BEYOND COMPASSION TOWARDS JUST ENGAGEMENT

Exploring Moral Exclusion of People Living with HIV in Local Church Contexts in Chitipa District of Malawi

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DEDICATION

To the memory and legacy of

Prof. Steve de Gruchy

An exceptional teacher and mentor. A teacher *par excellence* who encouraged and challenged his students not to settle for easy answers but to stretch ourselves and cultivate new and different ways of seeing. This study is a product of that challenge and encouragement.

To

Bishop David Zac Niringiye

A mentor, friend and family. You live life with conviction and passion. Your continued quest for justice for the marginalized inspires me to do the same. You encouraged me to undertake this journey and so I dedicate this study to you. Maybe in these pages you will find some helpful ideas for your new mission to advocate for social justice in Uganda.

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DECLARATION

Submitted in fulfilment of the requirements for the degree of Doctor of Philosophy, in the Graduate Programme in Theology and Development,

University of KwaZulu-Natal, Pietermaritzburg, South Africa.

I, Stella Joy Nagitta Kasirye, declare that:

- 1. The research reported in this thesis, except where otherwise indicated, is my original research.
- 2. This thesis has not been submitted for any degree or examination at any other university.
- 3. This thesis does not contain other persons' data, pictures, graphs or other information, unless specifically acknowledged as being sourced from other persons.
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- a. Their words have been re-written but the general information attributed to them has been referenced;
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16th February 2016

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Name of Supervisor

EDITING CERTIFICATION

We the undersigned declare that we have abided by the language editing policy of the School of Religion, Philosophy and Classics in the College of Humanities, University of KwaZulu-Natal. We also declare that earlier forms of this dissertation have been retained should they be required.

Lou Levine, Language Editor

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ABSTRACT

Four decades into the AIDS pandemic, stigmatization and discrimination of People living with HIV is highlighted annually as a leading obstacle in mitigating the impact of the pandemic. This persistence is occurring within a context of global commitment to getting to zero stigma. Historically, the church has contributed greatly in changing the trajectory of the AIDS pandemic at both a micro and macro level and is expected to play a pivotal role in making the Zero Discrimination Goal a reality. Yet, the church is still ranked among the most stigmatizing institutions.

While there is extensive research on HIV and AIDS related stigma and discrimination, there is a shortage of context-specific empirical studies that have applied stigma reduction strategies; particularly so within religious spaces. In spite of the agreement in the literature that stigma and discrimination are socially constructed and hence need to be understood within the broader context of society, power, and culture, current dominant research models and conceptualizations tend to be individualized and stereotyped with the discourse occurring within disciplinary silos.

Applying Pierre Bourdieu's social cultural theory, Albert Bandura's social cognitive theory and Foucault's theory of knowledge and power within a liberation theology framework, this study examined the extent to which the moral exclusion of people living with HIV (PLWHIV) from full participation in church life impedes the global commitment to eliminate stigma and discrimination and impacts on the church's calling to be an agent of justice in the response to the AIDS pandemic.

The storied experiences of moral exclusion of PLWHIV gathered through in-depth interviews, focus group discussions and participant observation, within local church contexts in Chitipa District of Malawi, are critically analysed using a social structural conceptualisation of stigma. Hence the study explored the social and structural factors contributing to the legitimation of persistent moral exclusion of PLWHIV from full participation in church life and identified liberating theological resources within the church setting that could become part of a framework for praxis against moral exclusion.

The findings revealed that the nature of stigma in the church settings takes on moral, social, cultural, spiritual and economic dimensions. Gender inequalities, patriarchy, symbolic power, symbolic violence, religious prejudice and moral policing were structures of injustice linked to the reproduction and legitimation of stigma within the Chitipa Church setting. Another revelation from the portraits was that the collective efficacy and solidarity was resulting in the creation of authentic communities emerging into new ways of being and doing church.

The study concludes that moving the discourse on HIV and AIDS related stigma and discrimination from the compassion towards the justice framework warrants the interrogation of the power structures underlying moral exclusion, through inter- disciplinary dialogue. That from within its own polity, the church has access to theological resources that have the potential to move the discourse on stigma and discrimination into the justice space. These liberating theologies of mission, leadership, community, people and culture provide a framework that the church can use either to pursue an intentional destigmatizing culture or measure the extent to which its structures legitimate the moral exclusion of PLWHIV.

As a contribution to the lack of stigma reduction tools, the study developed a liberative hermeneutic for missional justice that the church could adopt to create an enabling environment within which a culture of inclusion, participation and just engagement can be nurtured.

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GLOSSARY OF ACRONYMS AND ABBREVIATIONS

ABC - Abstain, Be faithful, Use a condom

AIC- African International Church

AOG - Assemblies of God

ART- Anti-retroviral treatment

ARV – Anti-retroviral

CAP- Church of African Presbyterian

CCAP - Church of Central African Presbyterian

CCAP- Church of Central African Presbyterian

COWLHA - Coalition of Women Living with HIV and AIDS in Malawi

FGD - Focus Group Discussion

G.T.Z UNAIDS – Getting to Zero

HECAWLP - Health Care Workers Living Positively

HIV/AIDS – Human Immune-Deficiency Virus/Acquired Immune Deficiency Syndrome

JONEHA - Network of Journalists with HIV

LGBT - Lesbian, gay, bisexual, transgender

MANERELA - Malawi Network of Religious Leaders Living with or Personally Affected by

AIDS – Acquired Immune Deficiency Syndrome

MANET - Malawi Network of People Living with HIV and AIDS

MIAA - The Malawi Inter Faith AIDS Association

MOH – Ministry of Health

MRTCG - Movement for the Restoration of the Ten Commandments of God

MSM - Men who have sex with men

N.R.S.V - New Revised Standard Version

NAC- New Apostolic Church

NAPHAM - National Association of People Living with HIV and AIDS in Malawi

PEPFAR - President's emergency plan for AIDS relief

PHA- Pentecostal Holiness Association

PLWHA- People living with HIV/AIDS

PLWHIV- People Living With HIV

RCC- Roman Catholic Church

SADC-Southern Africa Development Community

SDA - Seventh Day Adventist Church

TAs - Traditional Authorities

TASO – The AIDS Support Organisation

TCN - Tubepoka Church Network

UCLA – University of California Los Angeles

UNAIDS – United Nations Agency Responsible for HIV and AIDS

WCC – World Council of Churches

WHO – World Health Organisation

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GLOSSARY OF KEY TERMS AND CONCEPTS

Moral Exclusion

Moral exclusion occurs when individuals or groups are perceived as outside the boundary in which moral values, rules, and considerations of fairness apply. Those who are morally excluded are perceived as nonentities, expendable, or undeserving. Consequently, harming or exploiting them appears to be appropriate, acceptable, or just.

Stigma

Stigma has been defined as that part of identity that has to do with prejudice. Stigma has to do with isolating, labelling, rejecting, marginalizing and categorizing people by ascribing to them negative values. The negative value ascriptions are used as justification for the isolation. Stigma can be elusive and subtle in that it has to do with beliefs, perceptions and attitudes

Internalised Stigma

This refers to feelings of shame, embarrassment and guilt that people living with HIV have in relation to their sero-status. Unchecked these feelings may result in self hatred.

Discrimination

Discrimination the outward expression of stigma. Prejudices directed at People living with HIV.

Compassion

The ability to suffer with those in difficult life situations that often results in action on their behalf to change their situation.

Just Engagement.

Opening up the church space without prejudice to allow everyone including PLWHIV to participate in the life of the church, use their potential, gifts and skills to contribute to the ministry of the church

CHAPTER ONE: Introduction and Background to the Study

Moral exclusion occurs when individuals or groups are perceived as outside the boundary in which moral values, rules, and considerations of fairness apply. Those who are morally excluded are perceived as nonentities, expendable, or undeserving. Consequently, harming or exploiting them appears to be appropriate, acceptable, or just (Opotow, 1990, p. 1).

1.0 Introduction

The purpose of this study was to examine the extent to which the moral exclusion of People living with HIV (PLWHIV) from full participation in church life impedes the global commitment to eliminate stigma and discrimination or 'Getting to Zero Stigma' (G.T.Z. UNAIDS, 2010); and impacts on the church's calling to be an agent of justice in the response to the AIDS pandemic.

The "Getting to Zero Stigma" Vision for 2011-2015 was part of a bigger campaign by the Joint United Nations program on HIV and AIDS (UNAIDS) aimed at breaking the upward trajectory of the global AIDS pandemic. This warranted decisive action and a ground-breaking vision that would lead to zero new infections, zero discrimination and zero AIDS-related deaths by the year 2015 (G. T. Z. UNAIDS, 2010, p. 8). The zero discrimination aspect of the campaign was for advancing human rights and gender equality within the HIV and AIDS global response. The campaign was focused on ending HIV and AIDS related stigma and discrimination, gender inequality and the violence against women and girls that drive the risk and vulnerability of HIV infection by keeping them from accessing prevention, treatment, and care and support services. Strategies included enacting laws, policies and developing programs to create legal environments that would protect people from infection and increase their access to justice (G. T. Z. UNAIDS, 2010, p. 10). The church had also

added their commitment to the global community. At the first ecumenical conference by African church leaders on HIV and AIDS in Nairobi in 2001, those gathered acknowledged that the most powerful contribution the church could make to combating HIV transmission was the eradication of stigma and discrimination. They recognized the urgency of the situation and agreed that for them to play their distinctive role, it was critical for them to rethink their mission and transform their structures and ways of thinking (Patterson, 2005). The Anglican primates gathering a year later to deliberate on the AIDS pandemic made the commitment below.

