holy Spirit, whereby members experience ecstatic moments of salvation where they feel filled with holiness. The denomination Dilger studied is more charismatic (i.e. more focused on informal and emotional services involving people being 'filled with' the Holy Spirit) but similar to and aligned with the Pentecostal in Zimbabwe. He argues that in high levels of poverty and economic insecurity, the church offers positive practices of healing and social support for those living with HIV and AIDS. The church provided a social space in which new and helpful understandings of HIV and AIDS might emerge. The church also provided dense networks of economic and social support to all its members.

Some studies suggest that the social and sexual control imposed on members by churches can lead to a reduction of high risk sexual behaviours. In South Africa for example, Garner (2000) found some churches influenced their members to reduce extra- and pre-marital sexual activity as a step to minimise their risks for AIDS. In Ghana, the preaching of various Pentecostal and Evangelical churches against 'immoral sexual behaviours' has served to encourage early and faithful marriages and reduce polygamous unions (Addai, 2000). In Kenya, the Deliverance church promotes abstinence before marriage, fidelity within marriage and mandatory HIV testing for those getting married – highlighting what Parsitau (2009) refers to as the social and sexual discipline of church members. In some contexts such efforts may have been successful in reducing risk behaviours. In Malawi, Trinitapoli and Regnerus (2006) found that married men belonging to a Pentecostal church reported lower levels of HIV risk behaviour than men of other faith groups, and that regular

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church attendance, regardless of denomination, was associated with fewer extramarital partners which served as an important factor in reducing HIV-related risk behaviours.

Different church groups have varying levels of influence on members' sexual behaviours (Addai, 2000). In Zimbabwe, Gregson et al. (1999) observed that members of Apostolic churches, which along with Pentecostal and spirit churches he refers to as 'spirit type' churches, are less affected by HIV because of their strict teachings about avoiding extra marital and premarital sex. He further suggests that the HIV epidemic may become an important influence in the future evolution of churches in Zimbabwe. The strict moral codes and the reassurance that spirit type leaders give to their members in the midst of a major HIV epidemic could make them increasingly attractive. One of the aims of my research will be to explore the ways in which Apostolic churches deal with stigma. The difference between Apostolics and Pentecostals is that Pentecostals are more charismatic and allow church members to access health services. There are different types of Apostolic churches; some allow church members to access health services but the majority do not. I focused on the Apostolic church in Zimbabwe in chapters 5 and 6 because they have higher rates of church membership than Pentecostals in Manicaland.

Garner (2000), looking at different Christian denominations in South Africa, found that only Pentecostal churches had any significant impact on reducing extra- and premarital sex. He identified four key variables to explain this level of social control: indoctrination, religious experience, exclusion and socialisation. The Pentecostal churches had tighter control over members' behaviour, backed up by their authority to expel or exclude those who chose to reject this control (Garner 2000). Such disciplining was also observed by Trinitapoli (2009) in a more recent study in Malawi. However, she found that the monitoring of church members' sexual behaviour was only one effort of several strategies by church leaders to curb the spread of HIV/AIDS. Members of congregations where pastors monitored their sexual behaviour spoke openly about HIV/AIDS and delivered HIV prevention messages as well as privately encouraging condom use and were most likely to abstain, be faithful and use condoms (the so-called ABC of HIV prevention).

Churches can encourage love, care and support to PLWHA and can impose social control with some positive effects on HIV-risk behaviour. However, the social control

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demonstrated by many church groups goes against the spirit of standard international criteria for HIV/AIDS control (e.g. UNAIDS, 2009), through perpetuating stigmatising links between HIV/AIDS and sin, and through supporting unequal gender relations that undermine women's ability to negotiate safer sexual encounters. This next section further discusses the ways in which churches contribute to stigma.

# 1.8.2 Ways churches contribute to stigma and hinder positive responses to HIV

Although there is much evidence for the positive role played by the church in supporting those with HIV and AIDS, there is a similarly large body of research that points to ways in which religious beliefs may serve as a hindrance to treatment and care efforts. Wanyama et al. (2007) in Uganda state how spirituality was a barrier to ART adherence. Some patients discontinued ART as a result of their belief that they had been spiritually healed. Uninterrupted ART is vital to sustaining viral suppression, preventing drug resistance and ensuring the clinical benefit of treatment. In DRC Maman et al. (2009) suggest that religious fatalism and a belief that their fate was in the hands of God might have served as a barrier to woman taking initiatives to prevent and treat their HIV infections.

In order to discuss HIV, churches must talk about sexual promiscuity and infidelity issues that are uncomfortable for many church leaders and commonly associated with immorality in Christian churches. Adogame (2007), argues that HIV stigma leads many churches in Nigeria to fear that church involvement in HIV/AIDS advocacy or care may be perceived as their endorsement of or provision of protection to stigmatised groups such as gays or female sex workers, who were not deserving of support due to their 'immoral behaviour'. Allman et al. (2007) argue that the stigmatization of same sex relationships by the church in Nigeria cause homosexual networks to be denied and hidden from religious circles, which in turn leads to increasing their risk of HIV and AIDS.

The way HIV/AIDS is talked about in most churches perpetuates stigma by suggesting that people who contract HIV are sinful and by emphasising personal blame. For example in Africa, stigma arises from the association of infection with sex, which churches emphasise should only occur in monogamous marriage, where HIV and AIDS should not be a problem in the context of faithful spouses who were not sexually active prior to marriage. The implication here is that HIV is not a risk for

those who adhere to the teachings of the church and that having it can only be the result of immoral and 'ungodly behaviour'. For those living with HIV, knowing the church association between immorality and HIV contraction can lead to the reinforcement of personal or internalised stigma (Plattner & Meiring, 2006).

Linking HIV to immorality can undermine prevention approaches and reinforce stigma surrounding HIV prevention by, for example, making condom use unacceptable. Such a trend is found across Africa. In Zimbabwe, Hallet et al. (2007) found that membership of a church is likely to delay sexual debut, but that church members are less likely to use condoms. Agha et al. (2006) found the same link between church membership and reduced rates of condom use in Zambia. In Uganda, Otolok-Tanga et al. (2007) found that church groups' emphasis on fidelity within marriage and members' belief that the sexual health of married people was not at risk, hindered people from developing a realistic sense of possibility of contracting HIV from their marriage partner.

Marshall and Taylor (2006) suggest that condoms are often perceived in church groups as a tool for unfaithful wives or those who have premarital sex. Pfeiffer (2003) documents how mainstream donor agency messaging about condoms contradicted positions adopted by churches, leading to condoms coming to be seen as an inappropriate public health strategy. Furthermore, reluctance to use condoms may be linked to lack of perceived risk; church members have lower perceptions of the risk of contracting HIV than non-members (Largade et al., 2000; Smith, 2004; Trinitapoli & Regnerus, 2006). Zou et al. (2009) examined the attitude of different religions towards HIV in Tanzania and found that shame – related HIV stigma was strongly associated with religious beliefs such as the belief that HIV is a punishment from God. Churches' positions on HIV and AIDS can risk undermining prevention efforts.

In South Africa, until recently the national church bodies often remained silent about HIV and AIDS. This contributed to the stigmatisation of HIV sufferers (Haddad, 2005). However Haddad (2005) states that this is gradually changing, as recently church leaders have taken on a more positive public stance on HIV education, prevention, care, support and lobbying for treatment. Nevertheless, despite changes in particular local contexts and churches, churches have not been seen to openly and publically challenge HIV stigma in South Africa (Haddad, 2008) or in Zimbabwe.

CONTEXT OF STUDY

## Summary

A variety of evidence suggests that despite some church efforts to tackle stigma and some positive HIV-related behavioural outcomes linked to church membership, the church is overall facilitating stigma in various facets. Research on how churches might be used as the basis of sustainable efforts to address HIV and AIDS stigma is scarce. Churches are in a unique position to make a sustained contribution to HIV stigma reduction because they are deeply and, for the most part, permanently embedded in communities, as opposed to most NGOs, which tend to receive short term funding from donors. I have sought to map out the paradoxical ways in which the church both challenges and contributes to stigma.

My research seeks to explore the extent to which church membership can be used as a starting point for stigma reduction. Despite the fact that churches often contribute to stigma and are frequently resistant to change, they cannot be side-lined in the effort to reduce HIV stigma in Africa. Engaging with churches and maximizing the pre-existing positive support role they play in communities will promote sustainable local social capital. There is need to assist PLWHA and carers in churches to lobby for the recognition of their wider needs and interests with regards to HIV and AIDS stigma. Second, there is need for community strengthening programmes to create health enabling communities characterised by trust, mutual support and high levels of local community projects. I believe that more can be done in using churches as the basis for such work. I will explore this possibility through examining the extent to which church groups can be used as social spaces to renegotiate the collective identities of PLWHA in less stigmatising ways, working together to build trusting relations to address HIV and AIDS stigma.

## CHAPTER 2: CONSTRUCTING A THEORETICAL FRAMEWORK FOR INVESTIGATING HOW CHURCH GROUPS TACKLE HIV STIGMA

## **Chapter overview**

This chapter highlights the limitations of biomedical health approaches and models for designing HIV and AIDS interventions and the need for greater understandings of the social psychological pathways through which social capital impacts on health. I provide an overview of the concept of HIV competence (defined in terms of the concepts of social capital, social identities and dialogue, social representations and stigma, empowerment and critical consciousness, power in the context of social capital and social change), which frames this thesis. Finally problems encountered in addressing HIV/AIDS stigma in churches will be discussed with particular attention to social capital.

## Introduction

My interest in the role of church groups in furthering or tackling HIV stigma is framed within Campbell's 'social psychology of participation' (Campbell, 2003; Campbell & Jovchelovitch, 2000) with particular reference to the concept of social capital, and the potential role of social capital in participatory health interventions. Campbell (2003) maps out the social psychological pathways through which social capital impacts health. I will use the concept of social capital affecting health in theorising how church groups tackle HIV stigma in Manicaland.

In this section I discuss the concepts of social identity, social representation, empowerment, critical consciousness, social capital and power. These concepts provide a useful starting point for my interest in addressing the relative lack of social psychological attention to community level determinants of health in understandings and responses to HIV and AIDS in southern Africa.

It is increasingly argued that it is only through the participation of grassroots communities in planning and implementing health programmes that HIV interventions and policies are likely to have an impact (UNAIDS, 2006; African Union, 2007). Dube and Wilson (1996) argue that local community groups should involve participate in designing and implementing grassroots initiatives to promote healthy behaviours,

because people are more likely to change their behaviour if they see that liked and trusted peers are changing theirs (see also Campbell, 2003). Within the field of social psychology, there is a growing recognition of the influence of local community conditions on health. Many studies (Baum, 1998; Campbell, 2003; Campbell and Jovchelovitch, 2000; Moscovici, 1984; Wilkinson, 1999) emphasize that social cohesion and strong local networks benefit health in a range of indirect ways.

#### 2.1 Social capital

Pierre Bourdieu first defined social capital as the aggregate of the actual or potential resources which are linked to a durable network of institutionalized relationships of mutual recognition (Bourdieu, 1986; Portes, 1998). Other scholars such as Kawachi, Putnam and Coleman further developed the concept in more detail. Putnam defines social capital as the classification of networks, norms and trust relationships that enable communities to address common concerns. He discusses it in terms of both norms (trust, reciprocity) and networks (organisational memberships) (Putnam, 2000). Coleman (1988) uses an economic model to define social capital as the set of resources that inhere in family relations and community organisations that are useful for the development of children. Putnam and Coleman focus mostly on the amount of social connectedness rather than a detailed analysis of the nature of any past or present connections (Arneil, 2006).

Social capital is considered to have a 'network' dimension (high levels of participation in community groups) and a 'norm' dimension (particularly, levels of trust and reciprocity amongst community members) (Kawachi, 2006). The former is generally considered to be a more powerful marker of social capital (Foley & Edwards, 1999) and here, following the work of Campbell et al. (2002), Gregson et al. (2004), Moser (1998), and Narayan and Pritchett (1997) in the African context, I define social capital in terms of peoples' participation in local community groups. It is through group membership that Campbell et al. (2007) argues communities are most likely to become HIV competent. Campbell defines HIV competence in terms of the ability of a community to work collectively to negotiate new behavioural norms (around prevention, care and treatment) as well as transforming stigmatising attitudes.

The social capital approach within the community health field posits that people are more likely to undergo health enhancing behaviour change if they live in communities that offer high levels of participation in local networks and organisations. These networks are associated with trust, reciprocal help and support and a positive local community identity (Gillies, 1998; Krueter, 1997).

Campbell (2003) argues that an important determinant of the success of participatory health promotional interventions is the extent to which they mobilise or create social capital. Social capital is central to health promotion for two reasons. First, communities that are rich in social capital are said to provide a supportive context within which people can collectively renegotiate social identities in ways that promote the increased likelihood of health enhancing behaviours (Campbell, 2003; Putnam, 1993). Second, members of communities with high levels of social capital are most likely to have high levels of perceived control over their everyday lives (Putnam, 1993, 2000).

The concept of social capital has faced criticism for its failure to account for the way in which various forms of social exclusion undermine the possibility of creating, sustaining or benefiting from social capital in marginalised communities. Community level determinants of health cannot be understood without reference to macro-level determinants of health, (e.g. Gillies, 1998). Likewise, to fully understand the effect of macro-level determinants of health on individuals one must also examine communitylevel factors. Community level factors will often play a key role in mediating between macro-level social disadvantage and the health status of a community.

Portes (1998) asserts that interventions seeking to increase levels of social capital can cause more harm than good. He argues that social capital can have negative outcomes because of the: (i) the excessive demands that strong social networks place upon members of cohesive groups to provide support to others, (ii) expectations of conformity that may result in restrictions on individual freedom as well as intolerance of diversity, (iii) the exercise of in-group solidarity to exclude members of out-groups, or in some instances, even to oppress them and (iv) the down-levelling of norms within solid groups that can hold back the prospects of upward social mobility. Hence there is need to distinguish between bonding and bridging of social capital to untangle conflicting definitions.

Bonding social capital is the strong association within groups that takes the form of trust and mutual support. Bridging social capital is the resources accessed by individuals and groups through connections to other individuals that cross class, race or ethnicity and other boundaries of social identities. It normally takes the form of bridges or partnerships between local communities and outside support agencies in integrated civic organisations.

The concept of social capital has been considered dangerously ambiguous because it is easily construed to support opposite theories of development (Szreter & Woolcock, 2004). The concept of social capital has been used by critical social theorists to support their belief that socially excluded people will gain the power to lobby powerful bodies to recognise and meet their needs through grassroots participation in strong community-based organisations. On the other hand, the notion of social capital has been used by neo-liberal free market theorists. They argue that grassroots organisations and networks have the power to take over many functions assigned to governments or international development agencies such as welfare support. I align with the former stance and will be mindful of the potential use of social capital to reduce institutional support for marginalised groups in my research.

A second criticism is that the social capital tradition mistakenly tends to portray social capital as an overwhelmingly positive social resource, and to ignore the fact that certain groups with strong cohesion (for example drug gangs) may have negative impacts both on their members and on the communities in which they operate (Portes & Landolt, 2000). I have taken this criticism into account when analysing my data on social capital in Zimbabwean churches by not assuming that church membership automatically has positive impacts on the health of members, or on the likelihood of church-goers experiencing or perpetuating AIDS stigma. This point is also taken up in my data collection and analysis sections.

#### 2.2 Social identities and dialogue

Social identity is defined as "a direct consequence of representations shared in a social group" (Wagner et al., 1999). Social identities consist of the aspects of oneself that arise from membership of particular social groups (Tajfel, 1981; Tajfel and Turner, 1986) or from one's position within networks of power, such as one's gender, ethnicity or socio- economic position. Identities are not static or permanent. They are

constantly constructed and reconstructed from one moment to the next (Campbell, 2003). Exploring how representations of PLWHA are used or challenged in community groups such as church groups can throw light on how the construction of an identity must build on and develop representations of relevant community groups.

Community groups can provide the social support and psychological resources to 'reconstrue' threats to one's sense of identity and well-being, such as the threat posed by the presence of large numbers of HIV-infected individuals in one's social circle (Breakwell, 1986; Campbell & Deacon, 2006). To this end, several qualitative studies have suggested that participation in local community groups can lead to reducing the stigmatisation of negatively defined others. Howarth (2006), for instance, found that resistance to race-related stigma among black youth in England was developed through participation in community dialogues and relationships, made possible by membership in black supplementary schools.

Social contexts enable or constrain the degree of agency that people have to construct identities or to behave in ways that meet their needs or represent their interests (Campbell, 2003). Instead of focusing on the individual, social identity theorists emphasise how health related behaviours are shaped and constrained by social identities that are collectively negotiated in the myriad of group interactions that people are involved in from one day to the next (Campbell, 2003; Campbell & Jovchelovitch, 2000).

Inter-personal and group discussions constitute the fabric of much human social life. In these interactions, individuals' views and inputs weave and clash through the process of dialogue and argument between people as they ask one another questions, exchange anecdotes and comment on another's experiences and point of view.

Both social identity and dialogue are ways of relating to the outside world and to the world of others, as discussed by Jovchelovitch (2006): "Without others there is no human life properly so called and it is in our relationship to significant others that we find both the ontological and social resources to become what we are." In making sense of the world, people must construct a sense of who they are in relation to others (Jovchelovitch, 1997).

## 2.3 Social representations and stigma

Social representations theory (SRT) opens a space in social psychology where genuinely new questions can be asked and contribute new answers to old problems. Currently, SRT is applied to and developed in a diverse range of fields. In this paper, I examine how SRT is used in the public health arena.

SRT is a socio-psychological theory which emerged from early debates about whether knowledge was rational and from the aspiration to arrive at a new understanding of the duality of the individual and society (Moscovici, 2001). The focus of SRT is not only what people think but also the specific processes by which these thoughts are shaped. Further, SRT seeks to understand how history, culture and institutions become embedded in the psyche of the individual, for example, how the unfamiliar becomes familiarised through processes such as anchoring and objectifying (Moscovici, 1984). Anchoring is the naming and classifying of novel encounters, ideas, things or even persons in relation to one's existing order of meaning. Objectification describes the process of how abstract or potentially threatening new ideas are solidified and made tangible.

One of the key points about SRT is that the psychological (individual perceptions and cognition) and the social (in terms of culture and social context) are not constructed as two different, separate entities – instead social representations are located simultaneously between individuals and the societies they live in (Howarth, 2001).

Social representations of oneself and others constitute the symbolic field within which the negotiation of identities takes place. Moscovici (1995) and Howarth (2006) draw attention to how different knowledge systems and their associated social identities are produced, defended, contested and transformed in everyday encounters, social spaces, relationships and positioning (Howarth, 2006). The knowledge we collaboratively produce today is rooted in our collective and competing histories and is concurrently reworked, resisted and transformed as people find new ways of 'mastering' our constantly changing realities (Howarth, 2006; Moscovici, 1984). These knowledge systems constitute the web of social representations out of which social identities are constructed, within their potential to 'be reworked, re-made and resisted'. Negative representations of people with particular devalued characteristics such as those with HIV and AIDS constitute stigma (Howarth, 2006).

Howarth's critical social psychology of stigma shows how stigma is intertwined with social identity and social representations. Although stigma often appears 'real' – frequently visible on the body of the stigmatised, such as skin colour--the processes though which stigma is constructed are often obscured (Goffman, 1963b; Howarth, 2006). Resisting stigma can only happen collectively through dialogue, debate and agency (Campbell, 2003; Campbell & Jovchelovitch, 2000; Howarth, 2006). My thesis examines the extent which church groupings provide social spaces for the forms of dialogue and debate through which stigmatising social representations are constructed and or challenged in rural Zimbabwe.

#### 2.4 Empowerment and critical consciousness

Community health psychology emphasises that health, particularly in marginalised communities, has an irreducibly social dimension and that as a result health problems can seldom be effectively challenged by isolated individuals. Brazilian education activist and social psychologist Paulo Freire states, "It is not possible to speak of an actor in singular, even less possible of actors in general, but rather of actors in intersubjectivity, in intercommunication" (Freire, 1970, p. 127).

Empowerment and the development of a critical consciousness have been posited by Campbell et al. (2007) as two of the social psychological processes which become possible in conditions of debate and dialogue in social groups such as churches or women's groups. The renegotiation of collective identities within groups needs to happen in conjunction with the development of group members' confidence and ability to act on collective decisions in favour of health-enhancing attitudes and behaviours. Powerlessness or a feeling of a lack of control over destiny severely undermines the health of people in marginalised or demanding situations (Campbell, 2003; Campbell & Jovchelovitch, 2000; Wallerstein, 1992). People who perceive themselves to be disempowered (i.e. who feel that they have little control of the important aspects of their lives) are less likely to feel that they can take control of their health.

Freire's conceptualization of education furthers our understanding of why disempowered people are less likely to take control of their health. He criticised the traditional education paradigm in Brazil that featured the didactic flow of information from the expert (agronomist) to the farmer who was deemed ignorant. He further argued against the extension of knowledge from an expert to an ignorant person. His idea had an extensive effect on the formal education system in his native Brazil and throughout Latin America.

Freire described the traditional approach of experts trying to transfer knowledge to ignorant learners as the 'banking concept of education', whereby experts attempted to deposit information into the minds of others the way one would deposit money into a bank. He argued that this style of education encourages passivity and acceptance of the status quo among students. He said that this approach treats people like objects or empty vessels to be passively filled with information chosen and delivered by professionals. He argued that this way of providing information is deliberately used by rich and powerful elites (including professionals) to oppress the poor and powerless (Freire, 1970; Freire, 1985; Rifkin & Pridmore, 2001). He called for a problem-posing approach to education in order to reverse this situation.

Freire's aim was to understand the processes through which subjects pose problems, and problematise everyday life experiences by engaging in critical discussion and then action (Diemer et al., 2006) Freire's emphasis on the full agency of learners opens up invaluable prospects for understanding and aiding participatory processes (Ramella and Dela Cruz, 2000).

Freire (1973/1999) argues that a vital precondition for positive behaviour change by marginalised social groups is the development of a critical consciousness. Two interlinked aspects of the critical consciousness--understanding and action--are outlined by Freire.

The first aspect of critical consciousness involves the development of group members' understanding of how social conditions facilitate their situation of disadvantage in ways that undermine their health. Developing this understanding involves discussing the social conditions that have fostered situations of disadvantage in ways that undermine health.

The second element (action) proposes that the development of a critical consciousness involves people moving through a series of stages. The first stage is characterised by the 'semi- intransitive' consciousness, where group members' understanding is focused on survival and causality is attributed to the supernatural, limiting perceptions of agency. For example, people with semi-intransitive consciousness may attribute an epidemic to punishment by a supernatural force for some transgression. Through dialogue group members may transition to an 'intransitive stage', characterised by naïve rather than critical consciousness. This is the stage where group members recognize the epidemic but lack insight into the way the social conditions undermine their well-being, and don't see their actions as capable of changing these conditions. Through a gradual process of profound critical insight, the process of critical insight leads to the final stage of 'critical transitivity'.

This final stage is characterised by the dynamic interaction between critical thought and critical action that may result when people learn to think critically about their life situations. However, life situations characterised by exploitation and oppression lead to the development of 'adapted consciousness'. This refers to a state where a person accommodates conditions imposed on them and acquires an authoritarian frame of mind (Freire, 1970; 1985).

Freire emphasised how marginalised communities can act collectively to produce social change in the Pedagogy of the Oppressed (1970). He suggested that the development of a critical consciousness is a process engaged through dialogical relations. Conscientisation is developed through discussing the contexts in which people live. This dialogue is, according to Freire, facilitated by outsiders who work with groups to co-construct a reflective and critical understanding of the broad range of social, economic, cultural, and psychological factors shaping local circumstance. This is what Freire refers to as 'praxis,' which is a reflection and action on the world in order to transform it.

'Problem-posing' using praxis has been practiced in diverse settings in public health, education and other areas to promote conscientisation in work with marginalised communities (Ramella & De la Cruz, 2000; Campbell, 2003; Cornish, 2004; Guareschi & Jovchelovitch, 2004). However, there is little written about how groups, and in particular church groups, can use the approach to address HIV/AIDS stigma in the public health discourse.

Freire's pedagogy emphasizes that the knowledge of different actors must be valued. Jovchelovitch (2006) further states that when one actor's knowledge is brought into dialogue with that of another, the process illuminates the 'diversity, expressiveness and limitations' inherent in all knowledge. The recognition of the contextual nature of knowledge enables interlocutors to critically reflect upon their own lived experience – how and why they each know what they know – and co- construct a new understanding of the world from which to act upon this context (Vaughan, 2010).

Freire's theory is prone to over-emphasis and simplification (Cornish, 2004; Roberts, 1996). He has been criticised for not engaging power and the broader social field in his discourse. Blackburn (2000) warns us how the notion of Freire may not promote dialogue but rather manipulation, domination and "the inappropriate imposition of a certain vision of power on people who may not want to be empowered in the way that is being prescribed". Hence, all participants in a dialogue must develop their own strategies of how best to address power.

Freire's idea that dialogue alone can lead to concientisation and transformative social action has been criticised as being hopelessly idealistic, referred to as 'utopianism' (Stanley, 1972). Also, Friere has been accused of insufficiently acknowledging the impact of context on the way his pedagogy may unfold in practice. Mayo (1999) critiques Freire as 'too theoretical' and argues that Freire does not provide sufficient 'concrete guidance.' Mayo's critiques are perhaps based in the limited view that Freire's work simply outlines a series of techniques or a method – rather than an approach to promoting social transformation. Freire warns that the techniques he has used in different settings cannot and should not be 'translated' from one context to another, but rather his approach to the development of (political) literacy, dialogue and praxis should be reinvented to fit with local context (Freire, 1978; Vaughan, 2010). Notably, Hooks (1993) suggests that Freire neglects the gendered nature of oppression and the historical and situated nature of any successful revolutionary social change.

My thesis takes this debate on valuing the knowledge of different actors into account in the use of community conversations seeking to develop critical dialogue. While the notion of participation in HIV and AIDS issues in churches appears to be hugely dominated by leaders, there is clear need to provide spaces for dialogue which will enable church members to pose problems they encounter in addressing AIDS stigma through critical consciousness.

#### 2.5 Power in the context of social capital

Bourdieu's conceptualisation of social capital is often posited as a more useful conceptual tool than Putnam's. Putnam's conceptualisation of social capital does not pay much attention to the role of power in the distribution and operation of social capital (Wakefield and Poland 2005; Grix, 2001). Bourdieu (1986) on the other hand, emphasises the role played by different forms of capital in the reproduction of unequal social relations. He states that unequal social relations are maintained through a range of social processes that sustain inequalities in the interlocking phenomenon of economic capital, human/cultural capital and social capital. For example he conceptualised neighbourhood social capital as resources inhered within networks consisting of neighbourhood residents as well as potentially other neighbourhoods and institutions that may be used by residents for individual or mutual action. This section will focus on Bourdieu's conceptualisation of the role played by social capital in reproducing or transforming social inequalities.

As already mentioned, this thesis conceptualises social capital in terms of people's participation in mutually beneficial social networks that underpin collective action in the interests of pursing mutually beneficial goals. Campbell (2003) points out that poor people are subjects of their own lives, yet also subject to forces beyond their control. Similarly, Jovchelovitch (1997) suggests the need for a 'double edged' conceptualisation of power to accommodate this complex dialectic of enablement and constraint.

On one hand participation in conditions where material and symbolic obstacles prevent the possibility of real social change can be a hollow exercise. In fact, participating in these futile activities can serve to legitimize the status quo through providing ineffective outlets for dissatisfaction and cosmetic solutions to on-going issues rather than providing an opportunity for marginalised people to pursue their

needs and interests. Access to social capital is entrenched in existing social systems, in which certain groups have exclusive access to resources by virtue of their dominant position (Wakefield and Poland, 2005).

On the other hand, conceptualisations of power necessarily allow for the possibility of empowerment. Power is not a phenomenon to be explained only through an inherent negativity; it can also be regarded as a space of possible action, where social subjects strive to change their social conditions (Campbell & Jovchelovitch, 2000). Power is inextricably linked to the sphere where people collectively participate in everyday negotiations that bring different social groups and identities into dialogue about the possibility of social change. Power is thus deeply rooted in participation. Whenever a community participates in activities and initiatives to enhance the interests of its members, it actualises the power it holds to participate in the shaping of its way of life. The dialectic of constraints and possibilities is the motor of social change (Bourdieu & Passeron, 1977; Campbell & Jovchelovitch, 2000).

## 2.6 Social change

Never doubt that a small group of thoughtful committed citizens can change the world; indeed, it's the only thing that ever has. (Margaret Mead)

In my research I have sought to focus on the potential effects of group membership on HIV stigma. I have asked: to what extent is participation in church groups likely to predispose members to stigmatise people living with HIV/AIDS? To what extent can church memberships serve to reduce HIV stigma? And what social psychological processes can enable this reduction in stigma?

Drawing on the social psychological processes outlined above, Campbell et al. (2009) argues that there are six characteristics of an HIV competent community context. An HIV competent community is a context in which community members are most likely to work constructively together to reduce HIV stigma and manage HIV and AIDS in their own lives and in the community.

Currently, there is a call for better understandings of "health enabling community contexts" (Tawil et al., 1995), and more specifically "HIV Competent Communities" (Campbell, 2003; Campbell et al., 2005; Nhamo et al., 2010), in which people are most likely to access HIV/AIDS services, and least likely to stigmatise the HIV-afflicted. Various strands of the psycho-social research literature point to possible pathways between health-enabling communities and their potential health-enhancing effects. Such community contexts are said to support the development of a health-enhancing reflection-action cycle, through providing opportunities for critical thinking about the obstacles to health and the renegotiation of health-damaging attitudes and behavioural norms (Freire, 1973, 1999). Ideally, such critical reflection and action also go hand in hand with an increase in the development of health-related agency amongst previously disempowered groups (Wallerstein, 1992).

Such opportunities for critical thinking and empowerment are said to be fostered by the presence of 'social spaces' within which community members can discuss and debate HIV/AIDS-related attitudes and behavioural norms with liked and trusted peers (Campbell et al., 2009). Such discussion can, in turn, facilitate the development of less stigmatising attitudes (Baum, 1998; Ogden & Nyblade, 2005). This could happen, for example, through the acquisition of improved knowledge about how HIV is transmitted and the symptoms of AIDS, through increased contacts with and familiarity with PLWHA, and/or through increased uptake of testing and counselling services leading to greater awareness of their HIV-infection status. The impact of a particular community group in reducing stigma will depend, in part, upon the nature of its primary activities and other characteristics including, critically, the extent to which it provides social spaces for people to engage in dialogue on HIV and AIDS, and the renegotiation of previously harmful behavioural and social norms and attitudes referred as HIV competent communities.

An AIDS competent community is a community context that enables or supports the renegotiation of social identities and the development of empowerment and critical consciousness, which are important preconditions for AIDS interventions (Campbell, 2003). Campbell, Wood and Kelly (1999) have discussed how best to define 'community' for assessments of and interventions to increase health enabling community contexts. While some theorists suggest that 'health enabling' communities ought to be geographical community (i.e. a neighbourhood) (Kawachi et

al., 1997) others suggest that they can include communities of interest (e.g. the Muslim community) or other groupings (ex. sex workers) (Campbell, 2003; Campbell, et al., 1999). In my study I have chosen the 'community of interest' understanding of community, focusing on three communities constituted by religious affiliation (Anglican, Roman Catholic and Apostolic).

Campbell says that AIDS competent communities are characterised by the following dimensions:

**Knowledge about HIV and AIDS** is the first dimension. In most instances people have knowledge about how to prevent HIV and an understanding of how to access the health and welfare system. People in high HIV risk populations generally have good factual information about HIV and AIDS. However, this information is often embedded in certain fears that make it difficult for people to translate it into action plans in their own lives.

What people often lack is not so much information but 'safe places' for dialogue. These safe places, called **social spaces**, are the second dimension of an AIDS competent community. They are spaces in which people can engage in debate and think critically about AIDS. They are spaces where people can renegotiate negative and disempowering representations of AIDS and how to tackle it, and develop more empowered and confident identities regarding their ability to contribute to solutions (Freire, 1973). Such spaces provide opportunities for the development of **ownership and responsibility** for the problem, overcoming the fatalism that often limits poor communities' faith in their ability to tackle overwhelming problems. Hence effective social spaces provide contexts where community members can develop a sense of ownership of HIV and AIDS and a sense of responsibility for tackling it.

Such social spaces also facilitate the identification of **individual and group strengths** that might be of use in tackling HIV/AIDS. Ideally such social spaces provide a trusting and safe environment where people can collectively reach decisions to behave in more health enhancing ways. Dialogue in safe social spaces ideally leads to participants developing a **sense of confidence and agency** in their ability to tackle the problem both as individuals and within their groups. **Social capital** is the sixth dimension of an AIDS competent community. **Bonding social capital** exists where local people are able to reach out to one another, in spite of their differences, to create a sense of common purpose to tackle the impact of HIV and AIDS on the community (Helliwell & Putnam, 2004). **Bridging social capital** involves communities forming links with outside organisations and agencies with the power to assist local people in achieving their goals (Evans, 1996; Woolcock, 1998).

Campbell's model is a useful starting point for furthering our understanding of 'AIDS competent communities'. In terms of the role of churches in tackling HIV/AIDS stigma, the framework must be expanded in order to include more specific references to the concrete strategies required to build 'church group competence to tackling AIDS stigma'.

#### Summary

My research seeks to contribute to the literature on how groups tackle AIDS stigma by examining the role of churches. I have presented the theoretical tools which I am going to use to analyse the role of church groups in addressing HIV/AIDS stigma: social identity and dialogue, social representations and stigma, empowerment and critical consciousness, social capital, power and social change approaches.

## **CHAPTER 3: METHODS**

Any research interview is a social process, an interaction or cooperative venture, in which words are the main medium of exchange. It is not merely a one way process of information passing from one (the interviewee) to another (the interviewer). Rather it is an interaction, an exchange of ideas and meanings in which various realities and perceptions are explored and developed. (Bauer & Gaskell, 2000).

## **Chapter overview**

To explore the research questions, I employed three methods: (i) a secondary analysis of cross sectional survey data; (ii) individual in-depth interviews and (iii) community conversations. This outline is followed by a discussion of public accountability as the most appropriate quality indicator of qualitative research. Finally I discuss the role of cross- sectional surveys as a secondary source of data for the quantitative research.

## Introduction

I used three main data sources to gain insight into how groups tackle HIV/AIDS stigma. These data sources with their methods and objectives are discussed in table 3 below.

## Table 3 : Data collection methods

Data source	Method	Objectives
Secondary source (community members including both church members and others)	Cross-sectional survey of 10 000 people	To examine potential associations between social group membership and stigmatising attitudes towards PLWHA
Key informants (PLWHA, church leaders, community leaders)	Individual in-depth interviews	• To explore specific questions and understand how communities perceive HIV and PLWHA.
Church members	Individual in-depth interviews	<ul> <li>To obtain church members' perceptions on how PLWHA are treated in church and wider community.</li> <li>To obtain detailed case studies from PLWHA on how they are treated and represented within their</li> </ul>
	Community conversations	<ul> <li>community.</li> <li>To identify key obstacles to reducing HIV/AIDS stigma.</li> <li>To facilitate dialogue among participants.</li> <li>To brainstorm action plans church members can take to reduce HIV and AIDS stigma.</li> </ul>

## 3.1 Study design and data Collection

This section presents how the study was planned, conceptualised and conducted. Table 4 below provides a thumbnail and timeline of the key stages of this study. As shown by the table and explained further below, I used data that was collected between 2003 and 2005 but was never analysed. The remaining sections will explain in detail the subject selection and data analysis of each method.

#### **Table 4: Project Timeline**

Steps & activities	2003-2005	2008 (T1)	2008 (T2)	2009 (T3)
Cross- sectional analysis data collection				
Proposal write up and submission				
Community entry				
Data collection of In- depth interviews (Phase 1)				
Data collection of CCs T1				
Preliminary Data analysis of CCs T1				
Data collection of CCs T2			J	
Preliminary Data analysis of CCs T2			ſ	
Data collection of CCs T3				
Data collection of In- depth interviews (Phase 2)				

## 3.2 The cross- sectional survey data (secondary source)

I was able to access and analyze a large cross-sectional dataset through my past work and ongoing collaboration with Biomedical Research and Training Institute (BRTI). BRTI, which is based in Harare, Zimbabwe, supports a longitudinal household survey project conducted by a research team of UK- and Zimbabwebased academics. They have been gathering data on HIV and related behaviour, attitudes and health since 1998.

Participants for the survey were recruited from 12 predominantly rural study sites which comprise four subsistence farming areas, two small towns, two forestry plantations, two coffee and tea estates, and two roadside trading areas. This cross-sectional survey is part of a longitudinal population-based open cohort study in the Manicaland province of eastern Zimbabwe. The baseline survey took place from July 1998 to February 2000 and was carried out in phased manner i.e. one site at a time. Follow-up surveys were conducted from 2001 to 2003, 2003 to 2005 and from 2007

to 2009. Here I used cross-sectional data from the third round (2003 to 2005) since the data from the most recent round of the survey are not yet available for analysis. The participants were men aged 17 to 54 years and women aged 15 to 54 years. The reason why men are defined as those above 17 while women are those above 15 is because women are considered to mature earlier than men.

Individual participants were interviewed using a structured questionnaire on sociodemographic characteristics including education, social group membership, psychosocial attributes, and willingness to care for a PLWHA (see questions 202, 204, 219, 299, 2991 and 607 in the appendix for full details).

## 3.2.1 Subject selection and details of subjects

This cross-sectional analysis is considered secondary since I did not collect the data myself. Participants for the quantitative study were recruited from households that had been surveyed in earlier rounds of research the large Zimbabwean research organization. Individual local residents eligible for the survey were 17-54 year old men and 15- 54 year old women. These individuals were identified by a household census. Recruitment was done by the community health workers of every village. The community health worker was given a recruitment guide with all the names of the people who were eligible to participate. Details of the study will be discussed further below.

#### 3.2.2 Data Analysis

I began by describing the patterns of social group membership amongst males and females using the following key questions: (i) What percentage of people are in social groups? (ii) What are the most common types of groups? and (iii) How does group membership vary by age, gender, education and location? Then I described the pattern of stigma by gender, age, education and location. Finally, I compared levels of stigma amongst those in and out of groups and conduct tests to establish whether observed differences were statistically significant.

To be consistent with the earlier study in Manicaland (Gregson et al., 2004), I defined social group membership restrictively to include only membership of self-reported

well-functioning groups. Respondents were asked about (i) groups that existed in their communities; (ii) groups they are a member of; and (iii) whether they would rate these groups as functioning "well", "OK" or "poorly"." The following types of groups were asked about: (i) church groups; (ii) women's groups; (iii) co-operatives; (iv) farmers' groups; (v) burial societies; (vi) savings clubs; (vii) youth groups; (viii) sports clubs; (ix) AIDS groups; and (x) political parties. The variable created for this question was Soccap (for '*soc*ial *cap*ital'). The following question was then asked: "What is the principal activity of the group you spend the most time with?" There were options for recording the reference number of the group or "none". The Soctype (for '*soc*ial group *type*') variable was created based on responses to this question (refer to question 299 in the appendix). Below is a list and brief description of the groups.

helping bathe the sick, and providing advice, such as about nutrition or encouragement to visit the clinic. Membership is primarily female.Rotating credit societyMembers contribute money to a central fund and, when they reach a certain amount, the money is shared for income generating projects such as buying seeds. Members		
They engage in Bible study, discuss marital issues, and perform community outreach         Burial society       Members contribute small sums of money to a central fund to cover basic funeral expenses for themselves and other members (when they pass away). Members commit to organizing proper burials for one another and often sing at funerals. Generally meet monthly.         Home based       Home based care groups are frequently linked to local churches or NGO. Members generally receive basic training in nursing and visit the homes of families with sick members. They offer emotional and practical support, often bringing blankets and food, helping bathe the sick, and providing advice, such as about nutrition or encouragement to visit the clinic. Membership is primarily female.         Rotating       Members contribute money to a central fund and, when they reach a certain amount, the money is shared for income generating projects such as buying seeds. Members can borrow trom the central fund at a low interest rate and non-members can borrow at a higher rate.         Women's       These groups are generally linked to government women's empowerment initiatives. These groups are often supported by government income generating grants.         Sports club       Usually all-male sports clubs organize tournaments (primarily soccer) against other regions.         Youth group       Generally inked to income generation, participants meet to exchange advice, share resources (such as seeds) and discuss challenges (such as drought).         Farmer's       Farmers, both male and female, meet monthly to plan crops, discuss weather patterns and new technologies, share labour and access NGO assistance.         HIV Group <t< th=""><th>Type of group</th><th></th></t<>	Type of group	
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group       and new technologies, share labour and access NGO assistance.         HIV Group       HIV groups include post HIV test clubs (mostly PLWHA), HIV/ART support groups, youth HIV awareness groups and peer HIV education groups. They are generally	Cooperative	
youth HIV awareness groups and peer HIV education groups. They are generally		
	HIV Group	youth HIV awareness groups and peer HIV education groups. They are generally

#### Table 5: List and brief description of groups

The Manicaland Study was not designed primarily with investigations of determinants of HIV/AIDS stigma in mind and relatively few questions on stigma were included in the questionnaire. In the current analysis, my interest was in stigmatising attitudes for which the most relevant question asked of respondents was whether they would be willing to care for a relative who is sick with HIV/AIDS. I constructed a variable denoting being unwilling to care for a relative who has HIV/AIDS and used this to represent stigmatising attitudes towards PLWHA in this analysis.

Gender of respondents was recorded as male or female. Respondents' ages were taken as respondent's reported age at last birthday (see question 202 in appendix). The question used was, "How old were you at your last birthday?" This question was checked for consistency with a previous question that asked for the month and year the respondent was born (see question 204 in appendix).

Education was recorded as the highest grade of school the respondent had completed using the question: "What is the highest grade of school you have completed?" The following choice of responses was provided: (i) none; (ii) primary level; (iii) secondary level; and (iv) higher. For each level, the number of years at this (highest) level was recorded. The variable used in the analysis was sec, a dichotomous variable referring to whether or not the respondent had any secondary school education (see question 219 in appendix).

Dichotomous variables were created for the independent variable (group membership) and the dependent (stigmatising attitudes) variable. Tests were conducted first for the presence of statistical associations between possible confounding factors (education, employment and location) and the stigma variable using logistic regression controlling for age. Three logistic regression models were run for males and females separately to test for associations between group membership and stigmatising attitudes: (i) crude 'unadjusted' model; (ii) age-adjusted model; and (iii) full model – adjusting for age and other confounding factors (i.e. level of education, employment and location).

I defined church group membership strictly to include only church members of selfreported well-functioning church groups. Dichotomous variables were created for the

independent variable (church group membership) and the dependent variable (stigmatising attitudes). Two logistic regression models were run for males and females separately to test for associations between church group and stigmatising attitudes: (i) age- adjusted model and (ii) full model- adjusting for age and other confounding factors (i.e. level of education, employment, marital status and location). All the analysis was executed using Stata 11 SE.

#### 3.3 The individual in-depth interviews

Individual in-depth interviews were used to sample and explore the diversity of views in a particular social context. An interview is an interaction that facilitates the exchange of ideas and meanings, in which various realities and perceptions are explored and developed (Bauer & Gaskell, 2000).

An individual interview is a one-to-one conversation. The personal worldview of the interviewee is explored in depth by inviting the interviewee to voice his or her detailed interpretations. These accounts provide useful background information about how church groups are responding to HIV within the churches they belong and make a comparison with their church groupings.

The individual interviews took place in four communities in Manicaland: Muonde, Muhacha, Matamba and Matohwe (pseudonyms). The areas are characterised by high levels of poverty and inadequate health services. Participants in individual interviews were recruited from the four communities according to the criteria discussed next in 3.2.1 subject selection and details of subjects. These people were identified by community health workers (CHW) and were between the ages of 15 and 54.

The individual interviews were semi-structured and conducted in Shona, my mother tongue and the language spoken throughout the region. All the interviews took place at a local venue or in the home of the respondent. These semi-structured interviews were tape recorded, transcribed and translated into English by a Shona speaking research assistant. The shortest interview lasted 45 minutes and the longest 90 minutes.

A general topic guide was designed for the participants. Below are the themes discussed (the topic guide is in appendix 3). Main topics discussed during the interviews were:

- Background information and church involvement.
- How the church is responding to HIV stigma.
- Church and community perceptions of HIV and PLWHA.
- Description and views of how HIV and PLWHA are treated in the church and community.
- Church activities towards church HIV sufferers and carers.
- Whether the church offers any space for HIV and PLWHA to disclose their HIV status.

## 3.3.1 Subject selection and details of subjects

30 semi-structured individual in-depth interviews were conducted with people who belonged to the three church groupings (Anglican, Roman Catholic and Apostolic). These informants were selected according to the following criteria:

- They belonged to one of the church groups and had not participated in community conversations.
- They were identified as good informants by a CHW. Good informants are those who have resided in the community for a long period, are considered to be active members of the church and have witnessed how the church responds to AIDS.

These interviewees were contacted by the CHW, myself and a social worker after the CHW had suggested the person as a potential participant. Good rapport was established by myself and assistant researcher (who was also a professional social worker). Most participants disclosed their HIV status though it was not a criterion of inclusion. Establishing views on how church groups respond to AIDS was paramount to my research, as reflected by theoretical framework that I was exploring and refining throughout the fieldwork period.

Method	Gender of participants	Site	Represented church group	
Individual in- depth interviews	8 males and 10 females	Muonde	Apostolic, Roman Catholic and Anglican	
	7 males and 11 females	Matohwe	Apostolic, Roman Catholic and Anglican	
	4 males and 5 females	Muhacha	Apostolic, Roman catholic and Anglican	
	4 males and 5 females	Matamba	Apostolic, Roman Catholic and Anglican	

#### Table 6: Demographic table of individual in-depth interviews

## 3.3.2 Method of data collection

Purposive sampling was used to recruit church members from the three church groups. The participants were recruited from their homes by the community health worker who was also our village guide. Village guides are women who BRTI has contacted in the past to assist with research. They are respected local women who have lived in the community for a long time. The village guide would discuss the objectives of the study with the participant and ask if they would consent verbally prior to my and the assistant researcher's arrival. When meeting the selected participants, we would discuss the objectives of the study and together read the consent form which they would sign if they agreed to be interviewed. No-one declined to be interviewed, however one apostolic woman stated that the church do not allow women to talk to men alone. We ensured that her interview was conducted by the researcher who is female. Most members were interviewed in their homes and a few were interviewed at a convenient place such as a local clinic or school.

#### 3.3.3 Method of analysis

I used Attride-Stirling's thematic network as a guiding tool for my analysis of the individual interviews. Attride-Stirling states that thematic network analysis, "simply provides a technique for breaking up text and finding within it explicit rationalizations and their implicit signification" (Attride-Stirling, 2001, p. 388). Being guided by my research questions and reading through the excerpts of my transcriptions. Attride-Stirling's methods of thematic analysis of linking an excerpt to basic, organising and

global themes enhanced my understanding of the rational and significance of my research.

Thematic analysis seeks to unearth the themes that are salient in a text and to construct visual thematic network maps that facilitate the structuring and depiction of these themes.

Attride- Stirling states six stages for questioning explicit statements made by research participants to uncover implicit social meanings such as how interviewees cited stigmatising attitudes within church groups. Below I discuss the stages I used by illustrating the steps I took during coding my data and thematic networks.

#### Categorisation and coding (step1)

The initial stage of the analysis involved reading through all the transcriptions. I took five transcriptions that I gave to an independent person who understands the context of Zimbabwe code 5 interviews after explaining how I coded my data. Though the person coded manually, our themes were almost the same. For example within the theme of 'misconceptions held' we both coded issues such as: (i) having sex with a virgin will cure HIV (ii) people refusing to go to the hospital believing that they have been bewitched (iii) HIV denial and (iv) visiting traditional healers. One of the codes we did not agree on was how other people cited HIV to be a spiritual battle that can be cured through prayer. We later agreed that it can be both a misconception or be used as a tool of shunning PLWHA.

I analysed all my interview transcripts in Atlas ti, the data set is referred to as the 'hermeneutic unit'. This is the source that stores all my primary documents. For an example of coding in atlas ti see appendix 8. This provided a clear overview of the codes.

#### Identification of themes (step 2)

After the first round of coding I had a total of 978 codes. The text segments (quotes) that belonged to each code were re-read and emerging silent themes were grouped. I managed to merge the codes and reduced the codes to a total of 350 and 30

respectively. An initial reading of my transcriptions resulted in identifying excerpts that facilitated coding of my data descriptively in sub basic themes. The next step of analysis involved organising these sub – basic themes into basic themes.

#### Constructing the network (step 3)

I had to organise these basic themes into organising themes. I clustered basic themes into larger issues that shared the same meaning. For example basic themes of symbolic stigma, denial, gendered blame, courtesy stigma, gossip about those who have disclosed, discourage condom use (Apostolic only) , encourage polygamy (Apostolic only) and silence women in church were categorised under unhelpful attitudes (see appendix 5). A similar process was followed for organising themes which were clustered together into global themes as categories. These global categories resulted from interpreting the core representations and social psychological motives underlying people's accounts and conversations about their strategies to tackle AIDS stigma and experience of how the church responds to AIDS stigma.

My analysis resulted in a web-like network (see chapter 5) that serves as an organizing principle and a representational means of interpreting my data. A detailed table that makes explicit the procedures that I employed in going from text to interpretation is inserted as appendix 5.

#### Exploring and interpreting the thematic networks (steps 4, 5 and 6)

The three stages involves going back to the original data after having the web like network. I refined my understanding of my themes, re-examined my excerpts with my themes. A detailed explanation of the interpretation of my analysis is presented in chapters 5 and 6. In chapter 7 I relate these findings and interpretations to my conceptual framework and research questions. Chapter 8 concludes with the objectives and discusses ideas of future research.

## 3.3.4 Atlas-Ti Coding frame

To facilitate further the analysis of community conversations (discussed in detail below) and individual interviews. I imported my transcripts into a qualitative software

programme called Atlas-Ti. Drawing on my methodological considerations, I read through every excerpt and then coded it being guided by the grounded theory approach.

#### 3.4 Community conversations

#### 3.4.1 Community conversations defined

I chose to use community conversations (CCs) because I consider them to be an appropriate way of exploring the role of churches in tackling HIV and AIDS stigma and facilitating stronger responses. As discussed above, dialogue between liked and trusted peers plays a key a role in enabling people to develop more effective responses to the complex and often taboo topic of HIV/AIDS. Community conversations create a space for mutual learning and result in new perspectives. The approach emerged from the work of the Salvation Army in Zambia and Enda Tiers Monde/San<sup>6</sup>e (Senegal) in the mid-1990s. It was then adopted by UNDP in 2002 as a result of their success in creating transformation at the community and institutional levels using this method (UNDP, 2005).

The term 'community conversation' describes discussions among local people, guided by a trained facilitator, that support critical thinking and problem solving around key community issues (Born, 2008). Community conversations have been used to address a range of issues including: mental health stigma among ethnic minorities in Scotland (Knifton, et al., 2010); increasing employment opportunities for high school youth with disabilities (Carter, et al., 2009); improving early childhood educational alignment (Rogers & McComas, 2010); and efforts to determine health issues and better meet health needs among populations such as rural people, particularly Native Americans, in North Dakota (Moulton, Miller, Offutt, & Gibbens, 2007) and elderly Cambodian refugees in Massachusetts (Grigg-Saito et al., 2008). The term has been applied to post-performance or talkback sessions in the field of community theatre or film screenings on issues ranging from the incarceration of African American men to environmental justice (Ellis, 2000; Born, 2008).

However, whilst the approach is widely used, there is little or no systematic account of the methodology of community conversations methodology in the peer-reviewed academic literature. Moreover, the vast majority of the few articles that exist discuss

initiatives in North America, with almost no academic writing on the use of community conversations to address issues in resource-poor countries. However, in the literature below, the United Nations Development Program (UNDP) has pioneered the use of this method in resource-poor communities in Africa, particularly surrounding gender and HIV issues in Ethiopia (UNDP, 2004). In this context, the effectiveness of this methodology in changing community attitudes and practices first came to light through the work of Ethiopian women's rights campaigner Dr. Bogaletch Gebre. She founded the African women's self-help centre Kembatti Mentti Gezzimma (KMG) and has been credited with almost single-handedly eradicating the practice of female genital mutilation in Ethiopia (Shetty, 2007) primarily through developing and implementing the community conversations technique.

Community conversations have been successfully implemented in a number of countries in Africa including Kenya, Ethiopia, South- Africa and Malaysia. For example, community conversations were used to challenge a high risk sexual practice in Kenya where a widow is supposed to be cleansed or purified after the death of her husband to prepare her for remarriage. This cleansing is thought to take place when the widow has sex with the men of her late husband's family. Through community conversations the community identified this practice as one that could potentially increase the spread of HIV. Through facilitated conversations the community were able to agree on an alternative method of cleansing that was non-sexual (UNDP 2005).

Although some researchers loosely use the term 'community conversation' to describe an informal focus group (Megwa, 2007) or discursive trends in a community (i.e. the ways people talk about issues in their lives) (Wexler, 2006), community conversations are generally considered to be a unique and new intervention type that is distinct from focus groups in several key ways (Ellis, 2000). Firstly community conversations are focused on generating action plans. They have an explicitly 'problem solving' agenda, aiming to spur critical thought that enables people to formulate local solutions to local issues. By comparison focus groups are more research oriented, aiming to gather information about social relations and understandings. In addition, community conversations explicitly aim to change participants' worldviews and conceptions of what is possible, while focus groups aim merely to understand things as they are.

Community conversations are an interactive process which bring people together, engaging communities in discussion and exploration of the underlying causes fuelling a social phenomenon such as HIV/AIDS stigma in their environment. The technique is explicitly based on the recognition that people have the capacity, knowledge and resources to transform individually and collectively once they develop a sense of ownership of a problem, confidence in their abilities to tackle it and are able to identify recipes for individual and group action in this regard (Getaneh et al., 2008).

#### **Conducting community conversations**

Nearly always used in the context of solving social problems, the methodology of conducting community conversations involves posing questions and thinking points about why problematic social situations are the way they are, what actual and latent local responses and strengths already exist in the community to tackle these and how problematic social relations could be improved. Community conversations are ideally conducted by facilitators who are regarded as local and invested in the community (UNDP, 2004) and who local people trust (Shetty, 2007). The facilitator brings together a group of people who consider themselves to be members of the same community, generally because they live in the same area and experience with the same local strengths and challenges.

Groups must be small enough to ensure that all members have an opportunity to speak, but large enough to maximize discussion and diversity of opinion—six to ten people. The facilitator poses questions to the group and invites discussion, emphasizing the importance of respectful disagreement, honesty and problem solving (Born, 2008). Dr. Gebre, the pioneer of community conversations in Ethiopia, recognizes that conversations may have to take up practical and immediately pressing issues in a community (such as a broken bridge) before moving on to deeper, systemic or taboo issues (such as female genital mutilation or HIV) (Shetty, 2007). The facilitator does not attempt to teach or advise community members; instead, his or her role is to bring out pre-existing community understandings and strengths and to encourage the community to analyse and solve local problems. As problems and solutions are discussed, the facilitator guides the participants to develop concrete action plans (Born, 2008). Ideally, the facilitator will convene

additional conversations on an on-going basis to discuss how implementing the action plans is going and develop additional strategies to overcome challenges.