We raise our voices to call for an end to silence about this disease – the silence of stigma, the silence of denial, the silence of fear. We confess that the church herself has been complicit in this silence. When we raised our voices in the past, it has been too often a voice of condemnation. We now wish to make it clear that HIV/AIDS is not a punishment from God. Our Christian faith compels us to accept that all persons, including those who are living with HIV/AIDS, are made in the image of God and are children of God (Statement of the Anglican Primates on AIDS, Canterbury, April 2002.)

A UNAIDS report with regards to progress made in relation towards zero discrimination stated:

Three decades into the response to the AIDS pandemic, people living with HIV continue to face stigma and discrimination. HIV related stigma has damaged the social and psychological wellbeing of many people living with HIV. It is associated with low social support, poor physical and mental health and a poorer quality of life. The people living with HIV stigma index shows that people living with HIV experience unemployment rates three times higher than national employment rates — 37.7% among people living with HIV compared to 11.7%. Reasons reported for unemployment include stigma, discrimination, restrictive practices and ill health. Evidence from the people living with HIV stigma index demonstrates the significant impact of stigma and discrimination on the health and ability of people living with HIV to be active members of their community. On average, one in eight people living with HIV report being denied health services and one in nine is denied employment because of their HIV-positive status. People living with HIV who are members of key populations face a double stigma because of their sexual orientation, gender identity, drug use or engagement in sex work. Their HIV-positive status increases their risk of experiencing violence, being denied services or being excluded from community activities (UNAIDS, 2014).

The rationale for this study derives from the paradox presented by the existence of remarkable global political will to end stigma and discrimination as embodied in the UNAIDS vision of Getting to Zero; the desire of the church to contribute to the global goal to end stigma and discrimination as expressed in the Nairobi, Bangkok and Namibia declarations; and yet the very little reported progress with regards to combating stigma and discrimination. This study sought to understand the factors underlying persistent stigma and discrimination that leads to the moral exclusion of PLWHIV, using Pierre Bourdieu's social cultural theory within the framework of liberation theology.

The study drew on the experiences of PLWHIV in the Tubepoka Churches Network (TCN) of Chitipa District in Malawi as a case study, analysing the factors underlying exclusion of PLWHIV in church contexts and demonstrated how they contribute to the slow progress with regard to the global goal to eliminate stigma and discrimination by 2015 and impact on the church's calling to be an agent of justice in the global response to HIV and AIDS. Moving beyond the deficit model of analysis towards an asset-based one, church resources for liberating qualities with innate potential to foster inclusion were also examined. It was posited that these liberating qualities, when applied to practice, can work as a deterrent to moral exclusion, serve as a useful map in navigating the roadblocks on the journey and hasten progress towards the global vision of 'Getting to Zero'.

This first chapter offers a broad introduction to the study from various angles. First, it provides a contextual focus for the study. Second, it locates the study within the ongoing broader discourse on HIV and AIDS related stigma and discrimination in Christian church contexts. This location prefaces the rationale for the study. The introductory chapter also presents the critical questions and objectives that have guided inquiry, analysis and

theorization. The chapter discusses and provides justification for the choices of theoretical frameworks as well as methodology. Finally, the chapter outlines the content of the whole study.

I will now outline the critical question as well as the objectives that guided this inquiry.

1.1 Critical Question

To what extent does the moral exclusion of PLWHIV from full participation in church life impede the global commitment to eliminate stigma and discrimination and impact on the church's calling to be an agent of justice in the global response to HIV and AIDS?

1.2 Sub Questions

- 1. What do experiences of PLWHIV in the Chitipa Tubepoka Church Network tell us about the extent and nature of moral exclusion in church settings?
- 2. What are the links between moral exclusion of PLWHIV in church settings, the theologies which undergird these exclusions and structures of injustice?
- 3. How can liberating theologies within the Church be harnessed to hasten the progress from compassion towards just engagement of PLWHIV in church life?

1.3 Objectives

- 1. To present a critical profile of the portraits of moral exclusion in church contexts from the experiential perspectives of PLWHIV.
- 2. To analyse the links between moral exclusion of PLWHIV in church settings, the theologies which undergird these exclusions and structures of injustice.

3. To interrogate church resources for liberating theologies with potential for fostering inclusion and facilitating the just engagement of PLWHIV in church life.

1.4 Rationale for the Study

The rationale for this study derives from the paradox presented by the existence of global political will to end stigma and discrimination as embodied in the UNAIDS vision of Getting to Zero (G. T. Z. UNAIDS, 2010), the church's willingness to use its potential and contribute to the global goal to end stigma and discrimination and yet a seeming inability or reluctance to address the structural forms of moral exclusion within the church. Before locating the study in ongoing discourse, it is critical that we conceptualize the terms stigma and discrimination as they are used in this study and their connection to moral exclusion.

1.5 Conceptualizing HIV and AIDS Related Stigma as Moral Exclusion

While it is not disputed that stigma and discrimination are two different concepts, when it comes to HIV and AIDS related discrimination, the two are very hard to separate and therefore, in this study I used them together (see Ncama et al., 2008); (Greeff et al., 2008); (A. N. Miller & Rubin, 2007).

Parker and Aggleton (2003) were among the first scholars to conceptualize HIV and AIDS related stigma as a social process. Departing from Goffman's concept of stigma as a 'spoiled identity', they conceptualize stigma and discrimination from a sociological perspective that takes into consideration the structural dimensions of the context (R. Parker & Aggleton, 2003). They called upon those that would research HIV and AIDS related stigma and discrimination to move beyond the limitations of the psychological and behavioural models, influenced by Goffman's definition to something broader. The current dominant models in

research on stigma and discrimination tend to individualize and stereotype stigma and discrimination and keep it masked.

We need to reframe our understanding of stigmatization and discrimination to conceptualize them as social processes that can only be understood in relation to broader notions of power and domination. In our view stigma plays a key role in producing and reproducing relations of power and control. It causes some groups to be devalued and others to feel that they are superior in some way. Ultimately, therefore, stigma is linked to the workings of social inequality and to properly understand issues of stigmatization and discrimination requires us to think more broadly about how some individuals and groups come to be socially excluded and about the forces that create and reinforce exclusion in different settings (R. Parker & Aggleton, 2003, p. 16).

Stigma has been defined as that part of identity that has to do with prejudice (Parker & Birdsall, 2005, p. 5). Stigma has to do with isolating, labelling, rejecting, marginalizing and categorizing people by ascribing to them negative values. The negative value ascriptions are used as justification for the isolation. Stigma can be elusive and subtle in that it has to do with beliefs, perceptions and attitudes. Discrimination, on the other hand, could be described as the outward expression of stigma. Prejudices directed at People living with HIV have often found social expression in practices such as denial of scholarship or employment opportunities. In church settings People living with HIV have been excluded from leadership positions because they are considered 'immoral'. One of the objectives of this study is to profile the enactment of stigma and discrimination within a church context.

Stigmatization and discrimination of People living with HIV culminates in moral exclusion.

According to Opotow,

Moral exclusion occurs when individuals or groups are perceived as outside the boundary in which moral values, rules, and considerations of fairness apply. Those who are morally excluded are

perceived as nonentities, expendable, or undeserving. Consequently, harming or exploiting them appears to be appropriate, acceptable or just (Opotow, 1990, p. 1)

Moral exclusion is to a certain extent an oxymoron. Moral connotes virtue, justice, and honour. On the other hand, exclusion is about leaving others out, denying them access. So in essence it is immoral to exclude others on the basis of rules that we consider fair whilst for the excluded those rules are not only unfair, but unjust as well. However, in the HIV and AIDS context, the term is very appropriate because People living with HIV are excluded in church settings on the basis of 'moral grounds'. According to Opotow et al. (2005), each contextual occurrence of moral exclusion is different, but all bear the following characteristics:

Seeing those excluded as psychologically distant from and unconnected with oneself; lacking constructive moral obligations towards those excluded; viewing those excluded as nonentities, expendable and undeserving of fairness and community resources that could foster their well-being and approving of procedures and outcomes for those excluded that would be unacceptable for those inside the scope of justice (Opotow, Gerson, & Woodside, 2005, p. 305).

'Moral exclusion' combines both concepts of stigma and discrimination. Hence, the three concepts are used interchangeably throughout this study.

1.6 Theoretical Framing and Methodology

The social structural nature of HIV and AIDS related stigma and discrimination as described above warrants the use of a theoretical framework and methodology that allows for interrogation of the power structures underlying moral exclusion, creates space for interdisciplinary dialogue and provides appropriate lenses for theological reflection. Liberation theology, used together with Pierre Bourdieu's social cultural theory, provides the theoretical framing for this study. Pierre Bourdieu's work in social cultural analysis provides a very useful theoretical frame, because it has to do with the role of power and culture in the

reproduction of systems hierarchy and social domination over time. Social theology methodology is used to provide a roadmap for analysis. Bourdieu was particularly interested in the study of those contexts where the domination of people through the reproduction of social hierarchies fuelled by power and culture goes on for long periods of time, without being questioned by those oppressed through those systems and condoned by the perpetrators, wittingly or unwittingly. One of the concerns of this study is that very early in the AIDS pandemic history, stigma was identified as a key driver of increased infection (see Bond, Chase & Aggleton, 2002; Mayer & Beyrer, 2007; Myer, Morroni, & Susser, 2003). Yet four decades into the pandemic stigma is still pointed out as the major hindrance to progress in making the pandemic history, pointing to the possibility of legitimating factors within the same contexts where efforts are being made to eliminate it. With the help of Bourdieu's social cultural lenses, this study has examined those factors that legitimize moral exclusion within church contexts and hence "put roadblocks on the road to Zero".