On this basis I selected my community conversations interviewees using purposeful sampling. Purposeful sampling is a non-representative subset of some larger population, and is constructed to serve a very specific need or purpose. In analysing my data I am focusing on how church groups perpetuate or reduce HIV/AIDS stigma. All the community conversations were conducted at an allocated venue in the various communities. The conversations took an average of 90 minutes. Participants in community conversation groups are to share a common past, or have a common future project and may have broadly similar concerns and values (Bauer & Gaskell, 2000). I assumed that church groups would constitute such a group. Each community conversations conducted. See appendix 2 for the topic guide used. An overview of the themes discussed were:

- Is there HIV stigma in the community? What forms does it take?
- Is the church tackling HIV stigma? If so, how?
- What activities are church members doing to tackle HIV stigma?
- What factors facilitate their actions?
- What hindrances did they face in implementing their activities?

## 3.4.2 Subject selection and details of subjects

The participants were selected according to the following criteria:

- A community health worker would verify that the person belonged to any of the three church groupings.
- Participants must participate in church activities but not hold any influential positions in church.

More women than men volunteered to participate in the study; this is partly because women are the ones who stay in the communities, while men go and search for work in towns.

Method	Gender of participants	Site	Represented church group
Community Conversations	36 males and 45 males	Muonde	Anglican, Roman Catholic and Anglican
	37 males and 44 females	Matohwe	Anglican, Roman Catholic and Anglican
	12 males and 15 females	Muhacha	Roman Catholic, Apostolic and Anglican
	12 males and 12 females	Matamba	Anglican, Apostolic and Roman catholic

#### Table 7: Demographic Table of Community Conversations

## 3.4.3 Action research procedure

The wider context of this study is my interest in the possibility of shifting HIV and AIDS management away from 'intervention by outsiders' in favour of 'facilitation of local responses' to tackle HIV stigma. The aims of the CCs workshops were to facilitate social space in which community members could engage in dialogue and debate about the impact that HIV and AIDS has on local people in the interest of:

- i. Airing doubts and uncertainties about HIV and AIDS, in the interests of addressing competing beliefs that stand in the way of acceptance of biomedical information about transmission and prevention.
- ii. Brainstorming what local community resources could be mobilised in order to facilitate HIV and AIDS management and factors most likely to facilitate or hinder the mobilisation of these resources.
- Facilitating the development of ideas regarding the types of individual and collective level action/change that could facilitate or hinder more effective HIV and AIDS management

## 3.4.4 Data collection

Community conversations and individual interviews were conducted between May 2008 and January 2009 over a three month gap. The cross-sectional data were collected between 2003 and 2005 by a research team (see chapter 4). All the qualitative interviews were conducted by myself with the assistance of a male social worker. The qualitative data were collected in three phases which I refer to as Time 1, Time 2 and Time 3. During T3 I conducted one round of CCs to two similar

communities with the ones that I conducted CCs. These two communities are referred as control groups since I only conducted one round of CCs. I included control groups in T3 because I wanted to find out if CCs had made any difference with regards to tackling HIV stigma or not. All the individual interviews and community conversations of each phase were transcribed and summarily analysed before conducting the next phase, allowing for the modification of the topic guides when required.

		Roman Catholic		Protestant		Apostolic	
Time	Activity	intervention	control	intervention	control	intervention	control
1: Mar,	individual interviews	6	0	6	0	6	0
2008	community conversatio ns	2	0	2	0	2	0
2: Sept, 2008	community conversatio ns	2	0	2	0	2	0
3: Jan, 2009	individual interviews	6	6	6	6	6	6
	community conversatio ns	2	2	2	2	2	2

#### **Table 8: Community Conversations Conducted**

#### 3.4.5 Method of analysis

For my CCs I used Attride-Stirling's thematic analysis as discussed in my individual in-depth method of analysis. I counted the number of helpful and unhelpful strategies suggested by CC participants at T1, T2, T3 and control group. I then presented the data using bar charts.

## 3.5 Action research

Similar to Freire's problem-posing approach, CCs provide space for dialogue between interviewees with the facilitation of an interviewer. Freire uses the term dialogue to mean discussion between social groups "in a trusting environment in which people who share ideas and experiences together develop new understanding and awareness" (Rifkin & Pridmore, 2001, p. 11). He further used the term 'praxis'

which he coined as process of reflection and action on the world in order to transform it (Freire, 1973/1999). Indeed, this is the same approach that is used in CCs.

Freire argues that marginalized people must undergo a process of conscientisation, defined as the process of developing a more critical understanding of the world. CCs provide a space where participants develop a deeper understanding of their own problems and take action to change them---what Freire calls a critical consciousness. The space creates opportunities for interactions that enable participants to be critically aware of the problems that they encounter in everyday life. This awareness through discussion and brainstorming strategies for change and external support can lead to empowerment to take action to address the problems.

Freire's theory has provided an essential contribution to our understanding that generating information is a process rather than a product. Within CCs there is no fixed or standardised way of generating information. CC focus on how people can use the information and knowledge available to them to address the problems that they have. In other settings this approach is known as Participatory Action Research (PAR) which builds on the experience of Kurt Lewin (Rifkin & Pridmore, 2001).

PAR is a type of research that involves all research participants in the research project, from the initial stages of planning through to the last evaluation. The approach involves local people, especially marginalized groups, who have traditionally been the objects and not the subjects of research. Hence this approach no longer views local people as providers of information about their problems or local situation but rather as "partners in generating, interpreting and using information" (Rifkin & Pridmore, 2001). Many terms have been coined to refer to this process; Participatory Learning Action (PLA) is currently the most popular. PAR and community conversations are similar approaches. One of the difference is that PAR is more of an action development project, whereas community conversations are purely action research oriented.

Past research indicates that projects must involve all the local people who are intended to benefit if programmes are to be developed and implemented successfully (Rifkin & Pridmore, 2001). My research aligns with this participatory approach,

seeking to create social spaces for conscientization among members of churches in Zimbabwe.

#### 3.6 Quality criteria and public accountability in qualitative research

Ultimately, this research project aims to contribute to the social psychology of participation discipline. To ensure sustained high quality research, I adopted a quality criteria for my quantitative cross sectional data that was centred on maintaining reliability and validity—vital components of high quality, verifiable research. For qualitative research, the validity and reliability criteria do not allow for an appreciation of the influence of the social context within which church groups are situated. Therefore, for the qualitative research, I used the six quality indicators developed by Gaskell and Bauer (2000); these are discussed further below.

The HIV competence framework, which I employed for my qualitative research, presents particular problems for the application of the concepts of reliability and validity. It is difficult to apply these criteria because many elements of HIV competence are expressed qualitatively and quantitative measures of HIV competence have not been developed. There is need to develop a set of criteria that will ensure that research quality can be assessed and maintained within qualitative research in the public health field. Gaskell and Bauer (2000) have made an effort to this end.

I have chosen the methodological framework and the types of quality indicators to be those most appropriate to the aims of this research project, which are (i) to examine whether social group membership reduces or facilitates stigmatising attitudes towards PLWHA (ii) to explore differences in the ways in which three religious sects (Anglican, Catholic and Apostolic) tackle HIV and AIDS stigma and (iii) to report on an action research study that used community conversations to promote stigma reduction in church groups.

Ultimately, when considering quality indicators for qualitative research, the central concern is ensuring public accountability. Gaskell and Bauer (2000) assert that social research be conducted within a public arena that is open to public scrutiny. Research itself must be relevant to the social good and must maintain public confidence. To facilitate public accountability, Gaskell and Bauer (2000) present the idea of

relevance and confidence. "Confidence indicators allow the reader and receiver of research to be 'confident' that the results of the research represent 'reality' and are more than the product of the vivid imagination of the researcher" (Bauer & Gaskell, 2000, p. 344). Relevance indicators, "refer to the extent to which the research is viable in the sense that it links to theory 'internally' or is a surprise *vis-à-vis* some common sense 'externally'" (Bauer & Gaskell, 2000, p. 345). Drawing on this perspective, Gaskell and Bauer propose six criteria of quality indicators that contribute to confidence and relevance: triangulation and reflexivity, transparency and procedural clarity, corpus construction, thick description, surprise as a contribution to theory and/or common sense and communicative validation. These are discussed below in relation to my methodology:

#### 3.6.1 Triangulation and reflexivity

Flick (1992) argues for the need to use triangulating theoretical perspectives and methods. Within the field of research on social capital, empowerment and critical consciousness and social change, the notion of triangulation and reflexivity has become associated with the use of several methods. Rifkin and Pridmore (2001) as well as Freire (1973/1999), discussed the need for reflexivity in research by emphasising the importance of on-going discussion between researchers about the problem. Addressing a problem from two (or more) perspectives or methods is desirable because, "social phenomena look different as they are approached from different angles" (Bauer & Gaskell, 2000, pp. 344-345).

In this thesis, triangulation has been ensured by the use of three methods of data collection (CCs, individual in- depth interviews and cross-sectional survey data). Reflexivity has been warranted through the CCs method since I conducted three rounds of CCs during my research. While the individual interviews enabled me to reflect on my role, the model I used to conduct the CCs was particularly conducive to extensive reflection for several reasons. First, I had more time with the participants because each CC lasted for well over an hour. Second, I conducted the CCs within a period of nine months (versus the interviews conducted over two months and participants were only seen once), which enabled me to have an in-depth understanding of different issues discussed during the CCs. Each method of data collection has highlighted complexities that are embedded within church groups in tackling HIV stigma.

#### 3.6.2 Transparency and procedural clarity (confidence marker)

It is relatively straightforward to explain how my quantitative cross-sectional data was collected and analysed for transparency and procedural clarity—and I do so throughout my analysis section. However, it is much more difficult to ensure transparency and procedural clarity when it comes to qualitative data, which in the case of this research, are the interviews and community conversations. Full replicability cannot be achieved with these qualitative research methods since conversations depend on individuals and will be always different. Nonetheless the use of computer analysis software called Atlas – ti and the use of another independent person to analyse the data (as explained in the individual interview section) contributed to this transparency by enabling others to see exactly how I linked each excerpt to a code, organized the codes to form basic themes and then developed global themes.

#### 3.6.3 Corpus construction

The main focus of corpus construction is to reach saturation level. Saturation level is when collecting new data no longer adds anything new. It is defined as an "iterative process, where additional strata of people or texts are added to the analysis until saturation is achieved, and further data do not provide [new] observations" (Bauer & Gaskell, 2000, p. 347). This concept is important in qualitative research because often there is a lack of systematic sampling, making it difficult to claim representativeness or external validity. Correct corpus construction also requires that data is all collected within the same period, and that the data is theoretically relevant and as homogenous as possible. This approach influenced the sampling for all of my research methods. In particular, I stopped collecting data for my CCs after reaching saturation level, i.e. when three CCs in a row and five interviews came up with basically the same points.

#### 3.6.3 Thick description

Thick descriptions of the research context enable the readers of research reports to immerse themselves into the data. Thick descriptions offer enough description to allow readers to either accept or reject the interpretations offered by the researcher. However, this notion strongly recommends the reader bring themselves "into the milieu of the social actors" (Bauer & Gaskell, 2000, p. 347). This principle influenced

my analysis; having been born and raised in Zimbabwe and witness to the effects of HIV and AIDS stigma daily, I had a deep understanding of the social context in which I was gathering data. This deep connection with and knowledge of the region and culture enabled me not to be just an observer but to interpret the data through the lens of the participants. Additionally, I provide the reader with an in-depth description of the context in which I conducted research. Also I provide extensive verbatim quotations from the transcripts so that someone who knows nothing about Zimbabwe can come to understand the context.

### 3.6.4 Surprise as a contribution to theory and/or common sense (relevance marker)

A surprise value in any research has been accepted as one of the quality criteria because it shows that the researcher has been open to findings beyond those that he or she expects. Gaskell and Bauer (2000) discuss two forms of surprise value. They suggest that surprise value can take two different forms: it can be a theoretical contribution to a specific discourse or can be associated with common sense. One instance of experiencing surprise during my research involved my expectation that I would find no differences in the way churches encourage people to access HIV services considering the high rate of HIV prevalence in Zimbabwe. Surprisingly most Apostolic churches didn't allow church members to go for HIV testing to the health centres.

#### 3.6.5 Communicative validation (relevance marker)

Another approach of validating data is to discuss your findings with your informants and obtain their agreement with what you find. However, Gaskell and Bauer (2000) do not see this as an essential element for the relevance of research. In fact, they caution against considering consensus with participants vital to good research because the observer and the participants might have different perspectives. Also the community may disagree amongst themselves. If the researcher is not able to report anything unless the participants agree then these different perspectives could result in denying the observer the opportunity to learn from and critique different perspectives. I have not reported my findings to the community during this period due to limited time and financial constraints.

#### 3.7 Ethical considerations for the study

As part of any research, ethical clearance has to be sought before conducting the research. For this research, I sought ethical approval and was granted it from ethics committees at the London School of Economics in England, the Applied and Qualitative Research Ethics Committee in Oxford (N97.039) and the Medical Research Council of Zimbabwe (MRCZ) (number 02187). In the communities, study approval was sought and granted by MRCZ and informed consent was granted by all the participants (see appendix 1). Consent was either written (thumb stamped for those that could not write) or verbal. As part of the agreement, we stated our commitment to maintaining honesty, privacy, confidentiality and trust. We honoured this commitment during the data collection. Pseudonyms and gender of participants have been used to avoid identifying the individuals and their communities.

Before each interview or community conversation, the research assistant or I discussed the role and contribution of the participants with each person involved. Participants were told that they were not getting any incentives apart from a token of appreciation in the form of a t-shirt and/or a meal. Specific permission to tape record the interviews was sought and granted at the beginning of each interview.

#### Summary

In this chapter, I have explained how I conducted the research in order to make it retraceable for others. I have explained the sampling of participants, how the data were analysed, methods of interviews up to the quality criteria and public accountability. The following three chapters present the empirical analysis of the actual data.

### CHAPTER 4: EXPLORING IF SOCIAL GROUP MEMBERSHIP REDUCES STIGMATISING ATTITUDES (Quantitative research)

#### **Chapter Overview**

This chapter examines whether social group membership reduces stigmatising attitudes towards people living with HIV and AIDS (PLWHA). I begin by presenting my research question; thereafter, I report on my analysis, results and conclusions. The analysis is based on quantitative data and is designed to investigate the first research question outlined in the introduction to this thesis, i.e. whether being in a social group reduces stigmatising attitudes and, if so, which types of groups help to reduce stigmatising attitudes. Although church groups are the most popular form of social participation (i.e. 4 163 out of 15 672), I have used social groups because the sample size of being church members is small considering the huge sample size. This secondary analysis was conducted using data from a large-scale cross-sectional population survey of 15 672 people in Manicaland, eastern Zimbabwe.

#### 4.1 Analytical Framework

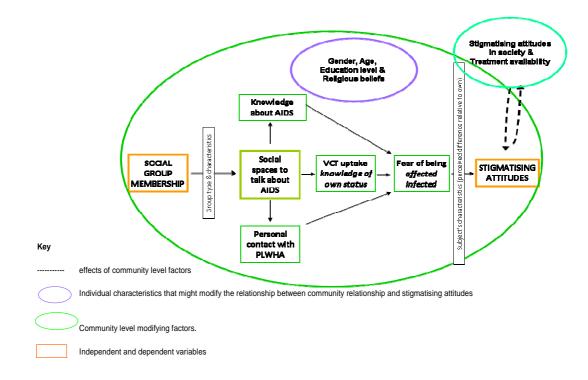
Earlier research has suggested that participation in well-functioning local community groups can be positively associated with successful avoidance of HIV in the Manicaland study communities (Gregson et al., 2004). Based in this earlier finding, I hypothesised that being in a well-functioning social group is associated with less stigmatising attitudes.

I developed a simplified analytical framework to explore the different trajectories through which social group membership could increase or decrease stigmatising attitudes. This framework is summarised in Figure 1 below and focuses on the individual-level determinants of stigmatising attitudes and behaviour.

The analytical framework is based on the literature review presented in Chapter 2 and represents an attempt to operationalise the theoretical framework developed in that chapter. Social groups are thought to provide social spaces within which members discuss and debate HIV/AIDS issues, which, in turn, can facilitate the development of less stigmatising attitudes. This could happen, for example, through acquiring improved knowledge about how HIV is transmitted and the symptoms of

AIDS, increased contact with and familiarity with PLWHA, and/or increased uptake of testing and counselling services leading to greater awareness of their own HIV-infection status.

## Figure 1: Individual-level determinants of stigmatising attitudes & behaviour: analytical framework



In this chapter, I begin to investigate my hypothesis and analytical framework by establishing whether a statistical association exists between group membership and less stigmatising attitudes towards PLWHA in cross-sectional data from our study communities in eastern Zimbabwe. For future investigations there is need to conduct further investigations using longitudinal data and investigations to explore the specific causal pathways suggested in the analytical framework.

The analytical framework also suggests that underlying levels and patterns of stigma vary between societies according, for example, to differences in cultural and religious

beliefs and availability of antiretroviral therapy. Within a given society, Parker and Aggleton (2003) suggest that attitudes towards, for example, a specific HIV-infected individual will depend not only on perceived differences in HIV infection status (which may be altered following testing and counselling) but also on differences in varying combinations of devalued social markers such as gender, age, sexual orientation, class, race or ethnicity. Such relations of power and control create space for some groups to devalue others based on these differences. Similarily, individuals in the same community may be more or less likely to hold stigmatising attitudes depending upon a number of factors including gender, age and education level. Where possible, I will control for these potential confounding factors in my analysis.

#### 4.2 Results

#### 4.2.1 Patterns of social group membership

Men and women who reported membership of at least one well-functioning social group were 34.2% (2128/6220) and 57.8% (5418/9376), respectively.

Figure 2 below shows broadly similar age patterns of group membership for both sexes. However, older men were somewhat under-represented and, for women, the age group of 30-39 years was slightly under-represented. Variations were noted between the different types of groups. To elaborate, fewer people between 15 and 19 years of age were in political parties, savings clubs, burial societies, farmers groups, co-operatives or women's groups. More of the 15 to 19 year-olds were in sports clubs and youth groups. The reverse pattern was observed for older people. The males in church groups tended to be younger than their female counterparts.

Figure 3 shows that a wide range of different groups are represented. However, church groups predominate in all areas for both sexes, being somewhat less popular for men and more popular for women in towns and estates. The other groups that are most popular for males were sports and youth clubs (for those residing in rural business centres [RBC]), burial societies (in more rural locations) and political groups (in towns). For women, burial societies were the next most common group.

The pie charts in Figure 4 show the distributions for males and female respondents by the type of group they spend most time in. The results show a similar picture to

what was seen for group membership (Figure 3). Males spend most time in church groups followed by sports clubs and burial societies. Females also spend most time in church groups followed by burial societies.

Figure 2: Distribution of male and female respondents participating in social groups by age-group

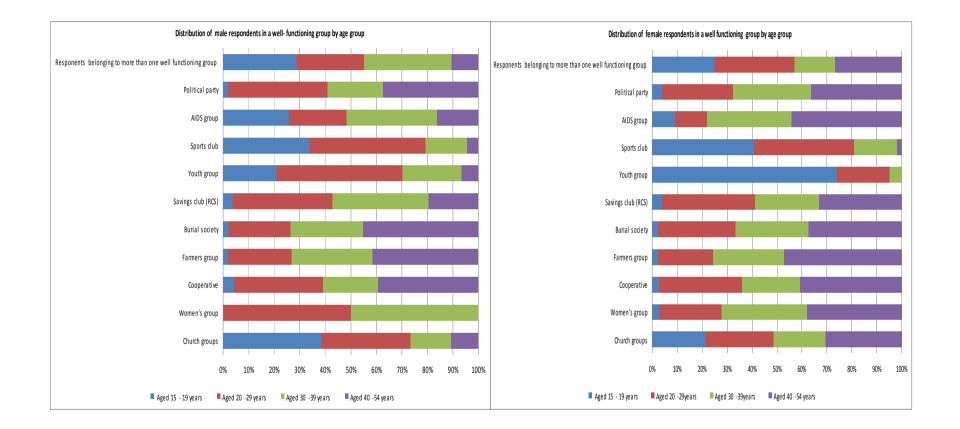
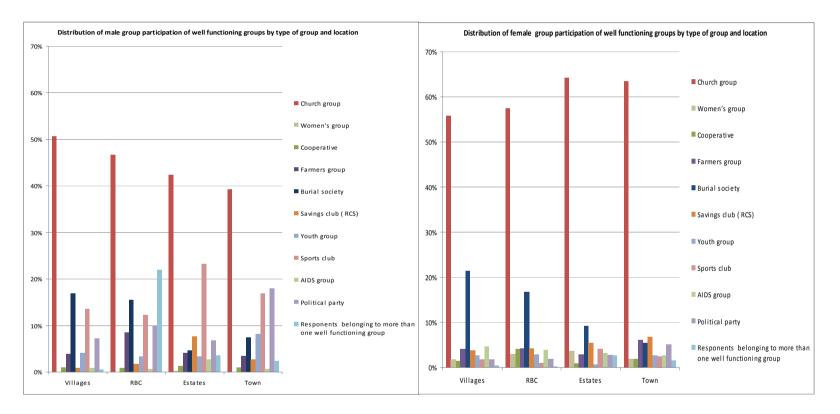
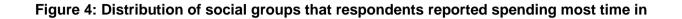
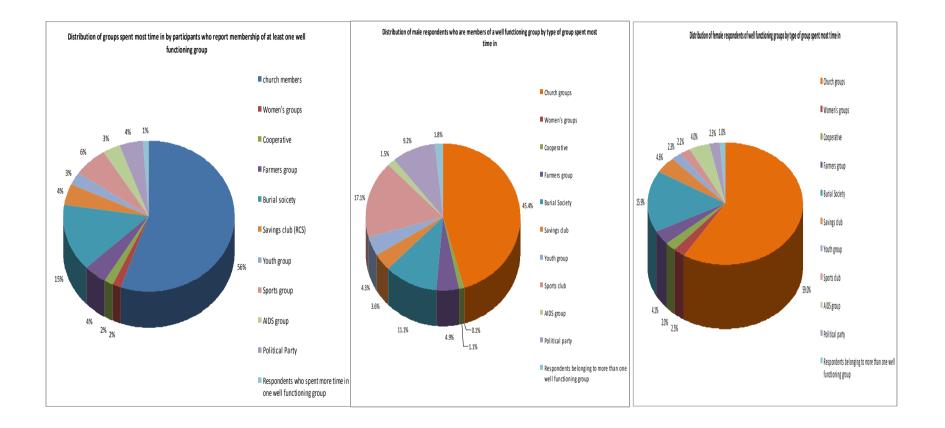


Figure 3: Distribution of male and female respondents in social groups by type of group and location







4.2.2 Socio-demographic and economic determinants of stigmatising attitudes

5.7% (95% CI, 5.1%, 6.3%; N=6220) of the men in the study reported stigmatising attitudes while 6.1% of the females reported stigmatising attitudes (95% CI, 5.6%, 6.5%; N=9376).

**Gender**: For both sexes, younger individuals were more likely than older people to be unwilling to care for a relative with AIDS (Figure 5). The data also suggest that there may be more stigma amongst females compared to males at young ages but that this difference disappears at older ages. After adjusting for differences in age, females were more likely than males to be unwilling to care for a relative with AIDS (age-adjusted odds ratio (aOR), 1.1, 95% CI, 1.0, 1.4; p=0.018).

**School education**: 76.3% (1476/6220) of males and 58.6% (3883/9376) of females who participated in the survey reported at least some secondary school education. Figure 6 shows the age-patterns of stigma by level of education for each sex separately. Males with secondary education were more likely than those without to be willing to care for a relative with AIDS (5.0% vs. 7.9%; aOR, 0.46, 95% CI, 0.34, 0.56; *p*<0.001). Amongst women, those with more education were more likely to be unwilling to care for a relative with AIDS overall (6.5% vs. 5.5%) but this difference was reversed after the younger ages of more educated women were taken into account (aOR, 0.65; 95% CI 0.53, 0.79; *p*<0.001). For both sexes, the greater stigma seen amongst less educated individuals disappeared at older ages (Figure 6).

**Employment**: 35.3% (2196/6220) of men and 11.9% (1115/9376) of women in the survey were in formal sector employment. Men and women with jobs were more likely to be willing to care for a relative with AIDS but this difference disappeared after controlling for differences in age and education (men: 4.5% vs. 6.4%; aOR, 1.03; p=0.8; women: 5.6% vs. 6.1%; aOR, 1.06; p=0.7).

**Location**: 5.7%, 5.6%, 6.8% and 5.3% of men in towns, estates, RBCs and villages, respectively, reported stigmatising attitudes (Figure 7). The equivalent percentages

for females were: 6.2%, 7.1%, 5.9% and 5.3%. For both sexes, no significant differences were found after adjusting for age.

Figure 5: Percentage of respondents unwilling to care for PLWHA by gender and age group

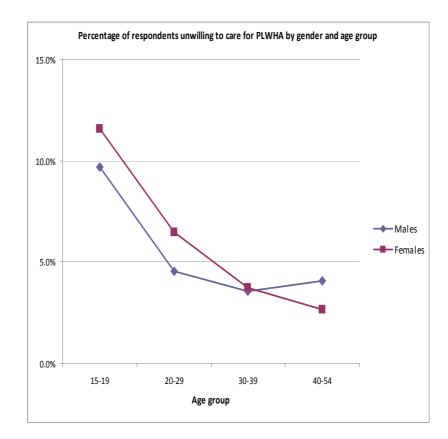


Figure 6: Percentage of respondents unwilling to care for a PLWHA by gender and highest level of education attained

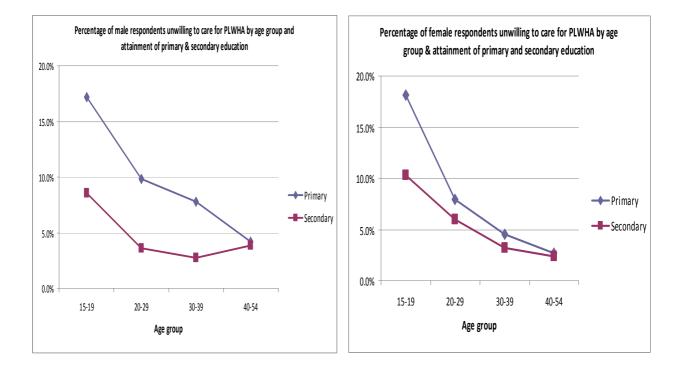
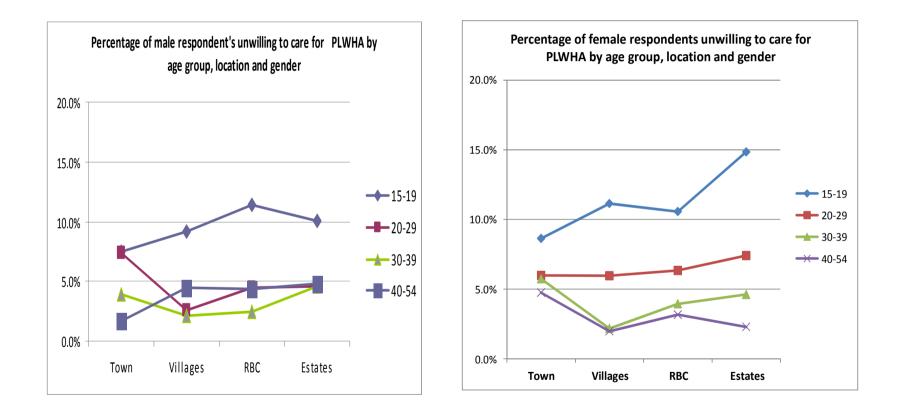


Figure 7: Percentage of respondents unwilling to care for PLWHA by age group, location and gender



#### 4.2.3 Statistical associations between social group membership and stigma

In the crude model, men who participated in groups were significantly less likely to report stigmatising attitudes than those not in groups (OR= 0.70; 95% CI, 0.55-0.89; p=0.003) (Table 7). This difference was still significant after controlling for differences in age between men who do and do not participate in groups (aOR =0.72, 95% CI, 0.57-0.92; p=0.008). Even after controlling for other confounding factors such as education, being in formal sector employment and location of residence, the difference remained statistically significant (aOR=0.75; 95% CI, 0.59, 0.95; p=0.019).

Similarly, females who participated in groups were significantly less likely to report stigmatising attitudes than those not in groups (OR= 0.54, 95% CI, 0.46, 0.64; p<0.001) (Table 8).The difference was still significant after controlling for differences in age between women who do and do not participate in groups (aOR= 0.68, 95% CI, 0.57-0.81; p=0.008). Again, the difference remained strongly significant even after controlling for other possible confounding factors such as education, being in formal sector employment and location of residence (aOR=0.70, 95% CI, 0.59-0.84; p<0.001).

Table 9: Tests for association between social group membership and being unwilling to care for PLWHA: crude, age-adjusted and fully-adjusted models (males)

ICR99% ClpaCR99% ClpaCR99% ClpaCR99% ClpAll men5.7% (5.%, 6.%)62.06.207.00	Males	% unwilling (95% CI)	N	Crude mode	el		Age grou	р		Full mode	el	
Imma functioning groups         Yes         4.5 % (3.6%, 5.4%)         21.28         0.7         (0.55, 0.89)         0.03         0.72         (0.57, 0.92)         0.01         0.75         (0.59, 0.95)         0.02           No         6.4 % (5.6 %, 7.1%)         4092         1         1         1         1           Age group         1.00         1.00         1.01         1.01         1.01         1.01         0.33         0.63         0.03         0.01         0.32         0.33,0.56         <.010           20-29 year olds         9.6% (8.3%, 11.1%         1757         -         -         -         1         -         1         -				OR	(95% CI)	р	aOR	(95%CI)	р	aOR	(95% CI)	р
Yes         4.5 % (3.6%, 5.4%)         2128         0.7         (0.55, 0.89)         0,003         0.72         (0.57, 0.92)         0.01         0.75         (0.59, 0.95)         0.02           No         6.4 % (5.6 %, 7.1%)         4092         1         1         1         1           Age group         1         1         1         1         1         1           20-29 year olds         4.5% (3.7%, 5.4%)         2250         -         -         1         1         1           20-29 year olds         3.6% (2.5%, 4.6%)         1204         -         -         0.45         (0.35, 0.58)         <0.01         0.43         (0.33, 0.56)         <0.01           30-39 year olds         3.6% (2.5%, 4.6%)         1204         -         -         -         0.45         (0.35, 0.58)         <0.01         0.32         (0.22, 0.46)         <0.01           40-54 year olds         41% (2.8%, 5.3%)         1009         -         -         -         0.40         (0.28, 0.57)         <0.01         0.22         (0.17, 0.38)         <0.01           Education         -         -         -         -         -         -         -         -         -         -         -         -	All men	5.7 %(5.1%,6.3%)	6220	-	-	-	-	-	-	-	-	-
No         6.4 % (5.6 %, 7.1%)         4092         1         1.00         1           Age group         1         1         1           20-29 year olds         4.5% (3.7%, 5.4%)         2250         -         -         1         -         1           20-29 year olds         4.5% (3.7%, 5.4%)         2250         -         -         0.45         (0.35, 0.58)         <0.01	men in well functioning groups											
Age group         15-19 year olds         9.6% (8.3%, 11.1%         1757         -         -         1         1           20-29 year olds         4.5% (3.7%, 5.4%)         2250         -         -         0.45         (0.35, 0.58)         <0.001	Yes	4.5 % (3.6%,5.4%)	2128	0.7	(0.55, 0.89)	0,003	0.72	(0.57, 0.92)	0.01	0.75	(0.59, 0.95)	0.02
15.19 yar olds       9.6% (8.3%, 11.1%       1757       -       -       1       1       1         20-29 year olds       4.5% (3.7%, 5.4%)       2250       -       -       0.45       (0.35, 0.58)       <0.01	No	6.4 % (5.6 %, 7.1%)	4092	1			1.00			1		
20-29 year olds       4.5% (3.7%, 5.4%)       2250       -       -       0.45       (0.35, 0.58)       <0.01	Age group											
30-39 year olds       3.6% (2.5%, 4.6%)       1204       -       -       0.35       (0.25, 0.50)       <0.01	15-19 year olds	9.6% (8.3%, 11.1%	1757	-	-	-	1			1		
40-54 year olds       41% (2.8%, 5.3%)       1009       -       -       0.40       (0.28, 0.57)       <0.01	20-29 year olds	4.5% (3.7%, 5.4%)	2250	-	-	-	0.45	(0.35, 0.58)	<0.001	0.43	(0.33, 0.56)	<0.001
Education         Primary ( or less)         7.9% (6.6%,9.3%)         1476         -         -         -         -         1           Secondary (or less)         5.0% (4.4%, 5.7%)         4744         -         -         -         -         -         1 <b>Employment</b> -         -         -         -         -         0.45         (0.35, 0.58)         <0.001	30-39 year olds	3.6% (2.5%, 4.6%)	1204	-	-	-	0.35	(0.25, 050)	<0.001	0.32	(0.22, 0.46)	<0.001
Primary (or less)       7.9% (6.6%,9.3%)       1476       -       -       -       -       -       1         Secondary (or less)       5.0% (4.4%, 5.7%)       4744       -       -       -       -       -       -       1         Employment       -       -       -       -       -       -       -       0.45       (0.35, 0.58)       <0.01         Yes       4.5% (3.6%, 5.4%)       2196       -       -       -       -       -       -       -       0.95       (0.71, 1.28)       0.75         No       6.4% (5.6%, 7.1%)       4024       - <t< td=""><td>40- 54 year olds</td><td>41% (2.8%, 5.3%)</td><td>1009</td><td>-</td><td>-</td><td>-</td><td>0.40</td><td>(0.28, 0.57)</td><td>&lt;0.001</td><td>0.25</td><td>(0.17, 0.38)</td><td>&lt;0.001</td></t<>	40- 54 year olds	41% (2.8%, 5.3%)	1009	-	-	-	0.40	(0.28, 0.57)	<0.001	0.25	(0.17, 0.38)	<0.001
Secondary (or less)       5.0% (4.4%, 5.7%)       4744       -       -       -       -       -       0.45       (0.35, 0.58)       <0.01         Employment       -       -       -       -       -       -       -       0.45       (0.35, 0.58)       <0.01         Yes       4.5% (3.6%, 5.4%)       2196       -       -       -       -       -       -       0.45       (0.35, 0.58)       <0.01         No       6.4% (5.6%, 7.1%)       4024       -       -       -       -       -       -       0.95       (0.71, 1.28)       0.75         Location       -	Education											
Employment         Yes         4.5% (3.6%, 5.4%)         2196         -         -         -         -         -         0.95         (0.71, 1.28)         0.75           No         6.4% (5.6%, 7.1%)         4024         -         -         -         -         -         1         -         -         1         -         -         -         1         -         -         -         -         -         1         - <td< td=""><td>Primary ( or less)</td><td>7.9% (6.6%,9.3%)</td><td>1476</td><td>-</td><td>-</td><td>-</td><td>-</td><td>-</td><td>-</td><td>1</td><td></td><td></td></td<>	Primary ( or less)	7.9% (6.6%,9.3%)	1476	-	-	-	-	-	-	1		
Yes         4.5% (3.6%, 5.4%)         2196         -         -         -         -         -         0.95         (0.71, 1.28)         0.75           No         6.4% (5.6%, 7.1%)         4024         -         -         -         -         -         1         -         -         -         -         -         1         -         -         -         -         -         -         -         1         -	Secondary (or less)	5.0% (4.4%, 5.7%)	4744	-	-	-	-	-	-	0.45	(0.35, 0.58)	<0.001
No         6.4% (5.6%, 7.1%)         4024         -         -         -         -         -         1           Location         Town         5.7% (4.3%, 7.1%)         1052         -         -         -         -         -         1           Estate         5.6% (4.6%, 6.6%)         2084         -         -         -         -         -         1.21         (0.86, 1.71)         0.27	Employment											
Location         5.7% (4.3%, 7.1%)         1052         -         -         -         -         -         1.21         (0.86, 1.71)         0.27           Estate         5.6% (4.6%, 6.6%)         2084         -         -         -         -         1.31         (0.97, 1.77)         0.07	Yes	4.5% (3.6%, 5.4%)	2196	-	-	-	-	-	-	0.95	(0.71, 1.28)	0.75
Town       5.7% (4.3%, 7.1%)       1052       -       -       -       -       -       1.21       (0.86, 1.71)       0.27         Estate       5.6% (4.6%, 6.6%)       2084       -       -       -       -       -       1.31       (0.97, 1.77)       0.07	No	6.4% (5.6%, 7.1%)	4024	-	-	-	-	-	-	1		
Estate 5.6% (4.6%, 6.6%) 2084 1.31 (0.97, 1.77) 0.07	Location											
	Town	5.7% (4.3%, 7.1%)	1052	-	-	-	-	-	-	1.21	(0.86, 1.71)	0.27
RBC 6.8% (5.4%, 8.3%) 1128 1.34 (0.99, 1.82) 0.06	Estate	5.6% (4.6%, 6.6%)	2084	-	-	-	-	-	-	1.31	(0.97, 1.77)	0.07
	RBC	6.8% (5.4%, 8.3%)	1128	-	-	-	-	-	-	1.34	(0.99, 1.82)	0.06
Village 5.3% (4.3%,6.3%) 1956 1	Village	5.3% (4.3%,6.3%)	1956	-	-	-	-	-	-	1		

Male respondents in social groups and unwilling to care for PLWHA- adjusted ORs by age group, education, employment and location

Note CI=confidence intervals for odds ratio (OR) and adjusted odds ratio (aOR)

Table 10: Tests for association between social group membership and being unwilling to care for PLWHA: crude, age-adjusted and fully-adjusted models (females)

Females	% unwilling (95% Cl)	N	Crude me	odel		Age gro	up		Full model	l	
			OR	(95% CI)	Р	OR	(95%CI)	Р	OR	(95% CI)	Р
All females	6.1%(5.6%,6.5%)	9376	-	-	-	-	-	-	-	-	-
females in well functioning groups											
Yes	4.6% (4.0%,5.1%)	5418	0.54	(0.46, 0.64)	<0.001	0.68	(0.57, 0.81)	0.008	0.70	(0.59, 0.84)	<0.001
No	8.1% (7.2%, 8.9%)	3958	1			1			1		
Age group											
15-19 year olds	11.6% (10.2%, 13.0%)	2016	-	-	-	1			1		
20-29 year olds	6.5% (5.6%, 7.3%)	3087	-	-	-	0.54	(0.44 , 0.65)	<0.001	0.51	(0.42, 0.62)	<0.001
30-39 year olds	3.7% (2.9%, 4.6%)	1960	-	-	-	0.32	(0.24, 0.42)	<0.001	0.29	(0.22, 0.38)	<0.001
40- 54 year olds	2.6% (2.0%, 3.3%)	2313	-	-	-	0.23	(0.17, 0.31)	<0.001	0.18	(0.13, 0.25)	<0.001
Education											
Primary ( or less)	5.5% (4.7%,6.2%)	3883	-	-	-	-	-	-	1		
Secondary (or less)	6.5% (5.8%,7.1%)	5493	-	-	-	-	-	-	0.70	(0.57, 0.86)	0.001
Emploment											
Yes	5.6% (4.2%,6.9%)	115	-	-	-	-	-	-	0.95	(0.71, 1.27)	0.739
No	6.1% (5.6%, 6.6%)	8261	-	-	-	-	-	-	1		
Location											
Town	6.2% (5.0%,7.5%)	1362	-	-	-	-	-	-	1.04	(0.79, 1.36)	0.798
Estate	7.1% (6.1%, 8.1%)	2535	-	-	-	-	-	-	1.28	(1.02, 1.60)	0.030
RBC	5.9% (4.9%, 6.9%)	1965	-	-	-	-	-	-	1.15	(0.90, 1.46)	0.266
Village	5.3% (4.5%, 6.0%)	3514	-	-	-	-	-	-	1		

Note CI= Confidence intervals for odds ratio (OR) and adjusted (aOR)

*4.2.4 Associations between group membership and stigma by type of social group* 

The percentages of those unwilling to care for a relative with AIDS and the ageadjusted odds ratios compared to respondents who were not members of any social group are shown for males in Table 7 and Figure 8 and for females in Table 8 and Figure 9. In the two figures, the effect is statistically significant if the 95% CI (shown by the horizontal line) does not cross the vertical line (which corresponds to an aOR of 1).

For males, group membership is associated with reduced stigma for church groups but not quite for non-church groups. For each type of non-church group, stigma is lower than amongst those not in groups at all although none of the differences are statistically significant. The biggest effect size is for AIDS groups but not many men are in these groups (n=31) so the 95% CI is very wide and the difference is not statistically significant.

For females, the effect of group membership is statistically significant (p<0.05) overall and also for church and non-church groups separately. The trend is in the same direction for most group types (exceptions are sports clubs and perhaps political parties) but the difference is only statistically significant for AIDS groups.

# Table 11: Impact of social group membership on stigma, Manicaland,Zimbabwe, by type of group, 2003-2005 (males)

	Unwilling to care	aOR <sup>†</sup> (95% CI)	
Type of group	% (95% CI)		
Cooperative	0.0 (0.0-14.8)	0/23	-
Farmers' group	3.8 (1.1-9.6)	4/104	0.84 (0.30-2.33)
Burial society	4.2 (2.0-7.6)	10/237	0.90 (0.46-1.74)
Rotating credit society	3.9 (0.8-11.0)	3/77	0.80 (0.25-2.56)
Youth club	4.4 (1.2-10.9)	4/91	0.73 (0.26-2.00)
Sports club	5.0 (3.0-7.7)	18/363	0.73 (0.44-1.19)
AIDS group	3.2 (0.1-16.7)	1/31	0.52 (0.07-3.87)
Political party	3.1 (1.1-6.6)	6/195	0.64 (0.28-1.48)
Any type of non-church group	4.4 (3.3-5.7)	51/1161	0.79 (0.58-1.08)
Church group	4.7 (3.4-6.2)	45/967	0.65 (0.47-0.91)
Any type of group	4.5 (3.7-5.5)	96/2128	0.72 (0.57-0.92)
Not a member at R3*	6.4 (5.6-7.1)	260/4092	1

ORs compared with men who were not members of any social groups at R3

<sup>†</sup>Adjusted for age

Member = member of at least one social group

**Figure 8:** Associations (age-adjusted odds ratios [aOR] with 95% CIs) between social group membership and stigma (unwilling to care for a relative with AIDS) by type of group (males)

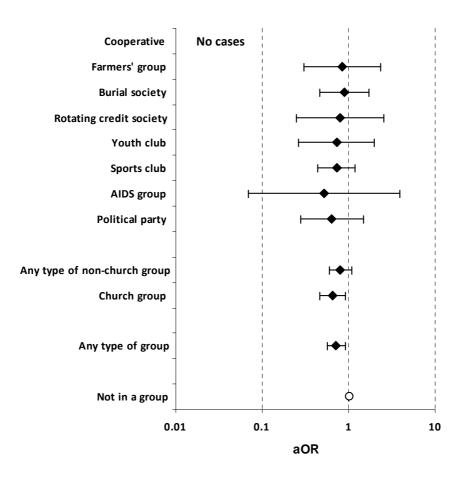


Table 12 : Impact of social group membership on stigma, Manicaland,
Zimbabwe, by type of group, 2003-2005 (females)

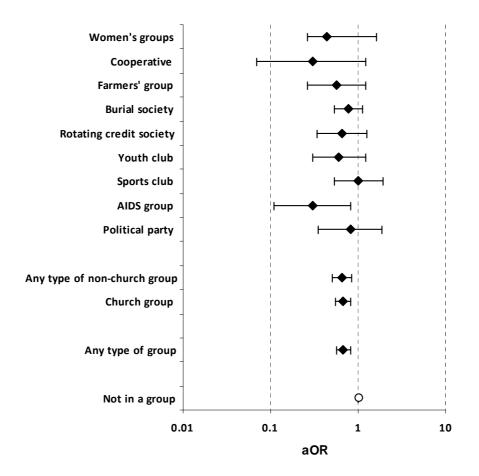
	Unwilling to care	$aOR^{\dagger}$ (95% CI)	
Type of group	% (95% CI)		
Women's groups	3.6 (1.2-8.3)	5/137	0.44 (0.26-1.60)
Cooperative	1.9 (0.2-6.5)	2/108	0.30 (0.07-1.23)
Farmers' group	3.2 (1.3-6.4)	7/221	0.57 (0.26-1.23)
Burial society	4.4 (3.1-6.0)	38/863	0.78 (0.54-1.12)
Rotating credit society	4.0 (2.0-7.3)	10/248	0.66 (0.34-1.26)
Youth club	7.3 (3.4-13.3)	9/124	0.60 (0.30-1.21)
Sports club	9.2 (4.7-15.8)	11/120	1.00 (0.53-1.90)
AIDS group	1.8 (0.5-4.6)	4/218	0.30 (0.11-0.81)
Political party	4.7 (1.8-10.0)	6/127	0.81 (0.35-1.86)
Any type of non-church group	4.1 (3.4-5.1)	92/2222	0.66 (0.51-0.84)
Church group	4.8 (4.1-5.7)	155/3196	0.67 (0.55-0.83)
Any type of group	4.6 (4.0-5.1)	247/5418	0.68 (0.57-0.81)
Not a member at R3*	8.1 (7.3-9.0)	320/3958	1

ORs compared with women who were not members of any social groups at  $\ensuremath{\mathsf{R3}}$ 

<sup>†</sup> Adjusted for age

Member = member of at least one social group

**Figure 9:** Associations (age-adjusted odds ratios [aOR] with 95% CIs) between social group membership and stigma (unwilling to care for a relative with AIDS) by type of group (females)



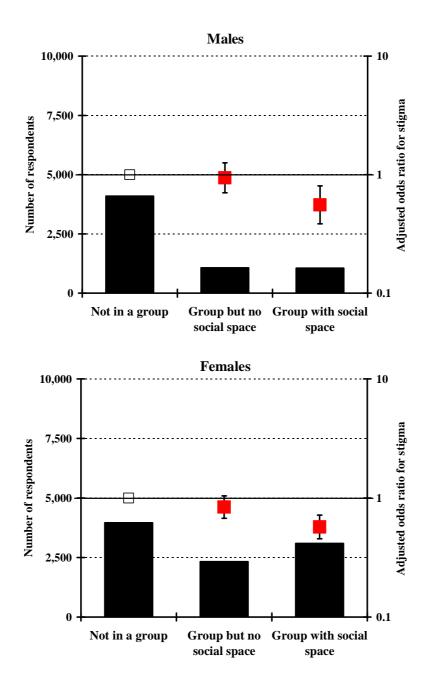
### 4.2.5 Mechanisms through which participation in community groups could reduce stigma

Fifty percent of men and 57% of women who were in groups reported that the community groups they spent most time in met at least once a month and discussed caring for PLWHA either formally or informally (i.e. provided social spaces for discussion of HIV /AIDS). Men and women who participated in groups that did not provide social spaces for discussion about HIV/AIDS had similar levels of stigmatising attitudes to those who did not participate in community groups (Fig. 10.). In contrast, men and women who were members of groups that did provide social spaces for discussion about HIV and AIDS were less likely to express stigmatising attitudes – men: 3.2% versus 6.3% (odds ratio adjusted for age, education, marital status, employment and location of residence (aOR) = 0.56, p = 0.002); women: 3.7% versus 8.1%. (aOR = 0.57, p < 0.001).

Fig. 11 shows the results of the tests of the mechanisms by which the social spaces for discussion about HIV/AIDS created by community groups could help to reduce stigmatising attitudes, as suggested in the analytical framework. For both sexes, exposure to social spaces for discussion about HIV and AIDS is associated with greater VCT uptake and greater contact with PLWHA.

For women, exposure to social spaces for discussion about HIV/AIDS is also positively associated with HIV/AIDS knowledge, but for men, a small but significant negative association was found. For each sex, there is evidence for associations between greater HIV/AIDS knowledge, VCT uptake and contact with non-relatives with AIDS and reduced stigmatising attitudes, although the effects are only statistically significant for HIV/AIDS knowledge and, in women, for contact with PLWHA.

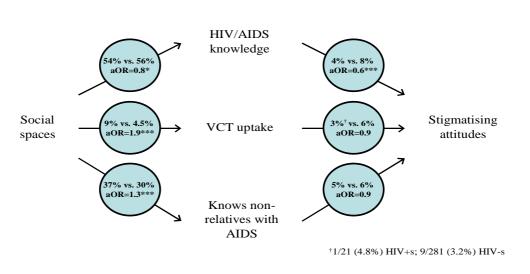
**Figure 10**: Effect of community group membership on stigma by provision of social spaces for discussion about caring for people living with AIDS and gender



<u>NOTE</u>: Histograms show numbers of respondents not in community groups and in community groups according to whether the group provides social spaces for discussion about caring for people living with AIDS. Grey squares show adjusted odds ratios for stigmatising attitudes compared to respondents who were not members of community groups plotted on a logarithmic scale<sup>1</sup>

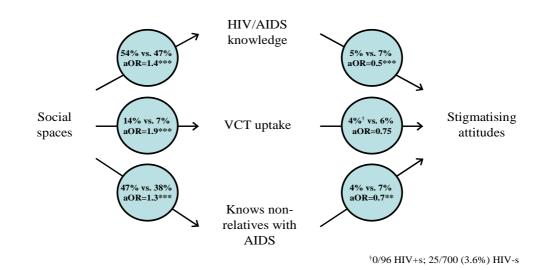
<sup>&</sup>lt;sup>1</sup> Variables adjusted for are age, education, marital status, employment and location of residence

**Figure 11:** Patterns of association between membership of community groups that provide social spaces for discussion about caring for people living with AIDS, hypothesised intermediary factors (knowledge about HIV and AIDS, VCT uptake, and contact with non-relatives with AIDS), and stigmatising attitudes



#### Males

Females



**NOTE**: factors adjusted for both males and females are age, education, marital status, employment and location of residence

4.2.6 Associations between group membership and stigma by type of church

The pie charts below (Figure 12 and 13) show the distributions for males and female respondents by the type of church/religion they belong to. For males, Protestants have the largest membership (36%) followed by Apostolic, Traditional, Roman Catholic, Pentecostal and other churches respectively. For females, Protestant churches are the most common (37%) followed by Apostolic, Roman Catholic, Traditional, Pentecostal and other churches respectively.

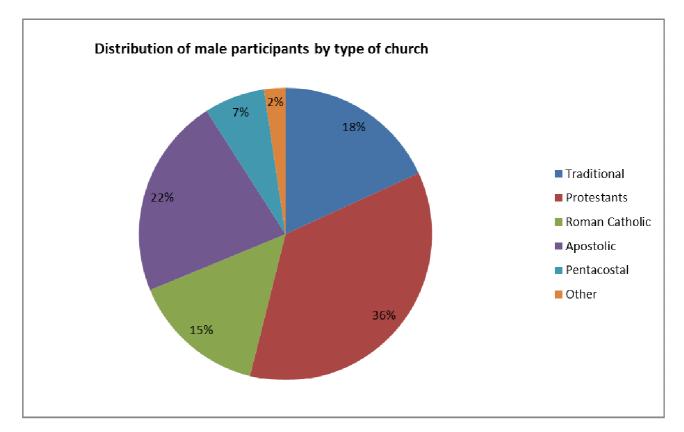
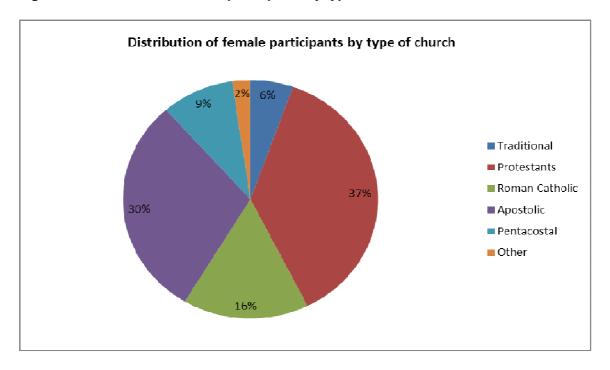


Figure 12: Distribution of male participants by type of church



#### Figure 13: Distribution of female participants by type of church

In the age adjusted model, men in Protestant, Catholic and Apostolic churches, participating in a church group (i.e. within a group of church members who meet at a time outside of regular weekly church gatherings) reported less stigmatising attitudes than those in the same church who do not participate in church groups, although the differences are not statistically significant. For men in Pentecostal and other churches, participating in church groups appears not to have any stigma reducing effects. However this may be partly because the sample sizes are smaller for these churches. Even after controlling for other confounding factors such as education, being in formal sector employment, marital status and location of residence, these patterns remained the same.

For females in all types of churches, participating in a church group is associated with less stigmatising attitudes. The difference is statistically significant for women in Apostolic churches (p=0.001) but not for females in the remaining church types. Slightly fewer women in Apostolic churches participate in church groups than is the case for women in other types of churches. However it appears that participating in these groups may be particularly effective in reducing stigma for Apostolic women.

Table 13: Impact of social group membership on stigma, Manicaland, Zimbabwe, by	
type of church, 2003-2005 (males)	

	Membership functioning	Effect of group membership on stigma amongst church members						
Type of group	% (95%	A	ge group adju	sted	Full model*			
			aOR	(95% Cl)	Р	aOR	(95% Cl)	Ρ
Protestants	23.5 (21.7-25.3)	516/2200	0.68	(0.41-1.11)	0.12	0.65	(0.40-1.08)	0.09
Roman Catholics	19.2 (16.7-21.9)	176/915	0.67	(0.32-1.42)	0.30	0.71	(0.33-1.53)	0.39
Apostolic	23.0 (20.8-25.3)	314/1365	0.63	(0.35-1.13)	0.12	0.64	(0.35-1.16)	0.14
Pentecostal	26.2 (22.0-30.7)	108/413	1.29	(0.56-3.00)	0.55	1.36	(0.58-3.21)	0.48
Other	21.4 (15.0-29.0)	31/145	1.67	(0.28-10.05)	0.57	2.06	(0.29-14.75)	0.47
Traditional or none	0.4 (0.1-1.0)	5/1172	-			-		

\* Adjusted for age group, education, employment, marital status and location of residence

### Table 14: Impact of social group membership on stigma, Manicaland, Zimbabwe, by type of church, 2003-2005 (females)

	Membership functioning	Effect of group membership on stigma amongst church members						
Type of group	% (95%	A	ge group adju	isted	Full model*			
			aOR	(95% Cl)	Р	aOR	(95% Cl)	Р
Protestants	46.5 (44.8-48.1)	1619/3485	0.92	(0.68-1.24)	0.57	0.86	(0.63-1.17)	0.33
Roman Catholics	40.0 (37.6-42.6)	599/1495	0.71	(0.42-1.20)	0.20	0.71	(0.41-1.22)	0.21
Apostolic	37.8 (36.0-39.7)	1059/2798	0.54	(0.38-0.77)	0.001	0.54	(0.37-0.77)	0.001
Pentecostal	48.3 (44.9-51.7)	416/862	0.74	(0.43-1.28)	0.28	0.74	(0.42-1.30)	0.30
Other	44.7 (37.9-51.6)	96/215	0.70	(0.23-2.17)	0.54	0.76	(0.23-2.48)	0.65
Traditional or none	0.2 (0.0-1.1)	1/507	-			-		

\* A djusted for age group, education, employment, marital status and location of residence

### 4.2.7 Patterns of social group membership and associations with stigma in qualitative research study areas

Figure 14 shows the distribution of male and female respondents in social groups in the towns and villages where in-depth qualitative studies were conducted. As was the case for all the study sites, respondents reported church groups as the type of social group they spent most time in. The church groups percentages were as follows: (i) males in villages: 51% (204/397); (ii) females in villages: 54% (676/1,224); (iii) males in towns: 39% (116/295); and (iv) females in towns: 64% (311/490).