Moral exclusion, as has been pointed out earlier in this chapter, is unjust and dehumanizing, and this study therefore approaches it from a liberation platform for theological reflection and methodology. Jose Miguez Bonino has described liberation theology processes as a reflection process that begins with the participation of marginalized people in the struggle for liberation through a critical analysis of the realities of their struggle from the perspective of their faith. This process culminates in the development of a framework of theological interpretation that strengthens and clarifies their participation in the struggle (Bonino, 1975). Historically, liberation theology has been a helpful and enabling framework for those oppressed to become active agents in their own liberation, overcome oppressive situations, become creators of their own destinies and develop their own theology in the process. This

study leverages this advantage. Liberation theologies are contextual, but they all share the same methodology. Since this study is seeking to address stigma and discrimination, a social phenomenon that is influenced by social and cultural power structures within a religious context, the use of social theology methodology was deemed the most appropriate. Social theology methodology derives from liberation theology. In 'Tentative Reflections on Religion, Rationality and Research in Social Theology,' de Gruchy (2006) outlines social theology methodology in four critical steps. These are: faith commitment, social analysis, theological reflection and strategies for action (de Gruchy, 2006b) These critical steps are further elaborated in the second chapter on Theoretical Frameworks. This methodology contributes to bridging the methodology crisis gap. This gap is further discussed in the next segment. The choice of this methodology was deliberate, in that it allowed for interdisciplinary dialogue to happen as part of the research process. The significance of this study is partly in its contribution to bridging some of the research gaps identified by key scholars on HIV and AIDS related stigma and discrimination. For this study I have chosen to contribute to several gaps as identified by R. Parker & Aggleton, (2003), Patterson (2011), Manda (2011) and de Gruchy (2011). These gaps are articulated below.

1.7 Significance of the Study: Narrowing the Gaps

The gaps in research on HIV and AIDS related stigma and discrimination, as identified by de Gruchy, Patterson, Parker, Aggleton and Birdsall, call for the need to pay attention to four critical areas that form the core of this study: the methodological challenge; a shortage of context-specific empirical studies; a broader conceptualization of stigma and discrimination to reflect its interface with cultural and power structures and the need for inter-disciplinary

dialogue to inform discourse. I will discuss each gap and point out how this study seeks to contribute to the narrowing of those gaps.

1.7.1 The Conceptualization Gap

Richard Parker and Peter Aggleton, in their conceptual framework for the understanding of stigma and discrimination and its implications for action, propose a new research agenda. They propose that this new agenda needs to be undergirded by a different conceptualization of stigma – an understanding of stigma as "social processes linked to the reproduction of inequality and exclusion" (R. Parker & Aggleton, 2003, p. 19). They highlight the need for 'context specific empirical investigations' that use this broad conceptualization of stigma and discrimination and interrogate its underlying structures. This study seeks to contribute to that research agenda within the context of the church.

1.7.2 The Ecclesiology Interface Gap

Patterson, a leading scholar on HIV and AIDS related stigma and the church, points out that "despite the recent emphasis on AIDS related stigma, there has been relatively minimal research into the interface between stigma and ecclesiology" (Patterson, 2011). She proposes several reasons behind this lack of research. One of those reasons central to this study is the unwillingness to ask painful and challenging questions, because they present a threat to the identity of the church. According to Patterson, "researching the interface between stigma and ecclesiology would involve questioning beliefs, teachings, traditions and practices upon which the institutional identity of the church has been constructed" (Patterson, 2011). Patterson cautions that the interface between stigma and ecclesiology requires an 'interdisciplinary conceptualization of stigma that can provide a secure base for theological reflection.' She proposes that this can be done using context-specific case studies.

Case studies that offer a denser and more nuanced understanding of what is going on in situations of stigmatization in which all those concerned have the chance to articulate their thoughts and fears and have them taken seriously. In religious institutions in particular, there is a disconnection between what happens in theory and what people actually do or believe in their private lives. This is in effect, a stigmatization of reality. A stigma tool which engages with this disconnection as well as with individual attitudes is sorely needed (Patterson, 2011, pp. 360-361).

While the goal of this study is not to produce a "stigma tool", it takes on Patterson's challenge to contribute to the process by providing a case study that will help with the understanding of the nature of HIV and AIDS related stigma as it occurs within a specific church context. Given the greater need for such case studies within faith communities, this study uses the experiences of People living with HIV with stigma and discrimination within the local church context in Chitipa District of Malawi as a case study. The Chitipa church context provides the social system that this study uses to explore stigma as a social process involving interactions between culture, power, and tradition in a religious institution.

1.7.3 The Justice and Theological Perspective Gap

Lucinda Manda, advocating for a theo-ethical framework for the HIV and AIDS context, emphasizes the need for the move beyond compassion into the justice sphere, but recognizes that "while much research has been done on justice within the political and social sciences, there remains a need for further reflection from a religious perspective" (Manda, 2011, p. 210). This study sought to move the conversation around the engagement of PLWHIV within the church context from the comfortable zone of compassion towards the more complicated yet critical sphere of justice.

1.7.4 The Methodology Gap

De Gruchy contends that stigma and discrimination are among the most theologized issues. At the same time, he points out that most of the discourse around HIV and AIDS related stigma has been mono-disciplinary and that the emergence of a theology that enables us to hold together the all-encompassing nature of the pandemic and its relationship to fundamental themes such as gender, poverty, globalization, ecological crises, climate change, African identity, sexuality and racism has yet to be seen" (De Gruchy, 2011, p. 188). He proposes that to embrace the wide scope of the AIDS pandemic and to avoid fragmentation of the experience of PLWHIV, it is imperative that the theological methodology to guide discourse around HIV and AIDS related issues should incorporate insights from the social sciences such as sociology, psychology and anthropology. To narrow this gap, this study used liberation theology alongside Bourdieu's social cultural theory. These gaps not only form the core purpose of this study but also define its objectives and drive the critical questions of inquiry clearly articulated earlier in the chapter.

1.8 Background and Context

I will now proceed to give a contextual background to the study. For this I have chosen to use a historical chronicle. McDonagh (1994), theologizing about AIDS, stresses the importance of chronicling the pandemic as part of the reflection process. His argument is that because theology happens in time, to critically analyse the HIV and AIDS stigma and discrimination drivers on the global scene within the global church and the African church and specifically Malawi, it is critical to chronicle the AIDS pandemic in time (McDonagh, 1994). Chronicling helps to locate the study within the wider context of the global discourse on HIV and AIDS as well as its influence on the Malawi local context. Tracing the

progression of the global response is critical to isolating the political, social, religious economic and cultural factors that have impacted the local expressions of moral exclusion in the study context. The chronicle also serves to connect the global and the Malawi discourses on HIV and AIDS related stigma and discrimination. I will begin the chronicle from the progression of the global response, proceed with the African church and end with Malawi.

1.9 A Chronicle in Time

In 2006, at the International Conference on HIV and AIDS in Toronto, Peter Piot, the erstwhile Executive Director of UNAIDS, lamented the lack of progress in combating HIV and AIDS related stigma and discrimination:

Since the beginning of the epidemic, stigma, discrimination and gender inequality have been identified as major causes of personal suffering, and as major obstacles to effective responses to HIV. Yet there has never been serious political and programmatic commitment to doing anything about them. All these efforts have been relegated to the bottom of AIDS programs, together with human rights, and often with no funding attached to them. Piot calls upon the world community to make stigma and discrimination explicit programmatic priorities (UNAIDS, 2006).

As part of the commemoration of World AIDS Day in 2010 the Joint United Nations

Program on HIV and AIDS (hereinafter referred to as UNAIDS), launched a five year vision
to address the HIV and AIDS pandemic and code-named it 'Getting to Zero' (G. T. Z.

UNAIDS, 2010). The strategy was a bold and courageous casting of a fresh vision that
would help check the trajectory of the AIDS pandemic which up to that pivotal point was
moving in the upward direction. The vision was a commitment to work towards: "zero new

HIV infections, zero AIDS-related deaths and zero discrimination" (HIV/AIDS, 2010; G. T.

Z. UNAIDS, 2010). Launching the Strategy, the UNAIDS Executive Director, Michele

Sidibe, implored all UNAIDS partners to decisively move from slogan to action in the spirit
of social justice and human dignity. Two years after launching the 'Getting to Zero'

campaign, the Executive Director of UNAIDS introduced the 2012 Global AIDS report on a very hopeful note. He hailed the milestones that had been achieved with regards to the bold vision to eliminate the HIV and AIDS pandemic. Significant progress had been made in reducing new infections and AIDS related deaths, but on reducing stigma and discrimination much was yet to be done.

The pace of progress has quickened. Increments of achievements that once stretched over many years are now being reached in far less time. In just 24 months, 60% more people have accessed lifesaving HIV treatment, with a corresponding drop in mortality. New infection rates have fallen by 50% or more in 25 Countries – 13 of them in Sub-Saharan Africa.... Yet it is too early to congratulate ourselves; AIDS is not over. In many countries, people living with and affected by HIV still face stigma, discrimination and injustice (UNAIDS, 2012).

The 2013 Global Situation Report also highlights stigma and discrimination as persistent obstacles to effective HIV and AIDS responses all over the world, intimating that we have not made much progress towards the zero stigma goal. Perhaps the most impassioned plea to the world to tackle HIV and AIDS related stigma more decisively is best reflected in the UNAIDS executive director's press release on Human Rights Day in 2013. Michel Sidibe reminded the world of the need to take courage and make a commitment to end the AIDS pandemic. He reiterated that this dream is achievable if we can make it a global goal to defend the human rights of all, especially those living with HIV and AIDS. We cannot separate ending the AIDS pandemic from the fight for human rights.

I believe we can end the AIDS epidemic by 2030. This is a goal we should all aspire to—but it can only happen if the human rights of all people vulnerable to and living with HIV are realized. HIV has taught us that health and human rights are intricately linked and that we need to protect and respect human rights and be courageous enough to confront society's wrongs. How can the world accept that some people have access to safety and services while others are excluded because of legal and social status, income or sexual orientation? Even where HIV services exist, punitive laws and law enforcement can stand as implacable barriers. We must reject this double standard wherever we encounter it. Human rights must be respected and fulfilled for everybody. People who are suffering, who are underground or who are hiding do not deserve silence—they deserve justice. People living

with and vulnerable to HIV have fought for and, in many places, won their human rights—the rights to non-discrimination, to participation, to health in the form of HIV prevention and treatment, and to life. They have turned traditional development on its head by demanding "nothing about us without us", refusing to be passive beneficiaries, demanding to be themselves agents of change. But millions more do not benefit from health or human rights. Achieving our vision of zero new HIV infections, zero discrimination and zero AIDS-related deaths will demand human rights. Everyone has equal dignity and value, and everyone deserves the right to health and to life. Let us build on Nelson Mandela's legacy and make it the future—through "human rights for all." Ending the AIDS pandemic is a matter of human rights (Sidibé, 2013).

The UNAIDS special report on Africa observes that "AIDS thrives on stigma and spreads where individuals are marginalized or wherever society forces a group of people to live in shame and hiding" (Yisma et al., 2014). The church (generally speaking) has been one of these places that have forced people to live in shame and hiding. While recognized for its significant contribution in mitigating the impact of HIV and AIDS, scholars have noted that "the church has often participated in perpetuating stigma and discrimination through its structures" (W. Parker & Birdsall, 2005). Having looked at the progression of the global concern with regards to the slow response in addressing HIV and AIDS related stigma and discrimination, I will now examine the response of the global church community, given that this study is located within a church setting.

1.10 The Church Response on HIV and AIDS Related Stigma and Discrimination

In 2001, at the African Church Leaders Gathering convened by the World Council of Churches in Nairobi, the leaders acknowledged the role churches had played in driving stigma and discrimination through their structures. At the same meeting, they also recognized that this is one area where the church could play a pivotal role.

Our tendency to exclude others, our interpretation of the scriptures, and our theology of sin have all combined to promote the stigmatization, exclusion and suffering of people with HIV and AIDS. This has undermined the effectiveness of care, education and prevention efforts and inflicted additional suffering on those already affected by HIV.... For the church the most powerful contribution we can make is the eradication of stigma and discrimination (WCC, 2001).

The rationale for this study arises from this paradox. On the one hand, there is global political will to address the issue of HIV and AIDS related stigma. There is recognition from the church leadership that they can play a pivotal role in making the Zero Discrimination Goal a reality. Yet, the church is still ranked among the most stigmatizing institutions. At the same time, the church ranks highly among the institutions that have contributed greatly in changing the trajectory of the AIDS pandemic at both a micro and macro level. Moving from the global commitments and response, I will now chronicle the Malawi response to the AIDS pandemic, through the four presidential terms since the onset of the AIDS pandemic in the country.

1.11 1985-1994: Silence, Stigma and Feminization of AIDS

Malawi's first AIDS case was reported in 1985. However, it was not until 3 years later in 1988 that the National AIDS Control Program was put in place to coordinate a national response. The first country AIDS strategy was put together in 1989, five years after the first case was identified. At this point in Malawi's history, the country was led by President Hastings Kamuzu Banda. He has gone down in history as Malawi's most puritanical leader. Banda was a staunch Presbyterian and he made that a state religion. During his time it was illegal for females to wear trousers and it was a punishable offence. That was just one example of the extreme puritanical laws. Such laws were believed to be one of the ways of preserving Malawi's culture and traditions and guarding against the negative influence of

what was regarded as 'western immorality'. There was no national television and sexuality was treated as a taboo subject not to be discussed in public spaces. Information going out to the available media was highly censored. A human rights report on Malawi summarized the Malawi political situation as below:

Malawi is proof that repression can work. Decades of one party rule and restriction on the free flow of information have ensured that this small Central African nation is familiar to few in the outside world beyond a small circle of specialists.... Its stability has been bought at a terrible cost of human lives snuffed out or forced to endure years of detention without trial. Intellectual life can scarcely survive the dead hand of the censor and political life is non-existent outside the omnipotent ruling party.... Religious minorities are also targets of official discrimination...Banda's quarter century has been idiosyncratic in the extreme. Malawi is a country which imposes prison sentences on men who wear their hair below the collar or wear flared trousers and on women who wear trousers or their skirts above the knee. Hundreds of books, films and records have been banned (Carver, 1990, pp. 1,4,17).

AIDS was treated as a taboo subject, since it was closely associated with sex outside the sacred confines of marriage. The only way of gauging the extent of the spread of HIV at the time was through antenatal clinics where routine testing was done to pregnant mothers when they went for antenatal check-ups. It is estimated that during that period, based on statistics from a few urban antenatal clinics, "HIV prevalence among pregnant mothers rose from 2% to 30%" (Stanecki, 1994, p. 5) A study on the changing patterns of mortality at Queen Elizabeth Hospital in Blantyre showed a 37% increase in mortality due to HIV and AIDS, from 13% in 1972 to 49% in 1992 (Harries & Mvula, 1994).

This chronicle of the pandemic is relevant to the study for two particular drivers of stigma and discrimination. Very early in the Malawi AIDS pandemic, silence drove infection.

Stigma was attached to the pandemic because it was associated with sexual immorality and other "immoral" behaviours and this was from the church point of view, as overtly communicated by the presidency. It was also here that the seeds of stigma against women

were sowed. The statistics were based on antenatal tests and so women were accused of introducing AIDS in the families and then passing it on to the unborn babies and infecting their husbands. Judgment had been passed by a nation in denial. In 1994 there was a change of government, marking the end of one party rule. The turn of events would also influence the trends in the AIDS pandemic in Malawi.

1.12 1995-2005: Openness, Liberality, Moralization and Linkages with Poverty

As part of his inauguration speech in 1994, President Bakili Muluzi publicly acknowledged the existence of HIV and AIDS in the country and called for a more strategic response. The right to freedom of speech was reinstituted. Muluzi was Muslim and in sharp contrast to the puritanical Presbyterian Banda, public discourse on matters of sexuality was uncensored. This created a more conducive environment for a countrywide education campaign. The media was liberalized and Malawi became a multiparty democracy.

Between 2002 and 2003, Malawi suffered a severe famine. Famine early warning systems analysts cited AIDS as one of the major contributing factors to its severity. The silence in the early phase of the pandemic drove it underground. An increasing number of people were being diagnosed with HIV, becoming chronically ill and not being able to engage in economic activity. The lack of information about the pandemic led to speculation as to the cause. It was quickly associated with witchcraft. Already poor families spent their meagre resources moving from one traditional healer to another in search of a cure.

The "disease burden", as it was then called, was taking its toll on the already frail health infrastructure. Statistical reports attribute 70% of the hospital deaths in government health

facilities in these years to AIDS related illnesses. A World Health Organization study done during this phase ranked AIDS as a leading cause of death and that it had overtaken malaria (Bowie, 2007). Health practitioners were handling increasing numbers of patients and there was ignorance and fear. Patients would be abandoned by families at the health facilities and the health practitioners were not in a position to offer much. Stigma surrounding AIDS had taken root so deeply in the communities that people would remain in hiding until they were almost dying before they would come to the health facilities.

In 1999, 13 years after AIDS was first identified in Malawi, the church came on board. It was at a very big conference named "Breaking the Silence". Unfortunately, the church's "coming out" was also marked with a strong anti-condom declaration. I remember facilitating a church leaders' discussion on the topic and one of the leaders boldly told me: "Condoms are of the devil and so is everyone who uses them." The church became actively involved in education campaigns, but the message was about abstinence and faithfulness as the only ways to stem the pandemic. Many churches set up "AIDS ministries" in their local churches to care for the sick and look after orphans. The technical working group on faith communities and AIDS was established as a platform to mobilize for a faith-based response. Non-governmental organizations with Christian origins launched major initiatives. Among these were World Relief Malawi's mobilizing for life and World Vision's hope initiative. In 2001, following the development of a new national AIDS strategy, the national AIDS commission was set up to replace the failing national AIDS control program. Around 2003, the erstwhile American President, George W. Bush's President's emergency plan for AIDS relief (PEPFAR), and the United Nations Global Fund for AIDS, Tuberculosis and Malaria were launched. These were funding mechanisms that made it possible for the HIV and AIDS response in Malawi to go nationwide. PEPFAR's preferential treatment of faith communities allowed more churches to come on board. Anti-retroviral medicines became available at three health facilities in Malawi. During this phase, HIV prevalence in the country stabilized between 11% and 17%, with the urban areas having the higher statistics, while the rural areas felt the social impact a lot more.

With regards to stigma and discrimination in the HIV and AIDS response, this phase is very critical to our contextual appreciation. It was during this phase that AIDS became closely associated with death, a stigma it has not been able to shake off. It was more common to hear of people 'dying of AIDS' than of 'people living with HIV'. The long silence about the pandemic had led to many false theories as to how people got HIV and how AIDS was spread. There was fear and this became a driver for the home based and health facility based stigma. Caregivers and health care workers were afraid of contracting HIV or AIDS through casual contact. The churches' collective anti-condom campaign stigmatized what at the time was the most viable preventative measure for people who were sexually active. Even if people knew they were at risk, they were afraid to negotiate for safer sex because they would be branded 'immoral'. This was more so for the women who were victims of infidelity, because culturally it was more acceptable for men to have multiple sexual partners so they were the only ones who could negotiate for safe sex if they felt at risk, while the women were asked if they were prostitutes.