After church groups, men in towns spent most time in political parties and sports clubs. In villages, church groups were followed by burial societies and sports clubs. More men in villages participated in church groups than was the case for those residing in towns; for women, it was the reverse - besides church groups, many women in villages spent most time in burial societies.

Social group membership was associated with reduced stigma in the qualitative study areas for both men (aOR, 0.62, 95% CI, 0.39, 0.98; p=0.039) and women (aOR, 0.62, 95% CI, 0.45, 0.86; p=0.004) and in both the towns (aOR, 0.59, 95% CI, 0.40, 0.89; p=0.011) and the villages (aOR, 0.71, 95% CI, 0.49, 1.02; p=0.064) although the effect was only borderline significant in the villages given the limited sample size available.

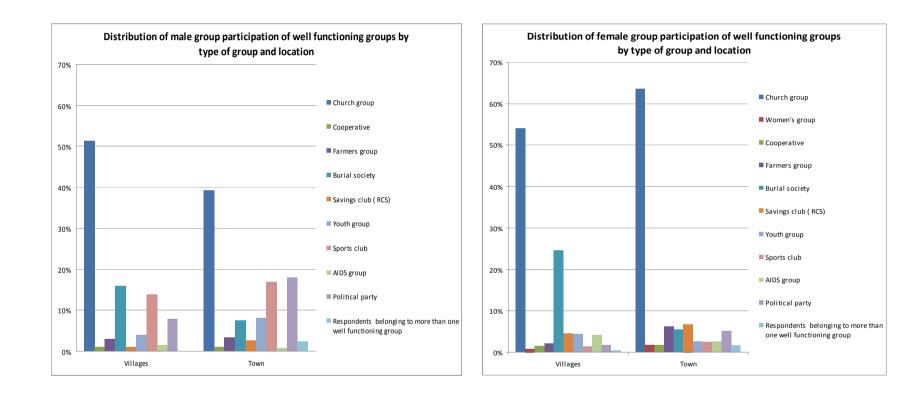


Figure 14: Distribution of male and female participation in well- functioning groups by type of group and location

#### 4.3 Discussion

In these predominantly rural areas in Manicaland province in eastern Zimbabwe, as elsewhere in the country, HIV prevalence has been declining but remains at a high level (Gregson et al., 2006; Gregson et al., 2010). This chapter used data from 12 communities in eastern Zimbabwe to examine if there is any social capital in groups that facilitates or hinders group members' attitudes towards PLWHA. Community group membership was widespread amongst men and (especially) women in eastern Zimbabwe.

Overall, participants who reported spending time in social groups were less likely to report being unwilling to care for a relative who is a PLWHA, which is the variable I used for stigmatising attitudes. This association remained statistically significant for both sexes after controlling for age and other possible confounding factors. Furthermore, the effect was seen in church groups and a broad range of non-church groups. Members of AIDS clubs and church groups were significantly less likely to have stigmatising attitudes towards PLHIV compared to men and women who were not members of community groups. Similar trends, though not significant, were seen in a wide range of different types of groups.

Other factors that appeared to be associated with less stigmatising attitudes towards PLWHA in this population included male gender, older age and higher school education. Employment status and socio-economic strata of residence were not associated with stigma for either sex with the exception of residence on an estate which was associated with greater stigma in the full model for women. I can infer that within the estates it can be difficult to care for a patient due to work commitment and also shortage of accommodation.

In the study, we also developed and tested a new explanatory framework derived from the literature. The data from Zimbabwe support the theory encapsulated in the framework, in that most community groups provided social spaces for informal or formal discussion about caring for PLHIV and members of groups that provided these social spaces were especially unlikely to have stigmatising attitudes towards PLHIV. Furthermore, members of community groups that provided social spaces for AIDS discussions had better knowledge about HIV and AIDS (women only), higher uptake

of VCT services, and greater exposure to PLWHA—factors that, in turn, were associated with less stigmatising attitudes.

Social capital has been found to be helpful in HIV prevention (Campbell, et al., 2002; Gregson, et al., 2004; Pronyk, Harpman, et al., 2008b) but I found only one previous study on its effects on stigma. In South Africa, Chiu and colleagues also found social components to be associated with less stigmatising attitudes towards PLWHA (Chiu, et al., 2008). As far as I am aware, the current study is the first, to provide evidence on the possible causal pathway. This is important because an understanding of how community groups can reduce stigma could be helpful in identifying strategies for strengthening and expanding their role.

#### 4.4 Limitations of the data and analysis

An important limitation of our study is that the data were taken from a cross-sectional survey. Therefore caution should be exercised when interpreting the results because we cannot provide conclusive evidence on direction of causality. The observed association between group membership and lower stigma could be due to the beneficial effects of group membership or might be because people with less stigmatising attitudes are more likely to join social groups.

In the study areas in eastern Zimbabwe, large numbers of male and female residents reported participating in community group activities. Thus, it is possible that these groups have contributed to reducing overall levels of stigma within the study populations. Furthermore, efforts to provide support for community groups (Pronyk et al., 2008a) and to promote discussions about HIV and AIDS within group meetings or informally could be an effective means of reducing current levels of stigma. However, more studies - and particularly longitudinal studies that establish causality and assess the impact of increasing ART availability - are needed in contrasting contexts to confirm our findings and assess their wider generalisability.

A further limitation is that the measure of stigmatizing attitudes was created from a question that asked about willingness to care for a relative who is HIV positive. Responses could have been affected by people's ability to care for a sick person as

much as by their having stigmatising attitudes. Participants who reported being unwilling to care for a relative with AIDS may have expressed their view due to practical obstacles. Those who lived in estates and, to a lesser extent, in towns were more likely to report being unwilling to care for a relative with AIDS possibly due to constrained living conditions. However, this was not the case for participants in formal sector employment ( who may have less time to care for sick relatives) and the statistical association between community group membership and reduced stigma remained after differences in residence were controlled for in the analysis (Tables 9 and 10).

Relatively few men and women reported stigmatising attitudes towards PLHIV. This may have been because of the narrow operational definition used in the study but could also reflect social desirability bias which might possibly have been greater amongst community group members. In particular, a high percentage of the survey respondents reported being willing to care for a sick relative with AIDS; respondents may have felt obliged to say 'yes' when asked this question in the context of an HIV/AIDS survey.

It would have been interesting to have comparable data on willingness to care for a friend, neighbour or work colleague with AIDS.

#### 4.5 Implications and links to qualitative research

Our results provide *prima facie* evidence that social groups may have a helpful part to play in reducing HIV stigma. However, caution is needed at this stage since the results are based on a simple cross-sectional analysis. Given these results, the next steps in the quantitative analysis would be to investigate the likely direction of causation using prospective data from round 3 and 4 of the Manicaland survey. Also, I could not explore other factors such as treatment availability as suggested in the analytical framework since treatment had not yet been widely rolled out.

#### 4.6 Conclusions

Overall, being in a well-functioning social group was closely associated with less stigmatising attitudes. Similar patterns were noted in the villages and towns where the qualitative studies were conducted. The majority of participants stated that church groups were the community groups they spent most time in which confirms our understanding that church groups are the most established social networks in such rural communities. Furthermore, participating in church groups appeared to have similar effects in reducing stigmatising attitudes across the most popular types of churches (the main possible exception being Pentecostal churches for males).

#### Summary

This chapter has provided strong evidence for an association between community group membership and and less stigmatising attitudes towards PLWHA. However, it is still diffcult to establish the direction of causal link. I hope that a later cross sectional analysis will enahance our understanding on association of well functioning community group membership and stigmatising attitudes.

In pursuit of exploring the causal pathways between social group membership and stigmatising attitudes, in chapter 5 I explore how church groups address AIDS and in chapter 6 investigate how community conversations can provide social spaces to address stigmatising attitudes in church groups and communities in towns and villages.

### CHAPTER 5: HOW ARE CHURCHES RESPONDING TO AIDS? (Qualitative research, part I)

#### **Chapter Overview**

This chapter examines how churches are responding to HIV/AIDS by means of a thematic network analysis of individual in-depth interviews conducted with 30 church leaders and members in 2008 and 2009. I begin by presenting my thematic analysis of the interviews, using Attride-Stirling's (2001) thematic network analysis method. Thereafter I present my findings arranged in seven sections, each of which reflects a theme arising from the analysis.

#### Introduction

This chapter addresses the second research question of this thesis, namely: In what ways are churches responding helpfully and unhelpfully to HIV? Exploring this question enables the development of a better understanding of (i) ways in which churches do or do not perpetuate HIV/AIDS stigma and (ii) possible differences in the responses of our three denominations of interest (Anglican, Roman Catholic and Apostolic).

The chapter draws on individual interviews with 30 church members, 10 from each of the three denominations. 10 of the interviewees were church leaders and 4 were PLWHA. These interviews focused on the responses of local churches to the HIV epidemic. Interviews were analysed using thematic network analysis, seeking to generate a data-driven account of how the different churches have responded.

In light of the literature on church groups, and also reports in the popular press about different church's responses to AIDS (Afrol News, 24 March, 2010), I expected to find differences across the three denominations. Surprisingly however, I found many more similarities than differences. For this reason I have collapsed the 30 interviews into a single corpus of data, and except where otherwise stated, most of the data in this chapter refers to common themes that emerged across interviews from each of the three groups.

The only areas of difference relate to attitudes to condoms, the role of women in the church, and attitudes to polygamy. These differences will be flagged as they arise in the course of my discussion of the data.

My approach to qualitative interviewing was informed by Bauer and Gaskell's (2000), which seeks to map out diversity of responses across data set that represents the social representations held by this group of people, rather than trying to generate an account of the attitudes of individual respondents. In this chapter we seek to describe representations as the properties of groups rather than as the attributes of individuals.

My coding frame (See Appendix 5) divided responses into two broad global themes, namely positive and negative responses to PLWHA. Within the positive responses category, further differentiation was made between helpful attitudes and helpful activities. Within the negative responses category, references were only made to unhelpful attitudes, so a distinction between attitudes and activities was not necessary.

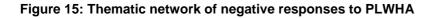
Thematic networks are presented separately for the positive and negative responses which are discussed in turn below. In summary: (i) a greater number of positive responses were mentioned across the data set than negative ones and (ii) there was a difference in the balance of positive and negative attitudes and activities, with heavy emphasis on positive rather than negative actions, but a greater emphasis on negative rather than positive attitudes.

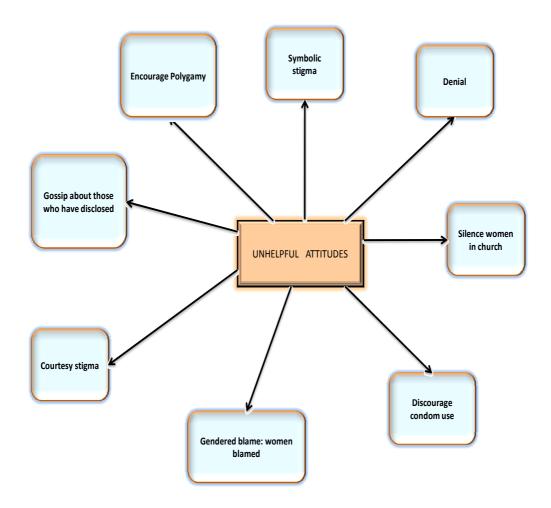
It appeared that churches were able to make kind and helpful action towards HIVpositive people socially acceptable. However, the churches were less able to convey positive attitudes towards people with HIV since these negative attitudes were driven by church teachings. Church teachings on sin and morality made it difficult for church members to openly express positive attitudes to PLWHA.

However, church teachings on love, compassion and care for the sick enabled churches to advocate and support individual acts of kindness and support for PLWHA—due to their status as sick people in need of care. We discuss this contrast between kind actions and negative attitudes further below.

#### 5.1 Findings: Thematic network of negative responses to PLWHA

The thematic network below presents findings of negative response to PLWHA. Interviewees cited how the church negatively responded to AIDS. Codes highlighted include: symbolic stigma, denial, silence of women in the church, discouraging condom use, gendered blame on women, courtesy stigma, gossip about those who disclosed their HIV status and how polygamy is encouraged among the Apostolic. All these codes were then grouped as unhelpful attitudes.





#### 5.2 Findings: Unhelpful attitudes in relation to the fight against AIDS

Church members articulated many unhelpful attitudes towards people living with HIV and AIDS.

#### 5.2.1 Symbolic Stigma

Symbolic stigma describes the moral judgements that cause discrimination (Herek and Capitanio 1998). Symbolic stigma is cultural association of HIV sufferers and other stigmatised groups such as HIV carers. Symbolic stigma is different from other types of stigma, such as instrumental stigma and resource based stigma because it involves a concern about what HIV/AIDS symbolises or judgements regarding HIV/AIDS such as that PLWHA are promiscuous or homosexuals deserve to be infected. The term was developed by Pryor et al. (1999) in relation to the stigma of HIV in the USA in the 1980 because of the disease's association with homosexuality given the high number of gay and bisexual men who were HIV positive. The other types of stigma involve avoiding a disease victim due to fear of infection (instrumental stigma) and when people are against the allocation of limited resources to PLWHA known as resource stigma (Maughan-Brown, 2004).

In my research, respondents frequently linked HIV status to a negative moral judgement, suggesting that some people deserve HIV or are to blame for becoming HIV positive because of immoral or sinful sexual behaviour. Some respondents cited how HIV was associated with blame and deviance in church:

While the church has not really spelt out its response towards HIV and AIDS sufferers, what we see among church members is an attitude that lays blame squarely at the HIV and AIDS sufferer. (Anglican male)

People with HIV were viewed as sinners by some of the respondents: "HIV and AIDS sufferers are sinners because they would have been unfaithful to their marital partners" (Roman Catholic female). Others said, "Some women deserve contracting HIV because they frequent beer halls sharing the same beer with married men when the wife is at home waiting for their husbands" (Apostolic female).

The interviews abounded with references to women with HIV as prostitutes: "For women to disclose one's HIV positive status to church members would be confirming

that the person was prostituting even though they were not" (Anglican male). And there was frequently a generalised attitude of blame in the way people talked:

> Most HIV sufferers deserve to be infected since they were promiscuous. Some of the ladies would have sexual relationships with a lot of men so that they get money to pay rent. Most of the prostitutes are HIV positive, I don't feel sorry for them. (Roman Catholic female)

> If you come and stay here and observe what some ladies do at night, you won't even feel sorry for them. Some women approach your husband when they know that he is married. Do you think I can feel sorry for such a person if she has HIV, when she wanted to destroy my family? (Anglican Female)

#### 5.2.2 Denial

There was evidence for high levels of denial, which emerged in different ways across the interviews. People spoke of AIDS being considered a taboo topic in many church settings:

> It's hard to accept when one is HIV positive, people first consult traditional healers even though they go to church. Traditional healers will then tell them that they have been bewitched... (Roman Catholic Female)

At times people prefer not to acknowledge that someone is HIV positive in church. They normally say the person has a spiritual demon therefore it has to be cast out. When we can all see that it is not demonic...... (Apostolic female).

#### 5.2.3 Church leaders not comfortable discussing AIDS

Many interviewees said that church leaders were not comfortable discussing HIV:

Church leaders don't talk openly to the congregation about HIV and AIDS. I think they are just not comfortable talking about it. (Anglican male) At times these church leaders are scared to talk about AIDS. Once they start talking some members will not attend church anymore. They will think that the church leader will talk about them in church. Besides I think it's safe for them not to talk about AIDS in church until people accept HIV/AIDS. (Female Anglican)

The church thinks that talking openly about HIV and AIDS in church exposes the family and removes the respect they had. Therefore it is considered a taboo topic and they don't talk about it. (Anglican male)

#### 5.2.4 Discouraging disclosure

Many spoke of a general atmosphere which discouraged people with HIV from disclosing their status within the church community:

We see a lot of people collecting their ARVs at the hospital and not tell the church that they are taking ARVs. I think it's good that they don't disclose because as soon as church members know the word will spread in the community. (Anglican female)

It's better for people not to disclose their HIV status. When people suspect that one is HIV positive they will start to refer to that person as a HIV sufferer and not their real name. (Roman Catholic Female)

At times people think if they tell the pastor it's a secret. It's not like that, by the end of the week everyone in the area will know that so and so is HIV positive. I think it's much better to keep it a secret if you don't want the whole community to know. (Anglican Female).

#### 5.2.5 Gendered blame

A large literature highlights that female disempowerment in relationships with men is a key driver of the AIDS epidemic because this disempowerment undermines women's ability to negotiate safe sexual encounters (Haddad, 2002; Shisana et al., 2010). Furthermore attitudes that blame women for the spread of HIV and AIDS are seen as a key aspect of the stigmatisation of women with AIDS (Joffe & Bettega, 2003). As will be discussed below, there was evidence for such negative attitudes and norms in all church sects, but even more so in the Apostolic group.

In some situations (though not all, discussed further below) conservative church attitudes to women resulted in church attitudes blaming women who had AIDS. This blame took the form of implying that HIV infection was a punishment for promiscuous behaviour:

Some of the women deserve to get infected, especially here in our community. You see the women sharing a scud (African brewed beer) with a married man at the beer halls. These women are ruthless; they snatch married men away from their wives, so they deserve it when they get infected. (Apostolic female)

We have other female AIDS sufferers who used to frequent beer halls, they behaved as if they were immune to HIV. I am not saying all of them deserve to be infected but I don't feel sorry for that group of people. (Anglican Female)

#### 5.2.6 Gossip about those who have disclosed

Members of all three churches referred to the prevalence of negative gossip about HIV-infected and AIDS-affected church members. In some cases, this caused a very negative backlash for those who had disclosed:

It is not easy for church members to disclose their HIV status because it becomes the subject of discussion around the whole community. It is not fair for people who would have gathered the courage to disclose their status since everyone will label them and they withdraw themselves from the public. (Apostolic female)

Relatives cannot disclose a patient's HIV status. People will label them as a relative of a HIV and AIDS sufferer and will be stigmatised as well. It's even worse when it's your husband. (Roman Catholic female)

#### 5.2.7 Church discouragement of condom use (Apostolic only)

The above-mentioned negative attitudes were held in all three churches. However, there were further negative attitudes that were specific only to the Apostolic churches.

The first of these was their discouragement of condom use, as the following quotation expresses:

"Some churches do not mind members using condoms, but we do not allow condom use in our church. If one uses them secretly the prophet will expose that person and ask them to repent" (Apostolic male).

In the Anglican church people said they were encouraged to use condoms. In one of the communities the church leader distributed condoms after the service. The church members and leaders took a more progressive approach by acknowledging that people are better off using protection than being vulnerable to HIV:

"As a church leader I promote condom use especially to those who cannot exercise self-control, rather than letting them die of HIV and AIDS" (Anglican male)

We cannot pretend that people are not having unprotected sex. As a church we have youth advisors, they encourage youths to abstain but we do understand that at times people are not abstaining. We also take the opportunity to encourage those indulging in sex to use protection. (Anglican male)

Surprisingly, given the publicity about the official Catholic stance being against condom use, (e.g. the Pope's negative attitude to condoms) the Roman Catholics in our sample also appeared to be (albeit more cautiously) supportive of condoms:

> "Although condoms are not allowed by our top leaders, in church most members use them because that is one way of preventing

these sexual transmitted infections (STIs)" (Roman Catholic female)

#### 5.2.8 Polygamy (Apostolics only)

Whilst polygamy is not a feature of social life amongst Anglicans or Roman Catholics, it is accepted in some Apostolic churches. This is a custom that pre-dates the AIDS epidemic, but in the context of my research was referred to by Apostolic church members as a way of curbing the spread of HIV and AIDS:

"In our church we encourage men to marry as many wives as they want rather than sleeping with different women without showing any sign of commitment. It's a good way because it prevents the spread of HIV and AIDS" (Apostolic male).

#### 5.2.9 Silencing of women's voices in church (Apostolics only)

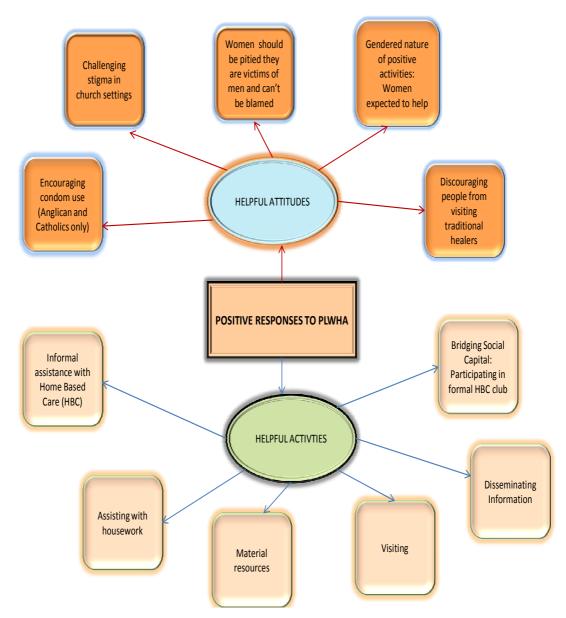
The other Apostolic-specific feature in the 'negative attitudes' analysis section is the belief that women should have no voice in church activities—a belief strongly held by the Apostolics in our sample:

"Women can only stand up and say something in church only during their women-only fellowship days, but not at church meetings where everyone is there. Women should submit to their husbands – this is the reason why they are not allowed to say anything when men are present." (Apostolic male)

In singling out the Apostolic as an environment which silenced women, I am not implying that the Anglican or Roman Catholic churches actively promote female empowerment. They too believed that women should be under male leadership both in the personal and public spheres of life. However, within these constraints, women did take positive leadership roles in limited areas of church activities such as being a secretary, cell group leader and deaconess:

> In church we have women leaders. The positions that we get as females are the same with males except from that of being a priest. We still do not have female priests. Men are the ones who are allowed to hold those positions. (Anglican female)

# 5.3 Thematic network analysis of helpful AIDS-related attitudes within the church



#### Figure 16: Thematic Network: helpful AIDS-related attitudes

#### 5.4 Findings: Helpful AIDS-related attitudes within the church

#### 5.4.1. Sympathy for women with AIDS

I have referred to the academic literature linking the stigmatisation of PLWHAs and conservative attitudes to women, and illustrated some of the ways in which women are blamed for the spread of the epidemic. However not all attitudes to women were negative and punitive. In some cases AIDS affected women were regarded with compassion and support. A strong theme that emerged in many of the interviews was that women living with HIV should be seen as objects of pity:

Sometimes women are faithful, they would have been infected by their unfaithful husbands who might already have passed away when the woman experiences full blown AIDS people empathise with her. We know of such cases and some people empathise with them. (Apostolic female)

In most cases women are not promiscuous. They wait for their husbands even if they go away for a long time. The sad thing is that when the men come back from where they would have gone such as South Africa, they infect women with HIV. We have seen women who have been diagnosed with HIV when we know that they were waiting for their husbands. People should feel sorry for such women. (Male Anglican)

With married women we understand when they are infected. You know that men are like bulls: society has said it and we know that most men cannot survive with one woman. This should not happen to women. (Female Anglican)

This quotation illustrates a common theme of pity and empathy for married women who contract HIV. These women are often represented as innocent victims of their husband's bad behaviour. Church members appeared more able to empathise with these women than with unmarried women, who are seen as deserving HIV because some of their actions were perceived as threatening to married women:. We have seen women who are single who want to compete for men. That shouldn't happen at all. When these women get infected, people don't feel sorry for them. In fact people feel that they deserve to be infected. Some of them snatch people's husbands. It's just not fair..... (Anglican female)

#### 5.4.2 Recognition of women's role in helping the AIDS afflicted

People also acknowledged that many of the positive responses to AIDS had come from women rather than men. For example informants stated that HIV/AIDS care has been a women's duty, with men not being culturally expected to take on such duties:

> Within the home if your child suffers from HIV and AIDS, the mother is the one who normally takes care of your child even if they were married before. Even if the husband is still fit we just have to do it. That is our culture. (Anglican female)

People who take care of HIV sufferers are women, even in cases where the woman has died first. If a child is sick the grandmother automatically assumes the duty of rearing; men don't take up these responsibilities. (Roman Catholic Female)

Not all men recognized the role of women in caring for HIV sufferers. However, the majority of the interviewees agreed that women had assumed the gendered burden role of nursing HIV sufferers within the home.

#### 5.4.3 The offering of health-protective advice in church settings

Much has been published on the negative influence of traditional healers on the health and well-being of people with AIDS (Willms et al., 2001; Peltzer, Mngqundaniso, & Petros, 2006). I regarded a helpful response to HIV to be any report by church members that their church leaders urged them or their peers not to visit traditional healers if they were, or suspected they were, HIV positive. Anglicans frequently reported that they were encouraged to use biomedical services, as the following quotation indicates:

In our church we have people who are nurses and doctors, they have been encouraging people to go for VCT and take advantage

of the treatment programme of free ARVs, as opposed to consulting traditional healers (Anglican male)

This was only the case with Anglicans and Catholics. The Apostolics actively encouraged their members to consult *Maporofita* (Spiritual prophets) who were part of the church sect. Although these were different to traditional healers insofar as they make predictions on the basis of the spiritual visions, they are still not biomedical trained and for this reason are possibly not the best source of help for people with AIDS (Peltzer et al., 2006). Below is a quote from one of the participants:

We have two people who have recently died after attending a deliverance session<sup>†</sup> at an Apostolic conference that was held last week. Those people were HIV positive and were urged to go to the hospital but because of their religious beliefs they didn't listen. Instead they attended the Apostolic conference and were told to drink holy water and not to go to the hospital. It's sad they died afterwards. (Roman Catholic male)

People nowadays now know that it's best to go to the clinic as opposed to a witch doctor or prophet. At church we are encouraged to go to the hospital and get diagnosed. Pastors have buried lots of people who have died as a result of not accessing health services when they knew that they were HIV positive but decided to visit the witch doctor. But Apostolics are a problem. They don't want to go to the hospital (Anglican Female).

#### 5.4.4 Support for condoms by some church groups

Another way in which the Anglicans and Catholics were more positive in recognising that their members needed to respond to AIDS was in their relative tolerance of condoms, as already discussed above.

As the priest of the Anglicans, I distribute condoms to my members (...) I can't blame condoms because people are indulging in

<sup>&</sup>lt;sup>†</sup> It is a term mostly used by Christians referring to the removal of demonic spirits or evil spirits that causes people to sin or be ill.

unprotected sex and are dying of AIDS. So would you want me to leave the youths to die? (Anglican male)

#### 5.4.5 Actively challenging stigma in church settings

Above I have referred to many references in our interviews to the way in which churches linked AIDS with issues of shame, blame and denial. However there was also lots of evidence that suggested that in some cases, church leaders and members actively challenged stigma in church settings.

#### Encouraging disclosure in church

Some of the Anglicans and Roman Catholics cited how church leaders encouraged church members to disclose their HIV status:

Our priest always encourage people to disclose their HIV status to a trusted person in church. Although most people do not disclose they always encourage church members to disclose their status. (Anglican male).

Our father makes it easy for people to come to him if they have any HIV issues. I remember recently when he said that people are dying of AIDS and some of you are taking care of HIV patients. Why can you not come to us and discuss some of your problems, we can support you spiritually to be strong-- we know it's not easy (Roman Catholic Female).

In most instances it appeared as though this encouragement by the church was largely ignored.

#### Encourage kindness and tolerance

All the participants including Apostolics stressed that their churches encourage them to show kindness and tolerance to HIV and AIDS sufferers. Some of them even quoted the Bible stating how Christians should not judge others but help each other. Words of encouraging kindness and tolerance were vivid in all the excerpts:

> It does not matter how the person got infected, we all have to be kind and tolerant to HIV and AIDS sufferers. Even in the Bible it is

stated that we are not suppose to judge others (...) Besides some of the people will be innocent victims. These will be women infected by their husbands. (Anglican female)

I can't say when one is HIV positive that person has sinned. It is unfair to pass such comments when some people are innocent victims (..) It hurts my sister to be infected with HIV when you have been faithful to your husband. At church we are encouraged to be kind and to love those patients. (Roman Catholic female)

#### Encourage people to take care of HIV and AIDS sufferers

Churches encouraged members to take care of HIV and AIDS sufferers. Members cited how church leaders preached about taking care of sufferers:

As church members we are always encouraged to take care of our sick relatives. These days with an upsurge of HIV and AIDS sufferers the message that is being preached is focused on how important it is to take care of HIV and AIDS sufferers. (Roman Catholic male)

In our church pastors talk about how good it is to help people who are HIV positive or even HIV orphans because God will reward us. We at times have a day when we make contributions to AIDS orphans in church and we pray for them. (Anglican Female)

These days church leaders talk about helping HIV sufferers using the Bible. Although the sermon won't be specifically about HIV sufferers, church leaders just slot it in and encourage people to help HIV sufferers in the communities. I used to help another HIV positive person in this community, she didn't want to go back to her home town. She had no relative we all got together and assisted her though she later died. (Anglican Female)

#### 5.5 Helpful activities related to HIV/AIDS linked to churches

#### 5.5.1 Disseminating HIV and AIDS Information

Many interviewees discussed how HIV information was commonly available within their communities. This partly explained why I found informants to have very high levels of correct information on HIV and AIDS:

Everyone knows the mode of transmission of HIV and AIDS, we hear the message in the radio, televisions, even in church that is the message that is being preached nowadays. We cannot say people don't have information. Even a young child knows that AIDS is there. (Anglican male)

Today even when you go outside and ask a young child about AIDS, every child knows about it. At school children at the age of six years are now taught about AIDS. (Roman Catholic Female)

#### 5.5.2 Preaching about HIV in a positive way

Interviewees cited how pastors disseminate HIV information during sermons:

Although the theme will not be HIV and AIDS, at church, leaders talk about how young people are dying because of this deadly disease (*Shuramatongo*). They always caution people to be careful with their lives. (Anglican female)

At church our priest always tell people that AIDS is not a death penalty. People are encouraged to tell church leaders if they become HIV positive or are caring for a person living with HIV. You know it's not easy to disclose but they talk about it at church. (Anglican male)

Although at church we don't have sermons that specifically address HIV, our leaders always talk about HIV and how people are living longer than before. I think at times they are scared to talk about it because they will be having limited information. If you could come and talk to us our 'Father' (like a priest) will be happy to host you. (Roman Catholic Female)

Roman Catholics and Anglicans were more vocal in stating how their churches openly discuss HIV. This was different from most Apostolic church groups who stated that they talked about it but didn't give clear evidence to how their church leaders actually did so.

#### 5.5.3 Encouraging VCT

Roman Catholic and Anglican church members stated how people are now encouraged to seek VCT before they get married, as the following quotation shows: "At church nowadays the youths are encouraged to go for VCT before they commit themselves in marriage or indulge in unprotected sex" (Roman Catholic female). Linked to this excerpt was how church leaders and priests encouraged mourners at funeral orations to seek VCT treatment early and not wait until they are critical: "At funeral orations priests and church leaders always encourage mourners to seek treatment early and not leave until one is bed bound" (Anglican female).

Apostolic church members on the other hand rarely mentioned VCT and access to health services when one is HIV positive. Their message centred mostly on how people will get caught by the holy spirit in church if they are promiscuous.

### 5.5.4 Church encourages members to treat HIV and AIDS patients with respect

Several interviewees stated how the message preached by church leaders encourages members to treat HIV and AIDS patients with respect:

At church we are always reminded to treat all patients including HIV and AIDS sufferers with respect. Some HIV and AIDS carers do not share the same household utensils with patients. People at church are always reminded of how important it is to treat patients with respect and not avoid using the same utensils. (Roman Catholic female)

During sermons priests always encourage us to treat each other well. They normally back their preaching with teachings from the Bible. Of recent the priest told us that if you ill-treat someone with HIV. You should know that you won't go to heaven. He encouraged us that even if we try to do little good things for PLWHA such actions will go a long way--the lord will bless us (Anglican Female).

While this sentiment came up among members of all three churches it was most common among Roman Catholics and Anglicans.

#### 5.5.5 Visiting people living with HIV and AIDS

Many interviewees reported visiting PLWHA as a result of empathy, care and at times the feeling of love or 'feelings that they cannot describe'. These interviewees reported a broader of emotions, being confronted with HIV and AIDS in their communities, some interviewees reflected on how this motivated them to visit HIV and AIDS sufferers:

We visit HIV and AIDS sufferers because these are people who are in our communities. One cannot afford to turn your back on them, yet these are the very people that we grew up with and at times some of them are members of the same church. Also the fact that we have stayed together for a long time we are more like relatives now... (Roman Catholic female)

My neighbour is HIV positive and bed bound. We visit her daily and offer the food that we would have brought along. At times we cook for them because the children are still young and she is the only breadwinner, we just have to help. Apostolic male)

#### 5.5.6 Household chores by church members

This urge to visit HIV and AIDS sufferers usually entails assisting with household chores, which includes fetching firewood, cleaning the house and at times doing laundry. Interviewees cited how they cannot avoid assisting with household chores when the house they have visited is a mess:

At times when we visit HIV and AIDS sufferers, the patient will be surrounded with dirty plates, wearing dirty clothes and some of them would not have bathed for days. One cannot contain the dirty smell in the house. I visited a HIV and AIDS sufferer who had messed himself and the carer was just wrapping the blanket around him without removing the dirty. We had to clean the mess, the sight was unpleasant, I could not eat for a day. (Roman Catholic male)

#### 5.5.7 Home based care encouraged by the church

When visiting PLWHA, interviewees cited how they would end up doing home based care activities. This situation was exacerbated when the visitor was known to be Christian home based care giver. In particular an interviewee cited how she at times felt reluctant to visit carers because every time she visited the care givers would abandon the home based care activities and expect her to do everything alone. The only thing that motivated her was encouragement from church:

The problem that we encounter when we visit these HIV and AIDS sufferers, if the carers know that you are a Christian home based carer they always expect you to do all the home based care activities alone. I hate it because we would have taught them what to do when we first visited, but they still abandon the person when we make follow ups. I just do it because at church we are encouraged to do so (...) I am reluctant to visit such patients at times. (Anglican female)

However, whilst there was a definite trend in some settings to encourage helpful activities by church members, there was a clear assumption that this help was the work of women rather than men. Several quotes referred to caring as women's work, for example the quote below on how women cared for dying husbands, but not vice versa: "Women really do take good care of their husbands if they get ill first. But men do not normally do the same. In most cases men become rough and would not show that love" (Roman Catholic female).

#### 5.5.8 Contributing material resources to PLWHA and their carers

Interviewees cited the difficulty of visiting PLWHA when they were unable to bring any assistance to the ill person's home. As part of the cultural tradition, visitors of sick people should assist with any material resources. Participants cited how they would bring different types of foods to patients. These included among others, fruits, vegetables and cooked food:

When we visit patients we always carry different types of food because culturally one cannot visit a patient without carrying anything. If one does not bring anything you will be forced to give the carers money. These days where do we get money? So it is easy to take vegetables or fruits from your garden. (Roman Catholic male)

Some people feel that they cannot visit an HIV patient because one is expected to bring along something when they visit. We have all agreed that things are hard as you know. We won't stop visiting patients, we try as much to take any crop that we have from the garden or at times explain that we just made an effort to visit without anything. (Anglican Female)

Our church used to get donations from outside the country but those have stopped. In church people are encouraged to bring any clothes, shoes or food they have to make a donation to some people living with HIV in church who cannot afford to fend for themselves and for AIDS orphans. (Anglican Female)

All the three church groups reported providing material resources to HIV patients and AIDS orphans. The Roman Catholics and Anglicans appeared to be more actively involved compared to the Apostolics who mostly prayed and offered holy water to the patients.

#### 5.5.9 Bridging social capital

Additionally, the gendered care of PLWHA was accompanied by a call by Roman Catholic and Anglican churches to scale up home based care activities, deemed to be more efficient at curbing the gendered burden of care. Interviewees applauded the work being done by a Roman Catholic non- governmental organisation (NGO) called CADEC that also recruit men. Although interviewees cited challenges of unwillingness by a lot of men to enrol in the home based care program. However,

they acknowledged the need for more external organisations activities to assist in tackling AIDS: "We have a home based care club set up by our church called CADEC and most HIV and AIDS sufferers participate in the club" (Roman Catholic female).

We have home based care activities that are being done by a Catholic based organisation called CADEC. I am sure this disease would have reduced if only we had more external organisations like them that were working in our communities (...) but they are trying their best and we appreciate what they are doing. (Anglican female)

FACT is also working within our communities, although they have downsized due to funding. They trained some of the peer educators who are now conducting home based care activities. But most of the peer educators have died due to AIDS. (Anglican Female)

We appreciate what BRTI is doing in our communities. If only you could come back and teach us what you guys are doing. We value the effort you make, we hope you will continue to work with us in our communities. As you know most programs have stopped working in our communities. (Roman Catholic male)

Most women were the ones who took the initiative to visit PLHIV and assisted with household chores. Although there was a home based care program for men, most men didn't participate. Maybe this was because culturally women are expected to take care of the home while men work outside the home for the family.

#### Summary

The individual in-depth interviews conducted with 30 interviewees highlighted a number of interesting aspects of how members of three religious church groups are responding to AIDS.

In some ways, all three church groups expressed unhelpful attitudes in relation to associating AIDS with blame and deviance, denying discussing AIDS in church and

gendered blame of AIDS to women. However in many ways, compared to the Apostolics, there were elements of a progressive and pragmatic nature in the Anglican and Roman Catholic responses to AIDS. These churches challenged stigma in church settings, disseminated HIV and AIDS information and encouraged condom use among other activities.

These interviews also revealed how Apostolic church members discouraged members from consulting trained medical staff. Although Apostolics generally acknowledged that AIDS existed, our interviews suggested that many Apostolic members do not visit the hospital, instead choosing to consult their prophets in church.

The way church groups addressed AIDS stigma is examined in greater detail in the next chapter, which reports on the CCs that were conducted in parallel with the individual in-depth interviews.

Saying the very word "AIDS" would cause the person to think endlessly. One would think that by being called an AIDS patient..... it means their days are numbered, they will die very soon.... they will lose all hope of life. I think it's better for them to find solace in thinking that they have diarrhoea not AIDS perhaps this would reduce their stress (Male Anglican T1).

#### **Chapter Overview**

This chapter focuses on the potential contribution of grassroots community groupings to the reduction of HIV stigma. Three rounds of community conversations were held with members of the Apostolic, Anglican and Catholic sects. Participants met three times (May 2008, September 2008 and January 2009) in three groups of approximately 10 people to discuss HIV stigma. While the same participants were sought for each round of community conversations only 80% attended all three rounds. Approximately 5% attended only one and 15% only two of the three sessions. New participants were invited to join sessions when original participants did not show up in order to maintain a minimum of eight people in each community conversation. This chapter presents my analysis of participants' discussions of possible ways of tackling stigma and their accounts of factors that might facilitate or hinder putting these strategies into action.

I found that community conversation (CCs) workshops provided participants with opportunities to formulate a range of creative plans to tackle stigma in their communities. However over time it emerged that various obstacles stood in the way of putting these plans into action in their lives beyond the context of workshop discussions. These obstacles included factors such as lack of good role models, economic and political factors external to the community, on-going risky behaviour, community fear of PLWHA, misconceptions held, shunning of PLWHA, gendered burden of blame placed on women and limited assistance from outside agencies.

Whilst I have no empirical evidence about the impact of peoples' talk in CCs and their actions in the community outside of the CCs, I draw on Freire's (1970) argument that reflection is a necessary pre-condition for action to frame my findings. My findings suggest that CCs have an important role to play in promoting reflection and action planning amongst participants. However, external constraints limited the extent to which people were able to turn this reflection and planning into action.

#### Introduction

Can the community conversations approach be used to develop more effective responses to stigma amongst members of the three main churches in Zimbabwe (Apostolic, Anglican and Roman Catholic)? As outlined in Chapter 3, three rounds of CCs were held with 60 members of the three church groupings in which participants discussed possible ways of tackling stigma and sought to understand factors that would facilitate or hinder them in putting these strategies into action.

In light of reports of high HIV/AIDS knowledge and a decline in the HIV prevalence rate in Zimbabwe (Avert, 2010), suggesting that Zimbabweans are gradually coming to terms with the epidemic, I expected to find low HIV/AIDS stigma among all the three church groupings. Surprisingly I found that despite high HIV/AIDS knowledge. HIV stigma was rife. Given that stigma festers and grows in conditions of taboo and silence (Duffy, 2005), I envisioned that the first step to tackling stigma would be to provide people with safe social spaces, in the form of community conversations, to talk about it. In these conversations, participants were encouraged to examine assumptions underlying stigma (i.e. that talking about sex with young people encourages bad behaviour; that HIV is spread by 'bad women'). Safe social spaces and dialogue enable people to critically discuss issues surrounding HIV and share knowledge with their peers. Through these discussions, people can construct new collective understandings and reframe their social representations of AIDS in ways that make sense to them given their local culture. These conversations also build participant confidence as well as a sense of empowerment and responsibility to go out and engage in stigma-reduction actions.

This chapter is in three sections. In the first section I examine church members' views of strategies to tackle stigma by presenting the six key strategies suggested by CC participants to tackle stigma, as well as the factors CC participants suggested

would facilitate implementing these strategies and hinder them. The second section focuses on the extent to which CCs provided people with social spaces to talk about stigma and build their confidence to carry out strategies to tackle stigma. I qualitatively and quantitatively explore changes in amount and composition of discussion of stigma in the CCs over time and in comparison to the control group. To assess type of discussion, I coded and counted comments that expressed positive or negative sentiments towards the community's capacity to tackle stigma. My examination of positive sentiments focussed on both ideas of what could be done to tackle stigma and expressions of confidence and empowerment to put into place these strategies. Negative sentiments were those that focused on obstacles to stigma reduction. Discussion of obstacles at times may indicate a sense of fatalism or disinterest in change, while at other times may indicate realistic critical thinking about macro- social barriers that are beyond the control of the community, such as material poverty and national-level political instability. In the third section I examine the trajectory from passivity to empowerment and in doing so I present a reflection and action path. Section four assesses the capacities and limitations of CCs as an approach for tackling stigma and building AIDS competent churches.

My research revealed that community conversation workshops did indeed provide participants with opportunities to formulate a range of creative plans to tackle stigma in their communities. However over time it emerged that various obstacles stood in the way of them putting these plans into action, including structural factors and poverty which limited access to health services. These limitations of CCs will be addressed in the course of my discussion of the data.

#### 6.1 Community conversation participants' views on stigma

In this section I report on the themes that emerged from my analysis of CC participants' views on tackling HIV stigma. My analysis revealed six key strategies that participants felt would enable them to tackle stigma, four elements that they found facilitated implementing these strategies and four elements that hindered implementing these strategies.

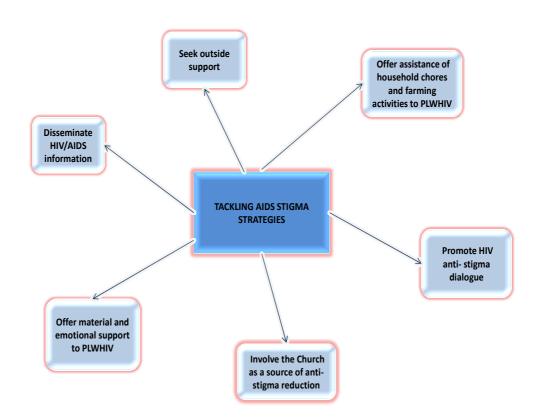
#### 6.1.1 Stigma reduction strategies suggested by CC participants

Below I present a detailed qualitative account of each of the strategies to tackle AIDS stigma that emerged during the CCs. These strategies were often embedded in

highly emotional discussions. Through the course of discussing the six strategies for tackling stigma that CC participants came up I will illustrate ways in which I believed an increase in critical thinking occurred amongst participants from community conversation one (called time one or T1) to community conversation three (called time three or T3).

Here again I emphasise that I do not seek to make claims about participants' actual behaviour in this discussion. All I seek to talk about is the way in which they talked about stigma and factors that facilitated or hindered it, in the CCs. Although my data provide no evidence for whether or not people acted, I rely on Freire's model of the reflection- action cycle, to claim that reflection is a necessary precursor to action. CCs (i) provided people with an opportunity to reflect on AIDS stigma and how they might tackle it and (ii) helped them build their confidence in their ability to make some contribution to tackling it. However I am aware that although reflection is a necessary condition, it is not always a sufficient one. Indeed in this chapter I conclude by discussing some of the obstacles that prevented our informants from putting some of their well-intentioned stigma reduction plans into action. Below are themes specific to tackling AIDS stigma.

#### Figure 17: Participant accounts of possible strategies to tackle HIV stigma



#### Participants accounts of possible strategies tackling AIDS stigma

#### Stigma reduction strategy 1: Disseminate HIV/AIDS information

One of the most commonly cited strategies to tackle HIV stigma suggested by participants was disseminating HIV/AIDS information, with group participants repeatedly suggesting that stigma was partly rooted in lack of information. One of the participants shared:

People talk in stigmatising language such as 'she has fewer days to stay before she dies' (*uyu ane mazuva mashoma tisati tamuviga*) just because that is the community language. People say that and do not know that they are stigmatising. If you would teach people in the community what you taught us, then people would desist from talking like that (Male Anglican T2).

CC participants reported getting involved in disseminating HIV/AIDS stigma information in their respective church groups and communities. In the following quotations, CC participants explain their churches' action to disseminate information on HIV and clearly link these dissemination sessions to significantly reduced stigma among PLWHA.

We are given time to talk every Sunday after the main service. We always tell people that if there is anyone in the service who is HIV positive and would like people to talk to we are there to help them. People have come to us with their stories and we have dealt with the cases confidentially (Female Anglican T2).

People are not shy to disclose their HIV status, ever since we announced our services at church, a lot of people have approached us disclosing their HIV status. Also people we hardly hear stories of referring to someone as a HIV sufferer and not their real name (Female Anglican T3).

That's why we say now we have people who are keen to help HIV sufferers. We have been holding inter-church gatherings to make sure everyone is on the same footing. Your teachings of working together have actually brought more unity among churches, and it has recently been said all churches should also talk about HIV/AIDS during their services. Now it seems HIV/AIDS sufferers are feeling proud of it because once you get there they will tell you "we have HIV" because once they say that people begin to be very helpful (Female Apostolic T3).

In the control groups, people did not suggest spreading HIV information, instead emphasizing the silence that surrounds HIV:

I want to say that people don't open up about their HIV status (Male Anglican Control).

One cannot afford to disclose their HIV status, it's much better not to do that. I wouldn't encourage people to do that. People still talk

about you and one will get more stress (Male Roman Catholic control)

Others in the control group cited how HIV disclosure among couples led to divorce, emphasizing control group participants' tacit support for silence:

Disclosing your status to your partner has caused some marriages to break, so people would keep their results unknown to the other least they may break their marriage. We have a case of a couple who divorced when the woman told her husband that when she visited the clinic she was tested for HIV and her results were positive. The man started to accuse the innocent woman of promiscuity and they ended up divorcing. (Male Roman Catholic T3 control).

As a woman I cannot disclose to my husband that I am HIV positive. My husband will chase me away even when he knows that he is the one who infected me. I agree that the best thing is not to talk about it until we are told together at the hospital (Female Catholic T3 control).

As the above quotations illustrates, participants in the control group discussions linked openness and discussion about HIV with negative outcomes. The underlying sentiment of this quotation and others is that HIV related discussion should be avoided and that silence and secrecy is the best way to cope with HIV.

#### Stigma reduction strategy 2: Promote HIV anti-stigma dialogue

Beyond information sharing, CC participants often claimed that participation in CCs had led to an increased willingness to discuss about stigma reduction in their respective homes at time 2 and time 3. Most participants spoke positively about how CCs had enabled them to share ideas on encouraging each other to promote anti HIV stigma:

These days we encourage each other to talk about how to tackle stigma at our respective homes (Roman Catholic Male T2).

To be honest, at first I didn't know how to talk about HIV/AIDS within my home. Ever since you have held these workshops, it's easy for me to talk to my family not only about HIV but how bad stigma is (Male Anglican T3).

Participants recognized that speaking openly about stigma was a vital step in reducing it and sought to recreate the safe conversational environment of the CCs in their everyday lives, and particularly in their churches.

#### Stigma reduction strategy 3: Offer material and emotional support to HIV sufferers

Offering support to PLWHA emerged in the CCs as a key strategy to combat stigma.

We managed to visit HIV sufferers and assisted them with household chores and fetching firewood for them as a way of addressing anti stigma strategies (Female Apostolic T2).

I managed to do laundry for other HIV sufferers and comforted them that don't have to blame themselves that they are HIV positive. I remember telling one person that we all know it's so unfortunate for one to be HIV positive, but that should not hold them back from being positive. I proceeded to tell her that she should consider herself lucky that she knows her status, a lot of people live without knowing their status. I did this to show the patient that people don't stigmatise her and there is nothing to worry about (Female Catholic T3).

Respondents reported that the assistance could take the form of material help, such as doing household chores for PLWHA, bathing and personal care of PLWHA or their children, assisting with collecting medicine from the hospital, and providing financial support (such as bus fare or help with children's school fees). It could also take the form of emotional support by showing love and kindness towards PLWHA or praying for them. The following quotations illustrate examples of support reported by CC participants:

I think I can say as a member of the women's church group we went and assisted a certain woman with HIV/AIDS. We went there as a group and prayed for her and assisted her with her chores such as washing clothes and sweeping her house (Female Anglican T3).

I managed to assist my neighbour who is suffering from HIV/AIDS. This person has a young child yet right now she can't wake up to cook and bath her kid, so I bath the child every morning and also give the child food (Male Apostolic T3).

Participants shared how they had assisted HIV sufferers to clean their homes, helped with their laundry and helped them with farming:

Generally we feel very happy when we help, and we feel that we would have accomplished something for a person in need when we get there and do all the chores, like cleaning, washing their clothes and cooking for them, when we leave we feel very happy that we have done something for our colleague. It feels really good and one feels that sense of satisfaction (Female Catholic T3).

I went to assist by working in the field for this person because I had realized that though this person was ill, they also had some crops that needs weeding and she had no enough energy to pull through (Male apostolic T3).

This was different in our control groups where respondents did not report that assisting anyone with HIV would help address stigma. They instead suggested that PLWHA were generally not open about their status and thus nothing could be done.

Here we don't really know anyone who is HIV positive (Male Apostolic T3 control).

Generally people are not opening up and they prefer going to traditional healers so there is nothing we are doing (Female Apostolic T3 control).

#### Stigma reduction strategy 4: Seek outside support

One recurring strategy to reduce stigma was that community members could harness outside support to spur larger discussions and greater openness about HIV. For example, participants appealed to researchers to scale up CCs to other church groups, schools and communities. Most participants cited how difficult it was for them to reach all people and how youths would not take heed of such important information from local people. For example, the issue of young girls dating older men was a major concern that participants felt outsiders could assist in addressing:

I think the men should also consider the future of these girls before they impregnate them or sleep with them. They also need to think about their current wives and families. I think you guys should also take this programme to schools and try to educate them because they don't even listen to us. Some of these children have single parents some have lost both parents which is tricky to warn them. I think you should also task the teachers to warn our children and you should also meet the youths (Female Roman Catholic T2).

When you go back to your work, can you ask your bosses if they can at least assist us with income to start an income generating project? Although we have lots of projects to do we cannot fund these ourselves because we don't have the money. We were thinking of a garden project that can assist some HIV sufferers because they don't have any food at all. It's also hard for use when we visit without holding anything for them (Male Anglican T2).

While occasionally respondents suggested outside interventions in an expression of helplessness, in many cases appeals for outside support were practical and recognized that local people had the central role to play in combating stigma but that outsiders could offer valuable support to facilitate or speed up stigma reduction.

#### Stigma reduction strategy 5: Involve the church as a source of stigma reduction

The church in time 1 was cited as a major obstacle to anti stigma strategies. One participant shared how HIV church members will not disclose if they were HIV positive or taking care of a HIV positive patient:

People cannot afford to disclose their HIV status to any church administrator that you have a patient who is HIV positive. If you do that you would have disclosed to the whole community. The next thing when you are walking in this community everyone now refers to you as a care giver for a HIV patient (Female Roman Catholic T1).

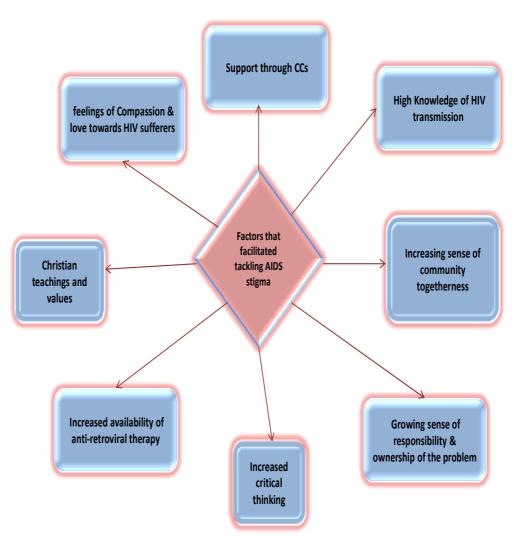
During time 3 people started to refer to the church as a space for anti-stigma strategies. Some participants shared within the CC how the church was being used as a source of hope for HIV sufferers:

These days' people in church are encouraged to disclose their HIV status in church. Most people are now disclosing their status to either the church pastor or some entrusted people in church. The church is disseminating anti- stigma information on Sunday. They even support their teaching with verses from the Bible (Female Anglican T3).

## 6.1.2 Factors CC participants suggested would facilitate implementing these stigma reduction strategies

During follow up conversations after the first CCs, that is during time 2 and 3, every single participant who had attended the previous CC reported that they had managed to carry out at least one of the stigma reduction strategies that had been formulated in the CCs workshop. Many had carried out more than one. This section reports the factors that facilitated putting these strategies into action.

#### Figure 18: Factors suggested that facilitated tackling AIDS stigma



Factors suggested that facilitated tackling AIDS stigma

#### Facilitator 1: High knowledge of HIV transmission

Levels of HIV knowledge appeared to be high right from the first CC, consistent with other studies (Avert, 2010). All participants from time 1 to 3 in all communities knew the different modes of HIV transmission and how to prevent contracting HIV. This high level of knowledge could facilitate enacting stigma reduction strategies because community members will likely be aware that casual contact with a HIV sufferer will not put them at risk. In the following quotation, a CC participant reports how high levels of knowledge about how to stay safe while caring for someone with HIV reduces fear of HIV and ultimately reduces stigma.

People now have the knowledge on how to look after an HIV patient without stigmatizing the sufferer (Female Anglican T2).

To be honest people know a lot about HIV stigma, they know that it is bad to stigmatise a HIV sufferer although a few still do that. A lot of anti-stigma information has helped people to embrace HIV sufferers (Male Roman Catholic T3).