The gendered nature of the AIDS pandemic became more visible in this phase. The famine helped the nation make the linkages between AIDS and poverty. Since the poor could not access the health giving medicines that were available at three urban clinics, the stigma became even more embedded. While the moralization of the pandemic was born in the

previous phase, it now became public. Beatrice Were, widowed due to AIDS at age 21, captures this type of stigma in this excerpt from an article she wrote on World AIDS Day 2006:

My personal story is typical of the way most African women contract HIV. In Africa, 60 per cent of new infections are in women; many of them are married... It wasn't that long ago that the Ugandan approach was the "ABC" model – abstinence, being faithful, using a condom. The three-step policy, while far from perfect, was at least realistic in promoting the use of condoms which used to be advertised all over Uganda. Now, under the influence of US donors, often driven by the evangelical right, billboards have been replaced by marches of virgins, and proposals for university scholarships for those who remain "untainted". A new wave of stigma has overtaken the country; people who are living with HIV are defined as 'loose.' (Were, 2006)

1.13 2006 to 2009: Progress and Participation

By the beginning of this phase, Malawi had a new leader, President Bingu wa Mutharika, a devout Catholic Christian and an astute economist. Mutharika's leadership phase was characterized by increased HIV and AIDS funding, not only from PEPFAR and the Global Fund. American and British universities also recognized Malawi as a research site. Johns Hopkins Bloomberg University, UCLA, Duke University, London School of Hygiene and Tropical Medicine and Baylor University (to name a few) all set up research projects in Malawi, with links to funding. The National AIDS Commission started decentralizing the funding access and more churches were able to access funding for community-based initiatives that centred mostly on home based care for the sick, orphan support and preventative education. Access to HIV testing increased and treatment was made more available but the rural areas were still poorly served and depended heavily on churches home based care programs most of them supported by Church Founded Health Facilities who provide 40% of the institutional health services in the country. The multi-sectoral approach took root in this phase both programmatically and in relation to funding. Very significant to

this phase was the development of an HIV and AIDS Policy for Malawi to provide a framework for the National HIV and AIDS strategy. The Malawi Inter Faith AIDS Association (MIAA) was formed to provide direction for faith communities and their special assignment from the AIDS Commission was to tackle more extensively the issue of stigma and discrimination, which was greatly attributed to the faith community.

It is during this phase that People living with HIV (PLWHIV) became more visible and the action against stigma and discrimination entered more emphatically into the public discourse on the pandemic. When the 'Nothing for Us without Us Campaign' was popularized it empowered PLWHIVs to stand up and make their voice heard in the debate. This phase saw the strengthening of support organizations such as the following: Malawi Network of People living with HIV (MANET +); Coalition of Women Living with HIV and AIDS in Malawi (COWLHA); National Association of People living with HIV in Malawi (NAPHAM); Network of Journalists with HIV (JONEHA); Health Care Workers Living Positively (HECAWLP); from the religious side, Malawi Network of Religious Leaders Living with or Personally Affected by AIDS (MANERELA). This development is very critical to the contextual understanding of this study, because it was during this phase that PLWHIV got national recognition and became incorporated into the National AIDS Commission. This was also a turning point in the discourse on stigma and discrimination in that those discriminated against and stigmatized became prominent spokespeople in the dialogue.

The most significant legacy of this phase in relation to this study is that it provided a legal framework to deal with the issue of HIV and AIDS related stigma, especially in health facilities and in the work place. The collective voice of PLWHIV which gathered strength in this phase and started addressing issues of stigma and discrimination contributed to

improving access to treatment. ARVs were moved from the domain of the privileged few to all that were eligible. MANERELA helped to move the church and other faith communities out of denial to recognize that HIV and AIDS were also present within the church leadership. As insiders, MANERELA was influential in toning down the judgmental sermons directed at PLWHIV in many church pulpits. They influenced the change in the condom debate to a certain extent.

All the combined efforts in this phase contributed to the first reported drops in the HIV prevalence in the country, reduction in deaths and new infections. Thyolo District, one of Malawi's high prevalence areas, where anti-retroviral therapy was first introduced and scaled up to cover the whole district, has reported some very sobering results that warranted increasing the pace in the journey towards zero. A retrospective study was done between 2000 and 2007. 50% of the district population was sampled and it involved 210 villages, 23 churches and 23 coffin workshops. The results were staggering.

In 2006, there were 57,438 people estimated to be living with HIV/AIDS, of whom approximately 11,487 were thought to be in urgent need of ART. By December 2007, more than 10,000 individuals had been started on ART with an additional 6,000 patients placed on treatment thereafter. These figures are well in line with the Ministry of Health (MOH) universal access target of providing ART to 80% of those in need of therapy. There were a total of 18,473 registered deaths, 15,781 coffins sold, and 2,762 church funerals conducted. There was a highly significant linear downward trend in death rates, sale of coffins and church funerals. Overall death rate reduction was 37% for the period. The death rates decreased over time as the percentage of people living with HIV/AIDS enrolled into care and ART increased. Extrapolating these data to the entire district population, an estimated 10,156 deaths would have been averted during the 8-year period (Mwagomba et al., 2010)

It is important to note that the church was a critical player in this study and the stance they took was very influential in the turnaround.

1.14 2010 - 2014: Tumult, Progress and Regress

This phase of the chronicle of AIDS in Malawi is as conflicted as the leadership struggles that characterized it. The phase starts with President Bingu wa Mutharika starting his second term in office. The president had fallen out with a good number of the development partners and so they had cut aid, including support for HIV and AIDS programs. The president had also fallen out with the vice president and she had been side-lined from the political process. Historically, the vice president's office was responsible for handling the AIDS pandemic. The AIDS Unit was then transferred to the office of the president and cabinet. Mutharika's resort to dictatorship in his second term of office alienated him, cut aid and led to both a political and economic crisis. Malawi experienced a fuel crisis that lasted two years and crippled a number of economic and social activities. Health services were hard hit. Malawi's human rights record deteriorated to record lows in the history of the country. For purposes of this study, it was during this phase that the homosexuality public debate brought to the surface the inherent stigma in the population. Mutharika will go down in history for his insensitive outbursts against homosexuality and fuelling national homophobia. In one such outburst he refers to people practicing or associated with homosexuality as dogs.

In May 2011, Malawi's President Mutharika publicly condemned those practicing and promoting homosexuality, describing them as being worse than dogs. Mutharika made the remarks in front of his supporters at Kamuzu Institute for Sports in Lilongwe on 15 May 2011. The *Daily Times* of 17 May 2011 quoted the president as saying: 'If, as human beings created in the image of God, we are failing to appreciate the differences between males and females and start marrying man-to-man or women-to-woman are we not worse than dogs that appreciate nature's arrangement? (Lennox & Waites, 2013).

It was also during this phase that Malawi's first openly gay couple went public. They were humiliated and imprisoned and they have become the face of the homosexuality debate in Malawi.

When the judicial system in Malawi convicted and sentenced a young gay couple, Steve Monjeza (age 26) and Tiwonge Chimbalanga (age 20, alias aunt Tiwo), to 14 years imprisonment with hard labor (NPR Staff and Wires, 2010) a fierce debate erupted not only in Malawi but also internationally. During their incarceration in prison, they were denied bail. Those who defended the couple's sexual choices, orientation, and preferences based their argument on the sanctity of individual rights and freedom. Those who lauded the court's decision to jail the couple for contravening religious, customary, traditional, and cultural laws and rights based their arguments on cultural and religious grounds (Amtaika, 2013).

More than any other event in this phase, this incident brought the homosexuality debate into the public space and also revealed how polarized the debate was between civil society and the religious community. Midway through his term of office, in April 2012, President Mutharika tragically died of a heart attack and Joyce Banda became Malawi's president.

President Joyce Banda, originally Presbyterian but also a practicing Pentecostal, came into leadership when the nation was in crisis. So much had gone wrong in Mutharika's second term of office and the nation was hurting on many fronts. However, she had much in her favour. There was goodwill in her favour both locally as well as on the international scene. The nation celebrated. She was a woman; she adopted a very reconciliatory approach to leadership. She committed to fight corruption and repeal Mutharika's anti human rights punitive laws. She quickly won back donor confidence and funding started flowing again. The fuel crisis ended. She sold the presidential jet as a gesture of her commitment to cut excesses of the presidency. She was made the SADC champion for the HIV and AIDS campaign. Accepting her role as the SADC position as AIDS Champion, President Banda committed to HIV and AIDS as a high priority on her agenda.

Banda has also pledged to repeal some of the repressive laws passed by Mutharika, among them the Indecent and Unnatural Acts, which criminalizes homosexuality. Human rights activists noted that the legislation heightened anxiety in Malawi's underground lesbian, gay, bisexual, transgender (LGBT) community, and compromised HIV prevention efforts among men who have sex with men (MSM) (MANA, 2012).

The rhetoric was welcomed by many and they looked forward to its implementation. However, as President Banda addressed the pressing economic challenges at the time of the fuel and foreign exchange crises, activists started questioning whether HIV and AIDS was still a priority. With two years away from the election campaigns, the president's energy gravitated towards securing her position in the next election. She recycled corrupt politicians from past administrations and got caught up in the midst of Malawi's worst corruption scandal codenamed "Cash Gate".

International development partners were not pleased with the turn of events and withheld funding. There was civil agitation and calls for the president's resignation. With attention on the presidential election campaigns, the priorities that were committed to got lost in the background.

Two years away from the 'Getting to Zero Campaign', vision end, HIV and AIDS related stigma is on the rise again. In 2013, under pressure from civil society organizations as well as international development partners, Banda's government issued a moratorium on laws banning homosexuality and released Tiwonge and Monjeza, Malawi's first openly gay couple, from jail. The Church and opposition parties were not happy. They felt that Banda had sold out in her bid to appease the donors and civil society. They now called for a referendum on gay rights with the church having the loudest voice. The Advocacy campaign for gay rights, championed by civil society, has often been met with very extreme and polarized views from some church leaders. Sometimes these encounters have been very hostile as one of the activists observed.

The advocacy has in some cases attracted extremities of thought and passion, with some senior government officials, and traditional and religious leaders openly expressing disgust at attempts to promote gay rights. Those opposed to the campaign have done so on the basis of culture, morality and Page | 26

religion. Arguing from the Bible, one leader and founder of a Pentecostal church has called for the death penalty to be imposed on those who practice and promote homosexuality 'as the Bible says' (Mmana, 2011). Quoting biblical verses, Apostle Samuel Chilenje argued that God punished Sodom and Gomorrah 'because of gays and lesbians'; 'The Bible says that everybody indulging in same sex acts must be put to death by stoning. Even those promoting it deserve the same treatment (MANA, 2011).

In Malawi, the homosexuality debate is part of the wider AIDS pandemic discourse. So when homophobia forces people to go into hiding, it also drives stigma and discrimination, making access to needed services challenging for men who have sex with men (MSM). Homophobia does not only render men vulnerable, but women as well. Studies have shown that a good number of men have resorted to being bisexual as a way of avoiding social prejudice, often passing on the HIV infection. Only time will tell the impact of this on the national HIV and AIDS statistics. Also, when the church is the loudest voice of judgment, people whose sexual orientation is homosexual distance themselves from churches and they are rendered morally excluded.

This phase in the chronicle of the AIDS pandemic in Malawi is conflicted. Ideally, it would have been a time of overall celebration. The nation had rolled out a very impressive treatment campaign and the journey to zero was becoming more feasible. The legacy of this phase to Malawi's AIDS pandemic journey is that it fuelled stigma and discrimination by criminalizing and politicizing homosexuality. The involvement of the religious community in the debate from a very judgmental stance took the country many steps backward. It is this very rich context that has motivated this study, whose purpose is to examine the extent to which the moral exclusion of People living with HIV from participating fully in church life impedes the global commitment to eliminating stigma and discrimination and impacts on the Church's calling to be an agent of justice in the global response to AIDS. The motivation for

this study has a strong link to my life story. I will now locate myself as a researcher by giving a personal chronicle of my journey in HIV and AIDS work.

1.15 A Personal Chronicle

I was born and raised in Uganda, the first African country to be associated with the discovery of AIDS. I went to graduate school in the United States of America and focused my research on HIV and AIDS in young people. In 1999 I moved to Malawi to set up an international non-governmental organization, World Relief Malawi, and I have lived in Malawi ever since. This study is part of the chronicle of my own personal journey with HIV and AIDS and the desire to make a meaningful contribution to the discourse around the related stigma and discrimination.

As researchers we come to each new inquiry field living our stories; our participants also enter the inquiry field in the midst of living their stories. Their lives do not begin the day we arrive nor do they end as we leave. Their lives continue. Furthermore the places in which they live and work, their classrooms, their schools, and their communities are also in the midst of stories. The stories we bring as researchers are also set within the institutions within which we work, the social narratives of which we are a part, the landscape of which we live (Clandinin & Connelly, 2000, p.1).

I bring to this study my own story, as a "life in the midst." The earliest memories of my engagement with the HIV and AIDS pandemic date back to 1986, my last year in High School. AIDS was first recognized in Uganda in 1982 at a small fishing village in southern Uganda bordering Tanzania, called Kasensero. By 1986, there was still much mystery around the pandemic that was referred to as 'Slim' because of its impact on the body weight of the patients. Richard Goodgame, a missionary doctor at my local church, Kampala Baptist Church, was working at Mulago, Uganda's main teaching hospital. He was seeing a growing number of people with signs and symptoms of what was called the 'Slim Disease'. Most of his patients were abandoned by their families and left at the mercy of the hospital. At the

time in Uganda, when one presented with signs and symptoms associated with slim, they were not treated kindly, let alone with dignity. They would be hidden away in the home so no one would know. It was often alleged that the PLWHIV had brought shame on the family, hence deserving of being treated as outcasts. Their clothes would be burned. Their eating utensils would be washed separately. People behaved this way because they were afraid of contracting "slim" by contact with people who had the disease or anything they had used.

Goodgame felt it was the responsibility of the Church to educate the nation about the pandemic and prevent the discrimination and stigmatization of people with 'Slim'. Using his medical training and missionary background, he came up with the 'Answers Project'. This was an educational program based on a booklet developed by Goodgame entitled "Medical Science and God's Word Answer Five Questions about AIDS". Young people from my church were recruited to be part of a countrywide educational program, beginning with the Baptist Churches. I was one of those young people. Miller, a South African theologian reflecting on the Answers Project, thought it was a redemptive effort that other churches in South Africa should emulate.

In Uganda, the "epicenter" of Africa's A.I.D.S. epidemic, a consortium of churches and Christian groups have distributed over 1000 Bibles and 80 000 tracts as part of the Answer Project, the brainchild of Dr. Richard W. Goodgame, a Southern Baptist missionary physician who teaches medicine at Makerere University Hospital in Kampala. The tract is distributed at seminars and presents medical facts about A.I.D.S. and how it is spread, examines Biblical teaching on sexuality and marriage, responsibility towards people who are suffering and how those dying of A.I.D.S. can have eternal life through Christ. Churches in Southern Africa also need to identify cities and areas with significant numbers of A.I.D.S. sufferers and respond redemptively (G. Miller, 1990, p.216).

Looking back as I reflect on this initial response of our church, I realize that we were as much part of the problem in our effort to provide solutions. Patterson's assessment was accurate. "People tend to be blind to the stigmatizing beliefs and attitudes they themselves hold, or Page | 29

which are common to their social, cultural or institutional context" (Patterson, 2011). We were so blinded by our Evangelical Baptist location that it remains uncertain as to whether our response was "redemptive" as Miller asserted.

In 1988, as a second year Social Work student, I visited the United States and volunteered at Tidewater AIDS Crisis Taskforce in Norfolk, Virginia. At the time in the United States of America, AIDS was considered a "gay people's disease." I was asked to participate in their Health Education Community Campaign and talk about my experience with AIDS in the Uganda context. That was a very formative time for me and provided the space for me to reflect on how different understandings of the factors underlying the spread of AIDS were very influential in determining the nature of prevention, care and support strategies.

Reflecting on that season, I now realize how the labelling of AIDS as the Gay Plague has had a profound influence on the global dialogue and has determined funding priorities, as Patterson points out (Patterson, 2011). This is a legacy that still has influence today.

Emmanuel Katongole, a Ugandan theologian, is one of the African voices working on "contextually relevant constructions of the pandemic that do not stigmatize". However, in the light of recent events on the continent, such as signing into law of the Anti-Gay Bill in Uganda and Malawi's punitive laws, there is still more work to be done. This study is a small part of that work.

My most vivid early encounters with HIV and AIDS related stigma are related to my work with the United Nations Global Program on AIDS, attached to the Uganda National AIDS Control Program, as an Information Officer. Because of my Christian convictions, whenever an education request came in from a Church or a Christian entity, my supervisor asked me to handle it. Thus, I came face to face with the unbelievable prejudice within the Christian

community and churches in particular when it came to the issue of AIDS. The judgmental attitudes kept this community, that had much to bring to the struggle with AIDS, on the outside and robbed communities of a contribution that would have made so much difference in the early days of AIDS in the country. This also launched my career in the area of HIV and AIDS. From 1989 I have worked with different non-governmental organizations of Christian persuasion in the area of HIV and AIDS Prevention Care and Support. For the last 15 years I have specifically worked within the context of Church Networks, most recently, the Tubepoka Churches Network. This study is based on a case study of people living with HIV in this network, and I will reflect later in the chapter on methodology about what it means to research within one's own context of work.

1.16 Tubepoka Churches Network

Tubepoka means 'Let us be United', in the Lambya language, one of the dialects spoken in Malawi's Chitipa District. It is a network of 400 local churches from 16 different denominations. The membership includes: Church of Central African Presbyterian (CCAP), Assemblies of God, African International Church, Baptist Church, Pentecostal Holiness Association, Last Church of God, New Apostolic Church, Last Church of Malawi, Pentecostal Holiness Church, Lutheran Church, Moravian Church, Roman Catholic Church, Seventh Day Adventist Church, Church of African Presbyterian, and African Church. The Chitipa District Local Church Network is also spread across the whole district and is organized in 10 zonal locations.

The Churches have come together to embrace the development agenda of their district. I am one of the founders of the Network and have been instrumental in shaping its direction. The vision of the Network is to become development agencies in their communities with Page | 31

capacities to identify the challenges faced by their communities and to come up with sustainable solutions for holistic community transformation. The mission of the Network is to build the capacity of the local churches in Chitipa to transform their communities through sustainable holistic and transformational development initiatives. The 400 local churches who are part of the network are serving as the primary development agencies in their communities. They provide sustainable solutions to their communities' challenges in the areas of health, education, agriculture, food security and economic empowerment. The local churches in the Network see themselves as the embodied Christ, a living body of Christ in their communities: his hands, heart, ears, eyes, mouth, and feet. The network has a very strong commitment to working with those who are affected by the HIV and AIDS pandemic. Churches in the network are implementing HIV and AIDS initiatives, including support groups for People living with HIV. The network churches therefore provide a rich context for the study of exclusion of People living with HIV from church ministries.