#### Facilitator 2: Increasing sense of community togetherness

Community members and family members became critical components of tackling AIDS stigma. HIV stigma was the norm during time 1, when participants said that only the patient's immediate family member would know that the patient was HIV positive, and would take primary responsibility for caring for the patient out of a sense of duty:

Family members do not disclose that they have a patient of HIV; they will take care of their AIDS patient without telling other people. When you ask them how the patient is feeling they will tell you that the patient is fine when it's not like that (Female Roman Catholic T1)

However by time 3 there was far more talk of community willingness to offer psychosocial support and assist with other chores such as collecting medicine from the hospital on behalf of the patient:

People nowadays have stopped stigmatising HIV sufferers. A lot of people are getting involved in anti-stigma strategies such as assisting with household chores. People in the community are becoming more receptive to HIV sufferers. Just like we buried another patient, people all came to support the family on the day of burial (Female Roman Catholic T2).

These days you hardly hear stigmatising expressions such as it's a matter of days before we are call for a funeral (*uyu hapana mazuva tisati tashevedzwa kumuviga*). People just offer words of

encouragement to the patient and assist them with any household chores.

In time 3 there was far more mention of a sense of togetherness, referred to by the African term 'Ubuntu' leading community members to tackle AIDS stigma together.

Let me say as a women's church group we managed to assist by making contributions and raising food for someone who was HIV/AIDS ill. We also managed to agree that we should make contributions so that when we visit as a group we would be able to leave something material for the patient. As this group yes we visit and pray for patients (Female Anglican T3).

#### Facilitator 3: Growing sense of responsibility and ownership of the problem

An increase in group members' references to wider community responsibility for AIDS patients suggested the possibility of CC participants gradually developing a sense of ownership of the challenge of responding positively to AIDS, as well as starting to identify individual and collective assets in the community for doing so (Freire, 1973). The following quotation is an example of a CC participant expressing a sense of responsibility to assist HIV sufferers.

> As you might know many people in this community are people from other areas who came to stay here so though we are strangers we decided that the only source of our help is us. So we decided that we should visit HIV/AIDS sufferers and bring them what we can afford, sometimes we go to see the patient and ask them what they want to eat then we try to make their desired things available (Male Apostolic T3).

We assist HIV sufferers because it is our responsibility to do that, we have to help. Who will help these people if we don't it? (Female Apostolic T3).

At times we are confronted with situations that you can't run away from. When you visit a patient you need to take with you fruits or vegetables, something else to give them. One feels bad visiting

without holding anything. It's a well-known fact that as a visitor one has to bring along something (Female Anglican T3).

Another patient assisted by CC participants during time 1 and 2 joined CCs in time 3 shared her testimony. In this quotation, she explains the importance of the support she has received, providing a clear example of the high level of responsibility for care that some community members have taken up:

We have HIV/AIDS patients in our group and I am one of them. At one point I never thought I could make it to this point. But here I am, fit, due to the support of these people. It is not just talking we are doing, we really do assist and I am a living example of how these people were assisting me. Some of them were going to collect my treatments on my behalf from Hospital. So when I got well I also made a commitment to join them and assist others as well, because it really works. These people were visiting me on regular basis. However they should keep the good work and they should not tire or lose momentum (Female Roman Catholic T3).

The final part of the above quotation also shows how some people with HIV themselves have even begun taking responsibility for helping others.

#### Facilitator 4: Increased critical thinking

Increased expressions of critical thinking were evident during time 2 and 3. Participants increasingly spoke of strategies for and experiences of tackling HIV stigma. This was quite different to the control groups, which did not come up with viable strategies and did not report efforts to reduce stigma. One such example is evident in the excerpt below:

As a group we selected a committee in church, then we went to visit the patient, we prayed for her at her home. We also came out in public as a group in church to assist HIV sufferers (Male Roman Catholic T3).

In church we were chosen to be a group that offer psychosocial support to HIV sufferers. We have told church members that we are there to help them and keep their information confidential. To be honest, we have heard a number of people approaching us disclosing their HIV status (Female Anglican T3).

It was never easy for us to encourage our leader to talk about anti stigma strategies in church. Now every Sunday in church people are encouraged to approach the HIV committee if they have any HIV concerns. To us it's a major milestone considering that we never talked about that (Female Anglican T3).

#### Facilitator 5: Increasing availability of anti-retroviral therapy

The roll out of anti-retroviral therapy (ARVs) served as an impetus for most people to know their HIV status and seek treatment between time 1 and 3. Some of our research participants managed to disclose their HIV status or encouraged others to disclose to their neighbours and relatives in spite of high levels of stigma within such a context:

Now that we have the information and the facility where people can access ARVs at Muonde, I think people are beginning to realize that HIV/AIDS is not a death sentence but just an illness that can be put under control (Female Anglican T3).

#### Facilitator 6: Feelings of compassion and love towards PLWHA

Participants were motivated to enact strategies to tackle stigma because of their genuine feelings of compassion and love towards HIV sufferers. In some cases this love arose from personal knowledge or exposure to PLWHA and at other times it arose from a sense of community solidarity and the capacity to empathize. The following quotations show how various respondents explain their motivation to help PLWHA:

At times you feel that it could be your child in that situation. That's why we had to stand by the patient until she passed away. We

were helping with bathing and all the chores (Female Roman Catholic T2).

We did this because these are people we live together with so as human beings we also feel we have to help others (Female Apostolic T3).

I think all I did was a function of love. I put myself in the situation of the HIV/AIDS sufferer and I asked myself what I would like other people to do for me. So I decided to do that for the HIV/AIDS sufferers so that others can follow suit (Male Anglican T3).

#### Facilitator 7: Christian teachings and values

The Christian ethos of helping others facilitated respondents' capacity to enact strategies to combat stigma. Most participants stated how being a Christian led them to be compassionate and loving towards HIV sufferers. Many referred to being blessed when helping PLWHA and quoted verses from the Bible to explain their motivation:

It will also be in fulfilment of what Christ requires of us as Christians. As Christ says in the Bible you saw me when I was sick and you did not help (Female Roman Catholic T2).

In some instances, the difficulties in obtaining support from friends and family members were mitigated by church members who felt they had a spiritual obligation to assist. Some participants cited how their spiritual belief provoked them to assist without being asked to. This observation supports previous findings that suggest that many church members empathize with HIV sufferers (Haddad, 2002). The excerpt below provides an example:

I think the whole issue of helping is a function of love. God commands us to love one another so especially in view of the fact that God loved the world so much that his only son was crucified for us, so we ought to love another and spread the good news of the Bible. This is a way that me may also be able to see the

Kingdom of God, so as Church goers we are obliged to love and practice that love (Male Roman Catholic T2).

Others cited how God will reward them if they assist a patient:

I think it is the belief that if we do this for the poor God will bless us and multiply our resources as well (Male Roman Catholic T1).

God will multiply our blessings, I am sure that's what the holy word teaches us. So that is what motivates us to help others (Male Apostolic T2).

#### Facilitator 8: Support through CCs

The CCs themselves facilitated respondent capacity to enact anti-stigma strategies. In the concluding talk section of CCs, most participants commented that participating in the CC project presented them with the first opportunity to think about HIV/AIDS seriously and figure out ways they could assist HIV sufferers. Others highlighted that it was through such an opportunity to talk about HIV/AIDS openly and share experiences in their entirety that they could at last begin to understand that some actions they had previously deemed normal were actually stigmatizing:

> I also want to keep encouraging you and thank you so much for coming and starting this project because we used to shun our patients and we were even afraid to touch them but now we know we can share a meal with our patients. This gave us the realization that we had been neglecting our patients. We started caring for them with vigour because you guys taught us very well (Female Roman Catholic T2).

> I want to support the previous speaker because the first days of AIDS here any preacher who dared to preach about it risked being ridiculed or even being beaten by the people. I want to say people did not accept or understand this issue even at funerals people would be angry if a preacher talked about it. Now because of you guys and your programme and also our effort in receiving your teachings and taking them into our communities we can see that people are now understanding and accepting that there is AIDS

and they need to be careful. When we look at it, the most affected generation are the youths. People of my age (47 years) are not that badly affected, of course I have the virus, which I got from my husband. But the younger generation are dying at a very high pace because they don't accept the existence of AIDS yet they are not satisfied with their wives (Female Apostolic T3).

Participants repeatedly thanked us researchers for facilitating dialogue:

I just want to thank this programme that you brought us. It is this programme that has brought us together from our respective neighbourhoods. For us to have this platform to share our views and go out there and help others it is all because of you guys. So the whole thing has been started by you guys and I want to thank you guys for this programme (Female Apostolic T3).

Right now we feel that without you guys, our HIV sufferers would be treated worse off now. So we get this good publicity of using CCs as a starting point to disseminate HIV stigma information in our church (Male Anglican T3).

Some participants were emotional, shedding tears during the discussion. Others shared how their personal lives had changed ever since they participated in CC workshops. These observations suggest that participating in CCs can itself be therapeutic and can lead to stigma reduction in the whole community. Tackling HIV/AIDS stigma within church groups is not straightforward. The process was often embedded in a lot of obstacles. These obstacles from our study suggest that while communities have great capacity to address their own problems, there are certain problems that they cannot address on their own. I will discuss these in detail below.

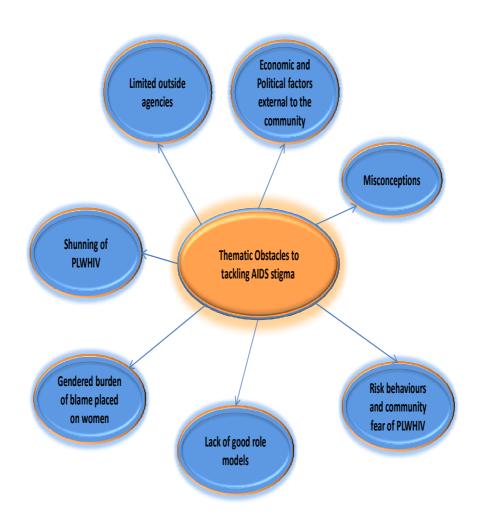
6.1.3 Factors CC participants suggested would hinder capacity to carry out stigma reduction strategies

In the previous section (1.2 Factors CC participants suggested would facilitate implementing these stigma reduction strategies) I outlined the 'assets and strengths'

(Moser, 1998) in communities that would facilitate implementing anti-stigma activities. I now move on to a discussion of the factors that constrained tackling AIDS stigma.

# Figure 19: Factors suggested as hindering capacity to carry- out stigma reduction strategies

# Factors suggested as hindering capacity to carry out-stigma reduction strategies



#### Hindrance 1: Lack of good role models

Lack of good role models in some communities, particularly in our control groups, was cited as one of the hindrances to AIDS stigma. The following quotation is one example:

There is the issue of role models, some role models are leading by very bad example. We have doctors who are very promiscuous, am I lying? If these are the people who are in the profession and they behave like this how will the rest of the people behave? (Male Roman Catholic T3).

Considering that doctors are highly regarded in communities, participants were particularly upset by these people—who were expected to serve as role models behaving promiscuously.

#### Hindrance 2: Economic and political factors external to the community

The economic instability within the country had a negative effect not only on PLWHA and their carers but also on community members' capacities to enact stigma reduction strategies. During the time of this research, the dollarization of the economy had a huge impact on people residing in the rural areas who had no source of income. Most people referred to how they couldn't even afford to fend for themselves, let alone provide for HIV sufferers in their communities. This resulted in other people failing to visit other HIV sufferers since they didn't have anything to give them.

> The challenge has been unavailability of food to these patients, and warm clothing, soaps and it is the unavailability of these things that may quicken the death of a patient (Female Apostolic T2).

Some participants even linked the harsh economic environment to apathy towards HIV avoidance. As one of the participants shared:

Someone will tell you, whether dying of HIV/AIDS, an accident or natural causes, why should I be afraid of HIV/AIDS? It's better for me to feed my family than die of hunger (Roman Catholic Female, T3).

Drawing on an earlier study (Nhamo et al., 2010), poverty still appeared to undermine the psychological empowerment most likely to predispose people to exercise agency in changing well- established behavioural norms. As I concluded most interviews, participants emphasized how poverty and famine had hampered their activities of combating AIDS stigma. As one of the participants emphasized:

> ....The major challenge has been poverty that made it difficult for us to meet the expectation of the patient. The most important thing that we also failed to make available to our patients has been food and a decent or good diet. Without food one may not help enough. Unfortunately we had a very poor harvest.... (Male Apostolic T3).

Unavailability of materials such as gloves in hospitals hindered a lot of PLWHA from accessing health services, leading to further stigmatizing:

Gloves are problem, even in the general hospital they say you should bring your own gloves to give the nurses to use for our patients. Without gloves they won't touch our patients. Where can we get them when we are using plastic bags. HIV sufferers feel stigmatised when we touch them with plastics. Again I cannot afford not to use anything when bathing them. The patient will feel that we are stigmatising them but I just can't risk myself (Female Roman Catholic T3).

Additionally, the political instability coupled with inadequate support or assistance of any kind of health or welfare assistance sometimes acted as a barrier for people to combat HIV/AIDS stigma.

Some of the people we encountered recently openly told us their status, so we embarked on a door to door campaign to raise money for these patients. But recently the political environment was not enabling (Female Anglican T2).

#### Hindrance 3: Ongoing risky behaviour

Community members felt they were unable to enact some of the stigma reduction strategies developed during CCs because of on-going risky behaviour in the

community. There was a prevailing attitude among respondents that ART patients were likely to resume risky sexual behaviours following health gains. This attitude towards ART patients re-oriented blame for the epidemic back onto PLWHA, undermining efforts to reduce stigma through emphasizing community solidarity. The following quotation is an example of a community member expressing fear and distrust of PLWHA, especially women:

There are some people who would have wasted so much. When they go on ARVs they recover and gain their weight again. Our husbands become attracted to them and go after them. So I think that's one of the challenges, because these AIDS patients may go back to the business of sleeping around when they recover. It's so painful to think that my husband would go after such a person (Female Anglican T1).

Others cited how some widows start prostitution after the death of their spouse:

Some widows come and handover their church uniform and pull out from all church groups to concentrate with sleeping around. Some even say they were missing out all along, and they abandon their children (Female Roman Catholic T2).

Other people in our control groups cited how multiple sexual partners were associated with manhood:

...that issue of trying to feel like a bull that one can sleep with as many females as possible (Male T3 control).

#### Hindrance 4: Community fear of PLWHA

Some community members cited how the fear of contagion led them to stigmatise HIV sufferers:

At times it's hard to take care of PLWHA when you don't have gloves. I can't risk myself, at times these patients fail to understand when we tell them that we cannot clean them without gloves (Female Catholic). I have heard that HIV is transmitted when one has open wounds and you also have them so when our blood mix there is a high chance of infection. I cannot touch someone who has open wounds when they are HIV positive (Female Apostolic).

#### Hindrance 5: Misconceptions held

Misconceptions surrounding HIV impacted negatively on community efforts to accept HIV/AIDS, which in turn potentially hindered tackling AIDS stigma. The interpretation of some community reactions to HIV/AIDS reflect ideas concerning HIV/AIDS sufferers as being bewitched.

Some patients do not even want to go to the hospital as they don't think they have AIDS, they think they have been bewitched so they spend all their time and resources going around traditional healers. They don't want to go to the hospital, saying they have been bewitched. Yet if they go to the hospital that's where they would be tested and get all the information and explanation. That's where they are told that they should accept it when people take precautions when looking after them to avoid the spread of the disease (Male Apostolic T3 control).

People also find solace in saying they have been bewitched, you would find the patient saying they saw the witch who caused their illness in a dream (Female Roman Catholic T3 control).

Other participants shared how having sex with a virgin was considered a cure of HIV/AIDS by some traditionalists:

We have cases of older men who are HIV positive raping young girls considered to be virgins. People have been told that there is no such cure but some men just don't listen (Female Anglican T3 control).

Another participant cited how having sexual intercourse with an Albino is considered a cure of HIV/AIDS by some people:

Today I was reading a letter that was written to a magazine by someone who said that he was told that if he sleeps with an albino their Aids will be cured.... (Female Anglican T3 control).

These misconceptions hindered community capacity to implement stigma reduction strategies. Some of the young girls were getting infected after being targeted by older men at the virgin parade. The virgin parade is a modelling pageant for virgin ladies that offer certificates to the ladies examined by elderly ladies and found to be virgins. Although the girls are not forced, most parents encourage their children to participate because failure of a child to participate will suggest that the child is no longer a virgin. Most single girls who are not virgins are considered prostitutes. Also parents are embarrassed to be associated with a girl child who is not a virgin in the community.

#### Hindrance 6: Shunning of PLWHA

The process of shunning HIV sufferers resulted in most HIV sufferers being subjected to various forms of social exclusion. All church groups cited how this process of 'othering' led some of them to deny that they were HIV positive. Most people cited how they suspected people to be HIV positive although they would not have openly disclosed their HIV status. Some of them will conclude that someone is HIV positive by seeing them queuing for ARVs that are dispensed at the local hospital every month. The fear of 'othering' within communities resulted in some carers hiding HIV sufferers from visitors:

These AIDS patients sometimes don't want to be visited, that is a real problem. Some people even those we are related to if they happen to have an AIDS patient at their homes they would not want anyone to know that they have someone who is suffering from AIDS at their home, and they would not want anyone to visit this sick person they would even hide him away from any such visitors if they do come (Male Roman Catholic T1).

There are still some people who are primitive in the way they view HIV/AIDS. Such people, if they have an AIDS sufferer at their

home, they try cover it up and avoid other people from noticing or coming to see the ill person (Female Anglican T2).

This issue of labelling PLWHA as promiscuous causes great desolation and undermines the likelihood of PLWHA receiving optimal care and support:

I have a friend who is suffering from AIDS, his relatives would not allow anyone to come and see him but it was out of bravery that I visited his place. When I got there his mother could not turn me away rather she allowed me to see my sick friend but afterwards she warned me against telling anyone about his condition and sickness as well. This is my best friend so I had the courage to go and see him. So some people refuse with their sick relatives to be seen, some AIDS patients themselves do not want to come in the open, some of them do not even want to go to the hospital even when they are sick ( Male Roman Catholic T2)

Some men deny that a woman is on ART as long as they appear healthy in their sight.

Some men are a problem even when people warn them from having sexual intercourse with women whom we know that they are on ART, they don't listen. They say the lady is 'intact' '*chakabatana*' she cannot be on ART (Female Roman Catholic T2).

Another HIV-positive person disclosed how the fear of being labeled as a mental health sufferer stops a lot of PLWHA from disclosing their status:

I think we don't open up about our status because we hear some bad comments from some people. Even when we are talking to other people, if I raise an idea that people do not really like, I will hear comments like "AIDS has now got in your brain." That is so painful because one would be feeling bad for having disclosed their status to the public. A lot of people who have not had an

HIV/AIDS sufferer in their families have such painful and crude comments to make about us HIV sufferers (Female Apostolic T2).

Others shared how some HIV sufferers appear to be guilty:

The other problem is the patients themselves, this normally happens when we go to see them they appear to be feeling guilty that they have HIV/AIDS. It so happens that these are people whom we had warned to behave well and when they fall ill they think maybe we are coming there to reinforce what we were saying. I have a feeling that they would be thinking that we were coming to say "we told you so". Yet we would be coming there to help them. Even if we were friends before you would find that this person feels very uncomfortable. So in such circumstances we don't know how we should proceed (Female Apostolic T3).

In the control groups in particular, I found that people disclosed not taking positive action towards PLWHA because of deeply entrenched fear of contagion.

Because this disease is scary and people are just afraid of getting this disease so in trying to be extra careful not to contract the disease we end up stigmatizing the sufferers. People are afraid that if they help these HIV/AIDS sufferers may be they can contract the disease. People do not have detailed information about the dangers in looking after an HIV/AIDS sufferer (Male Anglican T3 control).

#### Hindrance 7: Gendered burden of blame placed on women

The major burden of AIDS management in Africa is already carried by women. Women have a double burden of being particularly vulnerable to HIV and caring for PLWHA (Gregson et al., 2004). However, in this study, instead of recognizing the role women played and supporting them, I found underlying anti-women attitudes. Most women contended that their effort to prevent HIV/AIDS has been worsened by the promiscuity of men. Additionally, culturally women are encouraged to be submissive to their male counterparts. This curtails the capacity of women to

negotiate safer sex and, as this quotation suggests, shifts the blame onto women for risky behaviour by their husbands.

As a church we have a women's church group where we normally teach each other about how to treat our husbands. When someone reveals that her husband has AIDS she would feel that maybe she was responsible for that situation because it may mean they had failed to treat their husband well until he had to sleep around and bring the infection into the home (Female Anglican T2).

Women spoke of how difficult it was to negotiate for safe sex within marriage, even when men are unfaithful:

Because I have refused to have sex with him he thinks I am sleeping with other men. I try to tell him that I am doing this because his girlfriend's previous sexual partners have passed away due to AIDS related illnesses. I ask him whether he uses condoms or not but he tells me that's none of my business. Sometimes when I am walking around I see his car parked at his girlfriend's place, but he would never accept that it's his car. He says cars could be similar, but I know number plates are different. He does this because I have children with him and he knows that I will stay for my children's sake (Female Anglican T2).

#### Hindrance 8: Limited outside agencies

I expected high levels of bridging social capital (i.e. collaboration between outside and local agencies). My anticipation of outside agencies (NGOs) and government involvement in the communities contradicted my findings, which revealed very little opportunities to connect with and get support from outside organizations and the government. People thanked me and my research partner profusely, emphasizing that we offered one of the few connections with outside programming:

> We thank you so much for coming to work with us. Other agencies that were here moved out before the elections and they never came back... Could you please tell your superiors to help us with gloves to care for the sick (Male Anglican).

People also commented on a lack of healthcare support from the government:

I think all churches have said that they realize that HIV/AIDS is a reality and it is taking away lives of people but I also want to say the government should intervene and save its citizens (Female Apostolic T1).

#### Courtesy stigma

Courtesy stigma is being stigmatised as a result of being closely related to a person being stigmatised (i.e. the stigma of being associated with someone who has a negative trait or mark). Participants cited how HIV sufferers were 'audibly ' stigmatized and how PLWHA were identified as 'HIV sufferers' and carers were 'HIV carers' and were not addressed by their real names. Take this example where one of the participants shared how HIV sufferers are being treated:

> They are classified as people in the "programme " ("chirongwa") so we know when we see them in that queue (Female Apostolic T1 control)

People will refer to you as a person on ART "ari pachirongwa" or as a career of a HIV sufferer (Female Apostolic T3 control).

Other people cited how courtesy stigma resulted in non-disclosure of one's HIV status:

There are also some people in the church who hide this illness from fellow church members for fear of being despised. Some women even laugh at those women with husbands who are suffering from HIV even within the church. So the wife will not reveal to the church for fear of that kind of humiliation from fellow church members (Female Anglican T2).

As participants gave these examples in the control groups they all concurred that most HIV sufferers will never disclose their status in such conditions.

# 6.2 Extent to which CCs provided people with social spaces to talk about stigma and built their confidence to carry out strategies to tackle stigma

# 6.2.1 Amount of talk about strategies to tackle stigma

This section explores the extent to which CCs led to increased discussion about addressing HIV stigma. Initially during the first round of CCs, participants appeared to be hopeless, focusing on more obstacles to stigma as opposed to solutions. During the second and third round of CCs, amidst a lot of stories of stigma, the CCs successfully provided social spaces where participants felt comfortable talking about the stigma that existed within their communities and brainstorming actionable strategies to tackle it. During time 2 and 3, CCs participants constantly referred to how the CC workshops had led them to develop positive representations of HIV/AIDS. Those in the control site generally expressed resentful attitudes towards PLWHA or fatalistic attitudes towards their capacity to avoid the disease. These attitudes can be understood in the context of Zimbabwe's limited support from international organisations, insufficient pharmaceutical medicine and financial resources, as well as traditional beliefs associating HIV/AIDS with promiscuity. Contrary to the control groups, participants in our CCs sites spoke of how the CCs had given them hope and increased openness. CC participants reported changes in anti-stigma attitudes within their various church groups. HIV, which had been considered the unspeakable disease, was now widely talked about in churches. This was evident within the follow up CCs.

> You have helped so much and now we can discuss and talk to each other freely and we are now able to continue meeting as a group even after you guys have gone (Female Anglican T3).

Individuals started to talk about helping those with HIV and, as illustrated in the first quotation, even disclosed that they have close relatives with HIV:

I have a young sister who is suffering from HIV/AIDS so I have managed to get some medicines for my young sister so that maybe she can fight some opportunistic infections (Female Apostolic T2). I helped three HIV/AIDS patients. One was really sick and was now developing bed sores that were discharging some fluids. We also encouraged this person to go the hospital for treatments and medication. So at one point I went to the local hospital to source and collect drugs on behalf of this patient since he is no longer able to walk to the hospital, with time the patient was then carried to the hospital by a scotch cart (Male Roman Catholic T2).

This was different from the community groups in our control sites. People were not willing to talk about HIV status and did not mention helping people with HIV:

Yes, like we said before, even we ourselves we are not prepared to disclose our status to anyone. That is how the situation is. People misunderstood this disease, it's different from cholera where people can say openly. So we just assume that some people have AIDS maybe because their sexual partner has already passed on as a result of a suspected AIDS infection (Male Anglican T3 control).

The graph below shows total count of times strategies to tackle AIDS stigma were mentioned at T1, T2 and T3, and in the control.

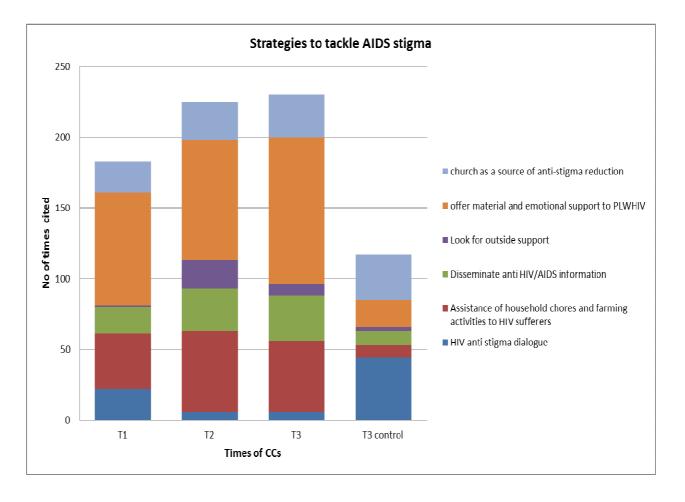


Figure 20: Strategies to tackle AIDS stigma

The graph above gives a simple quantitative description of how the mention of particular topics increased or decreased across community conversations from time 1 to time 3 relative to the control group (which took place at the same time as the third round of CCs). The regions where the control groups took place were similar to the regions where the CCs at T1, T2 and T3 took place. To count these strategies, I formulated the strategies and obstacles to action using a grounded theory approach and then refined the codes using interpretative analysis. As indicated by the graph above, during time 1 participants started to brainstorm actionable strategies on how to tackle AIDS stigma.

CC participants reported being able to convert knowledge into action in ways that control group members did not. This increased capacity to think of action plans echoes Campbell (2003) and Epstein (2007), who argue that what people often lack is not information but safe and trusting social spaces where they can collectively negotiate ways of making unfamiliar health-related information relevant to their own

specific lives. HIV/AIDS is still considered shameful by many people in Zimbabwe, as was evident in the control group. CC participants' reports on implementing antistigma strategies strongly suggest that CCs gave people opportunities to think of action and to view the problem as far more actionable than those in the control group. The following quotation illustrates a control group participant explaining that the stigma surrounding HIV is linked to the fact that transmission is primarily through sex, a subject that remains difficult for many people to talk about and associated with shame.

> I think the problem is to do with HIV's main transmission route. People talk of HIV being transmitted through sharp objects but to be honest the main route of transmission is through sexual intercourse. Over 90% of AIDS cases got it sexually. That's why people are ashamed (Male Roman Catholic Control).

Participants in CCs developed shared understanding of how to combat HIV stigma. CC dialogue on HIV stigma decreased from time 1 to time 2. During time 2 and time 3 the slight decrease could be a result of people reflecting on HIV stigma action that needed to be taken. During T2 and T3 participants started to share how they had offered material and emotional support to PLWHA. In contrast, shunning of PLWHA was high in our control sites.

Discussion about disseminating HIV/AIDS information increased sharply in time 2 then it was maintained throughout time 3. This was different from the control site, which had very little discussion about sharing HIV/AIDS information. This high level of discussion in the CCs might be a result of dialogical spaces that were provided by CCs. Sourcing for outside support increased in time 2 then decreased in time 3. This reduction can be attributed to the decline of non-governmental activities during that period.

The 'offering material and emotional support' category includes discussion of antisigma strategies, creating an array of hope and contesting stigma. The number of times these issues were mentioned increased slightly from time 1 to time 3. This can be attributed partly to the community conversations that provided fertile space in which people can actively think of how they can participate in tackling AIDS stigma and by other confounding factors beyond the scope of this research.

As Freire (1970) emphasizes, genuine communication can only be said to have occurred when both parties are able to learn from each other. This experience resonates with my research where CC participants begun to problematize stigmatizing attitudes and used the space to share their experiences of tackling it. CC participants shared their beliefs, misconceptions, experiences of living with HIV and caring for HIV sufferers. This finding echoes Jovcheovitch's (2007) emphasis on the social psychological theories of how the self is able to take the perspective of the other. Importance is given to the 'space of the between' which I refer to as the social space; this is where recognition and intersubjectivity lie.

### 6.2.2 Negative sentiments about capacity to tackle stigma

The process of facilitating strategies to tackle AIDS stigma was intertwined with obstacles to action and expressions of negative sentiments. These obstacles suggest that while communities can strive towards addressing their own problems, there are certain problems that they cannot address by themselves. These problems include lack of good role models, economic and political factors external to the community, on-going risky behaviour, community fear of PLWHA, misconceptions held, shunning of PLWHA, gendered burden placed on women and limited outside agencies. The graph below is a frequency count of all the obstacles that were discussed.

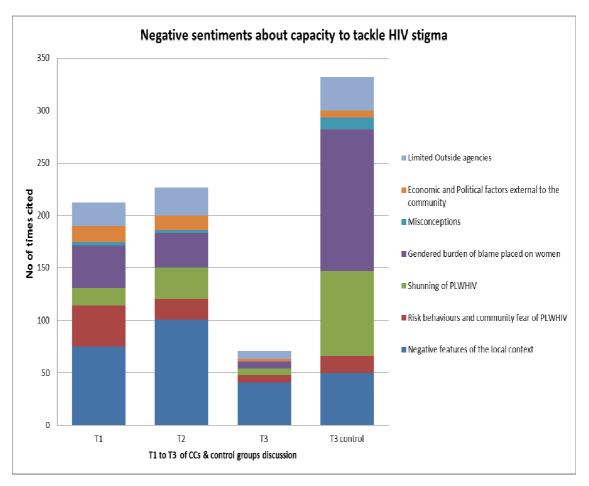


Figure 21: Negative sentiments about capacity to tackle HIV stigma

During time 1 and time 2, participants appeared to be somewhat hopeless about tackling AIDS stigma. Time 2 actually had more negative sentiments than in time 1. I infer that this could be attributed to participants not expressing themselves the first time they met researchers. Participants were aware of the level of stigma that existed in the community but did not discuss ways to address it during the initial CCs. Most participants discussed how nothing could be done to address AIDS stigma and that HIV sufferers were to blame for contracting the infection.

The amount of discussion of negative features of the local context increased in time 2 and then decreased in time 3. Although the study sites remained the same from time 2 to 3, the decrease in discussion of negative feature of local context might be attributed to implementing some of the strategies outlined in time 1 and 2. Additionally, the problem of limited availability of support agencies contributed immensely to the bad context in all the sites. Even in intervention sites in time 3 lack of role models was discussed the most as a hindrance to implementing strategies.

Discussion on obstacles to combating anti-stigma attitudes decreased in time 2. There was further decline in time 3 in the intervention sites. One of the factors I infer could be attributed to the dialogical space that was created by the CCs and had a wider positive impact on the community. There might be other factors that could have contributed but were not flagged up during the research.

I am not sure of the reasons of such high level of discussion about obstacles in the control sites. CCs created a haven where participants could engage in dialogue in trusting relations, listen to other people's perspectives, disagree, encourage and supported each other. These positive processes did not occur to a significant level in our control groups because I did not have any long term involvement with the control group participants over which to increase comfort and facilitate critical discussion.

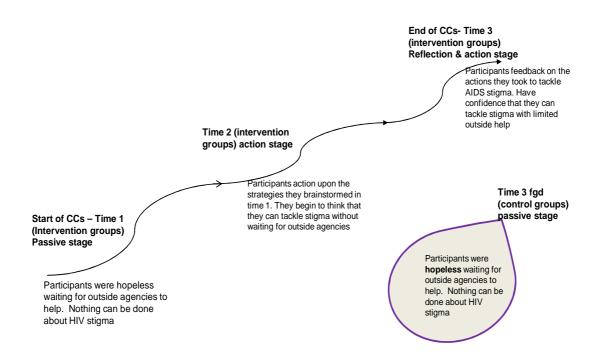
Negative sentiments increased slightly in time 2 and then decreased in time 3 in our intervention sites. I infer that this decrease between time 2 and 3 could be a result of critical reflection upon individual knowledge and shared knowledge among participants leading to the new knowledge co-constructed with others during CCs. This change echoes Freire's psychological theorisation of the process of conscientisation. He describes people moving through the stages of different forms of consciousness. After the stage of 'semi- intransitive' (see chapter 2), through initiating dialogue with others, participants may transition to a naïve consciousness characterized by an 'over simplification of problems' and an inability to identify realistic strategies by which their own actions may change circumstances (Freire 1973/1999).

The number of times that participants cited how misconceptions were a barrier to stigma reduction decreased from time 1 to time 2 and none were recorded in time 3 of our intervention sites. This was different in our control sites where a sizeable number of people discussed issues relating to misconceptions of HIV/AIDS.

## 6.3 Path from passivity to Empowerment

Below I present a reflection and action path of CCs to illustrate the extent to which people came to realize there was something they could do to fight stigma.

#### Figure 22: Reflection and Action Path from Time 1 to 3



This research has illustrated how CCs in the intervention sites provided a platform for community members to develop and re-think strategies to tackle AIDS stigma, as shown by the reflection and action path above. The dialogical path was never easy; at times participants would share their frustration of how limited resources and macro social factors had impacted negatively in their communities. However, CCs challenged some of the frustrations and emphasized that participants need to brainstorm actionable strategies within their scope to achieve social change.

Facilitation of CCs had an important bearing on how participants implemented their strategies. Their strategies were embedded in a context that was complex in two ways. First, the context comprised of high inflationary economy and high unemployment rate. Second, in most settings community members expected outside agencies to offer material support which was not the case with this research. Below I present the three stages that emerged in the data during CCs.

#### 6.3.1 Time 1: Passive stage

During the initial CCs, most participants cited how HIV anti-stigma obstacles where not possible to address. Other participants repeatedly asked if researchers were going to offer any form of assistance given the harsh economic living:

> We have a lot of AIDS orphans and no one is taking care of them. Would your organization help? (Male Apostolic T1)

> We understand that you told us that you cannot offer us any material assistance. We are requesting if you can tell your bosses that we would like to be assisted with a fence to block cattle from eating our plants (Male Catholic T1).

Can you help us with seeds, these days as you know things are hard. Some of us cannot even afford to purchase seeds (Male Anglican T1).

We thank you for coming, but the truth is that some of these AIDS patients are lying down because of hunger. If only you can help us with food (Female Catholic T1).

A tendency of blaming HIV sufferers was evident in time 1. Some participants blamed HIV sufferers for knowingly acquiring HIV therefore justifying why they deserve to be shunned. One such example is when some participants stated that another HIV sufferer deserved to have the illness since she used to be a prostitute. Among the participants was a woman whose husband was having a relationship with a prostitute:

They deserve to be ill-treated, my husband asked me to leave if I couldn't accept that he is seeing this prostitute. He knows that I wouldn't leave my children and this prostitute knows that I am the wife. I have stopped sleeping with him: What if I contract HIV? (Female Anglican T1).

#### 6.3.2 Time 2: Action stage

During time 2 participants reported on the strategies they had implemented towards tackling AIDS stigma. Most participants had managed to visit HIV sufferers, assist HIV sufferers with household chores and farming activities, offered spiritual support and comforted HIV sufferers, among other activities. During this stage participants didn't see their actions as contributing towards combating stigmatizing attitudes. Some participants viewed their actions as facilitated by the CCs and not have a sense of ownership to their strategies:

I didn't know you wanted us to implement these strategies. Although I did because we had discussed about it, if I had known I would have done more (Female Roman Catholic T2).

After you left the discussion we had with you compelled us to visit HIV sufferers. I couldn't just sit at home and not assist these people. I just did that because we had discussed about that; I had no idea that you wanted us to implement the strategies (Male Catholic T2).

#### 6.3.3 Time 3: Reflection and action stage

Through a gradual process of profound critical insight, participants began to report a lot of activities they had implemented towards tackling stigmatizing attitudes. Notably, participants overwhelmingly agreed that there was less shunning of HIV sufferers within their settings. I must note that there could be other factors beyond this research that could have facilitated a reduction in the level of talk by CC participants of stigmatizing attitudes. As participants reported on how they collectively worked together, I draw Freire's emphasis on how marginalized communities can act collectively to produce social change (Freire, 1974):

One of the problem that we faced occurred when we tried to visit HIV/AIDS sufferers. You know some people don't even know much about this disease due to the fact that they would shun some HIV/AIDS programmes done by FACT here. But it so happened that such a person had an AIDS patient at their home. They did not

know how to treat their patient well. I saw that, but then I tried to go to their place and took the opportunity to warn them against illtreating their patient, I discovered that it would be out of ignorance. Some people do not even take the advice and they just say AIDS sufferers are a problem and they are too demanding. I think churches should also teach their church members (Female Anglican T3).

As a group we discussed about how best we can assist these HIV sufferers. Therefore we always choose a day that we can get together visit some of the HIV sufferers, assist with household chores and give them a small donation which they always appreciate (Female Catholic T3).

# 6.3.4 Control group: Passive stage

In our control groups participants cited how stigmatizing attitudes were considered normal, particularly in a context where prostitution is rife. Although the research was conducted the same time as the final CCs (that is in time 3). Participants in T1 of CCs also shared the same sentiments. The tear like shape for control groups represents the stigmatising attitudes that were present within these sites at T3. Most participants shared that no-one had disclosed their HIV status and most of them held the assertion that stigmatizing attitudes cannot be tackled:

This disease was initially called a disease or a punishment for those who sleep around. So it is generally understood as a disease for prostitutes. People are ashamed that revealing their status will also imply that they have been sleeping around (Female Anglican control).

The same problem of disclosure makes it hard even within the church. As a church we just look at patients suffering from any disease, there is nothing specifically done to target HIV sufferers. The status is not disclosed even at funerals it is just said the person was ill, otherwise it will always remain a secret we have not

got to a point where people can talk about their status (Female Roman Catholic control).

# 6.4 Capacities and limitations of CCs as an approach for tackling stigma and building HIV competent churches

This study advances our thinking of how community groups can create spaces conducive for HIV knowledge dialogue, empowerment, ownership and bridging social capital, each of which are elements of 'HIV competent churches'. I now discuss the way that CCs contributed to each of the components of AIDS competence.

# 6.4.1 HIV knowledge

HIV knowledge is a necessary condition but not a sufficient one for coping with HIV. HIV knowledge among all the participants in this study was relatively high. My data revealed that although people had a large among of information about HIV/AIDS, this information was embedded in a context that did not offer 'safe social spaces' to translate the information into action. The lack of local trust and solidarity within churches and communities was not a haven for HIV disclosure. Some participants cited how the church acted as an obstacle to effective HIV prevention measures.

> You cannot afford to disclose your HIV status in church, people will start labelling you as a HIV sufferer. The worse thing is that the whole community will know about my status. The next thing is that the children will all be stigmatized and referred to as a child of a HIV sufferer (Female Anglican T1).

People know about HIV/AIDS: the information is disseminated on the radio, television, newspapers and in schools. However, we cannot even refer to informal communication when people talk about HIV/AIDS. These days we see relatives or people in the community dying of AIDS but the church doesn't talk much about HIV/AIDS stigma (Female Apostolic T1).

Even if you ask a young child they will tell you about HIV/AIDS. We have a lot of AIDS orphans who are being taken care of by grandmothers. The church cannot do anything because most of

the funders have withdrawn funding. We (the local church) are the new funders and we just cannot help them. I think that is why the church cannot do anything (Female Catholic).

Nyblade et al. (2009) has recognized the dangers of providing information without any resources to use this information. For instance, informing people of the risks of HIV and how to safely care for someone with HIV must be followed up with ensuring access to materials such as gloves and water. My research aligns with this understanding. CCs tried to fill this gap between having information and the resources to use it by creating spaces in which participants could discuss ways of putting the information they had into action.

## 6.4.2 Dialogue

During CCs, community groups discussed different strategies to address HIV stigma. One of the achievements of CCs was for participants to communicate possible strategies to tackle HIV stigma grounded in local context and problematize obstacles to strategies. Participants reflected on their strategies during time 2 and 3 and critically discussed barriers to enacting their strategies.

> I think that's true and people in this community should try and avoid this language of saying "nhingi ari muchirongwa" so and so is in the programme as a way of referring to HIV positive people who are taking ARVs, I have talked to some people who really do not want that label, so let's avoid such labeling terms otherwise we will undo what we have achieved as of now, no wonder why some people are going to collect their supplies of ARVs from that local hospital where they remain anonymous. I think let's allow them to use that term for themselves (Male Anglican T3)

> "Ehe", Yes, I think when we assist these patients we also help them to open up and share their problems and they also feel loved and they get that sense of belonging. I think they benefit (Male Roman Catholic T3).

There are issues when we visit HIV/AIDS sufferers as a group, let's say we visit twice and on our third visit say the patient gets worse the relatives may then begin to think of us as the cause of the deterioration of their patient. So issues of witchcraft would be coming up. This is something we encounter because when we visit we would be told that the patient has been moved away and at one point the patient had to shout and say I am here, he was hidden inside but he really wanted to see people who were coming to see him. This really embarrassed the relatives who really didn't want us to see him. These are some of the challenges (Male Roman Catholic T3).

The other challenge is that given the difficult economic conditions, us the HIV/AIDS sufferers expect people to bring food items but you find they are no longer bringing much yet these tablets require one to eat healthy food, people were really failing to bring anything for us, and it was not their fault, actually there is serious hunger (Female Roman Catholic T3).

Community groups used what Freire calls 'praxis' during critical dialogue to problematize the obstacles they faced in implementing their strategies to tackle AIDS stigma. CCs provided social spaces for community groups to debate, reflect on their strategies and the obstacles they faced in implementing some of the strategies raised. Fertile spaces were created to share personal experiences of living with HIV.

#### 6.4.3 Empowerment

In my discussion of the conceptual framework underpinning this research (see chapter 2), empowerment was singled out as an essential element in social psychological processes within community groups. Empowerment was apparent when participants exhibited the confidence to collectively work together to tackle AIDS stigma. As evident in the study during time 2 and time 3, community members began to discuss ways in which they managed to tackle AIDS stigma.

We managed to assist a HIV sufferer by accompanying him to the hospital to collect his medicine. We used our cart to transport him (Male Roman Catholic T3).

As a group we visited HIV patients at their homes. We concentrate on the ones that are bed ridden. People would bring along any vegetable they have in their garden and then contribute a small amount and give to the patient (Female Anglican T2).

..... we have a lot of work to do here, like this year we were faced with hunger, but in that hunger we also have people suffering from HIV/AIDS, and they need food and I have a neighbor who is bedridden and has HIV/AIDS. Just this morning they came to say they have run out of food. So I took a bucket of maize so that they can at least get something to eat.(....). As a church group we also do a lot of work to educate others about this problem, but as a family this neighbor has actually been our concern. It's the mother of that family who is ill, and the children are still very young. So my family do the chores like fetching water for this family and even cooking for them (Male Apostolic T3).

#### 6.4.4 Ownership

During the initial CCs, some community members appeared as if they didn't know how to tackle AIDS stigma and spoke in ways that suggested they felt the problem must be dealt with by outsiders. There was no sense that coping with HIV and addressing stigma was a responsibility of everyone in the community.

> I think for married couples to consider VCT, normally it happens when the wife catches her husband red-handed, that way it may become easy for the wife to drag the man for HIV tests or force the husband to use condoms. This would be because she would have seen it and proved that her husband has been sleeping around. Otherwise when there is no trigger or reason to suspect any suspicious behavior on the part of the other sexual partner then there would no need for VCT (Female Anglican T1)

> There is a girl whom I know but I just know that she was ill, I might not be sure that she is HIV positive, but she had all the signs and symptoms. She was staying with her grandmother and grandfather. This girl left this area to other bigger towns but when

she came back she was already ill so her grannies found it hard to accept her. They could not accept that she came back when she was already ill. (...)They would lock her outside and sometimes deny her food so much that she ended up asking for food from neighbours and church members until neighbours and church members had to intervene and talk to the grannies so that they can treat her well (Female Anglican T1).

Most participants cited how HIV sufferers were being labelled in the community and the lack of role models had perpetuated stigmatizing attitudes in various communities.

We see these things because we go to beer halls, so there are times when those commercial sex workers would be looking for clients, so we know a lot of people who have been clients to these ladies, so we won't be surprised when we see people getting ill. I have seen a lot of people getting ill, and once that happens people begin to isolate the person, even commercial sex workers would avoid that person who will be ill, even if one of their own gets ill they no longer want to associate with the ill one. Even accompanying one to the hospital will not happen. I hope I am saying what is happening here, isn't it John., In some cases in the beer halls you would find that when a person who is HIV positive comes in people would begin to whisper to each other and would not want to share even their beer with the sick one ( Male Roman Catholic T1).

However over the course of the CCs, community members started to share their experiences of addressing HIV stigma in church and at community level, illustrating a growing sense of ownership. Gradually during time 2 and 3, participants shared how they had disseminated HIV/AIDS information, visited HIV sufferers and assisted HIV sufferers with collecting medicine from the hospital. Examples of these activities that participants had implemented represent how people had a sense of ownership towards addressing HIV stigma.

#### 6.4.5 Bridging social capital

The research suggests that there is need for constructing sustainable bridges with powerful agencies such as the government and other local and international organisations. Although local people can make changes in their communities, their capacity to tackle HIV stigma on their own is limited and support from outside can increase the impact of local efforts. There is an urgent need to lobby for participation with powerful agencies such as policymakers, government and outside agencies to sustain tackling HIV stigma. The urgent need for constructing such bridges was evident in many CCs such examples are below:

But you guys, we have patients and we have raised the issue of food. Can you do something about that or at least look for other organizations that can help us? (Male Catholic T2).

These patients might be willing to get medical attention but there may be no money, no mode of transport for them to go hospital. So some of the challenges we face is material obstacles, we pray but what the patient might need is material assistance. Now with the use of foreign currency the economic hardships are even worse (Female Anglican T3).

#### Summary

This chapter has sought to highlight how CCs were used to address HIV/AIDS stigma. However, as is the case with all small scale exploratory research studies, caution needs to be taken in generalizing the findings outlined in this chapter, particularly due to the small sample size and the location of the study. Although the results are consistent with the findings from my previous empirical chapters and current theories on the interaction between group membership and community level factors, the study cannot provide conclusive evidence of causality.

I have explored the potential of CCs to facilitate social space for critical dialogue--a key feature of HIV competent churches. I have done so in the interests of contributing to debates about how church groups and communities can effectively participate at the grassroots level in planning and implementing health promotion programmes

such as stigma reduction. I have sought to show how CCs facilitated tackling HIV/AIDS stigma in rural Zimbabwe.

This research has illustrated how HIV/AIDS stigma is mediated by the material, economic, political, institutional and symbolic context. Most of the research on stigma does not explore the possibilities for established institutions such as church groups to challenge and transform the operation and effects of stigmatizing representations and practices (Marshall & Taylor, 2006; Plattner & Meiring, 2006). This study has made a modest, but I believe useful, contribution to this in existing research by highlighting a possible strategy for facilitating community participation as well as pointing to both the possibilities and challenges for churches tackling HIV/AIDS stigma.

The lack of external organisations working in the communities highlighted the unsupportive context in which church members were struggling with tackling HIV/AIDS stigma. Additionally, many responses from participants suggest that even in this apparently unpromising context the initiative taken by participants has started to curb different forms of stigma. Therefore community engagement using CCs facilitated some mobilization and the development of strategies to address HIV/AIDS stigma.

A key challenge that I faced was the need for people to depart from the norm of expecting outside agencies to assist them, but to instead mobilise the limited resources available in seeking to make their own active contribution to solutions. Although participants were willing, the high inflation and unemployment rates were a major setback to our study. CCs facilitated participants to brainstorm strategies to tackle AIDS stigma and reported obstacles to their strategies in the follow up CCs (time 2 and 3). These obstacles were then problematized by other participants who tried to brainstorm how best to tackle the obstacle(s) or alternatively agree that it was a macro-social obstacle that they could not tackle.

The next chapter brings together the findings of my three empirical chapters and I will reflect on the implications of my findings for future interventions seeking to enhance the role of churches in tackling AIDS stigma.

# CHAPTER 7: CREATING SOCIAL SPACES FOR POSITIVE CHURCH RESPONSES TO HIV AND AIDS: A PROPOSED SOCIAL PSYCHOLOGICAL PERSPECTIVE

### **Chapter Overview**

In this chapter I outline three social psychological models which have been supported by my research into the potential impacts of community group memberships on stigma. The first (Figure 22), maps out the six stages through which organic social capital is mobilised within community groups. The second model (Figure 23) illustrates how lack of effective dialogical spaces might lead to the perpetuation rather than reduction of stigma by community group members. The final model (Figure 24) synthesises my own empirical findings with work from 'the social psychology of participation' to highlight the psycho-social mediators between group memberships and stigma reduction. I conclude the chapter by making some remarks about the implications of my findings for policy and practice.

# 7.1 How do community conversations open up space for stigma reduction? A social psychological model.

This section highlights the contribution of my research to understandings of action research and engaging community dialogue as a strategy of social change. As far as I am aware, my work in Zimbabwe is the first action research study in southern Africa that maps out the detailed psycho-social processes through which dialogue in community groups leads to reflection and action to reduce stigma.

It has already been documented that focus group discussions provide a microcosm of the 'thinking society' (Lunt & Livingstone, 1996) and that community groups provide opportunities for heath enhancing change (Campbell et al., 2010; Campbell et al., 2002; Fawcett et al., 1995; Gregson et al., 2004). However, to date, there are no academic studies of the community conversations technique and the potential for community conversations to lead to new healthrelated social representations and practices. Moreover, despite widespread promotion of the community conversation method by highly influential global health bodies, particularly the WHO and UNDP (UNDP, 2004) there has been no intensive academic examination of the psychosocial processes underpinning successful community conversations.

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As far as I am aware, my thesis is the first in-depth multi-method case study of the role of social capital (in the form of community group participation) in facilitating or hindering stigma, and in serving as a potential resource for challenging and reducing stigma. I conducted detailed quantitative research on the impact of group memberships on stigma, and extensive qualitative research on the psycho-social processes through which group memberships impact on stigma, using both interviews and community conversations.

Many psychological studies that have viewed stigma as a property of individuals and have thus tended to conduct individual-focused research such as individual interviews and questionnaires. My qualitative research presents a conceptualisation of HIV stigma as a collective process, highlighting the strong role that community context plays in influencing stigmatising attributes. This conceptual approach necessitated the use of a research methodology that enabled me to explore group understandings. In addition to interviews and questionnaires, I used community conversations to explore the local social contexts within which individuals form attitudes towards PLWHA and to highlight their potential role in reducing stigma by providing opportunities for dialogue and renegotiation of social norms.

Gaskell and Bauer (2000 p.345) highlight how the social researcher always tries to make sense of another person from a social milieu – which is, in principle, an unending quest given the complexity of social phenomena. Understanding social conceptualizations and changing local perceptions to create more health enabling environments necessitates examining issues from multiple angles. In particular, researchers must have the tools to explore the organic interactions among social groupings as well as the impact of social context on individual perceptions. As I will discuss in this section, community conversations enabled me to go beyond focus groups to move from merely observing social interactions to actually creating potential spaces for social change. The individual interviews and quantitative analysis of questionnaires enabled me to understand how individuals construct their identities and behaviours in relation to social norms.

The cross-sectional analysis (showing that participants who reported spending time in social groups were less likely to have stigmatising attitudes), themes (including: challenging HIV stigma in church settings, disseminating HIV and AIDS information, assisting with material resources and informal assistance with home based care) and strategies (such as: offering material and emotional support to HIV sufferers and seeking outside support) discussed in the empirical chapters did not emerge in isolation from each other. These findings where

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interdependent and the connections between the analysis, themes and strategies are important in my proposed social psychological model of AIDS competent church groups (presented in § 7.3 Theoretical contribution).

My cross-sectional study has made two contributions. First the study developed and tested a new explanatory framework derived from the literature (see chapter 2 & 4). My data support the theory encapsulated in the framework, in that most people, when provided social spaces for informal or formal discussion about caring for PLWHA, were less likely to have stigmatising attitudes. This research represents the first empirically-based attempt to examine whether participating in a well-functioning group is associated with less stigmatising attitudes. Second, this is the first study to provide '*prima facie*' evidence that membership of community groups can help to reduce stigma. Provision of social spaces for discussions about HIV and AIDS within group meetings formally or informally could be an effective means of reducing current levels of stigma.

However, one of the limitations of the quantitative approach is the failure to document the processes that are involved in dialogical spaces. Additionally, my quantitative research was unable to establish causality, i.e. I could not determine whether less stigmatizing people choose to join groups or groups make people less stigmatizing.

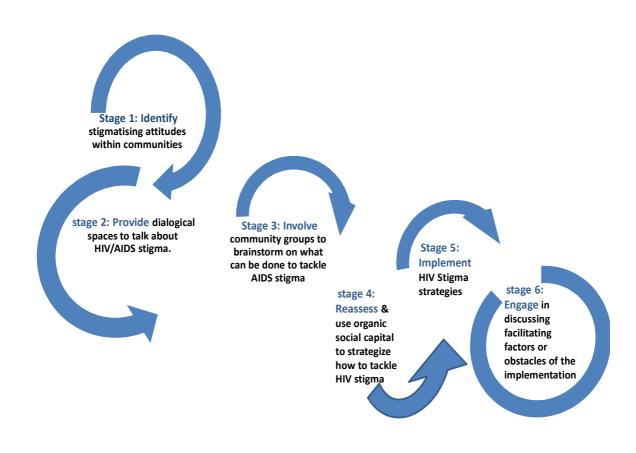
Another major limitation of quantitative analysis (see chapter 4) is the reliance on self-reports of stigmatising attitudes. It is well-known that results are prone to systematic reporting errors such as social desirability bias. I have tried to address this problem by examining a large sample size of 15 672 people and triangulating my methods (see chapter 3 and 4) through individual interviews and action research in the form of CCs. The use of triangulation allowed for multiple approaches to the data. This study pulls together quantitative and qualitative techniques in order to understand how community groups address HIV stigma and the negative and positive effects of church groups (see chapter 1).

The community conversation intervention method seeks to enable local communities to develop their own ideas and strategies—a very different approach from top-down intervention methods. Within the CC method, the participants retain power and control over the direction and content of the discussion. With the support from the facilitator, community members act as researchers

exploring HIV/AIDS problems within their communities, identifying available social capital, sharing knowledge regarding HIV stigma and taking action to tackle HIV stigma. CCs strive to be more democratic than outsider-developed interventions. They seek to build capacity and confidence in local resources, encourage self-determination and make interventions less expert driven.

CCs enabled participants to identify stigmatising attitudes within communities, discuss HIV stigma and brainstorm safe ways of tackling AIDS stigma. I found that CCs were generally able to create some form of dialogical space. In these conversations, participants shared obstacles to HIV competence within their church groups and communities (see chapters 3 & 6). During the initial stages of the CCs, participant expectations where focused on receiving material resources from facilitators (see chapter 6). This was illustrated with most participants asking facilitators what they were going to give to the community (see chapter 6). However, over the course of the CCs, dialogical space developed and participants began to move from focusing on hopes for donations to finding ways to contribute to addressing AIDS stigma. In figure 23, below I present the stages that can be used when working with community groups to promote health enhancing strategies such as HIV/AIDS stigma, arrows represent the different stages.

#### Figure 23: Proposed stages of mobilizing organic social capital within community groups



In my research with church groups, mobilising organic social capital and facilitating dialogical spaces to address HIV stigma were never easy steps. In figure 23, I attempted to convey the challenges inherent to moving from one stage to another through making the arrows rounded rather than straight. It was through an on-going process of dialogue that the church groups were able to reassess their beliefs, use organic social capital and implement HIV stigma strategies. This was never a linear process: three rounds of the cycle were conducted in the form of three CCs, spaced over the course of nine months (chapter 6). Within each cycle, church members reflected on the strategies implemented, and discussed the factors facilitating and hindering the implementation process.

My experience suggests that one-off CCs are probably not adequate. It will be necessary for groups to reconvene, preferably on two more occasions, to reflect on the thoughts shared by participants, and on the complexities of turning them into action. I found that CCs must offer adequate space and time for reflection and discursive engagement of factors facilitating and obscuring implementation of strategies. When CC participants in my study brainstormed strategies to tackle HIV stigma they needed to reflect on their strategies within the next round of CCs. If CCs are conducted without reconvening to reflect on what participants said, it will be difficult for people to work together to reflect on efforts made, adjust strategies and overcome barriers. From a research perspective, a single meeting would also make it impossible for researchers to assess whether attitudes and action planning appear to be improving.

The CC methodology was based on the above model of how interventions can be structured to work with communities to tackle stigma. It includes the following key elements: *Identifying* stigmatising attitudes within communities, *providing* dialogical spaces to talk about HIV and AIDS stigma, *Involving* community groups to brainstorm on what can be done to tackle AIDS stigma, *Reassessing & using* organic social capital to strategize how to tackle HIV stigma, *Implementing* HIV stigma strategies and *engaging* in discussing facilitating factors or obstacles of the implementation (see figure 23).

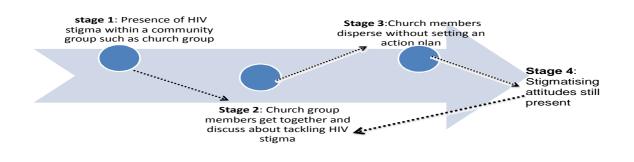
Action without reflection leads to what Freire (1972) has labelled 'adapted consciousness'. An adapted consciousness is when oppressed people have a limited ability to conceive of alternatives or do not have the confidence to challenge oppressive social relations (Campbell & Macphail, 2002). When communities continue to operate without critical refection on the reasons for or effectiveness of their approaches, they are unable to begin the process of tackling AIDS stigma. Humans have the capacity to reflect and strategize about the future but often do not undertake these processes critically, particularly in conditions of poverty, where they might have developed a sense of passivity or fatalism in relation to social problems, and a tendency not to see themselves as potential active agents in improving their lives. Lack of access to a reflective space potentially limits their intellectual confidence such as they will view their problems as a permanent fact and overwhelming. Freire states, "they would have internalised the values of the oppressors and find themselves unable, or unwilling to think critically about their situation in the world and what actions are open to them to improve such a situation" (Freire 1972, p.24).

Taking part in dialogue where norms are questioned and people are encouraged to come up with new ideas will enable individuals to critically think of the obstacles to HIV stigma reduction and find ways of implementing the strategies into their churches and wider community. Similar Squire (2007) in South Africa document the agency, courage and creativity that HIV affected and infected people showed in constructing positive and empowered identities in a context where few people had access to anti-retroviral therapy. This process of becoming aware of a problem such as HIV stigma, strategizing how to tackle it and having a space to reflect on obstacles and factors facilitating implementing strategies is a pathway to social change in community health.

## 7.2 Failure of dialogue

The goal of providing dialogical spaces to talk about HIV stigma was to enable church groups to identify how they could best tackle HIV and AIDS stigma, develop a sense of ownership of the problems they face, address negative representations of HIV sufferers and promote HIV dialogical spaces where individuals feel empowered to disclose their HIV status. When churches do not provide safe dialogical spaces where helpful activities and strategies to tackle AIDS stigma can be implemented, church groups cultivate the belief that being married and being considered a believer is a refuge from HIV. Some churches even propagate the attitude that HIV infection is a sign of moral failing. When these attitudes are perpetuated by churches, they discourage HIV afflicted individuals from seeking help from established institutions in communities such as churches. Figure 24 below illustrates how a lack of dialogical spaces on developing action plans enables stigmatising attitudes to perpetuate.

Figure 24: An illustration of how lack of dialogical spaces on developing action plans in church groups could perpetuate HIV stigma.



The thematic presentation suggested above in Figure 24 is based on the themes that were identified as hindering HIV competence within church groups from T1 to T3. These are symbolic stigma, denial, silencing women in church, discourage condom use, gendered blame, courtesy stigma, gossip about those who have disclosed and encouraging polygamy. The clustering of themes referred to as unhelpful attitudes (see chapter 5) and obstacles to strategies (see chapter 6) provides an understanding of HIV representation within church groups and communities (see analytical framework in chapter 4) if HIV stigma is not tackled.

Church groups contributed to perpetuating HIV stigma by: (1) being silent about HIV, making it difficult for sufferers to find refuge in their church; (2) associating HIV with promiscuity; (3) blaming PLWHA, and (4) humiliating PLWHA by asking them to confess in front of the congregation (this was limited to the Apostolic sects). However, church groups were instrumental in combating HIV stigma by: (1) showing love and compassion to PLWHA; (2) disseminating HIV/AIDS information; (3) distributing condoms (only in Anglican), (4) speaking openly about HIV at funerals; and (5) offering spiritual and social support to PLWHA and carers.

Among the Apostolic sect, HIV was frequently represented as a sign of moral transgressions. In other instances, PLWHA were viewed as sinners and therefore deserving to be infected with

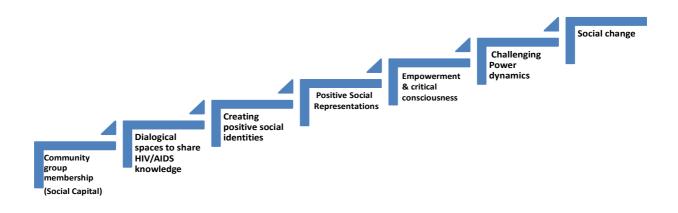
HIV. In this regard stigma was enacted, and the church generally appeared to have failed to offer comfort to the infected. I found evidence that, Alonzo and Reynolds (1995) suggested, HIV sufferers in seeking social support from established institutions as church groups, might have to accept the perspective of the condemners that HIV is a punishment they deserved from God.

## 7.3 Psycho-social mediators between group memberships and stigma reduction

My thesis illustrates a new and convincing application of the social psychology of dialogue in practice in a particular context. As such it provides a useful contribution both for social psychology (in terms of illustrating dialogical theory in action in one particularly interesting and topical setting), and also for the field of HIV stigma reduction interventions, in terms of mapping out the social psychological processes that should inform the design of participatory stigma reduction interventions, using organic social groups.

There have been on-going calls for new programmatic approaches to HIV in which stigmatised individuals and communities resist harmful attitudes towards HIV and are utilised as a resource for social change (Campbell et al., 2010; Parker & Aggleton, 2003). Campbell and Deacon (2006) point out that whilst lip service is frequently paid to the role that 'community participation' or 'community mobilisation' should play in stigma reduction, little is written about the mechanisms through which such participation might take place, or about the social psychological processes through which participation might lead to stigma reduction. In my thesis I have 'mined' the existing social psychological literature on dialogue, and its potential for reframing health damaging identities and social representations, and used this as a lens to frame my own empirical investigations of the role of community conversations as a potential stigma reduction strategy. This has resulted in the theoretical model of the stigma reduction process that I outline below in Figure 25 below, which illustrates the steps taken to bring about social change through mobilizing existing social capital using dialogue.

#### Figure 25: Model of mobilizing existing capital for social change



This model represents a synthesis of the theory of the psychological underpinnings of social change discussed in chapter 2 and findings from the empirical research (chapters 4, 5 and 6).

Freire (1970) argued that people do not process information the way banks process money, in that we do not simply receive and store information. Instead, Freire suggested that people filter new information through the lenses of their older understandings of the world. People cannot and will not simply replace old beliefs with new information. When confronted with new ideas or experiences, people work within their social context to develop new meanings and understandings that build on old understandings. This research sought to move from trying to disseminate HIV information (i.e. trying to deposit information in the 'banks' of local minds) to trying to facilitate group members' confidence and a dialogical space between individuals in which people could discuss and incorporate new ways of thinking into their worldviews through an act of 'mutual conscientisation'.

My research resonates strongly with the dialogical perspective in social psychology (as outlined e.g. by Jovchelovitch, 2007). A dialogical perspective focuses on the positive (though sometimes negative) potentials of reciprocal on-going conversation between two or more people sharing different views. I seek, through my analysis of the current literature (Chapter 2) and three empirical chapters (Chapters 4, 5 & 6) to further our understanding of the role of dialogue in the process through which community groups can mobilise existing social capital to promote social change. In many instances, communities have local social capital at their disposal but they don't realise how best to use the existing social capital as a resource for tackling social problems. My research shows how carefully facilitated community conversations have the potential to tap into these sometimes latent resources. As Moser (1998) has argued, even in conditions of extreme material poverty, poor people have access to 'portfolios of assets', with social capital constituting one such asset.

However my thesis also illustrates the limits of community participatory processes, through highlighting some of the obstacles that stand in the way of putting group decisions into action in conditions of poverty, social disruption and limited health and welfare services. This point is taken up further below.

## 7.4 Implications for policy and practice

The small- scale success achieved by my CCs was significant, especially considering that these successes took place within the adverse context of poverty, drought, limited foreign support, antiretroviral drug shortages and political difficulties. CCs facilitated the development of nuanced strategies to reduce HIV stigma on a limited scale within a local community. This project has strong implications for both policy and practice. It underpins the call for the development of context specific community-level HIV interventions and contributes to our understanding of the nature of what might constitute an 'HIV competent church group' and how to facilitate their development. This project also suggests that outside agencies should take heed of organic knowledge and utilize available resources in efforts to help communities, and proposes an approach (community conversations) and a social psychological model to assist in programme design and evaluation.

The notion of HIV competent communities emphasizes the capacity of local people to positively influence their own lives. However, I caution against asking too much of local responses to HIV. The need for bridging social capital—i.e. strong organizational, financial, research and medical support from national and international organizations and governments--remains essential. These local communities have less opportunity and resources to contribute to social change than more affluent communities. Drawing on my research, it is ultimately not possible for people to simply strategize and discuss their way out of poverty. CCs offer a strategy to enable people to make the best use of local resources such as kindness and social capital but do not remove the need for greater external support through providing better healthcare and poverty alleviation.

Many AIDS-affected communities are deeply rooted in poverty and anticipate programs to offer material resources. It is a slow process to help people understand that they have valuable indigenous forms of psycho-social support within their community which also constitute positive community enhancing resources. Karl Marx asserts that humans are historical beings rooted in a material reality (Blackburn, 2000). In the context of Zimbabwe, the harsh economic climate within communities often led participants to ask for assistance in income generating projects. These requests went beyond the scope of this research, in a way that went against the rationale of the CCs focus on indigenous resources, and its goal of building local peoples' confidence to see that they too have a role to play in solving social problems rather than simply waiting for outsiders to help them. However, over time from T1 to T3, participants did indeed come to focus less on their expectations of outside help from the researchers, and more on thinking through what they themselves could do to tackle stigma using their own indigenous resources And as a result I do believe that, even given the constraints of poverty and lack of services, the CCs did make some modest contributions to empowering people to behave with more support and tolerance to AIDS affected others in their community.

The high level of social capital in the form of AIDS competence that I identified and that were developed through CCs should not undermine an appreciation of underlying macro-social factors that could not be addressed by this research. Communities have limited resources and power to implement effective sustainable action. There is need for bridging social capital to support HIV competent community initiatives. The development of understandings of the role of bridging social capital, the types of bridging social capital that can be relied on even in difficult conditions, and the development of strategies to build it, is discussed in Chapter 8 when I talk about future research directions in my area of interest.

Echoing the works of other social constructionist theorists in community health, (e.g. Cornish, 2010; Campbell et al., 2007), the empirical results from my research show how social change can be facilitated when respected established community groups such as church groups have the confidence and strategies to tackle stigmatising attitudes. Most sub-Saharan Africans are religious and people are grateful for the care and support to HIV sufferers offered by church groups (Keikelame et al., 2010). However, as repeatedly discussed, church groups play contradictory roles in HIV stigma mitigation; while providing care for the sick, some churches also associate HIV with promiscuity and fuel gendered blame, where women are blamed for their HIV infection, irrespective of being infected by their male counterparts (see chapter 5 and 6). At a social constructionist level, gendered blame may be interpreted as resistance to social change by church groups, 'where sin is turned from sexual activity towards sin of stigma' (Keikelame, et al., 2010).

This study illuminates the complex nuances in church groups when discussing a controversial issue such as the role of churches in tackling HIV stigma. For example some church members cited how difficult it was to convince church leaders to think of initiatives to assist PLWHA and AIDS orphans. These findings extend social capital knowledge within the public health arena, providing a nuanced understanding of how community groups can mobilise existing social capital to be 'HIV competent groups'.

#### **Concluding Remarks**

The three models outlined above are offered as useful applications of social psychological theory to the challenge of understanding the potential impacts of dialogical social spaces on HIV stigma. They do so through mapping out the processes through which community conversations may, at best, provide opportunities for the renegotiation of harmful social representations, which open up the possibility of new forms of practice (Figure 23), and at worse simply perpetuate pre-existing negative representations without leading to change (Figure 24). They also highlight the psycho-social factors that mediate between community conversations and stigma reduction in situations where effective dialogue has taken place. More detailed recommendations and implications for future research are discussed in chapter 8.

### **Chapter Overview**

This chapter discusses the research process and the effects of the research project on me, the researcher, and the participants. I highlight the contributions that this thesis makes to the existing research literatures within the community health field. My recommendations for future research include the need for longitudinal analysis of the association between community groups and stigmatising attitudes. Other ideas for future research include more exploration of the HIV competence framework within church groups, the need to look at the potential for other social settings (e.g. the workplace) to generate HIV competence, and the need for more research into the way in which bridging social capital might facilitate the CC process.

## 8.1 Reflections on the Research Process

#### The effects of the research process on the researcher

This section presents an account of my reflections on the experience of working with church members on addressing HIV and AIDS stigma within their church groups. I would like to acknowledge my dual role as both a social psychologist researcher and as a person who has lost close relatives to HIV. While collecting data for my thesis, I experienced fluctuating levels of empathy, optimism and hopelessness about the situations presented. When participants shared how difficult it was to disclose their HIV status given the high levels of stigma, I realised that both my uncle and a close relative who died of AIDS five years ago did not disclose their HIV status because of stigma. Nine months and two weeks ago I lost a couple, my uncle and aunt respectively, to AIDS. They disclosed their HIV status to their children when it was too late to respond to antiretroviral therapy (ART), despite being active church members who were respected in their community.

Confronted with HIV daily as I hear news of relatives dying due to AIDS, as well as reading and analysing transcriptions for this thesis, I have experienced endless emotional reactions. The question that I pose is that if established institutions embedded in communities such as church groups had been supported in offering space for HIV dialogue, would we have lost the people we lost due to AIDS stigma? This question concerns us all as it relates to the pressing need for HIV sufferers to be able to quickly access health services without fear of

stigma within community groups and the wider community. Some might suggest that my close personal involvement in the social issues of my research was a disadvantage, and might have biased my findings in some way.

Thus some might argue, for example, that my clarity of vision might have been clouded by anger or disappointment when my research informants might have expressed naked stigma. Others might argue that my need to see hope in difficult situations might have led me to exaggerate the potential for community groups to bring about positive social change. All I can say in response is that I have worked hard to keep my mind open to both the potentials and limitations of community groups, and I believe that my first-hand knowledge of the situation has given me the potential to understand the complexities of living in a community with AIDS more than an outsider might have done.

I hope that my analysis of my findings – in which I have sought very hard to balance both the potential and the limitations of community groups – will convince the reader that despite my personal involvements I was able to conduct balanced research which provided a nuanced account of both the potentials and limitations for social change in such a complex social setting. From a personal point of view, any discomfort that I have suffered in conducting the research is balanced by my strong hope that my findings will contribute to recognition of the untapped potential of organic community groups as agents of possible change – and will contribute to the on-going challenge of preventing more HIV sufferers from dying as a result of AIDS stigma – as I discussed in chapter 1.

#### My thoughts on the effect of CC on research participants

I have spoken of the impact of the research experience on myself. How did participants experience their participation? During the initial CCs (T1) participants gave fairly short responses and appeared somewhat uncomfortable during the conversations. Although the participants cited HIV stigma as a problem and asked for more help from outsiders they were not relaxed during the conversation. They asked a lot of questions about why we are recording them and what we would do with the interviews, despite being told the purpose of the interview before they consented to participate.

In later conversations (T2 and T3) they gave longer responses. During T2 and T3 participants were more relaxed, telling the researchers stories of what had happened when we were absent from the community. While I do not think this change can be wholly attributed to the participants coming to regard the researchers as insiders, what is interesting to consider is how participants became comfortable enough to cite stories of how other people in the community secretly approach them seeking for help to access ARVs. One interpretation might be that the participants felt more comfortable to share their experiences in T2 and T3 since this was our second encounter with them. The participants may have become more open from T1 to T2 and T3 because they regarded dialogue as an appropriate and empathetic tool. Dialogue was presented to participants as a bridge to represent local voices to powerful agencies that could bring about social change to address HIV stigma within communities.

An additional factor in the increasing openness observed from T1 to T2 and T3 might be changes in the national political situation. The CCs were rolled out during a period of political turmoil during the pre- and post-election period of the Government of National Unity (GNU). Communities were suspicious of people who were from outside their communities. What interested me most was how CC participants moved from being suspicious to expressing their gratitude for being offered a fertile space to talk and take action against HIV stigma despite the challenging political environment. It is amazing how open people were considering the bad political situation. The participants frequently thanked me and my research assistant for choosing to work in their communities and for facilitating HIV stigma dialogue within church groups. The social spaces created a fertile ground in which some participants conceived ideas and took action. For example, some participants gained the confidence to disclose their HIV-positive status. CCs facilitated social spaces for church members to actively challenge stigmatising attitudes towards PLWHA and their carers.

## 8.2 Contributions to the existing literature

This thesis represents the first attempt at (i) examining the association of community groups and HIV stigmatising attitudes and (ii) using action research in the form of community conversations in addressing stigmatising attitudes in sub-Saharan Africa.

#### (i) Contribution to the current understanding of social capital

Considering the magnitude of the HIV epidemic in sub-Saharan Africa and that most people are practicing Christians who either attend church every week or are actively members of a church group, this thesis adds to the limited literature on addressing HIV stigma within established community groups such as church groups. I hope the findings of my thesis will be of interest to policy makers, public health practitioners, church leaders, governments and local people who are confronted with HIV stigma daily. Drawing on the few studies on HIV stigma in Zimbabwe highlighted in chapter 1, I hope that my research has made three contributions towards our growing understanding of social capital. First, chapter 4 has provided quantitative evidence that participating in well-functioning community groups can be associated with less stigmatising attitudes. Second, chapter 5 provides a detailed explanation on how social capital in the form of helpful activities and attitudes addresses HIV stigma. Lastly, chapter 6 focuses on how long-term assistance to HIV sufferers and carers can have a positive impact on tackling HIV stigma. These findings arose from my action-research in Zimbabwe, in which I ran community conversation interventions at three different times throughout one year, each four months apart.

Very little literature currently exists on the link between social capital and tackling HIV stigma. I hope my research will make a strong contribution to this understudied but promising field. My research findings will not only contribute to the existing literature but will also provide vital information on how communities with limited resources can mobilise social capital to address HIV stigma without waiting for external help. I hope that my three models of mobilising organic social capital within communities (see chapter 7) and my focus on the reflection action cycle (chapters 6 & 7) will increase awareness on how community groups can be supported in addressing HIV stigma. Additionally, the findings (chapter 4, 5 and 6) can be drawn upon to help established church groups and organizations planning to work with church groups understand on how best to utilise existing social capital to address HIV stigma.

## (ii) Contribution to understandings of the role of dialogical spaces in building health competence

Drawing on the importance of dialogical spaces discussed in chapter 7, I have attempted to contribute to the literature on the importance of transformative spaces. Transformative spaces are meeting places where community groups brainstorm and implement actionable

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strategies towards addressing HIV stigma. My findings have suggested that community members are fully aware of the different levels of HIV stigma (see chapter 4, 5 & &) and many (though not all) believed that the stigma was problematic. What people lacked was fertile space to transform the information they had about HIV/AIDS in ways that would make sense in the contexts of their own lives, and to action the desire of many to reduce stigma in their communities and to formulate feasible practical strategies for doing so. To be precise: (i) people often already have information about HIV stigma; (ii) many want to change or reduce stigmatising attitudes; (iii) but they need safe spaces to develop action strategies to bring about change.

I would like to go back at this point to the ideas expressed in chapter 2. There I outlined how established community groups such as church groups have the potential to facilitate dialogical spaces through which members can develop collective agency to tackle problems that undermine their health. Social change requires the presence of social spaces for dialogue at the level of community groups as opposed to individual levels, and transformative social spaces that facilitate the development of actionable understandings on health enhancing strategies (Campbell & Cornish, 2010; Nhamo, Campbell, & Gregson, 2010; Vaughan, 2010). This thesis provides a contribution to the theoretical understanding of the relationship between dialogical spaces (Campbell, Skovdal, & Gibbs, 2010; Freire, 1972; Freire, 1973/1999) and HIV stigma discourse. The lack of such safe spaces where community members can engage in dialogue and debate about ways of tackling a phenomenon such as HIV stigma is a huge impediment to social change. My discussion in chapters 6 and 7 on dialogical spaces seeks to increase awareness on the importance of mobilising existing local social capital to tackle HIV stigmatising attitudes within community groups.

## (iii) Contribution to our understandings of the potentials and limitations of the role of communities in social change

This thesis provides a contribution to our understandings of social change by outlining models of the stages that go into developing 'HIV competent church groups'. Chapter 2 discussed the limitations of biomedical approaches and presented models of designing HIV interventions. The previous chapter presented my theoretical model illustrating the processes of social change on health competence. I have highlighted the processes through which community groups can be supported in diagnosing HIV stigmatising attitudes. Social psychology provides an emphasis on importance of transformative social spaces for critical

dialogue to change negative social representations. This research project goes one step further in providing an action research study of the potential for dialogical spaces to lead to the negotiation of actionable strategies through which marginalised communities can improve their health. I have also highlighted how collective implementation of strategies facilitates the development of bonding and bridging social capital within various church groups. Creating space for marginalised communities to take the initiative to implement strategies enables group members to build their capacity.

I have examined how this process facilitates HIV competence within church groups, leading to situations where church groups took the initiative to address obstacles to stigmatising attitudes such as gendered blame, gossiping about HIV sufferers in church, victim blaming, discouraging disclosure and symbolic stigma. It is these processes that lead to the development of 'HIV competent church groups'.

Social change research has repeatedly emphasized the need to focus on individuals, peer groups and social environments (Bandura, 1996; Campbell & Cornish, 2010; Campbell, Williams, & Gilgen, 2002; Woolcock & Narayan, 2000). My research provides a new multi-method contribution to our understandings of how established community groups and social environments facilitate or hinder social change and the processes of how church groups can become HIV competent through the careful use of community conversation techniques.

This thesis has highlighted how the pathways through which church groups can become HIV competent are rocky and complex. HIV is not only a medical problem, but a social problem too. There are a multitude of social factors that influence behaviour regarding safer sex, care for PLWHA, as well as access to antiretroviral therapy and HIV services (see analytical framework in chapter 4). Dialogical spaces cannot be regarded as a 'magic bullet'. The findings from this research project highlight how addressing HIV stigma cannot be achieved through attention to dialogical spaces, social representations and social identities alone. Even at T3, people repeatedly referred to the way in which material factors limited their ability to put their action plans into practice. Addressing HIV stigma will also require material changes, particularly improving access to ARVs, nutritious food and adequate income that will enable families and communities to care for HIV positive members. In contexts of extreme poverty and competition for limited resources, we need to be aware of the multiple constraints facing efforts to support community groups in working together to improve their

health (Campbell & Cornish, 2010). Such challenges are particularly acute when community members cannot mobilise enough resources to take care of their own patients.

Yet even within these constraints my groups showed evidence of positive changes. Even in challenging social settings, church groups are well established and respected institutions that bring people together for meetings and have a degree of moral sway. As respected institutions, church groups encourage anti-stigma attitudes people are more likely to listen and implement strategies of tackling HIV stigma. My quantitative findings, suggested that people spend more time in church groups than in other community groups. Moreover, even in the challenging social situation I refer to above, those who were members of church groups had less stigmatising attitudes than those that did not belong to a church group (see chapter 4). My research suggests that if church groups are given the space to strategize and implement their strategies, they can become bastions of support to the whole community even in conditions of deprivation and instability. Church members have the organizational capacity and high levels of local respect to facilitate transformative spaces in which they can contest stigmatising attitudes using local resources.

## 8.3 Contributions to Methodological literature

My review of this research would be incomplete without reflection on its methodological implications for the theory of social capital and social change. Wilson and Halperin (2008) state that there is need for participatory approaches to be grounded in evidence. My thesis makes a methodological contribution to the field of participatory action research through providing a detailed multi-method study, with a longitudinal component, of participation in action. CCs are yet to occupy a central position within the community health discourse. The action research strategy of CCs that I have proposed together with the cross-sectional and individual interviews results, suggest a number of interesting points where CCs can help to clarify some crucial elements within the social change arena. Instead of assuming that rural people already agree and work together as is often the case in community research (Moulton et al, 2007), CCs accept that, particularly in the context of taboo topics such as HIV/AIDS, it will be necessary to actively create space for debate and dialogue. The existence of collective agency - even in small rural communities - cannot be assumed. The CCs approach views collective community agency as something that must be built among community members over time, not something that can be assumed present among rural people simply because they live near one another. In particular CCs add to our understanding of the process of how community groups can collectively facilitate social change by building HIV competence within their groups. CCs also allow for the potential to

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develop collective agency where community groups discuss and debate a societal phenomena (i.e. HIV stigma) and develop strategies for change.

While many theorists have emphasized the need for supportive wider social contexts such as food, money, access to ARVs, gender equality, fair trade policy between rich and poor countries and political milieu (Campbell & Cornish, 2010) in addressing HIV stigma (Skinner & Mfecane, 2004), the potential role of established community groups such as church groups in addressing HIV stigma has been relatively neglected. Keikelame et al (2010), Trinitapoli & Regnerus (2006) and Haddad (2002) make clear that optimising faith bases response to address HIV stigma can facilitate efforts to reverse the HIV epidemic in South Africa, strengthening the government's renewed efforts to HIV prevention.

During my primary research in Manicaland, Zimbabwe, the CCs showed that facilitation of dialogical spaces can enable community members to take ownership of unfamiliar issues. For example, the Apostolic sects in my research had a strong tradition which strongly denied opportunities for women to articulate their concerns, needs and opinions during church activities encouraging them to channel their concerns through their male counterparts. Compounded by very rigid conservative attitudes to sexuality, church groups had not traditionally been easy places for open discussion of the negative results of stigma. However, the facilitation of CCs in my study enabled Apostolic women and men to both enter into a dialogue and agree that HIV stigma was a huge problem within their church groups and the wider community. My research has provided numerous other examples of how people used the resulting social spaces.

#### 8.4 Suggestions for Future research

#### Next steps in exploring the contribution of social networks to HIV stigma reduction

As discussed earlier in this thesis (chapter 4) men and women who participated in community groups were less likely than their peers to have stigmatising attitudes towards HIV sufferers. Nearly all community groups (i.e. burial societies, rotating credit society, youth club, Sports club, AIDS group, political party and church group) would meet once a month and discuss HIV prevention either formally or informally--an indication that there were already social spaces occurring indigenously in communities. Community groups are thought to be able to facilitate improvements in health and health care if they can offer an enabling

context that supports members' confidence, social skills and perceived efficacy (Campbell & Macphail, 2002; Putnam, 2000).

Building on the finding that community group membership is associated with less stigmatising attitudes, I went on to develop a model of the role of community networks in addressing HIV stigma. A future project could be to construct more questions for the quantitative research that relate to stigmatising attitudes. Because I conducted secondary analysis of a pre-existing dataset, the quantitative questionnaire I used in my research only asked about participants' unwilling to care for a relative with AIDS. This question was an imperfect proxy measure of stigma because, as discussed in chapter 4, answering "I am unwilling to care for a relative with AIDS" can be influenced by factors unrelated to stigma, such as a lack of resources.

I recommend that future rounds of quantitative research in Manicaland should include more precise and detailed measures of stigma. The collection of longitudinal data on stigmatising attitudes will allow for the implementation of more rigorous methods of measuring stigma. My cross-sectional research is the first study in Zimbabwe, so I have no doubt of its value. However, there is need for more detailed questions. There is also a need for longitudinal studies that establish causality (rather than simply correlation as is the case in a cross-sectional study). As the ART roll out progresses, longitudinal studies will also provide valuable insights into the question of whether increasing ART availability has any impact on stigmatising attitudes.

# The impact of dialogue in other settings (e.g. the workplace) on the development of community-level HIV competence

One of the main contributions of this thesis is the presentation of evidence that wellfunctioning community groups may be important for facilitating transformative dialogical spaces to tackle HIV stigma and be HIV competent. Limited access to local social capital can exacerbate poverty and curtail healthier coping mechanism to deal with the challenges of HIV.

My own research has focused on organic community groups. However, there is growing reference to the potential role of the workplaces in providing opportunities for the

development of HIV competence (Scott et al., in press). An area that is particularly ripe for future research would be to explore HIV competence within work places. Exploring how the work environment offers space for workers and professional people to address HIV stigmatising attitudes would enable the application of the HIV competence framework to another arena of social relationships, particularly in the light of the current international development emphasis on the role of the private sector in supporting its workplace communities in responding to pressing social problems.

# Further enhancing our understandings of how church groups respond to HIV stigma

The individual interviews with various church members from Anglican, Roman Catholic and Apostolic church groups in this study suggested that the church played an ambiguous role in addressing HIV stigma. Negative responses included expressions of unhelpful attitudes and positive response took the form of expressions of helpful attitudes and discussions of helpful activities (see chapter 5). As Skinner and Mfecane (2004) highlight, HIV stigma is a social phenomenon and has to be understood at both individual and social levels. Consequently, investigating how individual PLWHA construct their social identities within church groups could provide an interesting area for future research.

# Using community conversations as an intervention to facilitate transformative spaces in church groups, and the role of bridging social capital in this process

My research has provided a useful starting point for understanding how social spaces within community groups are a vital component to tackling HIV stigma. Consequently possible areas for future research would be to have long term CC interventions were church leaders are taught how to facilitate HIV dialogue in church groups and build sustainable bridges with outside agencies. As Saegert (2006) points out, community building emphasizes the development of relationships within and outside the community and the use of community assets to leverage assets from outside to solve common problems.

The limited involvement of donors, development agencies and the government in Zimbabwe create huge barriers to tackling HIV stigma. In these circumstances even when communities initiate their own programmes to tackle HIV stigma, the lack of external support can undermine grassroots initiated programmes. Financial and material resources are severely

limited in Zimbabwe where there is an unemployment rate of above 90% (Avert, 2011). There is also a high level of political instability, particularly prior to the Global Political Agreement (GPA) which was approved in September, 2008 and took effect on February 11, 2009.

CCs can be viewed as supportive transformative spaces where negative experiences can be shared and negative identities contested. CCs facilitate a space where individuals can collectively develop the agency and confidence to brainstorm and action strategies to challenge HIV stigma. However, in a context such as Zimbabwe, there is need to create sustainable bridges with powerful agencies to sustain the material and symbolic context within CCs in the long term.

The importance of bridging social capital in supporting grassroots community groups is continually emphasized in the community development literature (e.g. Saegert, 2006). The main focus of my own research has been to focus on dialogical processes *internal* to the CC groups, with less attention to the interface between the community groups and potential outside support groups. Above I have repeatedly emphasized how external factors (availability of services, lack of food, lack of home nursing resources etc.) stand in the way of group members actioning the stigma reduction strategies they formulate in the CCs. The strengthening of bridging social capital (i.e. relationships between organic community groups and potentially supportive outside agencies) could be a valuable arena for both analysis and action in relation to understanding how to optimize the likelihood that CCs can be successful in putting their plans into action.

For this reason I argue that an important line for future research into CCs should focus specifically on the processes through which community groups interface with external support links (e.g. with NGOs, Governments, other community groups and so on) – and the extent to which these external support groups might assist them in carrying out action plans formulated in CC settings. This would provide valuable information of interest both to researchers, and also to those seeking to promote policy and intervention to support organic community responses to HIV/AIDS in particular, and to pressing social problems more generally.

## **Concluding Remarks**

This thesis has explored how the psycho-social processes necessary to address HIV stigma can be facilitated through the facilitation of social spaces in community groups. This final chapter has sought to provide an overview of the researcher's reflections on working on a topic that is close to my heart. I hope this research has made lasting impact on the research participants as much as it did to me such as continuing to action strategies on tackling HIV stigma within their church groups.

My research has sought to contribute to on-going debates in the theoretical literature on social identity and stigma, the empirical literature on church responses to HIV/AIDS, the methodological literature on action research and the policy literature on community conversations and involving churches in Africa in stigma reduction initiatives. I hope that these contributions will encourage policy makers, the government of Zimbabwe, and faith based organisations in sub-Saharan Africa and other regions to engage with community groups to create transformative social spaces. Empirically, this research reaffirms the view of many social constructionists that there is need to facilitate social spaces, work with local communities, support local empowerment and build sustainable bonding and bridging of social capital. I hope CCs can be used for best practice when working with community groups to tackle a social phenomenon such as HIV stigma.

I am not claiming that CCs were perfect and that they can fix everything. Although I witnessed a reduction in stigmatising attitudes, this cannot be entirely attributed to CCs. During my research some people were accessing ARVs, which would increase local hopefulness and openness surrounding HIV. Additionally, the reduction in stigmatizing attitudes that I observed could reflect social desirability bias where people report low levels of stigma since that was what I was researching. However, this research provides '*prima facie*' evidence that community groups such as church groups can facilitate HIV stigma reduction. Additionally, my quantitative chapter (see chapter 4) and CCs as discussed in chapters 6 and 7, provide evidence that social spaces within established community groups can promote critical dialogue. This dialogue can generate confidence and enable community members to promote social change. Provision of social spaces is a necessary rather than sufficient condition for tackling HIV stigma. There is need to work in collaboration with other powerful agencies, such as the government and large donor organizations, which control political and economic power. However, creation of social spaces for dialogue within

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established institutions such as church groups can be used as a starting point towards creating a long term health enabling community context.

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## **APPENDICES**

## **APPENDIX 1: INTRODUCTION AND CONSENT FORM**

My name is Mercy Nhamo/Claudius Madanhire. As we have told you before there are a lot of questions, and the interview is very long (perhaps as long as 3 hours). As you will see, the questions are very easy. We will stop and have a short break if you get tired. If our study is to be a success, it is important that people answer questions from their hearts as truthfully and frankly as possible. Because the interview is confidential, we hope that you will feel free to do this.

We are interested in how people in this community, specifically in churches are coping with HIV/AIDS, so some of the questions will be directly around that topic. But we also need to learn about more general relationships in this community as a background to this topic. For this reason we will also ask you a lot of general questions about your life in this place, how people live together, what is easy and what is difficult about life and so on. As you will see, the questions are very easy, and there are no right or wrong answers. All we are interested in are your own personal views.

#### COMMUNITY RESPONSE TO HIV/AIDS PROJECT MANICALAND

- The aims of the study have been explained to me, and I have been given the chance to answer any questions I have understood about the study and its goals.
- 2. I understand that the interview will take about 3 hours.
- 3. I understand that I will be given a T-shirt at the end of the interview. Apart from that I will not derive any personal gain or assistance from participation in the study.
- 4. I understand that the interview will be tape recorded. No one will have access to the tape recording apart from members of the research team.
- 5. I understand that any information that I provide will be treated in confidence.
- 6. I freely consent to participate in the interview, on the conditions laid out above. No one has put any pressure on me to participate.

#### Signed:

#### Name:

Date:

## **APPENDIX 2: COMMUNITY CONVERSATION TOPIC GUIDE**

The community conversation topic guide that I used explored the following questions:

- What are the modes and transmission of HIV?
- How are people with HIV and AIDS treated?
- Do you know what HIV and AIDS stigma is?
- What is the church doing towards HIV and AIDS sufferers?
- What is the church doing in fighting HIV and AIDS stigma?
- What other activities does your church do?
- Are there any problems that they encounter in doing their activities and what are those?
- What are the solutions to these problems?

#### The second round of interviews explored the following questions:

PART ONE: THIRTY MINUTES

- 1) What are the goals of your church?
- 2) What type of activity does your group do?
- 3) Who benefits from these activities and how?
- 4) What problems do you encounter in your group activities (examples)
- 5) What are the solutions to these problems?

#### PART TWO: CONTINUATION ABOUT STIGMA:

NO JUDGEMENT ALL I WANT TO KNOW IS WHAT IS POSSIBLE AND NOT (REALITY)

- 6) Since our last meeting have you achieved anything as individuals in relation to reducing stigma in this community?
  - If so what did you do examples?
  - If not why not?

#### APPENDIX 2: COMMUNITY CONVERSATION TOPIC GUIDE

- What factors facilitated your efforts?
- What difficulties did you encounter?
- 7) As a group have you achieved anything in fighting stigma in this community?
- If so what did you do examples?
- If not why not?
- What factors facilitated your efforts?
- What difficulties did you encounter?
- 8) What are other obstacles to stigma and action that you faced?

#### NB Is there anything else that you would like to tell me about stigma.

## **APPENDIX 3: INDIVIDUAL IN-DEPTH INTERVIEW QUESTIONNAIRE**

## Time 1 and Time 3 Individual Questionnaire:

## A: DEMOGRAPHIC DETAILS

- Age
- Marital status
- Level of education
- Work
- Number of children
- Informant's organisational involvement (church)

#### **B: PERSONAL BIOGRAPHY**

Can you please tell me a brief history of your life, from your birth up to this day? Do you know anything about Aids what is it? When did you join your church?

#### C: INFORMANT'S PERCEPTION OF COMMUNITY RELATIONS.

- C.1 GENERAL QUESTIONS:
- 1. What kind of place is this community? What is it like to live here? What are the good and bad things about living here? What are the bad things?
- 2. Tell me how you got involved in the church?

#### C.2: GENDER RELATIONS

- 1. Is there respect and consideration amongst men and women in this community? (examples) in what ways is there lack of respect between men and women? (examples).
- 2. What is the role of men and women in this church do they play different roles if so in what way?

#### C.3: INTER-GENERATIONAL RELATIONS

- Is there respect and consideration amongst the younger generation and the older generation in this community? (examples) in what ways is there lack of respect between youth and older people? (examples).
- 2. What is the role of youths in the church do they have a different role to adults? If so in what way?

#### C4: ORGANISATIONS LINKED TO HIV/AIDS:

- 1. What are the Aids related organisations or groups that exist in this community; can you tell me their names and the roles they play in this community?
- 2. What challenges and obstacles do they face in doing their work in this community?
- 3. Do they network with other local organisations?

# C5: HIV/AIDS IN THIS COMMUNITY – INFORMANT'S PERCEPTIONS OF HIV/AIDS

- 4. Is HIV/Aids a big problem in this community and why?
- 5. Do you think people in this community practise safer sex and why?
- 6. Are people with Aids open about their status? Why? Why not?
- 7. Should people be open about their HIV/Aids status? Why? Why not?
- 8. Are people kind and tolerant people with HIV/Aids in this community in general? Or not? Can you give me an example of someone you know who has been treated in a kind and human manner? Example of someone who has been treated with discrimination?
- 9. Are women and men with HIV/Aids treated differently? (give examples).
- 10. What care and support is available for people with HIV/Aids? From family members? (examples) neighbours?(examples) Church members? (examples).
- 11. The church (what do they do for people with Aids? Do they do it well? Badly? Why do you say this? Do they play any role in providing HIV prevention education, care attitude to treatment?

- 12. Do you think the church is doing enough?
- 13. To what extend does the church get guidance from the National church body/ leaders.
- 14. How does the church view HIV sufferers?
- 15. What is your comment on the statement that states that 'people who contract HIV/Aids are sinful'?
- 16. What is your comment on extra marital sex?
- 17. How do you view the use of condoms?
- 18. Do leaders talk openly to the congregation about HIV/Aids?
- 19. What hindrance does the church face in disseminating HIV/Aids information.
- 20. Are there any support groups for people within this community?
- 21. Do you think the church is doing enough or can do more in relation in combating HIV/Aids (examples).
- 22. If you were given an opportunity to lead the church what would you do differently with regards to HIV/Aids reduction? (examples).
- 23. Do you think that all churches respond the same towards HIV/Aids? If not what's the difference? (give examples)
- 24. Is there more that the church could be doing and what is it?

#### D.1 FEEDBACK/CLOSURE:

Is there anything important you think we left out?

How did you feel about the interview? Was it a positive experience? Did you have any problems with it?

Which questions did you find interesting? Why?

Which questions did you not like?

We have now finished the interview, thank you very much for your time and patience.

MANICALAND HIV/STD PREVENTION STUDY: ROUND 3 (SITES 7-12)

INDIVI	DUAL QUESTIONNAIRE		F	ORM B
M	J <mark>T3 number:</mark>		Questionnaire processing dates:       Consent form       Corrections completed       Data entered	
QUEST	IONNAIRE IDENTIFICATION			
Q101	<u>Census district:</u>		EA:	
Q102	<u>Village:</u>			
Q103	Name of head of household:			
Q104	<u>Category of respondent:</u>	Date left R2 area	R2 MUTNO	
Q105	Study site reference:		R2	
Q106	Household number:		R2	
Q107	Line number on household questionnaire:		R2	
INTERV	VIEWER VISIT		1 2	3
Q108	Date:			
Q109	<u>Time:</u>			
Q110	Interviewer:			_
Q111	Result**:			
CHECK	ED BY SUPERVISOR			
Q112	<u>Signature:</u>			_
Q113	<u>Date:</u>			
Follow-up New respo New respo New respo New respo New respo New respo New respo	IDENT CATEGORY         respondent (from R2)       1         ondent: previously under age       2         ondent: non-regular visitor       3         ondent: spouse or co-wife interviewed before       4         ondent: selected but unavailable R2       6         ondent: selected but unavailable R2       7         ondent: selected but refused R2       7         ondent: lousehold missed R2       9         ondent: over age R1 or R2       10         cify)       8		**RESULT CODES Completed Not at home Refused Partially completed Sick/hospital Other (specify)	1 2 3 4 5 8

				TICS Q. No:	
REF.	QUESTIONS & FILTERS	CODING CATEGORIES			SKIP TO
Q201	Record the current time (24 hour clock).	Hour / Minutes		hr mins	
Q202	Record gender of respondent.	Male Female		$\begin{array}{c c}1\\2\end{array}$	
Q203	In what month and year were you born?			mnth yr	
Q204	How old were you at your last birthday? Check consistency with Q203.	Age in <u>completed</u> years		yrs	- If 19+, go to Q215
Q205	Is your <u>natural</u> father still alive?	Yes No Don't know		1 2 98	- Q209 - Q209
Q206	In which year did he die?	Year of death Don't know		98	
Q207	Were you living with your father on a regular basis when he was: (1) in good health; and (2) unwell?	Well Sick	<u>N/A</u>	<u>Yes</u> <u>No</u> 1 2 1 2	
Q208	Where were you living when your father was: (1) in good health? (2) unwell? (3) after he passed away?	This household Local household Harare Mutare Rusape Other town (specify) Estate / mine (specify) Other rural (specify) N/A: died in accident	Well 1 2 3 4 5 6 7 8	Sick         Died           1         1           2         2           3         3           4         4           5         5           6         6           7         7           8         99	
Q209	Is your <u>natural</u> mother still alive?	Yes No Don't know		$\begin{array}{c c}1\\2\\98\end{array}$	- Q214 - Q214
Q210	In which year did she die?	Year of death Don't know		98	
Q211	Who was the main person responsible for looking after you when your mother was: (1) in good health? (2) unwell? (3) after she passed away?	Natural mother Father's new/co-wife Sister Brother Aunt Uncle Grandmother Grandfather Cousin Other relation (specify) No relation N/A: died in accident	Well           1           2           3           4           5           6           7           8           9           10           11	$\begin{array}{c c} Sick & Died \\ \hline 1 & 1 \\ 2 & 2 \\ 3 & 3 \\ 4 & 4 \\ 5 & 5 \\ 6 & 6 \\ 7 & 7 \\ 8 & 8 \\ 9 & 9 \\ 10 & 10 \\ 11 & 11 \\ 99 \\ \end{array}$	- Q213 - Q213 - Q213 - Q213 - Q213
Q212	Record whether these were paternal or maternal relatives.	Paternal Maternal	$\frac{1}{2}$	$ \begin{array}{c c} 1 \\ 2 \end{array} $	
Q213	Where were you living when your mother was: (1) in good health? (2) unwell? (3) after she passed away? Tick one box in each column.	This household Local household Harare Mutare Rusape Other town Estate or mine Other rural	Well 1 2 3 4 5 6 7 8	Sick         Died           1         1           2         3           3         3           4         4           5         5           6         6           7         7           8         8           99         8	

INDIVIL	UAL QUESTIONNAIRE:	BACKGROUND CHARACTERISTI	CS Q. No:	
REF.	QUESTIONS & FILTERS	CODING CATEGORIES		SKIP TO
Q214	Record father and/or mother's SITE/HHID/LINE if recorded in the household surveys.	Father Mother Neither	98	
Q215	Are you currently enrolled in school full-time?	Yes No		- Q218
Q216	How old were you when you left school?	Age in completed years Never been to school	99 yrs	- Q220
Q217	What was your reason for leaving school? If parents decided, probe for the underlying reason.	Insufficient funds Found a job To go to college or university Inadequate exam passes Needed to help at home Marriage Pregnancy/childbirth - voluntarily Pregnancy - expelled Caught having sex - expelled Expelled - other reasons Other (specify)	1	
Q218	How many "O" level passes do you have?	No. of passes		
Q219	What is the highest grade of school you have completed? For "years", enter number of years (excl. repeats) at highest level reached.	LevelNone0Primary1Secondary2Higher3	Years           1-7           1-6           1-6	- Q221 - Q222
Q220	Can you read a letter or newspaper in any language?	Yes No	1	
Q221	Did you obtain a pass in the Grade 7 exam?	Yes No or not attempted	$ \begin{array}{c} 1\\ 2 \end{array} $	
Q222	How long have you been living in this homestead?	Years Since birth Visitor	995 996	
Q223	How far is your homestead from the nearest ?	Town/Growth point Business centre Tarred road		
Q224	How long have you been living in (NAME OF VILLAGE)?	Years Since birth Visitor	995 996	- Q227
Q225	What type of place was your previous place of residence? Record place of current home if the respondent is a visitor. "Roadside" here means a tarred road. Record the name of the place.	Large town or city Small town Growth point Commercial estate/mine Roadside business centre Rural business centre Communal/resettlement area	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	
Q226	Why did you move/come to this area?	Work Partner's work Marriage Lost job Establish rural home III health - own III health - relative (specify) Visit relatives Parents moved Divorced/separated from spouse Other (specify)	1     2       3     4       5     6       7     9       10     11       12     2	
Q227	In the last three years, have you lived outside this community for a period of one month or more?	Yes No Not applicable (visitor: Q224)	1 2 996	- Q229 - Q229
		-3-		FORM B

INDIVIDUAL QUESTIONNAIRE:

#### BACKGROUND CHARACTERISTICS Q. No:

REF.	QUESTIONS & FILTERS	CODING CATEGORIES		SKIP TO
Q228	Record, total no. of months away, & details of longest absence. Use codes from Q225 & Q229.	Last three years	Longest: Mths Place Reason	
Q229	<ul> <li>How many days and nights have you spent during the last month visiting the following places?</li> <li>Ask for and enter number of days and then nights for each. NB: last month only. Request reason for most recent visit to each place.</li> <li>1. To visit rural home - harvest or holidays</li> <li>2. To visit rural home - harvest or holidays</li> <li>2. To visit rural home - other</li> <li>3. To visit nusband/wife in town/estate</li> <li>4. To visit other relatives</li> <li>5. To attend a funeral</li> <li>6. To buy/sell produce or shopping</li> <li>7. To attend hospital or clinic or see doctor</li> <li>8. To attend school or college/university</li> <li>9. For work purposes</li> <li>10. To visit friends</li> <li>11. To visit boyfriend/girlfriend</li> <li>12. Other reasons</li> </ul>	Harare Mutare Rusape Nyazura Nyanga Watsomba Other cities/towns Nyabadza/Nyahukwa Hauna Katiyo Eastern Highlands Estate Aberfoyle Sheba/St.Augustine's Selbourne Honde Mission Bonda Mission St Killian's Mission St Theresa's Mission Other rural areas	days         nights         reason	
Q230	Which church denomination do you belong to?	Traditional Methodist Anglican Roman Catholic ZAOGA Apostolic Faith Mission Marange Apostolic Zviratidzo Apostolic Other Apostolic (specify) Zionist Mughodi Other (specify) None	$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	Q233
Q231	How long have you been a member of this church?	Years Since birth	995	Q233
Q232	What was your reason for joining a different church? Record name of previous church.	Marriage: spouse's church Conversion / born again Sickness Family misfortune Church beliefs better Moved to a new area Other (specify)	$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	
Q233	Record ethnicity.	Black Other (specify)	$ \begin{array}{c} 1\\ 8 \end{array} $	Q235
Q234	Which tribe do you belong to?         Also, record totem and whether         Mozambican.         Totem         Mozambican?	Manyika Ndau Maungwe Zezuru Korekore Karanga Ndebele Nyanja Sena Malawian Other (specify)	$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	

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INDIVIL	OUAL QUESTIONNAIRE:	BACKGROUND CHARACTERIST	CS	Q. No:	
REF.	QUESTIONS & FILTERS	CODING CATEGORIES			SKIP TO
Q235	Have you ever been circumcised?	Yes No	1 2		- Q237
Q236	How old were you when this was done?	Age in years			
Q237	In which sector of employment do you work?	Estates: tea, coffee, forestry etc Manufacturing or building trade Police or army Teacher: primary school Teacher: secondary school Nurse Services or retail: shops Informal: petty trading (veg etc) Informal: subsistence agriculture Student Unemployed: <u>excl.</u> agriculture Other (specify)	1 2 3 4 5 6 7 8 9 10 11 12		- Q240 - Q240 - Q240 - Q240 - Q240
Q238	What type of work do you do?	Professional or managerial Self-employed: small business Skilled labour Manual/unskilled labour	1 2 3 4		
Q239	How many days is it since the last time you were paid?	Number of days		days	
Q240	How many times have you visited a bar or beer-hall in the last month?	Number of times			- Q243 unless '0'
Q241	Did you ever drink alcohol at beer halls on a regular basis?	Yes No	1 2		- Q243
Q242	What was the reason you stopped drinking at beer halls?	Church rules Got married Other (specify) Don't know	1 2 8 98		
Q243	Do you drink alcohol on your own?	Yes No	1 2		- Q245
Q244	When you drink alcohol, do you usually have more than 3 beers in one night?	Yes No	1 2		
Q245	Do you smoke cigarettes?	Yes No	1 2		
Q246	Do you take any drugs for pleasure?	Yes No	1 2		
Q247	Have you ever been married or in a long-term or cohabiting relationship? Relationships of 12 months or more should be treated as "long-term".	Yes No	1 2		- Q295
Q248	How many such relationships have you experienced in your lifetime?	Include current relationships.			
Q249	How old were you when you first entered such a relationship?	Age (Years)		yrs	
Q250	How long did this first relationship last?		maths	yrs	
Q251	How many times in your life have you broken up with a marital partner?	Check consistency with Q248.			- If none,go to Q262
Q252	How many years is it since you last experienced divorce or separation?			yrs	
Q253	Was it you or your spouse who ended this relationship?	Self Spouse	1 2		

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INDIVII	DUAL QUESTIONNAIRE:	BACKGROUND CHARACTERIST	TICS Q. No:	
REF.	QUESTIONS & FILTERS	CODING CATEGORIES		SKIP TO
Q254	What was the reason for the breakdown of this relationship?	Respondent thought to be unfaithf Spouse thought to be unfaithful Respondent HIV+ Spouse HIV+ Failure to have children Domestic violence Irreconcilable differences Respondent seriously ill Spouse seriously ill Other (specify)	ful     1       2     3       3     4       5     6       7     8       9     10	
Q255	For how long had you been married to this person?		mnths yrs	
Q256	Where did you and this spouse live together when you were married? Tick up to two places.	In this household Locally Harare Mutare Rusape Other city or town Estate/mine (commercial) Rural (communal/resettlement)	1 2 3 4 5 6 7 7 8 9 9 9 9 9 9 9 9 9 9 9 9 9 9 9 9 9	
Q257	How long after this divorce/separation was it before you married again?	Not yet remarried		Q259
Q258	Why have you not remarried?	HIV+: so unsafe to have sex III health Fear of AIDS Sake of children Not found partner Other (specify) Don't know	1 2 3 4 5 8 98	
Q259	How long after this divorce/separation was it before you had sex again?	Not yet restarted	maths yrs 99	Q261
Q260	Why have you not had sex again?	HIV+: so unsafe to have sex III health Fear of AIDS Sake of children Not found partner Not yet remarried Other (specify) Don't know	$\begin{array}{c ccccccccccccccccccccccccccccccccccc$	Q262 Q262 Q262 Q262 Q262 Q262 Q262 Q262
Q261	How many different people did you have sex with between the time your previous marriage ended and the time you remarried? i.e. not including the old and new spouses.			
Q262	How many times in your life has a marital partner of yours passed away? Check consistency with Q248 & Q251.			If none, go to Q272
Q263	How many years is it since a marital partner of yours passed away?		yrs	
Q264	For how long had you been married to your (most recent) deceased spouse?		mnths yrs	
Q265	Where did you and this spouse live together when you were married? Enter codes from Q256.	Place 1 Place 2		
Q266	What was the cause of your partner's death?	Accident/homicide HIV/AIDS related Tuberculosis Malaria Other (specify) Don't know	1 2 3 4 8 98	
		- 6 -		FORM B