1.17 Conclusion

This chapter set out to provide a contextual background to the study, provide a rationale for the study, introduce the research focus as well as the theoretical frameworks that have guided the study and provide a justification for the choice of methodology. In the next chapter, I will locate the study in the ongoing scholarly discourse, in the form of a chronological review of the literature on stigma and discrimination, particularly as it occurs within the church context.

CHAPTER TWO: Literature Review

2.0 Introduction

Paul Ricoeur in his work on hermeneutics asserts that "discourse shapes reality and gives direction and language to the narrative within which we are living" (Ricoeur, 1991). In this chapter I will locate the study in the ongoing discourse that has influenced the conversation around HIV and AIDS related stigma within the church context, the reality that this study examines. It is also worth noting though that the reverse of Ricoeur's assertion is also true. Reality shapes discourse and influences the language and narrative used in any given social context. This chapter sketches the portrait of moral exclusion of PLWHIV within church contexts, through a critical review of the literature in four thematic areas: social scientific conceptualizations of stigma and discrimination; Christian theological interpretations; representations and responses to the HIV and AIDS pandemic and experiences of PLWHIV; and finally the key public health debates with regards to HIV prevention and AIDS treatment. I have included the public health debates because of their impact on the discourse around stigma and discrimination.

Given the inter-disciplinary nature of this study, I have considered literature from the social sciences and Christian theological disciplines. I have chosen to do a chronological literature review to reflect the movement from the compassion framework in dealing with HIV and AIDS related stigma and discrimination and understand what has changed over the 40 years of the global response to HIV and AIDS. A chronological literature review is not intended in any way to imply that issues are strictly limited to the decades in which they are discussed. The review is an effort to understand how the discourse has progressed or regressed over

time. While for the most part I have drawn on academic literature and empirical studies, there are instances where I have referred to popular literature because of its significant contribution to the discourse. This study is part of narrowing the gap with regard to contextualised empirical studies on stigma and discrimination. Therefore, to be faithful to contextual relevance, I have chosen to explore mostly literature from Sub-Saharan Africa. With regard to theological representations, I have reviewed work within the boundaries of Christian theology, since this study is located in a context of Christian churches.

Due to the large volume of literature on AIDS and stigma in general, it is not possible to review all the literature in these fields. Instead, this review focuses on conceptualizations of stigma and discrimination and how they intersect with Christian theologies, public health debates on prevention and treatment, and the experiences of PLWHIV. Since the review goes back to the beginning of the AIDS pandemic, some of the literature may appear dated; however, it is critical to the understanding of the themes under review within that particular period.

2.1 The First Two Decades, 1980 to 2000: Spoiled Identities, Theologies of Retribution, Shame and Silence

Conceptualizations of stigma in social research, including that of HIV and AIDS related stigma in the first decade, took as their point of departure Goffman's work. Using the Greek idea of branding that was used for criminals, traitors, slaves and other people who were considered undesirable in society, he defined stigma as a 'spoiled identity' (Goffman, 1963). The spoiled identity was physically branded on one's body as indicative of the bearer having a blemished character and hence relegated to a despised social group. Goffman contends that

"stigma is a function of the relationship between undesirable attributes borne by the individual and the consequent stereotypes" (Goffman, 1963, p. 14).

Goffman's conceptualization has been criticised by various students of HIV and AIDS related stigma. Veena Das (2001) faults Goffman's conceptualization of stigma for its 'individualistic rendering of the individual as the sole bearer of value' (Das, 2001). Gillian Patterson (2005), in the same vein, points out that the narrow focus of Goffman's definition is characteristic of' Western notions of identity and would therefore cause analysis problems when applied in contexts where the enactment of stigma was at a societal level" (Patterson, 2005, p. 35).

I would argue that notwithstanding how narrow Goffman's conceptualization was, it resonates with the ways in which HIV and AIDS related stigma was enacted in the local church contexts in the first decade of the AIDS pandemic, re-appearing in subsequent decades, albeit in different forms. The branding metaphor carries the value of permanency. In the old Greek culture from which the word stigma originates, people were branded primarily to identify them as social deviants and to send out a message to the public that they were to be avoided, shunned and excluded because they possessed undesirable attributes that had the innate potential of polluting or contaminating those who came in contact with them. They bore these marks for life. This conceptualization of stigma resonates with the theologies of retribution that are characteristic of the first decade of the AIDS pandemic in church contexts.

2.2 Theologies of Retribution and Internalized Stigma

Theologies of retribution have to do with crime, reward and punishment, based on adherence to or violation of a moral code. Gerald West argues that in every religion there is some form of theology of retribution (West, 2011, p. 136). He uses the agricultural metaphor of sowing and reaping from the Christian religious context to illustrate the religious stigmatization stance. "What you sow, you will reap. More precisely, this agricultural metaphor and proverb has become inverted within most religions: what you reap is a good indication of what you must have sown. If you are HIV positive you must have done something to deserve it" (West, 2010, p. 42). As in Goffman's conceptualization of stigma, within the church, PLWHIVs in the first decade were weighted with the sole responsibility for being excluded, not taking into consideration the cultural contexts of their experience. Gerald Arbuckle (2004) defines "culture as a system of felt meanings encased in symbol, myth and ritual that dictates who should be included and excluded and it sometimes legitimates the violence that is required in order to maintain the exclusion" (Arbuckle, 2004, p. 8). PLWHIV were seen by churches as bearing the punishment for breaking the moral code and therefore deserving of being relegated to a despised group that had to be avoided and kept outside the church to avoid contagion. This moral code, within the Christian persuasion, contends Ezra Chitando and Lovemore Togarasei (2008), is dictated by interpretations of sacred texts from the Bible, which is the central tenet that guides belief and action and the resources for finding direction and answers for all the issues of the life (Chitando & Togarasei, 2008). G.G. Miller, a systematic theologian within the South African context, sums up the dominant theological narrative of the first decade in the AIDS pandemic when he refers to "AIDS as an example of judgment but not directly on homosexuals as such; but rather a judgment on promiscuous behaviour of all kinds, whether homosexual, heterosexual or drug abuse (G. Miller, 1990). In his work on breaking the silence conspiracy about AIDS within the church, Donald Messer (2004), revealed that for many church leaders AIDS was a punishment from God, an attitude that influenced their stigmatizing of PLWHIV in their midst (Messer, 2004). Sarojini Nadar (2003) challenges this polarised belief that HIV/AIDS [sic] was a punishment from God and invites Christians to" look more carefully and discern an alternative voice within the Bible that critiques the dominant theology of retribution and reward" (Nadar, 2003a, p. 345). She offers an African feminist re-reading of the biblical narrative of Job as an example of an alternative theological trajectory to the dominant theologies of retribution —" a trajectory that revealed the God of the Bible not as a punishing God but one who was present in the midst of suffering" (Nadar, 2003b, p. 356).

Goffman's conceptualization of stigma, coupled with the theologies of retribution, contributed to PLWHIV being branded as social deviants in the first and second decades of the AIDS pandemic and constructed their experience with moral exclusion within the church context. Theologies of retribution were not only considered a safe posture but in the eyes of the church a rational one as well. They provided a justification the church had for those that would question the church's stance of non-engagement with the AIDS pandemic in this first decade. For the church, stigma in the first decade was rationalized as a self-preservation and survival strategy. Mary Douglas (1966), in her ground-breaking work on taboos and pollution, articulates this rationalization in a lucid manner.

When society excludes and stigmatizes, it is trying to protect itself from contagion and ensure its own survival. The stigmatized person is believed to be a polluting influence, and therefore dangerous to the rest of the community. Potential polluters become scapegoats, individuals who have broken a taboo of some kind and must be cast out or punished. Religion plays a key role in the process by the way it underpins order. Order, says Douglas, is society's highest value, and it is laws governing purity and

pollution that safeguard it. It is religion that articulates the belief system and institutionalizes the rituals in which society's corporate life finds expression (Douglas, 1966, p. 11).

Patterson (2005) expands Douglas' theme of taboo as a necessary function of ordered society and argues that every society and institution, such as the churches, has encoded into its cultural identity an ordered system of values, beliefs and relationships that govern life, death, sex, reproduction and family, that protect it from hostile influences and preserve institutional purity (Patterson, 2005, p. 8). In the first decade of the AIDS pandemic, in an environment of so much ignorance about the pandemic, the church felt that the only way to guard its sanctity from the "onslaught" of AIDS was to exclude those that were considered to be 'contaminating' agents, the PLWHIV. The church regarded PLWHIV as having broken the taboos that supported the institutional identity fabric. As PLWHIV heard the theologies of retribution articulated from the pulpits of their churches, they felt the judgement. They responded by retreating in silence to a life of denial, shame and suffering.

2.3 A Culture of Silence and Internalized Stigma

Ackerman (2005) affirms that stigma is nourished by silence. She also recognises that "internalized trauma, fear of rejection, cultural restraints and wrong understandings of sin and punishment, as was characteristic of the theologies of retribution, all rob people of the ability to speak out and name their reality" (Ackerman, 2005, p. 49). A Tanzania-based study by Watt *et al* (2009) found that PLWHIV internalized a sense of shame, voluntarily excluding themselves from church. This self-stigmatization, according to the study, was a result of their churches constantly drawing a link between AIDS and sinful sexual behaviour. PLWHIV therefore avoided attendance at church or related events, especially when they were visibly ill, as this would be a form of public disclosure of their HIV status. They were afraid of the

hurtful responses of blame, judgement and humiliation that they would suffer from fellow church members (Watt, Maman, Jacobson, Laiser & John, 2009).