#### INDIVIDUAL QUESTIONNAIRE:

#### BACKGROUND CHARACTERISTICS Q. No:

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REF.	QUESTIONS & FILTERS	CODING CATEGORIES	SKIP TO
Q267	How long after this spouse died was it before you married again?	Not yet remarried 99	- Q269
Q268	Why have you not remarried?	HIV+: so unsafe to have sex       1         III health       2         Fear of AIDS       3         Sake of children       4         Not found partner       5         Under 1yr since partner died       6         Other (specify)       8         Don't know       98	
Q269	How long after this spouse died was it before you had sex again?	Not yet restarted 99	Q271
Q270	Why have you not had sex again?	Ill health2Fear of AIDS3Sake of children4Not found partner5Under 1yr since partner died6Other (specify)8	- Q272 Q272 Q272 Q272 Q272 Q272 Q272 Q272
Q271	How many different people did you have sex with between the time your previous marriage ended and the time you remarried? i.e. not including the old and new spouses.		
Q272	Are you currently widowed, divorced or separated from your most recent spouse/partner?		- Q295 - Q295 - Q295 - Q295
Q273	How many spouses/regular partners do you have at present? For women, ask how many other wives her husband has.	(Not zero!) Ask questions Q274 to Q290 for first spouse, then the second, and so on	
Q274	How old was your partner at his/her last birthday?	Age in completed years             Jon't know         98         98         98         98	
Q275	How old were you when this partnership started?	Age in completed years	
Q276	<i>Did you and your spouse have an HIV test before you agreed to get married?</i>	Both tested seperately 11 11 11 11	- Q278 - Q278 - Q278
Q277	Did you tell each other your results? Ask equivalent if only one tested.	Yes         1         1         1         1         2	
Q278	Has this person ever been widowed or divorced?	Yes: widowed         1         1         1         1           Yes: divorced         2         2         2         2           Yes: both         3         3         3         3         3         3         4           No         4         4         4         4         4         4         4	
Q279	Did you marry this person because he was/is married to your sister and she died or is unable to have children?	Inherited         1         1         1         1           Sister infertile         2         2         2         2         2           Neither         3         3         3         3         3         3	

NDIVIL	DUAL QUESTIONNAIRE:	BACKGROUND CHAI	RACTERISTICS	Q. No:	
REF.	QUESTIONS & FILTERS	CODING CATEGORIES			SKIP TO
Q280	Do you know the HIV status of this person now and whether it is the same as your own?	Yes: same as mine Yes: different to mine Yes: don't know mine No		$\frac{2}{3}$	
Q281	In the last few months has he/she been in good health, experienced recurring minor illnesses or been seriously ill?	Good health Recurring sickness Serious illness	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$		
Q282	Which of the following describes your and your spouse/partner's living arrangements best?		<u>1 2 3</u>	<u>4</u>	
	<ol> <li>Live together all of the time</li> <li>Live together but occasionally apart for work reasons</li> </ol>		$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	1 2	
	(3) Live together but separated for a period every year for work reasons (ie: seasonal employment).		3 3 3	3	
	<ul> <li>(4) Live apart but regular/frequent cohabitation (i.e.: return visits)</li> <li>(5) Live apart information behinding</li> </ul>				
	(5) Live apart, infrequent cohabitation		5 5 5		_
Q283	How long has he/she been living in (NAME OF VILLAGE)?	Years Since birth Stays elsewhere	yrs         yrs           995         995         99           996         996         99		- Q286 - Q285
Q284	Why did he/she move to this area?	Work Partner's work Marriage Lost job Establish rural home Ill health (own)	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	$\begin{array}{c c} 2\\ \hline 3\\ \hline 4\\ \hline 5 \end{array}$	
	Specify which relative:	Ill health (relative) Other (specify)		7	
Q285	What type of place was his/her previous place of residence? Record current residence if spouse	Large town or city Small town Growth point Estate/mine	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	$\frac{2}{3}$	
	usually stays elsewhere.	Roadside BC Rural BC Communal area	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	5	
	<u>Record the name of the place.</u>				
Q286	In the last 12 months, has he/she lived outside this community for a period of one month or more?	Yes No Don't know	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$		- Q288
Q287	Record, total no. of months away, & details of longest absence.	Total months away Longest: months Longest: place			
	Use codes from Q226 & Q229.	Longest: reason			

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NDIVIL	DUAL QUESTIONNAIRE:	BACKGROUND CHARACTERIS	TICS Q. No:	
REF.	QUESTIONS & FILTERS	CODING CATEGORIES		SKIP TO
Q288	How many nights during the last month did he/she stay in each of the following places?	Harare 1 2 Mutare	<u>3</u> <u>4</u>	
	<u>Ask for and enter number of nights</u> in each place.	Rusape		
	<u>NB: last month only.</u>	Nyabadza/Nyahukwa       Hauna       Katiyo       Eastern Highlands Est.		
		Aberfoyle Sheba/St. Augustine's Selbourne Honde Mission Bonda Mission St Killian's Mission St Theresa's Mission		
	Enter ''98'' if respondent does'nt know.	Other areas		
Q289	Which church denomination does he/she belong to?	Traditional         1         1           Methodist         4         4           Anglican         5         5           Roman Catholic         6         6           ZAOGA         7         7           Apostolic Faith Mn.         8         8           Marange Apostolic         9         9           Zviratidzo Apostolic (spec)         13         13           Zionist         15         15           Mughodi         20         20           Other (specify)         17         17           None         97         97	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	
Q290	Has he/she been circumcised?	Yes         1         1           No         2         2         2         98           Don't know         98         9	1         1           2         2           98         98	
Q291	Has he/she visited a bar or beer-hall in the last month?	Yes         1         1           No         2         2         2         98	$ \begin{array}{c cccc} 1 & 1 \\ 2 & 2 \\ 98 & 98 \\ \end{array} $	
Q292	What is the highest grade of school your partner has completed?	None00Primary11Secondary23Higher33	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	
Q293	In which sector of employment does he/she work?	Estates11Manuf'trg/building2Police/army3Teacher: primary4Teacher: secondary5Nurse6Services/retail: shops7Informal: trading8Informal: incl agric9Student10Unemployed: excl. agr11Other (specify)12	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	- Q295 - Q295 - Q295 - Q295 - Q295
Q294	What type of work does he/she do?	Prof/manage't1Self-employed2Skilled labour3Manual/unskilled4	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	
Q295	Did you vote in the last national or local elections?	Yes No	1	
Q296	Do youth play any role in local community leadership and decision-making?	No role Minor role Significant role		
				FORM B

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INDIVID	UAL QUESTIONNAIRE:	BACKGROUND CHAI	RACTERISTI	CS Q. No:	
REF.	QUESTIONS & FILTERS	CODING CATEGORIES			SKIP TO
Q299	Which of the following groups exist in your home area and which are you a member of? For those where he/she is a member: Would you say that this group functions: (1) well; (2) OK; or (3) poorly?	Church groups Women's groups Co-operative Farmers group Burial society Savings club (RCS) Youth group Sports club AIDS group Political party	Exist           1	Member         Rating	
Q2991	What is the principal activity of the group you spend the most time with?	Code from Q299 None		99	Q301
Q2992	Do group members discuss: (1) formally; (2) informally; or (3) both? In either formal or informal discussions, do group members advise each other on: (a) how to avoid HIV/AIDS? (b) care for people with HIV/AIDS? (c) support for orphaned children?	Formally Informally Both None	Meet         Avoid HIV           1         1           2         2           3         3           4         4	Care         Orphan           1         1           2         2           3         3           4         4	
Q2993	How often does the group meet?	Weekly Monthly Less often		1 2 3	
Q2994	Is the group sponsored by a church, school, political party, NGO or other organisation? Record name of organisation:	Church School Political party NGO Employer Other None		1 2 3 4 5 8 99	
Q2995	What proportion of the group are: (1) Male? (2) Aged under 20 years? (3) Married? (4) Have received secondary education?	Record as %s.		DK         %           998	
Q2996	Does the group assist or meet with: (1) Other groups of the same type? (2) Other groups of different types? (3) Other members of the community?		Assists           1           1           1           1	$ \begin{array}{c c}     Meets & Neither \\     \hline     2 & 3 \\     2 & 3 \\     \hline     2 & 3 \end{array} $	
Q2997	How many members of the group consume alcohol during or after the meetings?	All or most Some None or very few		1 2 3	
Q2998	Are the group meetings generally co-operative or conflictual?	Co-operative Conflictual		1	

INDIVIDUAL QUESTIONNAIRE:

#### INVITATION TO JOIN THE STUDY

Explain the purpose of the study - including potential benefits nationally and to the community. Explain what is involved in participating in the study - show/read invitation letter and consent form. Ask about and discuss any concerns the respondent might have. Seek consent to participate in the study - request signature on consent form.

Q301	<u>Indicate whether the respondent</u> _wishes to join/continue in the study.	Yes No	$\frac{1}{2}$ - Q303
Q302	Indicate the main reason why he/she does not wish to participate. * Ask for an appointment if reason is insufficient time.	Insufficient time* DBS samples Information too personal Other (specify)	$ \begin{array}{cccccccccccccccccccccccccccccccccccc$
Q303	<u>Record details of others present at</u> <u>this point.</u>	Children under 10 Husband/wife Other males Other females	<u>Yes</u> <u>No</u>

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INDIVIL	DUAL QUESTIONNAIRE:	SEXUAL RELATIONSHIPS	Q. No:	
REF.	QUESTIONS & FILTERS	CODING CATEGORIES		SKIP TO
Q401	10-15 minutes of informal discussion first to build ra Explain the need to ask questions on the respondent Stress the importance of providing accurate informa Stress that strict confidentiality will be maintained -	's own experience of sexual relationships. ation.		
Q402	How old were you when you had sex for the first time? Explain what we mean by "having sex".	Age in years Not yet had sex	99	- Q406
Q403	At what point before you had sex for the first time, did you speak to your partner and agree to have sex? Or did it just happen without you ever specifically tallking about it?	Talked in advance/agreed to have sex Happened without discussion/agreement Can't remember/don't know	$\begin{array}{c}1\\2\\3\end{array}$	
Q404	The first time you had sex, did you use any method of contraception?	Yes No Don't know/no response	1 2 98	- Q407 - Q407
Q405	Which method did you use?	Condoms Other modern Traditional	$\begin{array}{c c}1\\2\\3\end{array}$	- Q407 - Q407 - Q407
Q406	What is the main reason you have not yet started to have sexual relations?	Too young Not met partner Not yet married Risk of pregnancy Risk of HIV/AIDS Other (specify)	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	- Q413 - Q413 - Q413 - Q413 - Q413 - Q413 - Q413
Q407	How many days is it since you last had sex? .Skip to Q409 if less than one month.	More than one year		
Q408	What is the main reason you are currently abstaining from sexual relations? Options 1-4 could refer to the respondent or (if male) to his regular partner.	Current pregnancy Recent birth Terminal abstenance Self or partner has an STD Currently living apart Risk of catching HIV/AIDS Risk of passing on HIV/AIDS Religious reasons Not currently married Self or partner has HIV/AIDS Other (specify)	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	
Q409	Did you use condoms <u>throughout</u> the last time you have sex?	Yes No	$\begin{array}{c}1\\2\end{array}$	
Q410	Did you know the HIV status of the person you had sex with and whether it was the same as your own?	Yes: same as mine Yes: different to mine Yes: don't know mine No	$\begin{array}{c c}1\\2\\3\\4\end{array}$	
Q411	How many different sexual partners did you have before you got married? It not yet married, ask for number of partners so far.	Number of partners <u>"Married" here includes long-term</u> and cohabiting unions - ie: as in Q249.		
Q412	If you took a guess, how many partners other than yourself (and any co-wives) do you think your current spouse/partner has had in the last 12 months?	Number of non-regular partners		
Q413	Indicate data collection method used. For secret voting: (i) explain the procedure and the confidentiality safeguards carefully. (ii) enter fieldwork code on voting slips.	Secret voting Interview* <u>*Re-interviews MUST be conducted using</u> the same method as in Round 2.	R2 R3 1 1 2 2	

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NDIVID	UAL QUESTIONNAIRE:	SEXUAL RELATIONSHIPS	Q. No:
REF.	QUESTIONS & FILTERS	CODING CATEGORIES	SKIP TO
Q414	How many different <u>regular</u> sexual partners have you had in your <u>lifetime</u> ? By <u>regular</u> , I mean someone you have been having sex with for a year or more.	Number of partners	1
Q415	For how many years have you been using condoms <u>every time</u> you have sex with a <u>regular</u> partner? If you do not use condoms with your current regular partner(s), write "0".	Years	2
Q416	How many different <u>non-regular</u> sex partners have you had in your <u>lifetime</u> ?	Number of partners	3
Q417	For how many years have you been using condoms <u>every time</u> you have sex with a <u>non-regular</u> sexual partner? If you don't use condoms with non-regular sexual partners now, please write "0". If you have never had a non-regular sexual partner, please write "P".	Years	4
Q418	Of the non-regular sexual partnerships you have had in your lifetime, how many did you hope at the time would become <u>regular</u> partners?	Number of partners	5
Q419	How many different <u>regular</u> sexual partners have you had in the last two years? <u>For re-interview respondents</u> In other words, since we came last time.	Number of regular partners	1
Q420	How many different <u>non-regular</u> sexual partners have you had in the last two years? For re-interview respondents In other words, since we came last time.	Number of non-regular partners	2
Q421	How many different sexual partners have you had in the last 12 months?	Number of partners	3
Q422	How many of these partners were you having sex with for the first time?	Number of new partners in last 12 months ( <u>stress</u> )	4
Q423	How many of these new partners did you meet at a bar or beer hall?	<u>Stress</u> still talking about the last 12 months	5
Q424	How many sexual relationships do you consider yourself to be involved in at the moment?	Number of current relationships	6
Q425	How many different partners have you had sex with in the last month?	Number of partners in last month (total)	7

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NDIVII	DUAL QUESTIONNAIRE:	SEXUAL RELATIONSHIP	S Q. No:	
REF.	QUESTIONS & FILTERS	CODING CATEGORIES		SKIP TO
Q426	Explain that you now wish to ask some questions a Note: no longer any time restriction. Stress that the If secret voting is being used, ask the respondent to if he/she has not had any sexual relations in the la:	ese may be people he/she had sex with o enter a "P" in each box on the voti	th only once.	
			LAST DESIGNS	
Q427	How many times have you had sexual intercourse with this partner in the last 2 weeks?	Number of times	LAST PREVIOUS	1
Q428	On how many of these occasions did you and your partner use condoms throughout?	Number of times		2
Q429	What was the month and year when you <u>last</u> had sexual intercourse with this person?	Month first then year	math math yr yr	3
Q430	What was the month and year when you had sexual intercourse with this person for the first time?	Month first then year	math math yr yr	4
Q431	Where were you when you had sex with this person for the first time? If secret voting is being used, show respondent the picture codes.	Code		5
Q432	How many years old is this person?	Age in years	ута ута	6
Q433	Do you expect to have sex with this person again in the future?	Yes No		7
Q434	Is this person married to someone other than yourself?	Yes No Don't know		8
Q435	Have you given or received money in exchange for sex with this person in the last month?	Yes No		9
Q436	Did this person ever attend secondary school?	Yes No Don't know		10
Q437	Does this person often drink alcohol at bars or beer-halls?	Yes No		11
Q438	<u>Record details of others present at</u> <u>this point.</u>	Children under 10 Husband/wife Other males Other females	Y(1)         N(2)           Y(1)         N(2)           Y(1)         N(2)           Y(1)         N(2)           Y(1)         N(2)           Y(1)         N(2)	
Q439	Have you (or your partner) ever practiced dry sex? i.e.: inserting some herbs/substance to dry the vagina before having sexual intercourse.	Yes No Not heard of dry sex	$ \begin{array}{c} 1\\ 2\\ 8 \end{array} $	- Q451 - Q451
Q440	How often do you practice dry sex?	Almost always Sometimes Seldom	$\begin{array}{c c}1\\2\\3\end{array}$	
NDIVII	DUAL QUESTIONNAIRE:	SAMPLE COLLECTION		
Q451	Explain that you would now like to collect son other sexually transmitted infections can be c Explain that these tests are being done for rse for HIV and free treatment for STIs is availal Stress that strict confidentiality will be mainta	<u>arried out.</u> arch purposes only. However, fr ble at the local health centre.		
Q452	Blood spot sample obtained.	Yes No - <u>note reason.</u>		
		- 13 -	2	FORM B

REF.	QUESTIONS & FILTERS	CODING CATEGORIES		SKIP TO
Q501	In the last few months have you been in good health, experienced recurring minor illnesses or been seriously ill?	Good health Recurring sickness Serious illness	$\begin{array}{c}1\\2\\3\end{array}$	- Q503
Q502	In the last 2 years, how many times have you had an injection for medical purposes?			
Q503	How long is it since you last experienced an illness?	Days/weeks	days weeks	- Q508
Q504	What was the main symptom of the illness?	Fever - malaria (incl. cerebral) Fever - non-malaria Sickness/vomiting Diarrhoea/weight loss Swollen lymph nodes Skin complaints/rashes Genital conditions: incl. STDs Flu/pneumonia Accident/wound Tuberculosis	1         2           3         4           5         6           7         8           9         10           12         12	2000
Q505	Where did you seek assistance? Check whether assistance sought from more than one source.	Hospital/clinic only Clinic & n'anga Clinic & faith healer N'anga only Faith healer only Other (specify)	1 3 5 7 8 10 97	- Q508 - Q507 - Q507 - Q508 - Q508
Q506	Did you visit the n'anga (faith healer) before or after going to the clinic?	Before Same time After	$\begin{array}{c}1\\2\\3\end{array}$	
Q507	Why did you seek assistance from the n'anga (or faith healer)? Tick up to two options.	Clinic treatment not effective Spiritual cure needed Witchcraft suspected Holy water/bath or prayer Other (specify)	$\begin{array}{c c}1\\2\\3\\4\\8\end{array}$	
Q508	How true are the following statements for you in the last 3 months? <u>Ask each in turn.</u> (1) very much, (2) a little, (3) not really	I have felt depressed I have felt life was not worth living I have felt lonely I have felt content	$\begin{array}{c c} 2 & 3 \\ 2 & 3 \\ \hline \end{array}$	
Q509	For men: Some men experience pain during urination or have a discharge from the penis. During the last 12 months, have you noticed any such pain or discharge? For women: Some women experience an unusual discharge from the vagina or pain in the lower stomach. During the last 12 months, have you patiede und a discharge or pain?	Yes - discharge & pain (both) Yes - discharge only Yes - pain only No Don't know Clarify which & tick boxes as appropriate.	1 2 3 4 98	- Q511 - Q511
Q510	have you noticed such a discharge or pain? Have you <u>ever</u> experienced a discharge from the penis (vagina)?	Yes No or don't know	$\begin{array}{c}1\\2\end{array}$	
Q511	Some (wo)men experience sores in the genital area. During the last 12 months, have you noticed any such sores?	Yes No Don't know	1 2 98	- Q513
Q512	Have you ever experienced such sores?	Yes No or don't know	$\begin{array}{c c}1\\2\end{array}$	
Q513	When you last experienced a pain, discharge or sores in the genital area, did you seek assistance from any of the following?	Not had such symptoms	1 2 3 4 5 8 97 98	- Q523 - Q523 - Q523 - Q523 - Q523 - Q523
Q514	How long was it between the time when you first noticed symptoms and when you first sought help at a health clinic?	Days and weeks	days weeks	
Q515	How satisfied were you with the service that you received at the clinic?	Very satisfied Reasonably satisfied Not satisfied	$ \begin{array}{c} 1\\2\\3 \end{array} $	
Q516	Did the healthworker carry out a physical examination of the symptoms?	Yes No	$\begin{array}{c}1\\2\end{array}$	
Q517	What form of treatment did you receive? Check whether more than one.	Injections Pills/tablets Other (specify) None	1 2 8 99	
Q518	Have the symptoms continued or returned since you were last treated at the clinic?	Continued Returned Now stopped	$\begin{array}{c c} 1 \\ 2 \\ 3 \end{array}$	

REF.	QUESTIONS & FILTERS	CODING CATEGORIES			SKIP TO
Q519	How much were you charged for the treatment?		[		SKII TO
Q520	Was money deducted from your wages as a charge for the treatment?	Yes No Not employed Don't know	Z\$ [ 2 97 98		
Q521	Did you receive counselling at the clinic? Explain the nature of counselling.	Yes No Don't know	1 2 98		
Q522	Were you given"contact slips" and did you pass these on to your recent sexual partner(s) so that they could receive treatment?	Received & passed on Received, not passed on Not received Don't know	1 2 3 98		
Q523	Did you abstain from sexual intercourse or use condoms during the last time you experienced these symptoms?	Abstained from sex Used condoms Neither	1 2 8		
Q524	Have you thought about having an HIV test?	No Yes: but not done anything Yes: and found out how to get one Yes: and planning to have a test Had a test	1 2 3 4 5		- Q526
Q525	If cheap treatment was available for HIV/AIDS, would you have an HIV test?	Yes No Don't know	1 2 98		
Q526	What were - or would be - your reason(s) for going for a test? Probe - may be several reasons.	Ill & want to get best treatment Partner sick or died Past risky behaviour Past transfusion/injections General concern Contemplating marriage Contemplating marriage Contemplating partner(s) Life planning Child sick or died Spouse/partner tested HIV+ Wanted re-assurance not infected Prevent mother-to-child infection Doctor/nurse suggested it Other (specify)	$\begin{array}{c}1\\2\\3\\4\\5\\6\\8\\9\\10\\11\\12\\14\\15\\16\\17\\18\\20\end{array}$		
Q527	What factors deter(ed) you from having an HIV test? ie: possible implications of finding out he/she is HIV+. ? Probe - may be several reasons.	Psychological effects Stigma & discrimination Possible divorce/separation Job loss Fatalism - no cure Positive result accelerates death Could not face friends/family Fear - of being HIV+ Fear - of being HIV+ Fear - of violence Harm to partner Lack of confidentiality Too expensive Other (specify)	1 2 3 4 5 6 8 11 12 13 14 15 10		
Q528	Explain that a service is currently available at a n discuss and receive advice on the advantages an status with a fully qualified nurse. People who wish to know their status will be give mean you have to receive your results. Stress that the service is fully optional and confid The respondent and his/her partners are encours	earby health clinic where members of the d disadvantages of finding out their HIV en their test results but attending the clin lential.	e study infect	ion_	
Q529	Do you know of any place where you can go for voluntary counselling and testing (VCT) for HIV/AIDS? i.e. other than the temporary service in Q528.	Yes - certain Yes - maybe Unsure No	1 2 3 8		
Q530	How far is it from this place to the nearest voluntary counselling and testing centre?	Don't know	98	kans	- Q534
Q531	What type of place is this? "Roadside" here means a tarred road. Record the name of the place.	Large town or city Small town Growth point Commercial estate/mine Roadside business centre Rural business centre Communal/resettlement area	1 2 3 4 5 6 7		
Q532	How often is VCT available at this place?	Daily Weekly or monthly Only occasionally No longer available Don't know	1 2 3 8 98		

INDIVID	UAL QUESTIONNAIRE:	HEALTH & ACCESS TO TREATMEN	Г <i>Q. No:</i>	
REF.	QUESTIONS & FILTERS	CODING CATEGORIES		SKIP TO
Q533	What is the name of the organisation that provides this service? If respondent not had test (Q524) go to Q570.	New Start / PSI FACT BRTI Hospital/clinic (ANC/PMTCT) Hospital/clinic (other) Don't know Other (specify)	2 3 4 5 6 98 8	
Q534	On how many different occasions have you had an HIV test?			- If "0" go to Q570
Q535	How long is it since you last had an HIV test?	Period	mths yrs	
Q536	Did you have this test because: (i) you were told to; (2) you decided to on your own; or (3) you were persuaded to?	Told Decided Persuaded	$\begin{array}{c}1\\2\\3\end{array}$	
Q537	The last time you had an HIV test, how far did you have to travel from where you were living at the time to where you had the test?		kms	
Q538	In what type of place was the test done? "Roadside" here means a tarred road. Record the name of the place.	Large town or city Small town Growth point Commercial estate/mine Roadside business centre Rural business centre Communal/resettlement area	1 2 3 4 5 6 7	
Q539	How often was VCT available at this place at the time you had the test?	Daily Weekly or monthly Only occasionally No longer available Don't know	1 2 3 8 98	
Q540	What is the name of the organisation that was providing the VCT service?	New Start / PSI FACT BRTI Hospital/clinic (ANC/PMTCT) Hospital/clinic (other) Don't know Other (specify)	2 3 4 5 6 98 8	
Q541	How much did you have to pay for your HIV test?		Z\$	
Q542	Did you receive counselling before you agreed to have the test? Explain what is meant by counselling.	Yes No	$\frac{1}{2}$	
Q543	Did you receive pre-test counselling on your own, with your partner, or in a group?	Single Couple Group	$\begin{array}{c}1\\2\\3\end{array}$	
Q544	How long did the pre-test counselling take?	Time	hrs mins	
Q545	How satisfied were you with the pre-test counselling?	Very satisfied Satisfied Not satisfied	$\begin{array}{c}1\\2\\3\end{array}$	
Q546	After the pre-test counselling, did you feel fully prepared for having the test?	Fully prepared Partly prepared Unprepared	$\begin{array}{c}1\\2\\3\end{array}$	
Q547	Did you collect your test results?	Yes No	1	
Q548	Did you receive counselling after receiving the results?	Yes No	1	
Q549	Did you receive post-test counselling on your own, with your partner, or in a group?	Single Couple Group	$\begin{array}{c}1\\2\\3\end{array}$	
Q550	How long did the post-test counselling take?		hrs mins	
Q551	How satisfied were you with the post-test counselling?	Very satisfied Satisfied Not satisfied	$\begin{array}{c}1\\2\\3\end{array}$	
Q552	How would you rate the counselling you were given on how to protect yourself (or your partners) from HIV in the future?	Good OK Poor	$\begin{array}{c}1\\2\\3\end{array}$	
Q553	Do you feel you can protect yourself (or your partners) from getting HIV in the future?	Yes No Not sure	1 2 98	
Q554	Do you feel able to inform current and future sexual partners about your HIV infection status?	Yes No Not sure	1 2 98	
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<b></b>			-	
REF.	QUESTIONS & FILTERS	CODING CATEGORIES		SKIP TO
Q555	Did you feel pleased that you had decided to get tested?	Yes No	$\begin{array}{c}1\\2\end{array}$	
Q556	After the HIV test, did you: (1) Use condoms more or less than before? (2) Start having more or fewer sexual partners? (3) Increase or reduce the number of times you speak about HIV/AIDS with others?	More 1 1 1	Same         Less           2         3           2         3           2         3           2         3	
Q557	Was the result of this HIV test positive? Stress that do not have to answer these questions but information is confidential.	Yes No Don't know Prefers not to say	1 2 98 99	- Q562 - Q562 - Q562
Q558	With whom have you shared your HIV test result? Has their response been supportive or non-supportive?	Spouse/regular partner     1       Father     2       Mother     3       Other relative (specify)     4       Employer     5       Other (specify)     6	Supportive           1         2           1         2           1         2           1         2           1         2           1         2           1         2           1         2           1         2           1         2           1         2           1         2           1         2	
	Read through list and tick all that apply.	No one 8		
Q559	After getting your HIV test result, how many times have you? (1) Received follow-up counselling (2) Received medical treatment (3) Received legal or welfare support (4) Experienced stigma or discrimination (5) Experienced violence or aggression	$\begin{array}{c} \underline{\text{Many}} & \underline{\text{Severa}} \\ \underline{\text{times}} & \underline{\text{times}} \\ \hline 1 \\ 1 \\ 1 \\ 1 \\ 1 \\ 2 \\ 1 \\ 1 \\ 2 \\ 1 \\ 1$	Once         None           2         8           2         8           2         8           2         8           2         8           2         8           2         8           2         8           2         8           2         8	
Q560	Did you join a post-test club or a group for people living with HIV/AIDS and, if so, are you still a member?	Post-test club 1 PLWHA 1 Neither	$     \frac{\underline{Was}}{2}  \frac{\underline{Never}}{3} \\     \underline{8}     $	- Q562
Q561	How would you rate the helpfulness of this group in regard to: (1) very helpful, (2) helpful, (3) not helpful	Emotional/social support Protecting others from infection Advice on keeping healthy	P-TC PLWH.	A
Q562	When you went for this HIV test, did you go together with a spouse or someone you were thinking of getting married to?	Yes: spouse Yes: prospective spouse No N/A: no regular partner		- Q564 - Q569
Q563	Was the result of your partner's HIV test the same as the result of your own test?	Yes No	1	- Q565 - Q565
Q564	Did you give the result of your HIV test to the person you were married to at the time you had the test?	Yes No N/A: no regular partner	1 2 8	- Q569
Q565	Did you and your partner separate after you received your test results?	Yes No	$\begin{array}{c c}1\\2\end{array}$	- Q567
Q566	Whose decision was it to separate?	Own decision Partner's decision Joint decision Other (specify)	$\begin{array}{c c}1\\2\\3\\8\end{array}$	- Q569 - Q569 - Q569 - Q569 - Q569
Q567	How often have you had sex with this partner since you got your (latest) HIV test results?	Never Occasionally Frequently	$\begin{array}{c c}1\\2\\3\end{array}$	- Q569
Q568	How often have you used condoms with this partner since you got these HIV test results?	Never Sometimes Always	$\begin{array}{c}1\\2\\3\end{array}$	
Q569	Have you thought about having another HIV test?	Yes No or don't know	$\begin{array}{c}1\\2\end{array}$	
Q570	Have you ever heard of drugs for treating people who have HIV/AIDS?	Yes No	$\begin{array}{c c}1\\2\end{array}$	- Q601
Q571	Do drugs exist now that: (a) provide a complete cure for HIV/AIDS? (b) stop HIV from causing AIDS?	Name of drugs         Yes         No           1         2         2	DK Work? 98 98	
Q572	Do you know the names of these drugs?	Enter responses under Q571.		
Q573	Do you think these drugs work? (1) yes; (2) no; (98) don't know.	Enter responses under Q571. Go to Q601 unless knows of ARVs.		
Q574	Are there any unpleasant side effects or do you have other concerns about these drugs? <u>Record details.</u>	Yes: side effects Yes: other concerns No Don't know	1 2 3 98	
Q575	For how long does someone with HIV need to take these drugs?	Rest of life Don't know	3 98	

	UAL QUESTIONNAIRE:	HEALTH & ACCESS TO TREATMEN	f Q. No:	
REF.	QUESTIONS & FILTERS	CODING CATEGORIES		SKIP TO
Q576	From whom can these drugs be obtained?	Traditional healer Hospitals/clinics/pharmacies Don't know	1 2 98	- Q578
Q577	What is the nearest place to your homestead that these drugs can be obtained?	Local clinic/pharmacy District hospital Mutare or Harare Outside Zimbabwe Don't know	1 2 3 4 98	
Q578	Do you think these drugs will be available in your area soon?	Yes No or don't know	$\begin{array}{c}1\\2\end{array}$	
Q579	Do you know a relative, friend or neighbour who has received drugs that stop HIV from causing AIDS? *Note relationship of closest relative.	Relative* Friend/neighbour Work colleague Someone else No one	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	- Q581
Q580	Is this person now in good health?	Yes No Don't know	1 2 98	
Q581	Do you think you would be able to get these drugs if you ever needed them?	Yes - go to Q601 if Q557 <u>not</u> 'yes' No or don't know	1	
Q582	What is the main reason you would not be able to get these drugs?	Too expensive Not available locally Other (specify) Don't know	1 2 8 98	- Go to - Q601 if - Q557 <u>not</u> - 'yes'
Q583	Have you ever taken any drugs yourself that stop HIV causing AIDS?	Yes No	$\begin{array}{c c}1\\2\end{array}$	- Q585
Q584	What is the main reason you have not started taking these drugs?	Too expensive Not available locally Not permitted by church Side effects Not needed: in good health Other (specify) Don't know	1 2 3 4 5 8 98	- Q601 - Q601 - Q601 - Q601 - Q601 - Q601 - Q601 - Q601
Q585	How long is it since you first took these drugs?		weeks years	
Q586	Have you stopped taking the drugs?	Yes No	1	- Q588
Q587	Why have you stopped taking the drugs?	Too expensive Not available locally Not permitted by church Side effects Not needed: in good health Other (specify) Don't know	1 2 3 4 5 8 98	- Q593 - Q593 - Q593 - Q593 - Q593 - Q593 - Q593 - Q593
Q588	Are there particular times when you take the drugs?	All the time When feeling unwell When can afford or paid for Other (specify)	$\begin{array}{c c}1\\2\\3\\8\end{array}$	
Q589	Do you sometimes forget to take the drugs?	Never Occasionally Quite often	$\begin{array}{c c}1\\2\\3\end{array}$	
Q590	Do you know the name for the type of drugs you are taking?	ARVs Combivir Cotrimoxazole Other (specify) Don't know	1 2 3 8 98	
Q591	How much is one month's supply of drugs?		Z\$	
Q592	Who pays for these drugs?	Available free Self Relative Friend Employer	1 2 3 4 5	
Q593	Since you started taking the drugs, have you recovered from your illness?	Fully recovered Some improvement/still unwell No improvement/worse Healthy when started treatment	$\begin{array}{c c}1\\2\\3\\4\end{array}$	
Q594	After you started taking the drugs, did you: (1) Start having sex more or less than before? (2) Use condoms more or less than before? (3) Start having more or fewer sexual partners? (4) Increase or reduce the number of times you speak about HIV/AIDS with others?	<u>More</u> 1 1 1 1	Same         Less           2         3           2         3           2         3           2         3           2         3           2         3	
Q595	Have you experienced any unpleasant side effects since you started the treatment?	Yes No	$\begin{array}{c}1\\2\end{array}$	
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INDIVII	DUAL QUESTIONNAIRE:	HIV AWARENESS & IMPACT	Q. No:
REF.	QUESTIONS & FILTERS	CODING CATEGORIES	SKIP TO
Q601	Now I would like to ask you some questions of	about HIV and AIDS.	
Q602	Please tell me all the ways that an adult can get HIV infection and AIDS?         Are there any other ways?         Tick code 1 for each way mentioned spontaneously. Then proceed down the column, reading the description of each possible way not mentioned spontaneously. Make entries in the "probed" column as follows:         1       Yes: HIV can be transmitted this way         2       No: HIV cannot be transmitted this way         98       Don't know	Sex with a person with HIV/AIDS Touching a person with AIDS Mosquito bites Blood transfusion Injection with a dirty needle Sharing utensils with a person with HIV/AIDS Ritual scarification Other (specify)	Spont         Probed           1
Q603	Do you know of any factors which are likely to <u>increase</u> the chances that a person will get HIV and AIDS? <u>Ask in same way as Q602.</u>	Sex with a prostitute Many sex partners Other STDs present Using condoms Witchcraft or spiritual curse Other (specify)	Spont         Probed           1
Q604	What are the ways in which an infant or child could have become infected with HIV? Ask in same way as Q602.	At birth - if mother infected Witchcraft or spiritual curse Mosquito bites Injection with a dirty needle Breastfed by infected woman Blood transfusion Other (specify)	Spont         Probed           1
Q605	Are <u>all</u> babies born to women who have HIV born with the infection?	Yes No Don't know	1 2 98
Q606	Can all people infected with HIV be identified by looking at them?	Yes No Don't know	1 2 98
Q607	Would you be willing to take care of a family member with AIDS?	Yes No Don't know	1 2 98
Q608	How long does it usually take for a person infected with HIV to develop symptoms?	Number of years or months Don't know	998
Q609	How many people do you know who either died from AIDS or have the disease now?	Number ( > 0 ) Doesn't know of any	998 Q613
Q610	Of these people, how many live(d) in your household; in the same village/town; and how many live(d) somewhere else? Enter numbers of people in each category.	Household Village/town Somewhere else	
Q611	What was your relationship to each of these people? Enter numbers of people in each category.	Spouse/partner Father or mother Son or daughter Other relative Friend or neighbour Work colleague Someone else	
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INDIVIL	DUAL QUESTIONNAIRE:	HIV AWARENESS & IMPACT	Q. No:	
REF.	QUESTIONS & FILTERS	CODING CATEGORIES		SKIP TO
Q612	Did you help to take care of any of these people on a daily basis?	Yes No	1	
Q613	Have you been at risk of getting infected with HIV in the past?	Yes No Don't know	1 2 98	- Q615 - Q615
Q614	What was the reason you were at risk of getting infected?	Had multiple sex partners Regular partner had many partners Other partner with many partners Many friends/relatives dying of AIDS Other (specify) Don't know	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	
Q615	If you are not infected, do you think you are in danger of getting infected now or in the future?	Yes No Don't know	1 2 98	- Q617
Q616	Why do you think you might become infected? Do not prompt, but ask if any other reasons.	Has multiple sex partners (now) Regular partner had many partners Might marry a person who is already infected Many friends/relatives dying of AIDS Future partner may have other partners Other (specify)	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	
Q617	If you did become ill with AIDS, do you think you would be able to get help from your neighbours?	Yes No Don't know	1 2 98	
Q618	Is there discrimination in the community against people with AIDS?	Yes No	1	
Q619	If you thought your spouse/regular was having sexual intercourse with a casual partner(s) without using condoms, could you persuade him/her to stop?	Yes No No regular partner Don't know	1 2 96 98	
Q620	<ul> <li>Which of the following statements would you:</li> <li>(1) I have one partner who has other partner</li> <li>(2) My spouse/partner would not use condo</li> <li>(3) I have more than one partner because I of dying from AIDS is remote.</li> <li>(4) I pay/get paid for sex because my friend</li> <li>(5) There is no point trying to avoid AIDS at 60 I could avoid AIDS by sticking to one partner because it within marriage is becomin</li> <li>(8) Condom use within marriage is becomin</li> <li>(9) Condoms significantly reduce the pleasu</li> <li>(10) These days, most married men are faith</li> <li>(11) Drinking beer is an essential form of em</li> <li>(12) My friends have changed their sexual b</li> <li>(13) The changes I need to make to prevent</li> <li>(14) I find it difficult to maintain my commini</li> <li>(15) I am less worried about getting HIV no</li> <li>(16) I believe that new drug therapies make</li> </ul>	ers but does not always use condoms. ms with me on a regular basis. need the money and the possibility as do and because they encourage me. as I am probably already infected. artner or always using condoms. t or other illness than from AIDS. ng more widely accepted in this area. tre of having sex. full to their wives. tertainment and relaxation for men. ehaviour to prevent HIV HIV are a lot to ask tment to safe sex w that treatments have improved	True       Not true         1       2	

INDIVID	UAL QUESTIONNAIRE:	HIV AWARENESS & IMPACT	Q. No:	
REF.	QUESTIONS & FILTERS	CODING CATEGORIES		SKIP TO
Q621	Do you think there are things you can do which will prevent you from becoming infected with HIV in the future?	Yes1No2Don't know98NA (for those already infected only)99		- Q624
Q622	Are you or your spouse/partner currently taking any steps to avoid HIV and AIDS?	Yes 1 No 2		- Q624
Q623	What steps are you or your spouse/partner currently taking? Do not prompt, but ask if any other steps. Stress that includes actions taken by regular partner.	Sticking to one partner - self1Sticking to one partner - spouse2Condoms - self/spouse3Condoms - self/casual partners4Condoms - spouse/casual partners5Femidoms - self/spouse6Femidoms - self/casual partners7Femidoms - self/casual partners8Avoiding bars - self9Avoiding bars - spouse/casual partners10Abstaining from sex11Choosing younger partners12Choosing HIV- partners: tested13Choosing HIV- partners: untested14Avoiding widow(er)s15VCT - self16VCT - spouse17Other (specify)20		
Q624	<ul> <li>From what places or persons can condoms and/or femidoms be obtained locally?</li> <li>Do not prompt, but ask if any other places.</li> <li>If available, ask whether charge or free.</li> <li>If condoms/femidoms mentioned in Q622: From what place or person was the last condom (femidom) you used obtained?</li> </ul>	Available: Charge         Available: Charge         Available: Free           Partner         11         12           Shop/pharmacy         11         12           Hospital/clinic         11         12           Family planning centre         11         12           Community based distributor         11         12           Bar/beerhall/hotel         11         12           Peer educator         11         12           FACT employee/volunteer         11         12           Africare         11         12           (Only) outside the area         11         12           Other (specify)         11         12		
Q625	Have you ever discussed ways of avoiding HIV/AIDS with your regular partner?	Yes1No2No regular partner96NA (for those already infected only)99		- Q628
Q626	Have you and your regular partner started using a new method of family planning since hearing about HIV/AIDS?	Yes 1 No 2		- Q628
Q627	Which method(s) were you using before you heard about AIDS and which are you using now?	Pill     Befor       Condoms		
Q628	Have you heard about any meetings or other activities about HIV and AIDS?	Yes 1 No 2		- Q632
Q629	Have you attended any meetings or other activities about HIV and AIDS?	Yes 1 No 2		- Q632
Q630	Were any of these activities held locally or only somewhere else?	Local area 1 Elsewhere only - <u>specify location.</u> 2		- Q632

INDIVII	DUAL QUESTIONNAIRE:	HIV AWARENES	SS & IMPACT	Q. No:
REF.	QUESTIONS & FILTERS	CODING CATEGO	DRIES	SKIP TO
Q631	How many meetings have you attended in your area in the past 2 years that were held by the following people at the following places? If attended: how effective were these meetings in persuading people to change their sexual behaviour? 1. Very effective; 2. Fairly effective; or 3. Ineffective. If meetings attended at other locations, note the organisation and the most common meeting location.	FACT (FLAG) FACT (Other) ZNFPC Ministry of Health Local council Africare Local people/leaders FACT peer educators Other peer educators Employer BRTI Don't know	Work         Scheel Clinic         Bar         Other           /Hosp         /B-H	
Q632	<ul> <li>How many times in the last month have you heard HIV/AIDS mentioned</li> <li>1. On television</li> <li>2. On the radio</li> <li>3. In a newspaper</li> <li>4. In informal conversations</li> </ul>	TV Radio Newspaper Conversations	1 2 3 4	
Q633	Record details of others present at this point in the interview.	Children under Husband/wife Other males Other females	10 <u>Yes</u> 1 1 1	No 2 2 2 2 2 2
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NDIVII	DUAL QUESTIONNAIRE:	FERTILITY HISTORIES	Q. No:
REF.	QUESTIONS & FILTERS	CODING CATEGORIES	SKIP TO
Q701	Now I would like to talk to you about pregnancy and childbirth. Have you ever given birth (fathered a child)*?	Yes No	1 Q706
Q702	Do you have any sons or daughters who are now living with you?	Yes No	1 Q704
Q703	How many sons live with you? How many daughters live with you?	Sons at home Daughters at home	
Q704	Do you have any sons or daughters who are alive but do not live with you?	Yes No	1 Q706
Q705	How many sons are alive but do not live with you? How many daughters are alive but do not live with you?	Sons elsewhere Daughters elsewhere	
Q706	Have you ever given birth to (or fathered) a boy or girl who was born alive but later died? If no, probe: Any (other) boy or girl who cried or showed any sign of life but only	Yes No	1 Q708
Q707	survived a few hours or days? How many boys have died in this way?	Boys who died	
Q/0/	And how many girls died in this way?	Girls who died	
Q708	Sum answers to Q703, Q705 and Q707. Enter total.	Total	
Q709	In total, then, how many live births have you had (fathered)? Compare response with total in Q708. If numbers are different, probe and correct Q701-Q708, as necessary.		
Q710	If no births (Q708):		- Q722

<u>\*Note:</u> For male respondents use question wordings indicated in brackets.

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NDIVIDUAL	QUESTION	NNAIRE:	FERI	TILITY HIST	FORIES		Q.	No:
Q711	first one y <u>Record nan</u>	ou had". nes of all birth	s in Q712. Record	multiple births	(twins, triplets et	tc) on separate li	tw youlast time, startin ines. 1 the identity of the ear	-
Q712	Q713	Q714	Q715	Q716	Q717	Q718	Q719	Q720
What name was given to your (first/ next) baby?	<u>Record</u> single. (S) or multiple. (M). birth status.	Is (NAME) a boy or a girl?	In what month/year was (NAME) born? Ask for Child Health Card (CHC) as evidence of date of birth. Tick CHC box if date confirmed.	Was PMICT received? If yes, ask which type.	Is (NAME) still alive?	How old was (NAME) at his/her last birthday? <u>Record age</u> in	If alive: Is (NAME) living with you?	If dead: How old was (NAME) when he/she died? If "1 year": How many months old was (NAME) when he/she died? Record days, if < 1 month; months, if < 2 years.
		_	_	_	_	_	_	_
01 (NAME)	<b>S</b> 1 <b>M</b> 2	Boy 1 Girl 2	Month Year CHC?	NVP 1 AZT 2 Other 3 No/DK 8	Yes 1 No 2 (Goto Q720).	Age in yrs	Yes 1 No 2 Place (Q225) (Go to next birth).	Days Months Years
02 (NAME)	<b>S</b> 1 <b>M</b> 2	Boy 1 Girl 2	Month Year	NVP 1 AZT 2 Other 3 No/DK 8	Yes 1 No 2 (Goto Q720).	Age in yrs	Yes 1 No 2 Place (Q225) (Go to next birth).	Days Months Years
(NAME)	<b>S</b> 1 <b>M</b> 2	Boy 1 Girl 2	Month Year	NVP 1 AZT 2 Other 3 No/DK 8	Yes 1 No 2 (Goto Q720).	Age in yrs	Yes 1 No 2 Place (Q225) (Go to next birth).	Days Months Years
04	<b>S</b> 1 <b>M</b> 2	Boy 1 Girl 2	Month Year	NVP 1 AZT 2 Other 3	Yes 1 No 2	Age in yrs	Yes 1 No 2 Place (Q225)	Days Months Years
(NAME)	<b>S</b> 1 <b>M</b> 2	Boy 1 Girl 2	CHC?	No/DK 8 NVP 1 AZT 2 Other 3	(Goto Q720). Yes 1 No 2 (Coto Q720)	Age in yrs	(Go to next birth). Yes 1 No 2 Place (Q225)	Days Months Years
(NAME)	<b>S</b> 1 <b>M</b> 2	Boy 1 Girl 2	CHC?	No/DK 8 NVP 1 AZT 2 Other 3	(Goto Q720). Yes 1 No 2	Age in yrs	(Go to next birth).       Yes     1       No     2       Place (Q225)     1	Days Months Years
(NAME)			CHC?	No/DK 8	(Goto Q720).		(Go to next birth).	
07 (NAME)	<b>S</b> 1 <b>M</b> 2	Boy 1 Girl 2	Month Year CHC?	NVP         1           AZT         2           Other         3           No/DK         8	Yes 1 No 2 (Goto Q720).	Age in yrs	Yes 1 No 2 Place (Q225)	Days Months Years
08	<b>S</b> 1 <b>M</b> 2	Boy 1 Girl 2	Month Year	NVP 1 AZT 2 Other 3	<b>Yes</b> 1 <b>No</b> 2	Age in yrs	Yes         1           No         2           Place (Q225)	Days Months Years
(NAME)			снс?	No/DK 8	(Goto Q720).		(Go to next birth).	

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FORM B

INDIVIDUAL QUESTIONNAIRE: FERTILITY HISTORIES					Q	No:		
Q712	Q713	Q714	Q715		Q716	Q717	Q718	Q719
What name was given to your (first/ next) baby?	<u>Record</u> single (S) or <u>multiple</u> (M) birth status.	Is (NAME) a boy or a girl?	In what month/year was (NAME) born? Ask for Child Health Card. (CHC) as evidence of date of birth. Tick CHC box if date confirmed.	Was PMICT received? If yes, _ask _which _type.	Is (NAME) still alive?	How old was (NAME) at his/her last birthday? <u>Record age</u> _in	If alive: Is (NAME) living with you?	If dead: How old was (NAME) when he'she died? If "1 year": How many months old was (NAME) when he'she died? Record days. if < 1 month; if <2 years.
 	<b>S</b> 1 <b>M</b> 2	Boy 1 Girl 2	Month Year CHC?	NVP         1           AZT         2           Other         3           No/DK         8	Yes 1 No 2 (Goto Q720).	Age in yrs	Yes 1 No 2 Place (Q225) (Go to next birth).	Days Months Years
 (NAME)	<b>S</b> 1 <b>M</b> 2	Boy 1 Girl 2	Month Year CHC?	NVP         1           AZT         2           Other         3           No/DK         8	Yes 1 No 2 (Goto Q720).	Age in yrs	Yes 1 No 2 Place (Q225) (Go to next birth).	Days Months Years
 (NAME)	S 1 M 2	Boy 1 Girl 2	Month Year CHC?	NVP 1 AZT 2 Other 3 No/DK 8	Yes 1 No 2 (Goto Q720).	Age in yrs	Yes 1 No 2 Place (Q225) (Go to next birth).	Days Months Years
 (NAME)	S 1 M 2	Boy 1 Girl 2	Month Year CHC?	NVP         1           AZT         2           Other         3           No/DK         8	Yes 1 No 2 (Goto Q720).	Age in yrs	Yes 1 No 2 Place (Q225) (Go to next birth).	Days Months Years
Q721	Tick here, if further sheet used:						births listed abov births listed at R	
Q722	Q722 Compare Q708 with total number of births in history above (Q720). If numbers are different, probe and reconcile. If numbers are the same, check: For each birth: year of birth is recorded. For each living child: current age is recorded. For eage at death is recorded. For age at death 12 months: probe to determine exact number of months.							
Q723	For won	For men: go to Q838. For women: check follow-up checklist for pregnancy at time of Round 2 visit.				Pregnant - s Not pregnar	elf-report 1 1t 3	Q727
Q724	At the time we saw you last you were pregnant, what was the outcome of that pregnancy?				Live birth Miscarriage	1	Q726	
Q725	After how many months of the pregnancy did the miscarriage/stillbirth occur?				Months		Q727	
Q726	What name was given to this baby? Check whether this name appears on the list above at the appropriate time. If not, investigate.							
Q727			cies have you l ng any current			One or mor None	e	- Q836 & Q838.
					- 25 -			FORM B

NDIVIL	DUAL QUESTIONNAIRE:	RECENT PREGNAN	CY HIST	ORY	Q. No:	
REF.	QUESTIONS & FILTERS	MOST RECENT PREGNANCY		PREVIOUS PREGNANCY	PREVIOUS PREGNANCY	PREVIOUS PREGNANCY
Q801	Are you pregnant now?	Yes No Not sure	1 2 98	- Q803 - Q803		
Q802	For how many months have you been pregnant?	Number		- Q804		
Q803	When did your most recent (or "this for previous pregs) pregnancy end? Stress: including miscarriages.	mnth	yr	mnth yr	mnth yr	mnth yr
Q804	At the time you became pregnant, did you want to become pregnant then, did you want to wait until later, or did you not want to become pregnant at all?	Then Later No more	$\begin{array}{c}1\\2\\3\end{array}$	$\begin{array}{c}1\\2\\3\end{array}$	$\begin{array}{c}1\\2\\3\end{array}$	$\begin{array}{c}1\\2\\3\end{array}$
Q805	Did you continue to have sex with your spouse/regular partner during this pregnancy?	Yes No (Go to Q808) N/A (Go to Q808)	$ \begin{array}{c} 1\\2\\8 \end{array} $	$\begin{array}{c}1\\2\\8\end{array}$	1 2 8	$\begin{array}{c}1\\2\\8\end{array}$
Q806	Why did you continue to have sex during this pregnancy?	To avoid partner having other relations Other Don't know	1 ships 2 8			$\begin{array}{c}1\\2\\8\end{array}$
Q807	Did you use condoms every time you had sex during the pregnancy?	Yes No	$\begin{array}{c}1\\2\end{array}$	$\begin{array}{c}1\\2\end{array}$	1	$\begin{array}{c}1\\2\end{array}$
Q808	Have you seen anyone for antenatal care during this pregnancy?	Yes No (Go to Q821)	$\begin{array}{c}1\\2\end{array}$	$1 \\ 2 $	$1 \\ 2 $	$\begin{array}{c}1\\2\end{array}$
Q809	After how many months of the pregnancy did you first go for an antenatal check-up?	Months				
Q810	Whom have you seen?	Doctor/nurse Midwife - med'l TBA or midwife Other	$\begin{array}{c c}1\\2\\3\\8\end{array}$	$ \begin{array}{c} 1\\2\\3\\8\end{array} $	$ \begin{array}{c} 1\\2\\3\\8\\\end{array} $	$\begin{array}{c}1\\2\\3\\8\end{array}$
Q811	Where did you see this person? Go to Q814 if local.	Local clinic/hosp'l Other clinic/hosp'l At home Other	$\begin{array}{c c}1\\2\\3\\8\end{array}$	$\begin{array}{c}1\\2\\3\\8\end{array}$	$\begin{array}{c}1\\2\\3\\8\end{array}$	$\begin{array}{c}1\\2\\3\\8\end{array}$
Q812 Q813	What type of place was this clinic located in? Why did you attend this place rather than your local clinic?	Large town Small town Growth point Estate/mine Roadside BC Rural BC Communal/resettlem't PMTCT available More convenient	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	$ \begin{array}{c} 1\\ 2\\ 3\\ 4\\ 5\\ 6\\ 7\\ 1\\ 1\\ 2\\ 1 \end{array} $		
Q814	Was treatment available for PMTCT at this clinic at the time you attended?	Other (specify for last) Yes No Don't know	8 1 98	8 1 2 98	8 1 2 98	8 1 2 98
Q815	Did you discuss having an HIV test with a nurse or counsellor?	Yes No	$1 \\ 2 $			
Q816	Did you have an HIV test while attending for check-ups for this pregnancy or did you already know your status?	Yes No: knew status No: did not want (Go to Q821)	$\begin{array}{c}1\\2\\3\end{array}$	$\begin{array}{c}1\\2\\3\end{array}$	$\begin{array}{c}1\\2\\3\end{array}$	$\begin{array}{c}1\\2\\3\end{array}$
Q817	Did you collect the result of this test?	Yes No or N/A	$\begin{array}{c}1\\2\end{array}$	$1 \\ 2 $	1	$\begin{array}{c}1\\2\end{array}$
Q818	Do you have HIV infection? Stress confidential but voluntary.	Yes No (Go to Q821) No response (Go Q821)	$\begin{array}{c c}1\\2\\3\end{array}$	$\begin{array}{c}1\\2\\3\end{array}$	$\begin{array}{c}1\\2\\3\end{array}$	$\begin{array}{c}1\\2\\3\end{array}$

FORM B

INDIVII	DUAL QUESTIONNAIRE:	RECENT PREGNAN	CY HISTO	ORY		
REF.	QUESTIONS & FILTERS	MOST RECENT PREGNANCY		PREVIOUS PREGNANCY PR	EVIOUS PREGNANCY PR	REVIOUS PREGNANCY
Q819	Did you receive any treatment to prevent the baby from getting infected? If so, what type?	Yes: NVP tablet Yes: other (specify) No	$\begin{array}{c c}1\\2\\3\\4\end{array}$	$ \begin{array}{c} 1 \\ 2 \\ 3 \\ 4 \end{array} $	$\begin{array}{c}1\\2\\3\\4\end{array}$	$\begin{array}{c}1\\2\\3\\4\end{array}$
Q820	Did the baby receive any treatment?	Yes: syrup No Yes: other (specify)	$\begin{array}{c c}1\\2\\8\end{array}$	$\begin{array}{c}1\\2\\8\end{array}$	$\begin{array}{c}1\\2\\8\end{array}$	$\begin{array}{c}1\\2\\8\end{array}$
Q821	Was the baby delivered at a clinic/hospital or at home?	Clinic Home Still pregnant	$\begin{array}{c}1\\2\\3\end{array}$	$\begin{array}{c}1\\2\\3\end{array}$	$\begin{array}{c}1\\2\\3\end{array}$	$\begin{array}{c}1\\2\\3\end{array}$
Q822	Did you have any injections during this pregnancy?	Yes No	$\begin{array}{c}1\\2\end{array}$	$\begin{array}{c}1\\2\end{array}$	$1 \\ 2 $	$1 \\ 2 $
Q823	Did you receive any blood transfusions during this pregnancy? If still pregnant (Q801), go to Q837.	Yes No Don't know	1 2 98	1 2 98	1 2 98	$\begin{array}{c}1\\2\\98\end{array}$
Q824	Did this pregnancy end in a miscarriage, abortion or stillbirth?	Yes No (Go to Q827)	$\begin{array}{c}1\\2\end{array}$		1  2	1
Q825	How many months pregnant were you when this pregnancy ended?		mnths	mnths	mnths	mnths
Q826	Was this pregnancy ended intentionally because you knew or suspected you might have HIV?	Yes No Rather not say	$\begin{array}{c}1\\2\\3\end{array}$	$\begin{array}{c}1\\2\\3\end{array}$	$\begin{array}{c}1\\2\\3\end{array}$	$\begin{array}{c}1\\2\\3\end{array}$
Q827	Has your period returned since this pregnancy ended?	Yes No (Go to Q829)	$\begin{array}{c}1\\2\end{array}$	$1 \\ 2 $	1 2	$\begin{array}{c}1\\2\end{array}$
Q828	For how many months after this pregnancy ended did you not have a period?		mnths	mutits	mnfls	mnths
Q829	Have you resumed sexual relations since this pregnancy ended?	Yes No (Go to Q832)	$\begin{array}{c}1\\2\end{array}$			
Q830	For how many months after this pregnancy ended did you not have sexual relations? If 4 months or more, go to Q832.		mnths	mntis	mnths	mnths
Q831	Why did you resume having sex early after this pregnancy ended? If pregnancy ended in miscarriage etc (check Q823), go to Q835.	To avoid partner having other relation Other Don't know	1 1 1 1 1 1 1 1 2 8	$\begin{array}{c}1\\ \hline \\2\\ 8\\ \hline \end{array}$	$\begin{array}{c}1 \\ 2 \\ 8 \\ \end{array}$	
Q832	Did you ever feed this baby at the breast?	Yes No (Go to Q835)	$\begin{array}{c}1\\2\end{array}$	$\begin{array}{c}1\\2\end{array}$	1	$\begin{array}{c}1\\2\end{array}$
Q833	Are you still breastfeeding?	Yes (Go to Q836) No Child has died	$\begin{array}{c}1\\2\\98\end{array}$			
Q834	For how long did you breastfeed this baby: Exclusively? In total? If total > 6 mths, go to Q836.	Months Months				
Q835	Why did you not breastfeed this baby (for longer)?	Baby sick or died Mother sick Risk of HIV Pregnant Resumed sex Other	$\begin{array}{c}4\\5\\6\\7\\8\\12\end{array}$	$\begin{array}{c}4\\5\\6\\7\\8\\12\end{array}$	4 5 6 7 8 12	4 5 6 7 8 12
Q836	How long ago did your last menstrual period start? If less than one month, record answer as "0" months.	Months Years Before last birth Never menstruated	95 96			
Q837	Ask for date when the pregnancy b	efore this one ended:	if less that	n 3 years ago, go	to next colun	nn and Q803
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REF.	QUESTIONS & FILTERS				
Q838	For how much of the last 2 years have you and your regular partner been using a method of contraception?	None Some of the time Most/all of the time Not sure	$\begin{array}{c c}1\\2\\3\\98\end{array}$	- Q901	
Q839	Which were the main methods you used? Tick maximum of two methods.	Pill Injections Condoms Femidoms Sterilization Safe period Withdrawal Other (specify)	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$		
Q840	What were your main reasons for wanting to delay or prevent another pregnancy? Probe for other reasons, but do not prompt.	Enough children Birth spacing Child HIV+ risk Child orphan risk Mother HIV+: accelerate AIDS Not yet ready to have children Other (specify)	1 2 3 4 5 6 9		
Q901	Record current time.	Hour and minutes			hr min:
Q902	What are your views of the value of this research?	Useful Do not see the point No opinion			1 2 98
Q903	Record respondent's comments and your own observations in the space below. Give respondent a copy of the research results sheet and ask if he/she has any questions. Remind respondent of arrangements for HIV VCT and STD treatment.				
	ONDENT'S COMMENTS: research?				
<i>¶urther</i>	r HIV prevention, care and support act	tivities needed?			
ENUM	ERATOR'S OBSERVATIONS:				

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FORM B

# APPENDIX 5: THEMATIC NETWORK ANALYSIS OF CHURCH RESPONSES TO AIDS

Global	Organising	Basic Theme	Sub- Themes	Quotes
Theme	Theme			
Negative Responses	Unhelpful Attitudes	Symbolic Stigma (Associations of AIDS with blame	People with AIDS are sinners	"HIV and AIDS sufferers are sinners because they would have been unfaithful to their marital partners" <b>Roman Catholic female</b> .
		and deviance)	People with AIDS are prostitutes	"For women to disclose one's HIV positive status to church members would be confirming that the person was prostituting even though they were not" <b>Anglican male.</b>
			General attitudes of blame	"While the church has not really spelt out its response towards HIV and AIDS sufferers, what we see among church members is an attitude that lays blame squarely at the HIV and AIDS sufferer" <b>Anglican male.</b>
		Denial	AIDS topics taboo in church	"The church think that talking openly about HIV and AIDS in church exposes the family and removes the respect they had. Therefore it is considered as a taboo topic and they don't talk about it" <b>Anglican Adult male.</b>
			Church leaders not comfortable discussing AIDS	"Church leaders don't talk openly to the congregation about HIV and AIDS. I think they are just not comfortable talking about it" <b>Anglican male.</b>
			Discouraging disclosure	"We see a lot of people collecting their ARVs at the hospital and not tell the church that they are taking ARVs. I think it's good that they don't disclose because as soon as church members know the word will spread in the community" <b>Anglican</b> <b>female.</b>
			Refusing to have AIDS activities	"At church we don't have any AIDS related activities such as gardening schemes for HIV and AIDS sufferers. Just don't know why the church does not initiate such activities" <b>Anglican male.</b>

Aim: In what ways have church groups responded helpfully or unhelpfully to PLWHA

			Discouraging church members from visiting people with AIDS	"When people visit patients at times we are discouraged because carers hide their patients pretending they are sleeping when they are not" <b>Anglican female</b> .
		Gendered blame: Women blamed	Some women deserve to be infected	"Some of the women deserve to get infected, especially here in our community. You see the women sharing a scud (African brewed beer) with a married man at the beer halls. These women are ruthless. They snatch married men away from their wives, so they deserve it when they get infected" <b>Apostolic female</b> .
		Courtesy stigma (Stigmatisation of those with AIDS relatives)	HIV and AIDS sufferers relatives fear being stigmatised	"Relatives cannot disclose a patient's HIV status. People will label them as a relative of a HIV and AIDS sufferer and they will face being stigmatised as well. It's even worse when it's your husband" <b>Roman Catholic female</b>
		Gossip about those who have disclosed	Gossip about HIV and AIDS sufferers	"It is not easy for church members to disclose their HIV status because it becomes the subject of discussion around the whole community. It is not fair for people who would have gathered the courage to disclose their status since everyone will label them and they withdraw themselves from the public" <b>Apostolic female</b>
		Discourage condom use (Apostolic only)	Condom use not allowed in church	"Some churches do not mind members using condoms, but we do not allow condom use in our church. If one uses them secretly the prophet will expose that person and ask them to repent" <b>Apostolic male</b>
		Encourage polygamy (Apostolic only)	Polygamy as a way of preventing the spread of AIDS	"In our church we encourage men to marry as many wives as they want rather than sleeping with different women without showing any sign of commitment. It's a good way because it prevents the spread of HIV and AIDS" <b>Apostolic male</b>
		Silence women in church	Women not allowed to say anything in church	"Women can only stand up and say something in church only during their women's fellowship days not at church where everyone is there. Women should submit to their husbands therefore not allowing them to say anything when men are present" <b>Apostolic male</b>
Positive	Helpful	Women should be pitted, they are victims of men and can't be	Women viewed as victims of HIV and AIDS	"Sometimes women are faithful; they would have been infected by their unfaithful husbands who might already have passed away when the woman experiences full blown AIDS people empathise with her. We know of such cases and some people empathise with them" <b>Apostolic female</b>
Responses	Attitudes	blamed		

# APPENDIX 5: THEMATIC ANALYSIS OF CHURCH GROUPS

	Gendered nature of positive activities: Women expected to help and care, not seen as men's work	Women expected to care for HIV and AIDS sufferers	"Within the home if your child sufferers from HIV and AIDS the mother is the one who normally takes care of your child even if they were married before. Even if the husband is still fit we just have to do it that is what we are expected to do" <b>Anglican female</b>
	Discouraging people from visiting traditional healer	Helpful advice	" In our church we have people who are nurses and doctors, they have been encouraging people to go for VCT and take advantage of the treatment programme of free ARVs, as opposed to consulting traditional healers" <b>Anglican male</b>
	Encouraging condom use (Anglican and Catholics only)	Promote condom use	"As a church leader I promote condom use especially to those who cannot exercise self-control, rather than letting them die of HIV and AIDS" <b>Anglican male</b>
	Challenging Stigma in church settings	Encouraging disclosure in church	"Our priest always encourages people to disclose their HIV status to a trusted person in church. Although most people do not disclose they always encourage church members to disclose their status" <b>Anglican male.</b>
		Encouraging Kindness and tolerance to sufferers	"It does not matter how the person got infected, we all have to be kind and tolerant to HIV and AIDS sufferers. Even in the bible it is stated that we are not suppose to judge others () besides some of the people will be innocent victims these will be women infected by their husbands" <b>Anglican female</b>
		Encourage people to take care of sufferers	"As church members we are always encouraged to take care of our sick relatives, these days with an upsurge of HIV and AIDS sufferers the message that is being preached is focused on how important it is to take care of HIV and AIDS sufferers" <b>Roman Catholic male.</b>
Helpful Activities	Disseminating Information	Preaching	"Although the theme will not be HIV and AIDS, at church pastors talk about how young people are dying because of this deadly disease (Shuramatongo). They
			always caution people to be careful with their lives" Anglican female

# APPENDIX 5: THEMATIC ANALYSIS OF CHURCH GROUPS

	Encouraging VCT	"At church nowadays the youths are encouraged to go for VCT before the commit themselves in marriage or indulge in unprotected sex" <b>Roman Catholic female</b>
	Church encourages	"At church we are always reminded to treat all patients including HIV and AIDS
	members to treat HIV	sufferers with respect. Some HIV and AIDS carers do not share the same
	and AIDS patients	household utensils with patients. People at church are always reminded of how
	with respect	important it is to treat patients with respect and not avoid using the same utensils"
		Roman Catholic female
Visiting	Church members visit	"We visit HIV and AIDS sufferers because these are people who are in our
	HIV and AIDS	communities. One cannot afford to turn your back on them, yet these are the very
	sufferers	people that we grew up with and at times some of them are members of the same
		church. Also the fact that we have stayed together for a long time we are more like
		relatives now ()" Roman Catholic female
Assisting	with Assisting with	"At times when we visit HIV and AIDS sufferers the patient will be surrounded with
housewo	ork household chores	dirty plates, wearing dirty clothes and some of them would not have bathed for
	and fetching firewood	days, one cannot contain the dirty smell in the house. I visited a HIV and AIDS
		sufferer who had messed himself and the carer was just wrapping the blanket
		around him without removing the dirty. We had to clean the mess, the sight was
		unpleasant, I could not eat for a day" <b>Roman Catholic male</b> .
		" We also assist HIV and AIDS carers with fetching firewood for them because at
		times they don't even get the time to do so" Apostolic female
Informal	Home based care	"The problem that we encounter when we visit these HIV and AIDS sufferers, if the
assistance	ce with activities	carers know that you are a Christian home based carer they always expect you to
Home Ba	ased	do all the home based care activities alone. I hate it because we would have taught
Care (HE	BC)	them what to do when we first visited, but they still abandon the person when we
		make follow ups. I just do it because at church we are encouraged to do so () I
		am reluctant to visit such patients at times" Anglican female
Material	Food	"When we visit patients we always carry different types of food because culturally
resource	s	one cannot visit a patient without carrying anything. If one does not bring anything
		you will be forced to give the carers money. These days where do we get money
		so it is easy to take vegetables or fruits from your garden" Roman Catholic male

# APPENDIX 5: THEMATIC ANALYSIS OF CHURCH GROUPS

	Financial Assistance	" At church we have contributed money for other HIV and AIDS sufferers to go to the local hospital since they could not afford the bus fares" <b>Anglican female</b>
Bridging Soci Capital: Participating formal HBC c	in club	"We have a home based care club set up by our church called CADEC and most HIV and AIDS sufferers participate in the club" Roman <b>Catholic female</b>
Treat women respectful/ giv them voice in church activit (albeit under male leaders Anglican and Catholics)	ve positions with men ties	<i>"In church we have women leaders, the positions that we get as females are the same with males apart from being a priest. We still do not have female priests men are the ones who are allowed to hold those positions"</i> <b>Anglican female</b>

### **APPENDIX 6: INDIVIDUAL INTERVIEW TRANSCRIPT**

### **IDI- MATAMBA ANGLICAN FEMALE YOUTH**

DATE-	14/01/09
INTERVIEWER	MERCY Nhamo
TRANSCRIBER	Claudius Madanhire
SITE	Matamba
TIME	I HOUR

### **Respondent Background information**

NAME:	Chipo
AGE:	18
Sex:	female
Marital Status:	Single
Highest Education level:	Form 4
Employment status:	Unemployed

### **Churches represented**

1. Anglican church

### **Interviewer Observations**

This was a good interview, and this respondent was so forthcoming. She is one person who sees the need for the church to do more in terms of fighting in HIV/AIDS stigma

MERCY.YOU TOLD ME THAT YOU ARE BABRBRA MUTENDA AND YOU ARE 18 YEARS OLD, IS THAT SO? CHIPO. Sure

MERCY. ARE YOU MARRIED? CHIPO. No not yet

**MERCY**. WHAT IS YOUR HIGHEST LEVEL OF EDUCATION? CHIPO. Form four

**MERCY**. DID YOU PASS YOUR O' LEVELS? CHIPO. No I did not pass but I have taken the exams again last year **MERCY**. HOW MANY SUBJECTS DID YOU HAVE? CHIPO. I had three subjects

MERCY. AND RIGHT NOW ARE YOU WORKING? CHIPO. No

**MERCY**. SO YOU HAVE ANY KIDS? CHIPO. No I don't have any kids

**MERCY**. DO YOU HAVE ANY POST IN THE ANGLICAN CHURCH HERE? CHIPO. Yes, I am in the fundraising committee in the youths wing

MERCY. OK FUNDRAISING COMMITTEE

### **B. PERSONAL BIOGRAPHY**

**MERCY**. CAN YOU PLEASE TELL ME A BRIEF HISTORY OF YOUR LIFE, FROM YOUR BIRTH UP TO THIS DAY?

CHIPO. I was born by my mother, and we are two in my family but we have an elder sister who has a different mother. Her mother had since separated with my father. That makes the three of us if I include that sister, I am the last born. All of us have been given a chance to go to school. My brother and I are still to find work but the elder sister I was talking about is now working. My brother is in Harare, but I stay with my mother here.

**MERCY**. CAN YOU TELL ME ABOUT YOUR PRIMARY EDUCATION AND HOW YOU GREW UP?

CHIPO. I did my crèche and my grade one to seven at local primary school. In fact all of us went there for our primary education and I did my secondary education at a local Secondary school, that's where I completed my form four.

**MERCY**. YOUR MOTHER AND FATHER, DO THEY LIVE TOGETHER? CHIPO. Yes they are together.

**MERCY**. DO YOU KNOW ANYTHING ABOUT HIV/AIDS? CHIPO. Sure.

### MERCY. WHAT DO YOU KNOW?

CHIPO. I know that HIV/AIDS is an epidemic that has spread all over the world. I also know that this disease has no cure but has preventive methods. There are also ways of which an

infected person can follow and live longer. The person can take drugs, however those drugs can not cure HIV but prolongs the person's life span.

**MERCY**. WHAT TYPE OF DRUGS? CHIPO. I think they are called "antiretroviral drugs".

**MERCY**. WHEN AND WHY DID YOU JOIN THE ANGLICAN CHURCH? CHIPO. I was born and bred in that church.

**MERCY**. SO YOUR PARENTS GO THAT CHURCH? CHIPO. Sure.

### INFORMANT'S PERCEPTION OF COMMUNITY RELATIONS:

### **GENERAL QUESTIONS**

**MERCY**. WHAT KIND OF PLACE IS THIS COMMUNITY? CHIPO. In terms of what? Weather or what?

# **MERCY**. COMMUNITY RELATIONS AS WELL AS HOW PEOPLE LIVE HERE, YOU CAN ALSO TALK OF THE CLIMATE IF YOU FIND IT RELEVANT

CHIPO. I Think Matamba is a beautiful place, but there is a high percentage of people who behave badly but in terms of tourism it is a very good tourist attraction area, but what happens here is not good.

**MERCY**. WHAT DO YOU MEAN? CHIPO. I can say this place is infested with prostitutes.

### MERCY. OK, THEY ARE MANY, HOW DO YOU KNOW THEM?

CHIPO. I see them frequenting beer halls especially in local town if you go there you will see them. The fact that I stay here allows me to see a lot of things. Even a newcomer in this area can go and see what they do at local shops, and one may even conclude that a lot of people in **Matamba** are prostitutes, yet it's not everyone.

MERCY. WHAT HAPPENS AT THE LOCAL TOWN?

CHIPO. There are a lot of girls who are now prostitutes and there is a lot of promiscuous man there.

MERCY. ARE THESE MARRIED MEN?

CHIPO. Both, married and single men.

### MERCY. WHAT IS IT LIKE TO LIVE HERE?

CHIPO. This area is good to me especially the environment it is very beautiful but the behavior of some people here makes this place unpleasant. This is a small town if anything happens everyone will know about it.

### MERCY. SO THERE ARE NO SECRETS?

CHIPO. Even young children will know things that happen in this place.

**MERCY**. BESIDES PROSTITUTION ARE THERE ANY OTHER BAD THINGS ABOUT THIS PLACE? CHIPO. There is nothing else.

# **MERCY**. WHAT ARE THE OTHER GOOD THINGS ABOUT THIS COMMUNITY? CHIPO. Generally people here go to church but still those people who to church will behave badly.

### MERCY. WHAT WILL THEY BE DOING?

CHIPO. The same church goers are also found to be very promiscuous. The thing is there are many churches here so people will still go to church after doing their dirty works and I also like the environment.

MERCY. SO YOU GREW UP IN THIS CHURCH? CHIPO, Sure.

### **GENDER RELATIONS**

### MERCY. HOW DO MEN AND WOMEN IN THIS COMMUNITY RELATE?

CHIPO. They relate very well, to those who are married they live well, those who are not married have given rise to extra marital sexual relations.

### MERCY. WHAT DO THEY DO?

CHIPO. Even if you have boyfriend here you will realize that the boyfriend is also sleeping around with prostitutes.

**MERCY**. SAY IF YOU ASK THE BOYFRIEND WHAT WILL HE SAY? CHIPO. He will just deny it because he knows that it is not good.

### MERCY. SO WHAT WILL THE GIRL DO?

CHIPO. That's when we discuss and agree to go for VCT.

# **MERCY**. IS THERE RESPECT AND CONSIDERATION AMONGST MEN AND WOMEN IN THIS COMMUNITY?

CHIPO. Respect is there because married women are treated with respect and married men are also respected and singles are careful not to go out openly with a married person.

### MERCY. YOU ONCE SAID THEY ARE PROMISCUOUS

CHIPO. Yes they are promiscuous but they cheat in a way that is secret.

### MERCY. WHEN WOULD YOU SAY THERE IS NO RESPECT?

CHIPO. Say you have your husband and we see you respecting and treating each other respectfully yet privately they would be cheating.

# **MERCY**. CAN YOU TELL ME AN EXAMPLE OF SOMETHING LIKE THAT WHICH HAPPENED HERE?

CHIPO. I can give you examples but will I have to say the names?

### MERCY. NO DON'T SAY THE NAMES

CHIPO. There is a certain woman here who is promiscuous, yet she is cohabiting with this man who also happens to have a wife, but he cohabits with this woman.

### MERCY. IS THE WIFE HERE AS WELL?

CHIPO. I heard that the wife stays here. So these two live together yet there is a certain boy who is also going out with this woman and staying in the same area. This boy had just married but separated with his wife because of this woman. This woman is also cheating with this man she is cohabiting with to go to this boy. So it is a complex love triangle.

**MERCY**. WHAT IS THE ROLE OF MEN AND WOMEN IN THIS CHURCH DO THEY PLAY DIFFERENT ROLES IF SO IN WHAT WAY? CHIPO. They are given same roles

### **INTER-GENERATIONAL RELATIONS**

### MERCY. HOW DO THE YOUNG AND THE OLD RELATE IN THIS COMMUNITY?

CHIPO. That is not clear because sometimes we the youths sometimes feel badly treated by the elders. Sometimes while one will be walking around you will hear some women talking about our lives. Sometimes they even accuse you of something that you have not done for example they may say "you are so and so's child, then you are a prostitute". Yet they don't have any facts and evidence, sometimes one will be going with a genuine boy. So some

women do say so much bad things about us the youths and we don't know what they want us to do. Sometimes we think these women would be wishing that we become their daughters-In law.

### MERCY. DO THEY HAVE THE SONS?

CHIPO. Yes and we think maybe they would be trying to find a girl for their sons. Sometimes it sparked by a simple thing like dressing, if they see us putting on trousers they would just conclude that the child is now a prostitute yet it's just something popular and fashionable among the youths. I think the elders should know that dressing does not really show the behaviour of the person.

**MERCY**. IS THERE RESPECT AND CONSIDERATION AMONGST THE YOUNGER GENERATION AND THE OLDER GENERATION IN THIS COMMUNITY? (EXAMPLES) CHIPO. There is respect but there is not much respect.

### MERCY. WHAT DO YOU MEAN?

CHIPO. The youths do respect the adults but the adults do not reciprocate. You would find that the very person we would be giving the respect would saying bad things about the respect that we give them.

### MERCY. CAN YOU GIVE AN EXAMPLE OF WHAT YOU TALKING ABOUT?

CHIPO. Say I am passing through someone's homestead and they are relaxing outside on their yard. I may say, "good afternoon" but they may not even respond and one may repeat the greeting and they won't answer. Such things shows that they don't reciprocate our efforts. Then next one will not bother to greet such people and that's when they begin to say the youths are not respectful.

# **MERCY**. IN WHAT WAY IS THERE LACK OF RESPECT BETWEEN ELDERS AND THE YOUTHS IN THIS COMMUNITY?

CHIPO. I think it's only the changing times and regulations that make the elders think that the youths are not respectful yet the regulations have changed. I think long ago they followed their strict rules and regulations. So the elders want us to follow rules and regulations they followed long ago.

### MERCY. CAN YOU GIVE AN EXAMPLE OF WHAT YOU ARE TALKING ABOUT?

CHIPO. Like nowadays, if my sister is married and her husband passes away I may be told to go and stay with her yet I also have my own plans. If the sister dies some parents may even force the youth to go and stay with the husband yet the youth may not be attracted to this man, and sometimes people are made to stay together without even an HIV test. The parents

would be happy to maintain the son-in law in the family yet there cause of the sister's death could be HIV/AIDS.

**MERCY**. HAS SOMETHING LIKE THAT HAPPENED HERE OR IT'S SOMETHING YOU ARE THINKING ABOUT?

CHIPO. I have not witnessed or seen this happening but I just know some customs still follow these practices.

**MERCY**. WHAT IS THE ROLE OF YOUTHS IN THE CHURCH DO THEY HAVE A DIFFERENT ROLE TO ADULTS?

CHIPO. The roles are not different because "mother's union" has a uniform the youths also have a uniform. Even the choir, the youths participate, the youths are also given all the chores that the elders do in church.

### **ORGANISATIONS LINKED TO HIV/AIDS**

**MERCY**. ARE THERE ANY HIV/AIDS RELATED ORGANISTAIONS IN THIS COMMUNITY? CHIPO. There is FACT.

**MERCY**. WHAT DO THEY DO? CHIPO, They also do counseling.

**MERCY**. ARE THERE ANY OTHER ORGANISATIONS? CHIPO. That's the only I know.

**MERCY**. WHAT SORT OF COUNSELLING DO THEY DO? CHIPO. I think they do HIV/AIDS counseling.

**MERCY**. WHAT CHALLENGES DO THEY FACE IN DOING THEIR WORK IN THIS COMMUNITY?

CHIPO. They face problems. When people go for counseling some do understand but some will not understand and then begin to talk negatively about the counselling, some even saying there is nothing called Aids.

**MERCY**. ARE THERE PEOPLE WHO STILL THINK THERE IS NOTHING CALLED AIDS? CHIPO, They are there and some even say Aids is curable.

### MERCY. THEN WHAT IS THE CURE?

CHIPO. Today I was reading a letter that was written to a magazine by someone who said that he was told that if he sleeps with an albino their Aids will be cured. And the reply advised

the person that doing that will even make the albino HIV positive and if an albino is positive he will also put himself at risk of re infection.

**MERCY**. DO THEY NETWORK WITH OTHER LOCAL ORGANISTIONS? CHIPO. There is also BRTI, they also do counselling. I think they do network.

### HIV/AIDS IN THIS COMMUNITY - INFORMANT'S PERCEPTIONS OF HIV/AIDS

**MERCY**. IS HIV/AIDS A BIG PROBLEM IN THIS COMMUNITY? CHIPO. No, I don't think it's a big problem because these days if we gather people and ask them about HIV/AIDS they now know very much about.

**MERCY**. DO YOU THINK PEOPLE HERE PRACTICE SAFER SEX? CHIPO. I think they practice safer sex.

### MERCY. WHY?

CHIPO. Because if we look around for protector plus (condoms), people can get them readily from FACT people and the hospital as well, they are distributed and placed at convenient places like corridors.

### MERCY. SO WHY DO YOU THINK PEOPLE ARE PRACTISING SAFER SEX?

CHIPO. I think people are making use of these condoms because even at the hospital you will see people taking them meaning they taking them to use them to protect themselves.

### MERCY. ARE PEOPLE WITH HIV/AIDS OPEN ABOUT THEIR STATUS?

CHIPO. May be nowadays they beginning to open as a result of the adverts that we see on TV on daily basis, including what reverend Kapachavo says on TV makes it easier for infected people to open up.

# **MERCY**. SO IN THE CHURCH HERE DO PEOPLE TALK OPENLY ABOUT THEIR STATUS?

CHIPO. Yes some do say openly.

### MERCY. IN THE CHURCH?

CHIPO. Yeah, some do talk because in the church we have a week set aside for HIV/AIDS every month so much that the priest should also include HIV/AIDS issues in the sermon.

**MERCY**. SHOULD PEOPLE BE OPEN ABOUT THEIR HIV/AIDS STATUS? CHIPO. I think they should be open because that's one way they can be helped.

MERCY. DOES YOUR CHURCH OFFER ANY HELP?

CHIPO. Ah, there is nothing I know of... do you mean material assistance?

#### MERCY. ANY ASSISTANCE?

CHIPO. There are some who might be good with counselling.

**MERCY**. IN GENERAL ARE PEOPLE IN THIS COMMUNITY KIND AND TOLERANT TO PEOPLE WITH HIV/AIDS? CHIPO. They treated well.

# **MERCY**. CAN YOU GIVE ME AN EXAMPLE OF SOMEONE WHO HAD HIV/AIDS AND WAS TREATED WELL?

CHIPO. There was this woman who has since passed away. She was our next door neighbour. My mother went there and encouraged her to get tested when she was not feeling well. My mother talked to her at lengths. She then went for VCT and finally got the drugs and she lived for some time and passed away. But before she passed away my mother used to spend a lot of time with her. Many people were coming to see her, even church members from her church were coming to see her bringing her food and soaps. Her children were also supplied with gloves from the hospital to use when helping her since she was no longer able to go to the toilet.

### MERCY. SO THAT WAS WELL LOOKED AFTER

CHIPO. Yes **MERCY**. CAN YOU NOW GIVE AN EXAMPLE OF SOMEONE WHO HAD AIDS BUT WAS TREATED BADLY? CHIPO. Do you mean someone who is still alive or someone who passed away?

### MERCY. ANY, IT REALLY DOESN'T MATTER?

CHIPO. There is someone I just heard about, this person is still a youth, but she is infected by HIV/AIDS. She fell ill and she went to the hospital, and her parents struggled with her. She was counseled at the hospital because she was refusing to get tested. So she stayed for a long time but she was refusing to get tested then one day she just accepted to get tested and she was found to be HIV positive and she got help and now she is fit.

### MERCY. ARE WOMEN AND MEN WITH HIV/AIDS TREATED DIFFEENTLY?

CHIPO. It is just the same because they are all given the same kind of medication.

### MERCY. I AM TALKING ABOUT THE CARING IS IT THE SAME?

CHIPO. Sometimes women accuse their husbands of bringing the disease and they may refuse to care for them properly, but I have also realized that women will do that for a very short time otherwise they will still take good care to their husbands.

### MERCY. WHAT ABOUT MEN?

CHIPO. Men may even move out and only come back when the situation is better.

# **MERCY**. WHAT CARE AND SUPPORT IS AVAILABLE FOR PEOPLE WITH HIV/AIDS FROM THE FAMILY?

CHIPO. They do take care of the patient like in the case of someone who is bed ridden, so they would look after the patient.

### MERCY. WHAT ABOUT THE NEIGHBOURS?

CHIPO. Some may just bring something or just coming to say hi "how are you". That is meant to lighten the burden for the patient.

### MERCY. WHAT ABOUT THE CHURCH?

CHIPO. The church would come and pray for the patient. The church can organize all the youths to visit the patient.

### MERCY. THE CHURCH, WHAT DO THEY DO FOR PEOPLE WITH HIV/AIDS?

CHIPO.May be there is something...what is it....there are cases of people who are sick and they have not been tested so the church members can go and talk to this person, e have nurses in the church so they go and counsel the person until they go for VCT.

**MERCY**. AREN'T THESE INDIVIDUAL EFFORTS? CHIPO. They are.

### MERCY. DOES THE CHURCH HAVE ANY PROGRAMME IN THE CHURCH?

CHIPO. We just visit the sick and they don't really say the patients have Aids as no one would really say it out that they have Aids.

**MERCY**. SO THEY VISIT PATIENTS IN GENERAL? CHIPO. Sure.

**MERCY**. SO DO THEY HAVE ANY HIV/AIDS PROGRAMME? CHIPO. No, they have not done anything really about HIV/AIDS.

**MERCY**. YOU HAVE SAID THERE ARE THOSE WHO GIVE INFORMATION? CHIPO. They just teach and give people information but we haven't got to a stage where they can help the HIV/AIDS sufferers.

MERCY. IS IT THE PRIEST WHO TEACH PEOPLE OR YOU INVITE OTHER SPEAKERS?

CHIPO. Sometimes they do invite speakers, there is a woman from FACT who once visited us. She just came to give people a speech on HIV/AIDS as part of a FACT programme.

### MERCY. WAS IT HELPFUL?

CHIPO. I think it was helpful though nobody really would really come out in the open about having been tested.

**MERCY**. SO THE CHURCH HAS NOTHING TO OFFER TO HIV/AIDS SUFFERERS? CHIPO. Sure.

**MERCY**. WHAT IS THE CHURCH'S ATTITUDE TOWARDS HIV/AIDS SUFFERERS? CHIPO. They have a good attitude because they don't stigmatize them if they know about their status.

### MERCY. HOW DO THEY DO THAT?

CHIPO. When they chose a new committee they don't consider one's illness, they can still elect them to positions of leadership.

### MERCY. DO YOU THINK THE CHURCH IS DOING ENOUGH?

CHIPO. The church is not doing enough because there is no material assistance provided for HIV/AIDS sufferers.

# **MERCY**. TO WHAT EXTEND DOES THE CHURCH GET GUIDACE FROM THE NATIONAL BODY?

CHIPO. We co-ordinate with the body.

**MERCY**. WHEN YOU SAY THE CHURCH IS NOT DOING ENOUGH DO YOU MEAN THE CHURCH HAS NO PROGRAMME FOR HIV/AIDS SUFFERERS OR WHAT? CHIPO. They know that there are people with Aids but they cannot single them out.

**MERCY**. WILL THEY HAVE OPENED UP TO THE CHURCH? CHIPO. No, they haven't disclosed to the church.

**MERCY**. SO WHAT CAN THE CHURCH DO WHEN THEY HAVE NOT OPENED UP? CHIPO. I think the church should encourage people to come out in the open, of course such encouragement and announcement has been made before.

### MERCY. BUT ARE THEY OPENING UP?

CHIPO. Let's say I have HIV/AIDS and you are the Priest, I would not trust that you can keep my secret.

Pause...

CHIPO. It's natural and people are not sure whether their problems would be kept away from everyone in the community. If I tell you my problem and one day you see me not feeling well you will tell someone that let's go and see her she has HIV/AIDS. The person who is being told may fail to keep that secret.

**MERCY**. ARE YOU SAYING THAT'S THEREASON WHY PEOPE ARE NOT OPENING UP CHIPO. Yes.

### MERCY. SO WHAT DO YOU THINK SHOULD BE DONE?

CHIPO. The problem is that people cannot keep secrets, though the priest encourages people to go for VCT.

# **MERCY**. WHAT IS YOUR COMMENT ON THE STATEMENT THAT STATES THAT "PEOPLE WHO CONTRACT HIV/AIDS ARE SINFUL"?

CHIPO. I would not say they are sinners because I don't know how they got that disease, because besides sex HIV can also be spread by sharing sharp objects. This can be especially be true for people in the medical field like Doctors and nurses.

### MERCY. SO YOU THINK THEY ARE NOT SINNERS?

CHIPO. No they are not, like between married couples the husband may bring the virus to the innocent wife and this woman is not to blame for her infection, may this man can be blamed for not being satisfied with his wife.

### MERCY. WHAT IS YOUR COMMENT ON EXTRA MARITAL SEX?

CHIPO. I say it is very bad practice and that is causing HIV/AIDS to spread.

### MERCY. DO YOU THINK SUCH BHAVIOUR WILL STOP?

CHIPO. No, because the youths need a lot of counseling and guidance because they have too many boyfriends and the boy may also have 3 girlfriends and he might be sleeping with all the three girls.

### MERCY. THAT IS NOT REALLY EXTRA MARITAL SEX

CHIPO. Still that is very bad because they also contribute to the increase in the percentage of HIV infection.

MERCY. HOW?

CHIPO. A married man who sleeps around may get the infection from the commercial sex worker and infect their unsuspecting wives. Normally these men won't end with this one girlfriend, they will find another person and end up giving them HIV/IADS.

**MERCY**. SO IT MEANS PEOPLE ARE NOT PRACTISING SAFER SEX? CHIPO. Yeah, I think they don't really use protection.

**MERCY**. HOW DO YOU VIEW THE USE OF CONDOMS? YOU ONCE SAID PEOPLE COLLECT THESE CONDOMS IN HOSPITALS BUT NOW YOU TELL ME PEOPLE ARE SPREADING HIV/AIDS?

CHIPO. Some do use condoms, some have the knowledge but they don't want to use the information. Some do not have the information.

**MERCY**. YOU SAID CHUCH LEADERS DO TALK ABOUT HIV/AIDS IN THE CHURCH, WHAT EXACTLY DO THEY SAY?

CHIPO. They say HIV/AIDS kills and people you need to protect yourself by using condoms and people should stick to one partner, and the single are encouraged to get tested before they get married.

**MERCY**. OK THEY SAY THAT, WHAT HINDRANCES DO THEY FACE IN TRYIG TO DISSEMINATE HIV/AIDS INFORMATION?

CHIPO. There is no hindrance because people fear God in the church and they do understand. The priest would be representing God.

**MERCY**. ARE THERE ANY SUPPORT GROUPS FOR PEOPLE WITH HIV/AIDS WITHIN THIS COMMUNITY? CHIPO. There are no such groups.

**MERCY**. YOU ONCE TOLD ME THAT THE CHURCH IS NOT DOING ENOUGH, WHAT MORE VCAN THE CHURCH DO FOR HIV/AIDS SUFFERERS? CHIPO. Do you mean when they know those who have HIV/AIDS.

**MERCY**. YOU ONCE SAID THE CHURCH IS TALKING ABOUT IT BUT HIV POSITIVE PEOPLE ARE STILL NOT OPENING UP? SO WHAT CAN THE CHURCH DO? CHIPO. The church should start those support groups.

**MERCY**. HOW CAN THAT BE DONE WHEN PEOPLE ARE NOT OPENING UP? CHIPO. I think Pastor Kapachavo once visited our church, in the same manner people should open up to the Priest. **MERCY**. HOW WOULD THEY COME WHEN YOU SAID PEOPLE ARE AFRAID THAT PEOPLE WILL SPREAD RUMOURS ABOUT THEM? WOULD YOU TELL YOUR PASTOR YOUR STATUS IF YOU TEST HIV POSITIVE?

CHIPO. That will be seen when that happens, but I think our Priest should have love and increase how he deals with people directly, he should at least try to be more close to his members. He can start by coming and visiting people in their sections.

**MERCY**. IF YOU WERE GIVEN AN OPPORTUNITY TO LEAD THE CHURCH HERE WHAT WOULD YOU DO DIFFERENTLY WITH REGARDS TO HIV/AIDS REDUCTION? CHIPO. I will start with the youths, I will invite you guys from BRTI, FACT and even New Start Centre so that you can talk to the youths and counsel them, and some youths may even consider getting tested.

### MERCY. SO YOU START WITH THE YOUTHS AND THEN?

CHIPO. I will go to the mothers' union and lastly I will go the father's union, and I will be done because the Priest also attends fathers' union.

**MERCY**. SO YOU WILL NOT DO ANYTHING WHEN THESE GROUPS ARE COMBINED? CHIPO. I will still want people to initiate a discussion on how they reduce HIV/AIDS.

**MERCY**. DO YOU THINK ALL THE CHURCHES ARE DOING THE SAME? CHIPO. I have not heard of any church here doing anything different from what we do.

**MERCY**. IS THERE MORE THAT THE CHURCH COULD BE DOING? CHIPO. Ah I can't think of anything else, some people are already getting information when they go to hospital.

**MERCY**. IS THERE ANYTHING IMPORTANT THAT YOU THINK WE HAVE LEFT OUT? CHIPO. I don't think so because we have even talked about the community before we talked about the church.

**MERCY**. HOW DID YOU FEEL ABOUT THIS INTERVIEW? CHIPO. It was good.

### MERCY. WHAT WAS GOOD ABOUT IT?

CHIPO. You were asking about the practical things that are happening on the ground, only that you didn't tell what I should do if I come across an HIV positive person.

MERYCY. BUT YOU SAID ALL THIS INFORMATION IS GIVEN ALREADY? CHIPO. I just wanted to hear it from a different source. **MERCY**. WILL THIS PERSON BE YOUR BOYFRIEND? CHIPO. That is difficult people understand it differently.

**MERCY**. HOW DO YOU INTRODUCE THAT SUBJECT TO YOUR BOYFRIEND? CHIPO. We might start by talking about someone who is HIV positive and then until I propose that we go and get tested for HIV.

**MERCY**. WHAT WILL HE SAY? CHIPO. He might say we will go, but never avails himself.

**MERCY**. WHAT ABOUT IF YOU SUGGEST A DATE TO HIM? CHIPO. I wanted you to tell me how I can tell him to go and get tested.

**MERCY**. YOU KNOW HIM BEST, SO YOU KNOW BEST HOW TO CONVINCE HIM, SINCE HE KNOWS ABOUT HIV/AIDS YOU CAN JUST SET THE DATE WHERE THE TWO OF YOU CAN GO AND GET TESTED? CHIPO,. He might even post pone and find an excuse for every date I suggest.

**MERCY**. ALL THE DATES, HE WILL BE OCCUPIED? CHIPO. Yea.

MERCY. AND WHY WOULD YOU KEEP IN RELATIONSHIP WITH SUCH A PERSON? WILL HE BE SERIOUS?

CHIPO. Sometimes he even says he is serious and have already gone to meet the girl's Auntie, and the Auntie doesn't even encourage such tests.

**MERCY**. SOME ANTIES DO NOT EVEN HAVE THE INFORMATION, THE TESTING IS VERY IMPORTANT BEOFRE ONE GETS MARRIED. I THINK THESE ARE ISSUES THAT YOU SHOULD DISCUSS WITHIN YOUR RELATIONSHIP. IF HE REFUSES WHAT WERE YOU THINKING OF DOING?

CHIPO. Sometimes it is very difficult because to one will still be very much in love with this guy and it's difficult to dump him.

**MERCY**. WHAT IF YOU ASK HIS REASON FOR REFUSING AND CONTINUOUS POST PONEMENT?

CHIPO. That would be good.

**MERCY**. BECAUSE IF HE IS TALKING ABOUT MARRIAGE IT MEANS HE WANTS TO HAVE KIDS, SO IT'S IMPORTANT TO KNOW YOUR STATUS, HOW WILL YOU MOVE ON. IT'S BETTER TO GO TOGETHER FOR HIV TESTING AND GET TESTED AS A COUPLE CHIPO. Sure, that's good.

**MERCY**. DO YOU THINK YOU CAN TALK TO YHIM LIKE THAT? CHIPO. Yeah, sure.

**MERCY**. DID YOU HAVE ANY PROBLEMS WITH THIS CONVERSATION? CHIPO. No because you are a very free and cheerful person.

**MERCY**. WHICH QUESTIONS DID YOU FIND INTERESTING? CHIPO. Those questions about the support that is available from the church.

**MERCY**. WHY? CHIPO. Because the church has not really been doing much, so I liked it.

**MERCY**. WHICH QUESTIONS DID YOU NOT LIKE? CHIPO. I liked all the questions.

# **MERCY**. DO YOU HAVE ANY QUESTIONS OR COMMENTS TO MAKE BEFORE WE FINISH?

CHIPO. I just want to say what you are doing is very good, because we get the knowledge and though sometimes we have this information the way you talked to me made me think seriously about HIV/AIDS, and now I can also go and encourage fellow youths to do something about HIV/AIDS sufferers things like visiting the sick. I also think I will go and try to find ways of helping HIV/AIDS sufferers

MERCY. I ALSO WANT TO THANK YOU FOR THIS DISCUSSION, THANK YOU SO MUCH

THE END

# **APPENDIX 7: COMMUNITY CONVERSATION (CC T3) TRANSCRIPT**

DATE-	13/02/09
FACILITATORS	Claudius Madanhire
TRANSCRIBER	Claudius Madanhire
SITE	Muonde clinic

### **Respondent Background information**

NAME	AGE	
1.Samson	65	male
2.Rose	61	Female
3.Anna	50	Female
4.Dorothy	60	Female
5.Annammore	43	Female
6. Tatenda	50	Female
7. Martin	52	Male
8. Norest	69	Male
9. Simba	79	Male
10. Magarate	55	female

#### **Churches represented**

1. Anglican

### Facilitator's comment

Muonde being a rural area there is more coherence and working together as a community. I was just wondering whether I will manage to do two groups on my own today, I used to manage two groups a day when we were doing it together with Mercy. Having made my appointments in advance today I just felt this energy that I can do this, so today I also hope to meet the Apostolic group after this Anglican group. I never thought I could be having ten people, but since we had over recruited to make up for one or two non-attendance today everybody managed to come. I enjoyed seeing some of the people we had in our previous group discussions, it's so encouraging to see how these villagers value these group discussions

CLAUDIUS: LIKE WHAT WE USED TO DO LAST TIME WHEN WE MET FOR THESE DISCUSSIONS, IT IS VERY IMPORTANT FOR YOU TO SAY OUT YOUR NAME BEFORE YOU GIVE YOUR CONTRIBUTION SO THAT I WOULD BE ABLE TO IDENTIFY WHO WILL BE TALKING WHEN I LISTEN TO THE TAPE THAT WE ARE RECORDING TODAY. THIS IS NOT A TEST SO THERE ARE NO RIGHT OR WRONG ANSWERS, WE JUST VALUE YOUR VIEWS. I AM SURE MOST OF YOU STILL KNOW US BUT FOR THOSE WHO CAN'T REMEMBER, I AM CLAUDIUS MADANHIRE AND I USED TO COME WITH MERCY NHAMO, THOUGH SHE IS NOT AROUND SHE IS STILL VERY MUCH PART OF THE PROJECT.WE ARE STILL TALKING ABOUT YOUR CHURCHES. I WOULD ENCOURAGE YOU TO SPEAK UP WHEN YOU SAY YOUR VIEWS.

ALL. Ok

### PART ONE

1). CLAUDIUS. OK, SO WHAT IS YOUR GROUP DOING IN FIGHTING HIV/AIDS STIGMA?

MARGARET. I think as a group, or a church group we are actually part of an initiative which is aimed at encouraging openness and disclosure as well as giving information on what to do when one has been tested HIV positive. We also do encourage treatments for those who are already HIV positive, and for those who get tested and find that they still have a lot of energy, we are encouraging them to have regular check-ups and also for them to try and live positively with their HIV positive status.

SIMBA. We also at every church service we have managed to create time to talk about HIV/AIDS at every church service, this also helps us to educate our youths to avoid behaviours that may put them at risk of getting HIV/AIDS. However such HIV/AIDS talks are given in the church where everyone will be there. So everyone will be able to hear for themselves.

CLAUDIUS. THIS IS SOME KIND OF HIV/AIDS INFORMATION GIVING SESSIONS IN THE CHURCH, AM I RIGHT?

MARTIN. True, I like it most when people also realize such an effort, like I once said in our previous sessions, when a Priest like myself start to encourage such openness about issues of HIV/AIDS in the church some critics felt like I was doing something wrong because for most church members then, HIV/AIDS sufferers were being punished for their sins, a notion that I strongly disputed.

# CLAUDIUS. OK WHAT ELSE ARE YOU DOING TO FIGHT HIV/AIDS STIGMA IN THIS COMMUNITY?

TATENDA. As a church group, we also meet regularly to plan and organize ourselves; especially we will be discussing about HIV/AIDS sufferers in the community and then trying to find how we can help these patients. Normally we agree to bring something for the patients when we go to see them, sometimes we bring them soaps. We also do spent time talking to

these patients encouraging them and giving them the social support. So we do visit our HIV/AIDS sufferers in this community on regular basis.

CLAUDIUS. DO YOU HAVE AN EXAMPLE OF SOME OF THE ITEMS THAT YOU GIVE TO THESE PATIENTS?

ROSE. Soap like I said, food items, mostly this takes the form of our crops and vegetables from our gardens.

JOSEPH. Sure, as a church group we also move around praying for these patients and visiting them on regular basis and talking to these patients as well. Sometimes we also bring these patients some firewood and the women in our group will also do the cleaning around the place, if the patient wants we can even bath the patient, and we make our financial contributions so that they can buy something for the patient when we go.

SIMBA. Our children also need education, while we can pride ourselves about our youths in our church who are getting the chance to be educated and be advised, but I am worried about youths who don't go to church. I think something must also be done for those youths. I am also worried about church meetings that are done at night because some trouble-making youths who don't even go to church will seize the chance to do as they please and end up exposing themselves or others to the risk of HIV/AIDS infection.

CLAUDIUS. WHEN THESE CHURCH MEETINGS DO HAPPEN, AREN'T THERE SECURITY MEASURES AND LEADERSHIP WHO REALLY SHOULD LOOK INTO SUCH ISSUES?

SIMBA. While those systems might be there but when the number of trouble makers is big they become overwhelmed.

CLAUDIUS. SO HWAT DO YOU THINK SHOULD BE DONE?

SIMBA. I think such meetings and prayer sessions should be held during the day, and avoid night church gatherings.

MARTIN. As a Priest I do come across many things but I am only grateful that people are now receiving these issues not with fear and dismay, but they have learnt to accept HIV/AIDS sufferers, like I said to you the last time we met that I wanted our church centre to become a drop-in centre for HIV/AIDS sufferers. I am encouraged by the number of people who are now finding the courage to disclose their status not only to me but to the church in general, it's not only those who are already ill who are opening up, but even those who still look health are

now finding the courage to open up. I once said when I decided to distribute condoms people did not take it kindly, until I explained why I was taking that approach.

I think it's working people are really opening up and when they do that we encourage them to go for checkups and at least access ARVs from the hospital. I am really encouraged by the response of this community. Most of the people who are looking after HIV/AIDS sufferers are not treating them with discrimination. I am happy with what the church members are doing, but I once requested if we could get other people to talk to our church members about HIV/AIDS and caring for HIV/AIDS sufferers, yes we do talk about it but it is said "a prophet is without honour in his homeland" some people might like externals to come and explain these issues to them. There are people who would come secretly after I talk about HIV/AIDS and say "father" can you explain further.

My aim is to give information, so when I gave out information on how things like condoms are used people thought I was promoting what is wrong. So parents should not shy away from talking about these issues with their children because times have changed, there are no those Aunties and Uncles who traditionally had the role of grooming the young ones in all these issues. People are really beginning to understand what is happening. Am really happy with what this community is doing and we wish if you could continue doing this and maybe one day you should consider coming and giving a talk to our church.

### CLAUDIUS. OK, I THINK A FORMAL INVITATION TO YOUR CHURCH MAY BE CONSIDERED IF YOU EXTEND IT.

MARTIN. Instead of giving us Soaps and T-shirts why can't you just give us those soaps so that we can also give to those patients who are sometimes in a difficult situation.

### CLAUDIUS. SOAPS AND T-SHIRTS AND HOW YOU USE IT IS SOLELY YOUR DICISION TO MAKE ON HWO YOU WANT TO GIVE? WHAT ELSE ARE YOU DOING?

TATENDA. These information giving exercises to our youths are also often hampered by poverty, our young girls think that if they go out with older man they can get what they want and all their poverty can be a history. So it's one of the challenges that we face here. All these hardships associated with economic situation which is difficult is presenting a challenge to our youths. But I am also encouraged by the way things are going because HIV/AIDS sufferers are treated humanely here and people are beginning to feel free to talk about their HIV positive status.

ROSE. I think this programme you started of working with church groups such as ours is working very well because we are now overwhelmed by people who come to us disclosing

their HIV status, we encourage them to make use of the hospital. There were people who were ill and never wanted to consider HIV tests but when we went there and talked to them about it they decided to go and get HIV tested and now they are on ARVs and now looking very well.

ANNAMORE . I think this programme of yours has been there to lighten the issue of HIV positive status. There were also people who were keeping the information about their HIV positive status a closely guarded secret, they felt ashamed of their status, but I am sure now it's a thing of the past. This programme has actually made opening up really smooth and comfortable because we talk to people about this programme at church or any other community gatherings, and many people are coming to us and opening up. Like in our area, many people with HIV/AIDS who are on ARVs are collecting them from Muonde hospital. There was a person whom we never thought would spent the next month, but we talked to the person and encouraged them to consider going for HIV tests and seeing the Doctor and now that person is looking very health and we have also requested that the Doctor to make regular visits here in Muonde people no longer need to go to the local town to collect their monthly supplies and for check-ups. So I think what you have done here is working very well, because we go about our villages talking about it and encouraging them to get tested and be put on ARVs.

I think we have a big number of HIV positive people here maybe because people learnt about this when they were already HIV positive. I also think people have now learnt how to care for their HIV sufferers, we used to hear these people saying these people got themselves infected by HIV so they don't deserve any kind of treatment, but through regular talking with them now, they are treating HIV patients very well.

NOREST. I would actually want to say that I might be out of touch with some of these things because I am actually busy with work at my plot most of the time, but I want to ask anyone here to let me know if they find any challenges with regards to food for any of the patients they visit, I am more than willing to assist with food. They can tell me, I have maize which I think can assist others in need. So next time when you visit let me know what challenges you have I may assist, I don't mean to say I will give everything you need but I will definitely do something about it.

CLAUDIUS. MARTIN, YOU CAN LET HIM KNOW WHAT YOU THINK HE CAN HELP WITH FOR NOW?

SIMBA. This man has been assisting others in this community, I cannot list all the things that he has done for us in the community, he is just a kind person.

DOROTHY. I want to add on what Norest has said, I think I may want to say we have caregivers who move around the community and they know HIV/AIDS sufferers and they will list the patients.

CLAUDIUS. I DON'T THINK WE CAN GO INTO DETAIL ON HOW YOU WILL ASK FOR HELP FROM HIM, YOU CAN DO THAT LATER, AS OF NOW I WANT TO GO ON AND ASK WHO IS ACTUALLY BENEFITING FROM ALL THESE ACTIVITIES AND HOW?

ANNA. I came across some people who caring for their HIV/AIDS sufferer and they were complaining that the patient was nagging them yet they got themselves into this problem of HIV/AIDS infection, but I talked to them and made regular visits to them until they understood that their patient did not like to be HIV positive and they also learnt to be kind, patient and tolerant with their patient. In such a case I think it is those relatives who were ill-treating their relative who benefited from the information I was giving them and I also think the HIV sufferer also benefited because they started to receive better and humane treatment. There is also an ill person whom I gave information and encouraged until they took up HIV tests and began to receive ARVs and now they are feeling much better, I think that person also benefited. Overall our community benefits and the patients also do benefit. I also get this feeling of having done something good when I do all these things.

MARGARET. I also want to thank Norest for offering to help, I also have a certain couple who are HIV positive and they asked what they can do to access help. I was not part of this group before and I had advised that couple to go another local hospital where we hear people are given tablets, so they said they are getting tablets but their worry was food, so Norest I will definitely approach you after this session for those people.

CLAUDIUS. ARE THEY GETTING THOSE TABLETS FROM THAT LOCAL HOSPITAL?

MARGARET. Yes.

CLAUDIUS. CAN'T THEY GET THEM CLOSER LIKE AT MUONDE HOSPITAL? MARGARET. I am just getting to know about it now, so I will give them such information.

**DOROTHY**. The patient and the one caring for them will benefit for most because it's them who have a burden that would be lightened by our assistance.

NOREST. Even the name of the church get exalted.

**ANNAMORE**. People are now opening up because what they want is help, so I think it is them who benefits most because when they do open up, assistance will begin to come their

way. There is still a small problem with us people who are helping these people. Some soon after assisting will go around saying "had it not been my assistance, so and so would have died of Aids". It's a small challenge that calls us to treat what we do for and with HIV sufferers as confidential, not to seek self-gratification because such things will undo all our efforts. When we give them advice let's keep it confidential.

**MARTIN**. I think that's true and people in this community should try and avoid this language of saying "*nhingi ari muchirongwa*" so and so is in the programme as a way of referring to HIV positive people who are taking ARVs, I have talked to some people who really do not want that label, so let's avoid such labeling terms otherwise we will undo what we have achieved as of now, no wonder why some people are going to collect their supplies of ARVs from that local hospital where they remain anonymous. I think let's allow them to use that term for themselves. I wanted to say HIV/AIDS sufferers and their families do benefit from these activities. I have some female married patients who have confessed to me asking for forgiveness from their husbands because she felt she was responsible for their HIV infection.

That's something very difficult for a woman to do but she did that after we talked to them and counseled them properly, I think their benefit is that they would be able to forgive themselves and have peace of mind. I have women who did that and asked me to ask for forgiveness on their behalves from their husbands, I can not say their names, but these people have managed to recover and live peacefully. I feel a sense of achievement and accomplishment as a Priest and I feel like I would have done my job as a Priest, I am glade to say that the blame game is over in this community so is this whole idea of stigmatization is slowly being overcome here and we feel like one family here and as a Priest I feel a sense of accomplishment.

CLAUDIUS. SURE DON'T SAY NAMES HERE, ARE THERE ANY PROBLEMS THAT YOU ENCOUNTER IN YOUR GROUP ACTIVITIES?

**SAMSON**. I think some of the issues have already been highlighted but I also want to point out that we also have a vegetable garden that we have as a group to help HIV sufferers with vegetables and other herbal plants.

**DOROTHY**. I also wanted to say these things benefit us first and then the benefit would spread to the HIV sufferers and the community at large, because this information is first and foremost ours to use

SAMSON. We also get good publicity as individuals, group or community. We get that good record as a community, and right now we feel that without you guys, our HIV sufferers would be treated worse off now. So we get this good publicity.

# **CLAUDIUS**. BUT WHAT ARE THE OTHER CHALLENGES THAT YOU ENCOUNTER IN YOUR GROUP ACTIVITIES?

**ANNA**. Sometimes we visit these patients and give advice like encouraging them to consider getting HIV tested done on them, but sometimes you would hear someone saying "so you think I have Aids" and normally when we talk to them their care givers would have told us to help to encourage the patient to get tested. So their reaction might be very discouraging, but with time they will understand it.

**DOROTHY**. We got to these patients, on one occasion the patient the requested something from me, but when I brought it, those who were not ill decided to share among themselves and do not give the patient. So it could be happening that when we leave these food items for the patients those who are not ill will feast on it.

**MARGARET**. These patients might be willing to get medical attention but there may be no money, no mode of transport for them to go to hospital. So some of the challenges we face is just lack of something material to give, we can do the prayer but what the patient might need is material assistance. Now with the use of foreign currency the economic hardships are even worse.

### CLAUDIUS. WHAT DO YOU THINK ARE THE SOLUTIONS TO THESE PROBLEMS?

ANNA. I think giving information and at least making use of external people to give information will help people to understand that when we say what we say to them it would not be our being judgmental about their illness or circumstances. So when the same thing is said by external people some people will understand.

CLAUDIUS. WHAT ARE THE OTHER SOLUTIONS?

MARTIN. I think about material assistance Norest will help us with some of the things.

### PART TWO

**CLAUDIUS**. WE ARE GOING TO TAKE SHORT BREAK BUT IT IS A WORKING BREAK BECAUSE I WANT YOU TO GO INTO TWO GROUPS AND DISCUSS WHAT YOU DID OUR LAST MEETING. WE HAVE ALREADY LOOKED AT WHAT YOU ARE DOING AS A GROUP NOW WE WANT TO LOOK AT WHAT YOU HAVE ACHIEVED AS INDIVIDUALS AND AS A GROUP. SO LAST TIME YOU BRAINSTORMED ON ANUMBER OF ISSUES THAT YOU SAID YOU WOULD WORK ON AND THESE INCLUDE THE FOLLOWING.

### THINGS THAT COMMUNITIES BRAINSTORMED

DISSEMINATE STIGMA INFORMATION ENCOURAGE CHURCH MEMBERS TO DESIST FROM ACCUSING EACH OTHER OF WITCHCRAFT THERE IS NEED TO EDUCATE RELATIVES TO ACCEPT AND TREAT HIV SUFFERERS WELL RELATIVES SHOULD ACCEPT THAT THEIR CHILD HAS NOT BEEN BEWITCHED PEOPLE HAVE BEEN ENCOURAGED TO START NUTRITIONAL GARDENS ENCOURAGECARE GIVERS NOT TO HIDE PATIENTS WHEN WE VISIT DISSEMINATEINFORMATION ON HOW CARE GIVERS SHOULD TREAT PATIENTS DISCUSS OPENLY ABOUT HIV/AIDS IN CHURCH AND ENCOURAGE CARERS NOT TO HIDE PATIENTS WHEN PEOPLE VISIT THEIR HOMES PARENTS SHOULD BE STRICT WITH THEIR CHILDREN TO ABSTAIN FROM SEXUAL INTERCOURSE BEFORE MARRIAGE CHILDREN HAVE A LOT OF RIGHTS THAT SHOULD CHANGE PARENTS SHOULD STOP HARASSING TEACHERS THAT PUNISH CHILDREN

### GROUP ONE (Martin, Margaret, Norest, Samson, Dorothy)

WHAT THE CHURCH HAS MANAGED TO ACHIEVE

- 1. Margaret managed to visit some HIV/AIDS patients who were close or near her place and she gave 2kg sugar, tea leaves and fresh milk to one patient
- 2. Martin and Jospeh also gave information and shared their knowledge about how to look after Aids sufferers with the care givers
- 3. Dorothy helped with some firewood and fetching water for the HIV/AIDS sufferer.

### WHAT WE DID AS A GROUP

- 4. We also encouraged those who had already given up o caring for their patients to care with love and renewed hope
- 5. We also advised these patients to visit the hospital and get to see the doctor
- 6. We also visited the HIV/AIDS sufferers regularly and praying for them
- 7. we also distributed condoms and taught people that Aids is not a curse from God but just a disease

GROUP TWO (Simba, Rose, Dorothy, Anna, Anna)

### WHAT WE DID AS INDIVIDUALS

1 Simba visited the sick, helped with firewood, firewood and vegetables.

2. Simba gave HIV/AIDS information to those who are looking after the sick.

3. Tatenda Gave soaps to the HIV/AIDS sick persons and prayed for them

4. Dorothy advised a sick person to go for HIV tests and she accepted and now she is on ARVs and she has really recovered. She also gave the same patient a piece of soap and box of matches.

### WHAT WE DID AS A GROUP?

1.We are giving people HIV/AIDS information at church and community gatherings, and we are also encouraging people to consider VCT.

2. We also worked in the field of an HIV/AIDS patient, we did the weeding as a group, we also taught people against stigmatization.

3. We also gave vegetables, and we have herb gardens.

4. we also prayed for the HIV/AIDS sufferers and visited them regularly, we also encouraged them to form support groups, so that they can give each other support and reassurance.

### CLAUDIUS. NOW WHAT FACTORS FACILITATED YOUR EFFORTS?

MARTIN. We did this because we also care about our fellow human beings who are HIV positive, we also want to fight HIV/AIDS stigma as well to lower HIV infection rates, that's why we do that, as a priest it is also one of my duties.

SAMSON. We are also doing this to help fight the scourge of HIV/AIDS as well to help the affected. We are also doing this to show our love to our fellow human beings.

ANNA. We are also doing this in fulfillment of what is required of us as church members; we will be trying to show goodness. We will be trying to good as God commands us.

DOROTHY. In the church we have priests who preach to us and encourage us to do these good works. This is something that we encouraged to do every Sunday. Such sermons drive us to do this for others. Margaret. We would be trying to show the care giver that they are not alone and also to show the sick person that we still care for them as much as we would have done if they were fit. A problem will be lessened if shared.

MARTIN. As a church we also encourage our people to be practical, at times I also encourage people to use condoms because they have failed to stick to one partner. This might surprise some church members why as a priest I should encourage condom-use, but let me say that for people can only come to church when they are fit and health, so while we want to emphasize chastity and being faithful to one partner experience has shown that people are failing to do that.

Therefore I think until people learn to be faithful it's better to encourage them to use condoms until they have grown spiritually to a level where they can be faithful to one partner. I would think it's better to advice people to use condoms instead of pretending to be chaste when people in the church are dying of Aids.

ANNAMORE. I think the main thing for us would to fight HIV/AIDS and at least lower the rates of infection. So we also emphasize on HIV/AIDS information within the church so that we blend it with the teachings of God and we hope that way people can be warned and understand what is expected of them. That way we will also be fight HIV/AIDS in general

# CLAUDIUS. 4). WHAT IS DIFFICULTIES AND CHALLENGES DID YOU FACE?

MARTIN. I have discovered that those people who will be looking after patients tend to think that when we come to help we should just take over all their roles, because at times you would find that they would call you whenever the patient needs something. They would begin to think that we should take direct responsibility of their patient, yet we will be simply giving them and their patients the support, and I am sure this can be solved by explaining to them in very clear terms that we are not experts and we are not coming to take over their duties but we are simply helping.

DOROTHY. Some of the problems had already been said before but I can say one major challenge has been limited resources. This has been a very hard year and we really had to struggle because sometimes these patients expect to receive some material assistance over and above the prayers and counseling and keeping the company. So this year things were really tough but we always tried to bring them something when visited them, that's why we came up with an idea of gardens so that we can supply them with vegetables whenever we visit them. ANNA. Like I also said before some HIV/AIDS sufferers have misconceptions when we visit them, they think maybe we are there to spread rumors and tarnish their image when we visit them, but we always try to make them know that we are not judgmental about their situations but we are only coming in to help.

DOROTHY. To me these were very minor challenges given that we got all the support from the church and local leaders to do our work, and some community leaders helped by talking about HIV/AIDS at funerals.

# CLAUDIUS. IS IT DIFFICULT FOR STIGMA TO CHANGE?

MARTIN. While we can say it is only difficult because it is in the mind and one can never be too sure that we have completely eradicated, but judging from how people are treating HIV/AIDS sufferers now in this community I can say yes it is something that can be eradicated if the community is really committed. I am sure in our community this something that we have achieved because people treating HIV/AIDS sufferers as human beings not HIV/AIDS sufferers.

ROSE. I would agree with Reverend people need to be committed DOROTHY. Now that we have the information and the facility where people can access ARVs at St Theresa, I think people are beginning to realize that HIV/AIDS is not a death sentence but just an illness that can be put under control.

# CLAUDIUS. WHAT DO YOU CONSIDER TO BE OBSTACLES TO STIGMA AND ACTION?

NOREST. I think for us we can say there is already action so I would think it takes community commitment. Lack of it will mean nothing would have changed by now.

ANNAMORE. I don't see any obstacle for us, because we are still going forward.

# CLAUDIUS. IS THERE ANYTHING THAT THE CHURCH HAS IMPLEMENTED IN RELATION TO STIGMA SINCE OUR LAST MEETING?

TATENDA. I think we have said all that we have seen happening and what we did as well.

# CLAUDIUS. DOES ANYONE WANT TO ADD SAY ANYTHING BEFORE WE FINISH?

MARTIN. I just want to thank you guys for coming here, it shows a lot of commitment on your part, and I hope this is not the last time we are seeing you here and we hope to move together as we fight stigma. We hope soon you will be able to come to our church and give a

talk as I requested. I hope you will consider that request. Some Organisations who used to work here have completely forgotten us because since the days when they were stopped by the political situation we never saw them back, we just hope they are considering coming back again.

ANNAMORE. Please don't forget to send our warm regards to Sisi Mercy and tell her that we miss her so much.

CLAUDIUS. I WILL DEFINITELY LET HER KNOW THAT, LIKE I SAID BEFORE SHE ALSO SEND ME TO GREET YOU ON HER BEHALF. IT HAS ALWAYS BEEN PLEASURE TO MEET AND DISCUSS WITH YOU PEOPLE. THANK YOU SO MUCH FOR YOUR TIME AND PATIENCE. HOPE TO MEET YOU AGAIN?

SAMSON. Thank you for bringing us the soaps

CLAUDIUS. YOU ARE WELCOME. THANK YOU ALL

THE END!!

#### **Code Families**

HU: cc1 File: [H:\Atlasti\TextBank\cc1.hpr6] Edited by:Super Date/Time: 29/09/2011 19:30:54

#### Code Family: AIDS prevention behaviour Created: 06/12/2010 18:44:18 (Super)

Codes (38): [best for couples to get results together] [church cautioning people against extra marital affairs] [church encourage monogamy] [church encourage patients to access hospital even after being healed] [church encourages faithful polygamy] [church encourages people to access VCT] [church members are reminded of the ten commandments and about prostitution] [church promotes good morals] [church warning people against risk behaviours and HIV/AIDS] [condoms are better than not using nothing] [condoms are not 100% effective] [discussion on warning people from having multiple sexual partners] [encourage safe sexual methods] [encouraged to practice monogamy] [Factors facilitated condom use- people are failing to abstain] [HIV prevention- Abstinence though it's difficult to implement] [HIV prevention- Avoid using sharp objects] [HIV prevention- being faithful to one another] [HIV prevention- condom use] [HIV prevention- dialogue] [HIV prevention- Not having multiple sexual partners] [HIV prevention- self control] [HIV prevention- VCT and then try and remain negative] [HIV prevention - Naviripine] [HIV prevention dialogue- people should avoid using sharp objects] [HIV prevention methods faithfulness, abstain, VCT, PPTCT, using contaminated utensils] [joined church to stay away from risky behaviour] [Men don't want to be seen going to an area where prostitutes reside] [men owning to promiscuity] [parents shouldn't leave their children out at night] [people taking heed of the advice to refrain from risky behaviour] [prevention methods] [prostitues are now afraid of AIDS and seeing their colleagues dying] [sermons discourage polygamy and extra marital affairs] [sermons that encourage men to travel with their wives] [Sharing ideas on how to approach someone and make them disclose their status] [warning children against indulging in sexual behaviour] [youths are encourgaed to abstain until they get married and married people should be faithful] Quotation(s): 77

#### Code Family: AIDS promoting behaviour Created: 06/12/2010 15:49:54 (Super)

[abandoning church to indulge in sexual activities] [Apostolic men have polygamous marriages with over Codes (50): 50 wives] [Apostolic patients died after forbidden to go to hospital] [Apostolic warned against going to the hospital] [Apostolics don't want to go to hospital] [beer halls facilitating prostitution] [Cannot use condoms in the house its a sign of disrespect] [condom use on young people forbidden- deemed to be devils work] [couples only access VCT when they suspect that the other partner is unfaithful] [extra marital afairs] [extra marital affairs are endangering people's lives] [Have difficulties reaching polygamous apostolic families] [hindrance- apostolic sects refusal to seek medical treatment] [hindrance- children have a lot of rights] [hindrance- commercial sex works cannot disclose their status because they will lose clients] [HIV is different from other diseases] [HIV is shameful because the vast majority is through sexual intercourse] [HIV patient wanted to disclose their status at church but were advised not to] [Men deny being unfaithful until they are exposed by the holy spirit] [men in church are the ones who are more promiscuous] [men saying they cannot resist some beautiful women] [men take small houses from beer halls] [men would scramble to have sex with a prostitute just because she was a nurse] [People don't listen to advice of refraining from promiscuity] [people indulging in risky behaviour when they go out of the community] [people should be patient with HIV sufferers] [people utilise what they have learned for a short time] [prostitutes cannot disclose their HIV status, will lose clients] [Reaon for unfaithfulness- men cannot stay without sex for a long time] [risky behaviour- unmaried men who have too many sexual partners] [risky behaviours- partners staying apart for too long] [risky behaviours- prostitution] [risky behaviours- unfaithful married men infected women with HIV] [spiritual healers do not disclose if a person has HIV they just say you have an incurable disease] [testimony] [testimony- friend seduced her husband] [testimony- women asked husband about extra marital affair and was told to take it or leave] [testimony- women notice men cheating and men denies] [too many rights children can report a parent to the police] [unfaithful] [unfaithful women who are also responsible for infecting their husbands] [vulnerability of married women to HIV/AIDS] [when men are confronted of their extra marital affairs they accuse women of cheating] [widowed women taking married men] [Widows having problems to refrain from sex for three years after the death of their spouse] [youths are drinking alcohol and exposing themselves to HIV] [youths are dying of HIV/AIDS and don't value what adults say [youths dating older people who will infect them with HIV] [youths don't listen to their parents- parents plea for such interventions to reach youths [Youths indulging in risky behaviour] Quotation(s): 82

#### Code Family: Assistance to HIV sufferers Created: 06/12/2010 16:05:14 (Super)

Codes (39): [Assist HIV sufferers though most of them would have migrated here] [assist HIV sufferers with collecting medicine] [Assist HIV sufferers with their farming activities, fetching firewood & household cleaning] [Assist patients in general] [Assist with fetching firewood & water] [assist with laundry] [assisted a patient with gloves] [assisting HIV sufferers] [assisting HIV sufferers orphans] [assisting HIV sufferers with taking them to the bus stop] [assisting with herbal remedies] [Assisting with household chores] [bathing patients] [blankets have been donated to HIV orphans] [donations to HIV orphans-fertlizers, seeds] [donations to HIV sufferers] [encouraged church members to visit HIV sufferers] [encouraged friends to work in gardens] [factors facilitated- that is what the patient requested] [farming activities and fetching firewood for HIV sufferers]

[fetched firewood for patients] [Financial assistance to a sister who was HIV positive] [financial assistance to HIV sufferers] [financial assistance towards funeral proceedings] [financial support to go to hospital & buying medication] [food & vegetable assistance to HIV sufferers] [food assistance and bathing a patient] [Food assistance to a daughter who is HIV positive] [food assistance, praying and fetching water for HIV sufferers] [food distribution for HIV sufferers] [funeral assistance to the bereaved] [home based care advice] [hospital assistance and psycho-social support] [material assistance and prayed for HIV sufferers] [prayed and assisted with household chores] [vegetable group to assist HIV sufferers] [visiting AIDS orphans and food assistance] [Visiting patients and food assistance] [working as a group to assist HIV sufferers] Quotation(s): 152

### Code Family: bad community relations

Created: 11/01/2011 16:41:00 (Super)

Codes (28): [Bad behaviour is the main caus..] [care givers disclose a patient's HIV status] [church leaders secretly access health services] [church members are secretly using condoms] [encouarge unity in families and communities] [factors facilitated- some patients have no- way to turn to] [hindrance- conflict of beliefs] [hindrance- failed to identify care givers to talk to relatives] [hindrance- Failed to talk to care givers to establish good rapport with patients] [hindrance- youths eloping and not have a church wedding] [HIV sufferers like nutrituous food that is how we suspect] [Non disclosure to friends] [obstacle- some parents support the risky behaviour of children] [obstacles- carers think visitors have come to eat] [obstacles-church regulations deter people from disclosing] [obstacles- patients still think that people have come to gossip about their illness] [obstacles- people hiding ill patients] [parents blamed for not allowing teachers to discipline children] [parents told to pay for their children's indecent dressing] [patient accusing carer of eating their food] [people are seen on the queue for ARVs that is how we suspect some of them] [people bragging about assisting people with clothes] [punitive measures for tight dressing] [some patients residing in towns ccome to the rural areas when they are ill] [women no longer respect husbands] [youths absconding advice meetings] [youths are not listening to parents] [youths don't respect elders]

#### Code Family: bad context

# Created: 06/12/2010 15:44:42 (Super)

[Apostolics allow people to take ARV's and not family planning pills] [Apostolics are allowed to go to Codes (96): hospital if you make a request] [bad odour from patient] [bad role models- doctors are promiscuous] [bus fare too costly for AIDS patients] [care givers feeling ashamed that they have a HIV patient] [carers hid patients and some patients are not medication compliant] [child abuse] [church is not helping HIV sufferers because no- one has disclosed their status] [church still lags on HIV/AIDS information] [couples secretly take tests but pretend not to know their status] [different strains of TB] [Difficult to disseminate HIV/AIDS information to prostitutes] [dilemma of putting on gloves and being labelled as stigmatising] [disseminated good dress codes] [domestic violence] [example of prostitution] [factors facilitated- HIV/AIDS is a challenge witin our community] [failed to accompany patients to hospital- high cost of transport] [faith healing for patients] [guessing from symptoms that a patient has HIV- non disclosure] [harsh economic climate] [high death rates due to lack of access to basic sanitation] [high divorce rates and domestic violence] [high number of patients] [High prostitution] [high unemloyment rate- no industries] [hindrance- child abuse] [hindrance- counter accusations] [hindrance- devaluation of the Zimbabwe dollar] [hindrance- drought] [hindrance- failed to get food for a patient due to not affording] [hindrance- government don't support our home based care initiative] [hindrance- harsh economic living] [hindrance- lack of donor funding] [hindrance- lack of financial resources] [hindrance- lack of good role models- a nurse who used to prostitute] [hindrance- lack of skills to source donors] [hindrance- patients expect to be assisted but people don't have the resources] [hindrance- political activities] [hindrance- scared to talk to HIV sufferers about HIV/AIDS] [hindrance- transport problems] [hindrance- unavailability of medical drugs in hospital and medicine fees too costly] [HIV sufferers with close relatives such as parents are the ones that are being taken care of] [ill treatment of HIV sufferers] [information is not enough] [knowing one's status has led to divorce in marriage] [lack of committment and trustworthiness among partners] [leadership not transparent] [media- has negatively influnced our youths not to listen to parents] [medical drugs too expensive] [men are a problem and are hard to satisfy] [men being lured by dress code] [men killed wife former prostitute after catching her red handed with another man] [mother ill treated son because he never took care of his mother] [Neighbours can even take your husband] [No disclousure- but people know by seeing the signs] [No donor activities] [No gloves- people using plastics as gloves] [No gloves and material resources] [No HIV sufferers are disclosing their status] [No NGO activities] [No one has disclosed their HIV status] [Nothing has been done in relation to HIV/AIDS sufferers] [Obstacle- some people are not afraid of contracting AIDS, they say AIDS is like skin lotion] [obstacles- a lot of gossip in the community] [obstacles- child abuse] [obstacles- HIV patients refusing to eat] [obstacles- no money to help HIV sufferers] [obstacles- peer pressure] [obstacles- political disturbances] [obstacles- poverty & famine] [obstacles- rituals on children] [obstacles- shortage of gloves] [obstacles- some people are still shy to disclose their HIV status] [obstacles- transport problems] [obstacles- unavailability of gloves] [obstacles- youths are not encouraged to couple vct before marriage] [Parents may disown me if | am HIV positive since | am single] [parents should stop harassing teachers that punish children] [peer influence] [people are not disclosing because of some church that claim to be morally upright and holly] [People don't disclose their HIV status they rather consult tradititional healers] [People suspicious of witchcraft so are afraid to receive help] [Poverty- Patients feel weak when they take tablets with no food] [poverty- young girls being lured to have sex in exchange of food] [Reason for non- disclosure- no medicine in hospitals knowing will stress a patient] [scarcity of drugs in public ho..] [some pastors discusing HIV/AIDS will put their reputation at stake] [Teachers are not teaching children in schools due to remuneration] [Unavailability of gloves may contribute to shunning patients] [we are not prepared to disclose our status, the same applies to other people] [women have sex with dogs for money] [xenophobic attacks- preventing couples from travelling together] [young girls lure men] [young widows indulging in sexual behaviour with married men]

Quotation(s): 287

Code Family: beneficiaries Created: 18/01/2011 14:58:58 (Super) Codes (4): [care giver benefits through experience] [care givers benefit] [patient and carer benefits] [patients are benefiting] Quotation(s): 6

#### Code Family: critical dialogue Created: 11/01/2011 15:35:49 (Super)

[Can you make the research into booklets] [critical dialogue on taking care of HIV sufferers, encourage Codes (47): discloure & HIV information dissemination] [dialogue of keeping separate utensils for HIV sufferers] [discussion on confidentiality & labelling HIV sufferers] [discussion on how to feed and advice to a patient on ARVs] [Do breastfeeding HIV mothers receive any food?] [Good caring techniques] [groom children to uphold christian values] [HIV cannot survive in saliva for a long period] [misconceptions corrected in through dialogue] [social space- church has to focus more on HIV sufferers] [social space- community need to be sensitized that it is bad to stigmatise patients] [social space- families should have got this chance as well] [social space- have heard other people's views and this facilitates learning] [social space- have learned about the transmission routes] [social space- have learnt about modes of transmission] [social space- have learnt about stigma & will not do that.] [social space- have learnt not to judge people] [social space- have learnt that married people should be faithful] [social space- have learnt the importance of disclosure] [social space- have learnt to treat HIV sufferers well] [social spacehow can HIv be prevented] [social space- if everyone had got this chance then it would improve the situation] [social space- I have learned to do more for HIV sufferers] [social space- I have learnt what stigma means] [social space- learnt the importance of accessing VCT] [social space- parent let's not tire to give advice to our children] [social space- people shouldn't have separate cutlery for patients that's inhumane] [social space- there is need for education on how to disclose your HIV status to your partner] [social space- this should also be a community initiative] [social space- we have learned that iit's bad to ill treat HIV sufferers] [social space- we need to be lenient and patient to HIV sufferers] [social space- we should avoid modest dressing when we vist patients] [social space- would like to take up VCT] [social space - family members should accept HIV sufferers] [social space on bus stop diagnosis] [social space on how to care of HIV sufferers] [social space on reinfection] [social spaces- have learned to encourage HIV disclosure] [social spaces- have learnt that about the importance of disclosing one's HIV status] [social spcae- I have changed my attitude towards HIV/AIDS sufferers- I will treat them with more love and tenderness] [Soultion- educate people that AIDS is like any other disease] [This opportunity has opened our eyes] [use gloves when bathing patients] [VCT advice] [VCT is important for people to know their status and live healthy] [warn each other against indulging in risky behaviours] Quotation(s): 80

#### Code Family: Denial (pretend AIDS does not exist) Created: 06/12/2010 15:48:46 (Super)

[AIDs denial] [apostolic think a person has been bewitched and that it is not HIv/AIDS] [Apostolics don't Codes (52): want to go to hospital] [Apostolics say its enough to belive that your partner is faithful and there is no need for testing] [Can't imagine telling my husband that I am HIV positive] [Difficult for partner to accept if another partner is HIV positive] [fear to know one's HIv status and to lose friends] [fewar of marriage breakdown when a partner tests HIV positive] [gloves appear culturally as stigmatizing a patient so carers avoid using gloves] [Hard for people to disclose their status] [Having HIV was associated with being doomed to death] [hindrance- delay in getting tested] [hindrance- HIV/AIDS denial] [HIV AIDS denial, people always say they have been bewitched] [HIV come with resposonsibility and it is scary to accept] [HIV denial- people don't accept AIDS to be any other disease] [HIV denial- people say they have been bewitched] [HIV denial- some people don't belive there is or have AIDS] [HIV disclosure is difficult] [HIV disclosure to my wife will end the marriage] [HIV disclosure within the family might lead to divorce] [HIV has no cure] [HIV is shameful- people will know that you have been promiscous] [HIV patients go for faith healing] [HIV positive result will shock people if the person is still fit] [HIV stigma cannot be eradicated in this current drought] [HIV stigma is difficult to erradicate as long as HIV is there] [HIV stigma is getting better and cannot be erradicated] [HIV sufferers say they have malaria] [HIV/ AIDS denial condoms cannot be used daily] [HIV/AIDS denial- a friend asked me where I had seen someone who was HIV poistive] [men will never accept a HIV result, women will have to explain themselves how they got infected] [obstacles- afraid that youths might comit suicide if they know that they are HIV positive] [obstacles- some HIV sufferers spread the virus to a lot of people] [othering- these youngsters should go and implement what they have learned] [Parents may accept but other family members may not accept that I am HIV positive] [patient afraid of being bewitched] [People are ashamed of the positive result] [people are not disclosing their HIV status] [People cannot accept AIDS like any other disease] [people cannot accept AIDS to be any other disease] [People still think that someone has been bewitched when they see that it is HIV] [some HIV sufferers say they have been bewitched] [Some HIV sufferers say they have TB and not HIV] [some patients refuse to seek health services] [some people ignore HIV programs and fail to treat patients well] [Some people may believe when they see a HIV positive person] [some people will never stop to be promiscuous until they get infected] [This disease is still hard to accept] [women don't accept when they are said to be HIV positive, they know it's men is responsibility] [women running away from their husbands cause they have tested positive] [younger generation is hardly hit with HIV/AIDS because of denial] Quotation(s): 139

#### Code Family: Disseminate HIV information Created: 06/12/2010 15:50:31 (Super) Codes (33): [advice to youths] [Advising youths about HIV/AIDs issues] [Advising youths to abstain until marriage]

[Announced in church that we are here to help people] [call for men and boys to behave in the community] [chief talks openly about HIV/AIDS at funerals] [chiefs disseminate HIV/AIDS information at funerals] [children should abstain before marriage] [church disseminate HIV AIDS information] [church host AIDS workshops] [destigmatise HIV/AIDS from being attributed to witchcraft] [discouarage youths from premarital sex] [disseminate HIV/AIDS information & condoms] [disseminate HIV/AIDS stigma information] [disseminated HIV/AIDS information through acting drama in the community] [disseminating HIV/AIDS information of HIV/AIDS at funerals by community leaders] [Doctor comes every month to treat HIV sufferers] [doctor coming into the community] [HIV pamphlets distributed at schools] [HIV/AIDS dissemination from community health workers] [HIV/AIDS information and encourage VCT uptake] [HIV/AIDS information from community health workers] [INFORMATION and encourage VCT uptake] [message to people against indulging in risky behaviour] [Priest disseminated HIV/AIDS information from this program encourage us to embrace HIV sufferers] [sensiting people especially apostolics to seek health services] [social space- HIV tests are being conducted at the local hospital] [teaching youths] [workshops for youths]

Code Family: Factors facilitated disclosure Created: 14/01/2011 17:39:35 (Super) Codes (1): [disclosed because of need of help] Quotation(s): 1

#### Code Family: Future planned actions Created: 06/12/2010 16:11:13 (Super)

[call to start fundraising activities] [community leaders should encourage HIV sufferers to disclose where Codes (56). they came from] [Convince church leaders to include HIV/AIDS teachings] [educate care givers to treat patients well] [encourage church leaders and members to visit HIV sufferers] [encourage each other spiritually] [Encourage fidelity in marriage] [encourage HIV disclosure in church] [encourage HIV sufferers to enrol in HIV programs in the community] [Encourage IGPs] [encourage parents to protect their children and not allow them to engage in night activities] [Encourage people to seek VCT services] [encourage youths to behave well] [encouraged church members to to make material donations] [fundraising activities] [fundraising activities helping people in church] [fundraising for patients] [Fundraising initiatives] [Goals of group] [Government should interven for some church groups to go to hospital] [government should stop enacting laws of majority rule since it's hard for parents to control the children] [HIV positive partners should avoid arguing and live positively] [HIV/AIDS programs should target prostitutes who are hard to reach] [implement- encourage care givers to treat patients well] [implement- encourage disclosure in church] [Implement- encourage VCT in the community] [implement- will assist HIV sufferers after they disclose their status] [implement- will talk to my husband about accessing VCT services] [initiativegovernment should enact a law that forbids prostitution] [initiatives- government should intervene] [Initiatives- IGP] [initiatives- it's good to show love to HIV sufferers] [initiatives- will start helping the sick seriously] [Initiatives- would like to help peole who are no longer able to go to hospital on their own] [Initiatives- would like to organise a group that help AIDS patients] [Intervention- government should talk to church leaders to allow their church members to seek health services] [Its best for couples to take HIV tests together and not as individuals] [men should take the initiative to take care of the sick as well] [men should travel with their wives] [Need for bridging social capital i.e government and other NGOs] [Need for church to educate other church members on being grateful] [Need to encourage HIV sufferers to disclose where they came from] [prostitutes should be arrested] [prostitutes should be peer educators] [relatives should treat HIV sufferers well] [Sermons to talk about AIDS] [social space- will disseminate HIV/AIDS information] [social space- will encourage any potential girlfriends to seek VCT] [social space- will put into pracitce what I have learned] [social spaces- doctors and nurses should disseminate home based care information] [Solution- have faithin God] [solution- police should arrest prostitutes] [try and reach out to men who don'tr go to church] [warning message to accept HIV sufferers and not judge them] [way forward- donors and government should work together] [women should pray for men not to indulge in extra marital affairs] Quotation(s): 101

# Code Family: gendered burden

Created: 11/01/2011 16:17:30 (Super)

Codes (12): [conferences offering spiritual support to other women] [he main issue there would be h..] [hindrance- if wife disclose first, man will accuse her of infecting him.] [men bring HIV to faithful wives] [Pain of HIV sufferers] [teachings to women concerning marriage] [women asking for forgiveness for the infection] [women being taught marriage issues] [women benefit] [women blaming themselves for men contracting HIV] [women encouraged to accompany their husbands when they are going for long trips] [women running away from their husbands cause they have tested positive] Quotation(s): 18

#### Code Family: good context Created: 06/12/2010 15:44:05 (Super)

Codes (50): [Access to ARVs] [Access to ARVs has made people realise that HIV/AIDS is not a death penalty] [access to health service] [ART adherence] [ARV knowledge] [ARV programme roll out] [benefits of ART] [caring for HIV sufferers without any relatives in the community] [church assisting the elderly] [church members becoming friends and relatives] [Church people are the only ones that might find it easy to accept HIV sufferers] [church saupports HIV sufferers] [churchs average the vorking together to combat HIV/AIDS] [collaboration with Methodist and Roman Catholic] [commercial sex as peer educators

was a good initiative] [community & family involvement] [community encouraging HIV sufferers to seek health services] [community taking initiative] [encourage harmony in community] [encourage VCT, ARV uptake and access to health services] [factors facilitated- as a group the community took us seriously] [factors facilitated- community commitment] [factors facilitated- in church people listen to you] [Factors facilitated- knowledge gained from home based care activities] [free health service] [good family values] [good values for youths] [HIV drugs roll out] [HIV sufferers are being treated well nowadays] [HIV sufferers are receiving treatment so there are a few bed ridden patients] [HIV sufferers feel loved] [HIV transmission dialogue] [HIV/AIDS programs in church] [husband may accept my status because we discuss about HIV/AIDS at home.] [IGP projects] [learning good ways about community living] [less prostitution compared to before] [living in harmony with each other] [marriage advice] [men teaching each other at men's association] [no segregation] [offerred caring advice to carers] [Parents may accept because I am the only child] [Patients on ART have now improved such that they are active and fit] [people say they are on a program] [Roman Catholic church helps to keep local hospital fees low] [VCT advice to a patient] [women are the first to know their HIV status when they go for ANC] [work in collaboration with other church groups] [youths mother and father advisor in church]

Quotation(s): 94

#### Code Family: HIV negative disclosure and those that are ill for a long time Created: 11/01/2011 15:21:51 (Super)

Codes (3): [HIV patients disclose when they are critical] [People who are HIV negative are the ones that disclose their status] [People who are ill for a long time are the ones who disclose their HIV status] Quotation(s): 3

#### Code Family: HIV sufferers are a problem Created: 11/01/2011 16:11:31 (Super)

Codes (6): [hindrance- at times patients demand things that cannot be afforded] [hindrance- some of these patients are cheeky] [hindrance- some patients don't want care givers to use gloves] [HIV sufferers don't want carers to use gloves] [some patients are a problem- they don't appreciate what people do] [some patients are violent] Quotation(s): 13

# Code Family: knowledge of HIV transmission

Created: 07/12/2010 16:50:14 (Super)

Codes (17): [HIV knowledge] [mode of HIV transmission- carring for a patient with wounds when one has open wounds too] [mode of HIV transmission- delivering mothers sharing blood stained linens] [mode of HIV transmission- mother to child transmission during giving birth and breast feeding] [mode of HIV transmission- too many sexual partners] [mode of transmission- blood transfusion which is HIV positive] [mode of transmission- having sexual intercourse with HIV partner] [Mode of transmission of HIV make it so immoral to be HIV positive] [modes of HIV transmission] [modes of HIV transmission] [modes of HIV transmission- blood transfusion if the blood is not tested correctly] [modes of HIV transmission- having a sexual relationship with a person who is HIV positive] [People appear to understand HIV/AIDS information at church] [risk of HIV infection when open wounds of a HIV positive person gets in contact with yours] [social space- it's better to use gloves than be infected just because of culture] [taught to take care of the sick] [taught to treat HIV patients well] [teaching on home based care] Quotation(s): 50

#### Code Family: Look for outside support (proactive and not fatalistic) Created: 06/12/2010 15:51:05 (Super)

Codes (9): [An appeal to researchers] [appealing for help] [Asking for assistance from researchers] [bridging social space- People would like to hear the information from you experts] [call for large scale CCs] [call for researchers to talk to the youths & church members] [expected you guys to teach us about sex] [talk to prostitutes to refrain prostituting] [we can only do so much without donor or government intervention] Quotation(s): 31

# Code Family: macro social factors

Created: 11/01/2011 16:22:36 (Super)

Codes (7): [hindrance- no gloves] [hindrance- poverty] [hospitals not functioning properly - people told to bring gloves & buy medicine from pharmacy] [Initial ARVs uptake can make some lose appetite] [nindrance- cost of transport and not easily accessible] [unavailablity of resources contributes to shunning of patients] [using plastic bags as gloves] Quotation(s): 21

#### Code Family: Misconceptions

Created: 06/12/2010 15:50:11 (Super)

Codes (15): [Being slim is associated with being HIV positive] [critical patients after receiving holy water were told they will be fine] [fortune lost through paying witch doctors] [Give holy water to HIV sufferers] [Having sex with multiple partners is a sign of manhood] [hindrance- accussing each other of witchcraft] [misconception of flies corrected through dialogue] [misconceptions] [misconceptions- HIV sufferers being told that they have been bewitched] [misconceptions- stained linen when washed will reactivate the virus] [misconceptions- virus stays on fresh blood] [misconceptions of transmissions of HIV- flies transmit HIV] [Not using gloves when carring for your child is a sign of love] [prostitution is a sign of manhood] [traditional healers and faith healers advising HIV patients to have sex with a virgin to be cured] Ouotation(s): 19

#### Code Family: Normalising anti- stigma attitudes Created: 06/12/2010 15:52:22 (Super)

Codes (69): [A friend disclosed his HIV status] [A rise in HIV disclosure] [acceptance of HIV sufferers and information in the community] [Announced in church that we are here to help people] [apostolic accessing health services] [Avoid passing negative comments] [Care givers now know how to behave] [care givers shouldn't hide patients] [case study- brother who has HIV and family has accepted] [case study of HIV disclosure] [case study of HIV sufferer taking up VCT advice] [church accept HIV sufferers when they come and sympathise with them] [church has set up an AIDS committee to disseminate HIV/AIDS information] [church makes us understand and receive HIV sufferers well] [church recognizes that HIV/AIDS is a reality and people are dying] [community members now accept HIV sufferers] [compassion and love by community members] [encourage people to accept HIV sufferers] [factors facilitated- there was no one to help the patient] [factors facilitated- to act as a role model to the carers] [factors facilitated- wanted peopel to know that there is nothing shameful about HIV/AIDS] [Family should accept this disease has spread all over the country] [family will accept my HIV status because my sister died of AIDS] [friends may give good advice on how to carry on with HIV] [Giving an example of importance of disclosure] [Have a brother who died due to HIV/AIDS] [hindrance- community become care care givers of prostitutes when they are sick since they would have migrated into that community] [HIV copping- healthy diet] [HIV disclosure] [HiV disclosure- negative] [HIV disclosure to relatives] [HIV disclosure within the family might lead to divorce] [HIV dislclosure among some church members] [HIV dissemination from the media] [HIV patient disclosing that she is in the same 'ship' with others] [HIV patients disclose if they know that they are getting assistance] [HIV sufferer confided in a care giver] [HIV sufferers are no longer stigmatised] [HIV sufferers from outside who are flight on TV came to disclose their status] [HIV/AIDS is a national problem] [HIV/AIDS is being treated like any other disease such as TB or diabetics] [mother will take care of children if they are HIV positive] [Patients accessing ART are beginning to disclose their HIV status] [Patients confessing their sins to the pastor when he visits] [patients praying for themselves and their families] [People disclose after being encourgaed to disclose at the hospital] [People disclose because they would need assistance] [People disclose their HIV status because of access to ART] [People disclose their HIV status through confessing their sins in church] [people now start to care for the sick] [People thought HIV was for the promiscous but now it has changed] [People treat HIV sufferers well because they would want not want their family members to be ill treated] [positive comments to HIV sufferers] [quotes that reveal that a person is HIV positive- I am now in the programme] [seeking health advice from health services] [sensitize community members thaty HIV sufferers are human beings like you and I] [sharing case studies of diclosure] [sharing food with a HIV patient is not a problem] [social space-I have learned to treat HIV sufferers well, maybe one day I will be like them] [social space- I have learnt that HIV/AIDS is just like any other disease] [social space- learnt the importance of disclosure] [social space- when people develop a positive attitude there is nothing shameful about the disease] [Support in medication compliance] [treating HIV sufferers with dignity] [we are fighting HIV stigma] [we are tackling AIDS stigma] [we have no bed ridden patients] [we will continue treating our ..] [women are now told their results when they go for ANC so that they protect the unborn child] Quotation(s): 132

# Code Family: obstacles to disclosure

Created: 15/01/2011 17:28:20 (Super)

Codes (3): [church prophets revealing that someone is HIV positive through holy spirit] [Not easy for couples to access VCT] [Not possible for married people to go for VCT regularly] Quotation(s): 4

## Code Family: offer support and love to PWAs

#### Created: 06/12/2010 15:52:02 (Super)

Codes (90): [bathing patients] [bus fare assistance to HIV sufferers] [care givers helping HIV sufferers] [church assisting at funerals buying a coffin for the deceased] [church assisting HIV sufferers] [church comforts mourners and assist financially] [church donations to HIV sufferers] [church offering psycho-social support] [church offers financial and psychosocial support] [church offers material support] [church offers moral support] [church offers spiritual support] [church pray and fast for patients] [church to identify social support such as friends and relatives] [church treat HIV sufferers like any other patient] [church treats HIV sufferers well] [compliment to the man who assist others in the community] [contributed money for transport to go to hospital] [Counselling care givers] [Encouraged not to blame HIV sufferers for their illness] [Encouraged to treat HIV patients well] [factors faciliatated- Priest appeal to assist HIV sufferers] [Factors faciliated- A priest who act as a good role model in the community] [Factors faciliated- One day I might need help] [factors faciliated- people desperately need help] [factors facilitated- empathised with patients & carers as well as love] [Factors facilitated- intrinsic motivation and love for one another] [factors facilitated- it's painful to see someone suffereing from this disease] [factors facilitated- I might know my HIV status] [factors facilitated- I might need help tomorrow] [factors facilitated- love for one another] [factors facilitatedpatient was failing to raise money] [factors facilitated- patients don't feel neglected] [factors facilitated- patients have no energy to help themselves] [factors facilitated- self sacrifice and love for other human beings] [factors facilitated- the patient felt cold so firewood would offer warmth] [factors facilitated- these are human beings, we feel we have to help others] [factors facilitated- these are our church members] [factors facilitating- bringing a positive spirit to the sick] [factors facilitating- found the urge to asisst HIV sufferers] [factors facilitating- love and the oneness in the community] [factors facilitating- sympathising with Patients] [gendered budern of women- taking care of men and children] [Have offerred herbal treatment to HIV sufferers and these have helped patients] [Healthy foods to eat when one is HIV positive] [HIV patients receiving help from church]

[HIV sufferers are being treated well nowadays] [HIV sufferers used to be isolated] [home based care activities] [home based care activities by women] [home based care and psycho-social support to a HIV sufferers] [I feel good that I have done something for the community] [laundry and financial assistance] [learnt to be patient with HIV sufferers] [Long back HIV sufferers used to despised but now it has changed] [material assistance to HIV sufferers e.g soap, food, mealie meal etc] [meeting regularly to find how best to assist HIV sufferers] [More people are voluntering to help HIV sufferers] [Mother took care of the HIv positive sister because her inlaws send her back after the death of her husband] [No bed ridden patients] [Now HIV sufferers are now embraced] [Offer nutrition advice to HIV sufferers] [offerred food] [offerred fruits to a HIV patient] [offerred vegetables and soap to HIV sufferer] [offerring food assistance to the group members] [Parents will care for a child who is HIV positive] [Patients are excited when they see people visiting] [Patients assisted with laundry and household chores] [Psycho-social support to HIV sufferers & carers] [Show patients that we still love them] [showing love to HIV Sufferers in church] [source blankets for the elderly] [testimony- took care of a HIV person] [testimony- took care of a HIV positive sister] [took care of patients without relatives in the community] [transport assistance] [vegetable & herbal assistance] [Visit patients in general] [visited and prayed for patients, offer psycho social support and offer material assistance] [visited HIV sufferers] [visited HIV sufferers and assisted in accessing medical attention] [Visiting patients and assisting with household chores] [visiting patients and financial support] [visiting patients and offerring material assistance such as mealie meal] [visiting patients in hospital] [We are doing it for God] [We are the new funders] [well to do people in church helping the poor] [wives take care of men when they are ill]

Quotation(s): 288

#### Code Family: Other

Created: 06/12/2010 15:50:17 (Super)

['Holy spirit' can reveal if one is HIV positive or not] [A carer became positive after carring for her HIV Codes (83): positive mother] [A family started their own orphanage without any funding] [A hospital vehicle with ARvs was once raided by thieves] [After church youths don't want to stay to hear announcements so they leave] [answer of saliva- after 5 litres of saliva consumption] [Apostolic leaders and those who are well to do access medical help while the majority are not allowed] [ARVs need a lot of food] [attending conferences in other towns] [beneficiaries- those who listen to advice] [both the patient and myself will be benefiting] [CADEC now focuses on farming skills and not HIV] [care givers benefit] [church expect people to come back to church and offer their testimonies] [church feel used when patients leave without any sign of gratitude] [church is guided by the spirit] [church members and people passing by benefit from the teachings] [church members benefit from all the teachings from church] [church refers sufferers to the hospital if they are medical problems] [Church still lags behind HIV/AIDS information] [church teaches people the word of God] [community benefits] [cultural expectiations of gratitude] [did not learn anything] [disseminating herbal and gardening information] [every person benefits from church activities] [factors faciliated- people desperately need help] [factors facilitated- that is what the patient requested] [factors facilitated- the patient was a vistor and had no option] [Healed from HIV at church] [healing sessions at church for HIV sufferers] [hindrance- tangled in our daily chores] [hindrance- youths don't listen to elders] [hindrances- got tied up with household chores] [hindrancessome patients when they see a lot of visitors they always think that they are now to sick] [HIV carers benefit because their duties are relieved] [HIV patients shouldn't disclose their status because other disease people don't] [HIV sufferers benefit more] [HIV sufferers coming to church to be healed and then abandon the church] [holy spirit is suppose to give widows the go ahead to marry] [importance family structure for women will accept men even when they know that they have extra marital affairs] [Many people have been healed of AIDS from church] [men come home when they are drunk] [Most HIV carers are people who are residing at home not doing anything] [mothers fear for their sons dating older women] [Not possible for married people to go for VCT regularly [obstacles- worried about youths who don't go to church] [only men can have many wives, women should have one men] [parents should stop harassing teachers that punish children] [Parents will try and calm me the patient] [People are authorised to go to hospital after healing has failed] [People cured of HIV] [people should pray not to face challenges in their marriage] [prayed for a person with stroke and managed to walk] [prayers should be included in government schools] [preach the word of God] [question- can HIV be transmitted through saliva] [question posed of how to practice safe sex with a husband who is been away for a while] [secuirty blanket that the community will help anyone if they are in need] [Some HIV sufferers are a problem] [Some HIV sufferers don't even go back to the hospital to check if they are positive because they would have been healed by the bishop] [Some members changing churches after recovery- no sign of gratitude] [Some patients after they are well, stop coming to church] [some patients are told not to drink alcohol or smoke but they always do that] [some patients die without disclosing where they come from] [some patients neglect the church and tell members that they are not the one that healed them] [some people in church are still struggling with their faith] [started a herbal garden] [stigma defined] [There is need for couples to agree to the church they want to go] [Top leaders of apostolic sects go to hospital while the masses are forbidden] [virginity testing for youths] [we are benefiting] [we are supporting our seminarians] [when partners accuse each other they would have seen a certain behaviour] [wife was angry to the husband for being infected with HIV] [women are also a problem because it takes two people] [work together with other church groups] [wrong definition of stigma] [young boys giving school fees to girlfriends to pay rent] [Youths are encouraged to marry from church] [youths benefit] [youths debates on dress codes and HIV/AIDS] Quotation(s): 121

#### Code Family: outside support Created: 06/12/2010 15:47:48 (Super)

Codes (31): [Apostolic children being immunized at home, guarded by police and the nursing staff] [As a result of your teachings Apostolics are now going to hospital] [Being grateful- we would like to thank you for coming here] [bridging social capital] [bridging social capital- apostolics are now going to hospital] [Being grateful- we would like to thank you for coming here] [bridging social capital] [bridging social capital- berg grateful for what you are doing] [bridging social capital- BRTI to continue with these programmes] [bridging social capital- DAMASCO- church elders] [bridging social capital- donor disctributing food] [bridging social capital- FACT/NAC/WAC] [bridging social capital- I have learnt a lot from the time I have attended your sessions] [bridging social capital- Munyaradzi home based care programme] [bridging social capital CADEC] [factors facilitated - never

realised that we can do that until you came] [factors facilitated- so that people in the community can see what you taught us] [Factors facilitated- this program has helped us and we want to show people what we are benefiting] [factors facilitated- through this program we now know how to care for a HIV patient with fear of contracting the disease] [factors facilitated- you taught us to do that] [factors facilitated- your coming & FACT helped us to be more serious on taking care of patients] [Linkage Zimbabwe disseminate nutrition information for HIV sufferers] [political party assisting HIV sufferers] [questions to researchers] [Reason for attending- Know that you talk about HIV/AIDS] [Report a neighbour because they couldn't vacine children who had measles] [social space- this is such valuable lessons and the community just missed.] [Solutions- educate care givers not abandon patients] [thank you for coming and bringing us together] [We still need to be taught about HIV/AIDS] [working together in church to combat HIV/AIDS- thank you for your programmes] [You should teach us on how to treat HIV sufferers well] [Your coming has made us feel a sense of community] [your programme cut across all church denominations]

Quotation(s): 109

#### Code Family: spiritual help & obligation Created: 06/12/2010 15:51:49 (Super)

Codes (28): [church as a source of hope] [factors faciliated- we would have done God's will] [factors faciliating- church expectation] [factors facilitating- being a care giver] [factors facilitated- it's our duty as christians] [factors facilitated- A patient was in a desperate situation] [factors facilitated- as a care giver I have to help HIV sufferers] [factors facilitated- as human beings we are obliged to help others] [factors facilitated- assist care givers from their chores] [factors facilitated- bible verse from Romans that talks about love] [factors facilitated- christianity requires us to be kind] [factors facilitated- church sermons drive you to do that] [factors facilitated- donations in church] [factors facilitated- God is love, that is the way we might see the kingdom] [factors facilitated- God will reward you] [factors facilitated- helping is opening blessings from God] [factors facilitated- we would like to fight HIV stigma] [factors facilitating- As a community leader, it's a duty] [Factors facilitating- You see someone in a desperate situation and you know you just have to help] [Human effort has failed to cure HIV, but God can cure it] [Praying for HIV patients] [spiritual help] [we are benefiting because God rewards us] [We are doing it for God] [We benefit because God will reward our effort] [women taught by tyhe bible to be submissive to their husbands] [worshipping God and praying] Quotation(s): 87

#### Code Family: stigmatising treatment of AIDS sufferers and carers (discriminate) Created: 06/12/2010 15:48:20 (Super)

[A carer became positive after carring for her HIV positive mother] [a church leader said a patient will not Codes (68): survive when they visited] [AIDS is a punishment from God to those who sin] [Anyone dying is said to be HIV positive because of high HIV rate in this area] [bus stop diagnosis] [care givers warning vistors against telling other people about their patient] [church against indecent dressing] [courtesy stigma] [destigmatise HIV/AIDS] [difficult to disclose your HIV status to neighbours, friends & relatives] [Difficult to find who infected the other apart from discorded couples] [Family may stigmatise me if they know that I am HIV positive] [fear of contagion] [Fear of HIV patients going back to prostitution after taking ARVs] [fear of receiving bad comments because of HIV disclosure] [fearto disclose to church members] [friends may disclose your HIV status to your partner before you do] [Friends shun a friend who is HIV positive] [Gossip about HIV sufferers] [grand daughter was ill treated by grandparents because of her HIV status] [hindrance- finding patients in a helpless position that people cannot support] [hindrance- HIV sufferers would be stripped their role] [Hindrance- HIV/AIDS stigma] [hindrance- lack of love and jealous from neighbours] [hindrance- some HIV sufferers don't want visitors] [hindrance- some patients don't want visitors] [Hindrance- some relatives abandon patients and call for us (home based carers)] [HIV is only caused by unfaithfulness] [HIV is shameful- people will know that you have been promiscous] [HIV patients don't disclose their HIV status] [HIV patients have own cuttlery] [HIV stigma cannot be eradicated] [HIV sufferers are considered to be mental health sufferers] [HIV sufferers are labelled as promiscuous] [HIV sufferers are responsible for their action] [HIV sufferers don't disclose their status people just suspect] [HIV was labelled as a disease for the prostitute] [internalised stigma] [men abandon wife when they become ill first looking for other women] [men shouted by wife when they are HIV positive] [Neighbours will gossip, laugh at HIV sufferers and discriminate them] [obstacles-some carers abandon patients] [Once men show AIDS symptoms all the respect is gone] [people despise HIV sufferers] [people gossip about HIV sufferers] [people in church announce that they have some-one sick not a HIV sufferer] [people refuse to share a beer with a person suspected to be HIV positive] [people say they have someone not feeling well and people will suspect that the person might be HIV positive] [People stigmatise HIV sufferers through gossiping] [People suspect that someone is HIV positive when the see the symoptoms of hair falling, the skin looks softor aclamor for more food at gatherings] [People who are promiscous are the ones that get infected with HIV] [People who disclose are those that are bed ridden and not the ones that are active] [people who have extra marital affairs should pay] [People with HIV are more likely to suffer from T.B] [Realtives taking care of HIV sufferers disclose HIV sufferers status to other people] [Reasons for non- disclosure- people laugh at HIV sufferers] [segregation in church] [some care givers give up their duties for vistors to take over] [some care givers pretend to treat patients well when people visit] [Some HIV patients don't have anyone to take care of them] [some HIV sufferers disclose to family and not to outsiders therefore] [Some HIV sufferers have mental health problems] [some relatives abadon HIV sufferers] [stigmatising of HIV sufferers] [the shona name is fierce and heavy- shuramatongo] [To say a person has AIDS it means their days are numbered] [victim blaming] [warned a girl against dating a HIV widower] Quotation(s): 218

## Code Family: turning to church for help

Created: 11/01/2011 15:18:47 (Super)

Codes (7): [factors facilitated- wanted the church to take a lead stance in combating HIV/AIDS] [HIV patients seeking

helping in church] [People coming to church in search of help] [People turn to the church for help after they get infected] [Source of hope- trust the Lord] [Trusting God] [Use bible teachings to refrain adultery] Quotation(s): 7

# **PUBLISHED PAPER**