According to social scientists Campbell, Skovdal and Gibbs (2011), theologies of retribution, supported by a narrative of moralistic judgement, further entrenched HIV and AIDS related stigma and discrimination in the church by eliminating the platform for debate, thus promoting a culture of ignorant silence. In a review of literature exploring churches as social spaces for addressing issues of stigma, they made this observation:

The anchoring of HIV/AIDS [sic] within existing religious frameworks of meaning contributes to stigma through rendering it literally 'unspeakable' in terms other than immorality and shame. Furthermore, churches framing of HIV/AIDS [sic] within discourses of immorality and sin foregrounds 'bad' individuals and their specific behaviours in understanding HIV transmission, rather than opening opportunities for discussion of social roots of HIV/AIDS [sic] (e.g. in factors such as interface of poverty, age and gender in some settings. This limits the possibility of critical thinking around stigma, which would be the starting point for the development of more constructive and less stigmatizing understandings of, and responses to HIV/AIDS [sic] (Campbell et al., 2011, p. 1212).

One of the areas where critical thinking was affected leading to additional stigmatization of PLWHIV was in the area of prevention efforts.

2.4 The ABC Prevention Strategy, Public Health and Morality and Stigma

Towards the end of the first decade of the global response to the AIDS pandemic, Uganda initiated a prevention strategy that was codenamed ABC (Abstain, Be Faithful, use Condoms.) The three components were considered complementary and each targeting a different population group. Abstinence was aimed at the young people who were not yet sexually active, to encourage them to delay the onset of sexual activity. It also targeted those who wanted to change behaviour even though they were already sexually active and practice secondary abstinence. Okware *et al* describe the B aspect of the strategy thus.

In its purest sense, the B of the ABC entails practising sex with just one partner, in a long term or lifelong relationship such as marriage and only after determining that both partners are not infected. Shades of grey do exist, however, with for example polygamous marital relationships and also those who engage in serial monogamy. In relation to this the concept of 'zero grazing' was developed – this is an agricultural term which refers to feeding one's livestock exclusively within the paddock. The humorous double meaning that applies to HIV prevention maintains that one keeps to an exclusive and monogamous relationship. Zero grazing was described as being 'equivalent to a highly effective vaccine for HIV (Okware, Kinsman, Onyango, Opio, & Kaggwa, 2005, p. 626).

These A and B aspects of the strategy were welcomed by the faith communities especially the churches and they relentlessly promoted them within their communities. It is the C aspect of the strategy that church leaders did not welcome (see Gusman, 2009, p. 71). The condom strategy was intended for those who were sexually active and especially if they were in multiple sexual relationships. The population was encouraged to use condoms correctly and consistently. The male condom was the one marketed as effective for the reduction of not only HIV but also other sexually transmitted infections. A female condom was later developed, but it did not become popular. Condom promotion as a prevention strategy raised very heated debate and the biggest critics were the church leaders. The church leaders publicly spoke out against condoms. They maintained that condom promotion was an affront to the moral values of the church, promoted promiscuity and compromised the message of loving faithfully (see Parikh, 2007). Uganda experienced significant drops in the levels of incidence and prevalence by applying this combined strategy and the strategy was recommended for other countries to adopt (see Halperin et al., 2011; Otolok-Tanga, Atuyambe, Murphey, Ringheim, & Woldehanna, 2007; Parsitau, 2009). Unfortunately, the stigma attached to condom use rendered it less effective in many sub-Saharan countries, because they were in denial (see Heald, 2002; Pfeiffer, 2004).

I will focus on the studies that were done in the Malawian context that reflect the impact of this stigmatizing attitude and the effects it had on the experiences of PLWHIV. Malawi is a predominantly Christian country, with an estimated 75% of the total population having membership to a local Christian church. Consequently, when the church speaks people listen (Rankin, Lindgren, Kools, & Schell, 2008). Also the church has more connection to the populace than most other institutions, given that in most cases people will go to church more than once a week. When the ABC strategy was introduced as part of the HIV and AIDS prevention strategy, the response of the church leaders was very similar to that of the Ugandan church leaders and according to some studies maybe more extreme (see Chimbiri, 2007; Rankin et al., 2008; Trinitapoli, 2009; Watkins, 2004). The Christian church leaders focused their prevention messages around abstinence and marital faithfulness. They made it clear that they were not going to encourage the use of condoms and their churches and ministries were not going to be part of the social marketing of condoms. As far as they were concerned, condoms were associated with promiscuity and infidelity and were a big part of the spread of AIDS in the country. This position was held so strongly that the churches even came out with church position papers against condom use and these were also published in the local newspaper. In the early days of the response to HIV and AIDS in Malawi the church was known more for their anti-condom position than for all the other work they were doing to help PLWHIVs. In an empirical study done in Malawi that focused on men's attitudes towards condom use as a prevention strategy, Kalipeni and Ghosh (2006) found a perplexing dynamic that helps explain why the women felt vulnerable. Below is part of their summary findings:

80% of the men revealed that they were worried about contracting HIV/AIDS [sic] while at the same time 35% of them admitted having extra marital relations. Furthermore, a substantial number of the

men indicated that it is advisable to use a condom with one's spouse for AIDS protection and yet only 8% had ever used a condom. In addition many of them (47%) were even prepared to sleep with a beautiful bargirl (Kalipeni & Ghosh, 2007, p. 1125).

Asked what their reasons were for not putting into practice what they knew about prevention, one of the participants in the study said:

We are also getting conflicting messages today. The governments say use condoms!! But the Catholic church, the CCAP Church, the Moslems say if we use condoms we will go to hell, that they are immoral gadgets designed to make you sin. A year ago I heard Reverend (name withheld) on Radio Maria argue that the government is supporting promiscuity by handing out thousands of condoms every month. He said condoms are not 100% effective in preventing infection, noting that the only sure way to protect oneself is strict monogamy or abstinence. Which preaching should we follow? How do we protect ourselves? (Kalipeni & Ghosh, 2007, p. 1124).

What Kalipeni and Ghosh found contradictory was that the married male participants dismissed condom use, even when they knew it was important, because their churches and the mosques preached that they were linked with immorality. Yet the same participants ignored the message to stop promiscuity and practice fidelity, which also came from their church leaders. Rankin et al (2005), in a study on the vulnerability of women in the HIV and AIDS response in Malawi, pointed out that the stance of the religious leaders, more than anybody, put the women in a more vulnerable position. Even when women knew that they were at risk because of the infidelity of their husbands, they could not negotiate for safer sex options because their churches had outlawed condom use, the only prevention option available to them. They were afraid that they would be accused of unfaithfulness, abused physically and worse still sent away or abandoned by their spouses (Rankin et al., 2005, p. 6). They also found that while HIV tests were a mandatory requirement by church leaders prior to marriage, discordant couples were left without prevention options if they wanted to go ahead with their wedding. Rankin *et al* accuse the Malawian religious leaders of obscuring reality by their moralistic stand with regards to condom use.

Until the female condoms, which are relatively expensive and unknown in Malawi, become available to women, the insistence by religious leaders upon abstinence and faithfulness alone obscures reality, which is male promiscuity and female disempowerment. Husbands are the main routes of transmission to married women. Indeed religious groups do little to nothing to change socially structured gender inequalities, so they offer no useful relief to women in the matter of HIV prevention. Having heretofore essentially conspired with men against women, religious organizations will have to take note of the governmental and NGO commitments for women lest they end up confirming the status quo and refusing to assist women in lessening risk-taking behaviors. Whether they possess the will to make necessary changes remains an unanswered question (Rankin *et al.*, 2005, p. 14).

The above summary conclusion of the study by Rankin *et al* (2005) on the vulnerability of women, demonstrates that by stigmatizing the most accessible and best proven effective means of prevention at the time, the church leaders legitimized the further entrenchment of stigma in their structures and widened the inequality gap. The issues raised in the public debate on HIV and AIDS prevention are part of the reason that a broader conceptualisation of stigma would be needed to be able to interrogate the layers that constitute stigma and discrimination within the church contexts. By the end of the second decade of the AIDS pandemic, social scientists were beginning to question the narrow conceptualization of stigma as a 'spoiled identity' (R. Parker & Aggleton, 2003). Theologians were also beginning to question the church's culture of silence and non-engagement (see Clifford & Aid, 2004; Dube, 2002; Frederiks, 2008; Messer, 2004) It is from the social sciences and academic theologians that the application of new conceptualizations of stigma to the discourse emerged that would change the conversation, redefine the theologies and influence the changing experiences of PLWHIV in the church.

2.5 The Third Decade: 2001 to 2010: Stigma as a Social System, Theologies of Compassion

Drawing on research done primarily within the social sciences, Parker and Aggleton (2003) recognized that there was a contextual disconnect between the conceptualization of stigma and discrimination that was dominating research around stigma and influencing the responses that were informed by the research. They argued that in the global south, where AIDS was taking its toll at the turn of the century, stigma and discrimination were manifesting as social and cultural phenomena affecting families, villages and communities and not simply consequences of individual behaviour. The latter, while more relevant to the global northern context, was dominating inquiry in the global south. Their premise was that it was critical that those seeking to understand HIV and AIDS related stigma and discrimination take cognizance of the importance of historical and cultural contextual influences in shaping the form stigma and discrimination will take in particular settings (R. Parker & Aggleton, 2003, pp. 15-17). Picking up on the contextual importance raised by Parker and Aggleton (2003), Jessica Johnson (2012) has argued that the concept of stigma as a descriptor of the experiences of PLWHIV loses its relevance when divorced from the social contexts in which their lives unfold. This is because the wealth of the discourse, taken in context, is made richer by the intertwined complexities of the histories, struggles, relationships and challenges that define the narratives of PLWHIV (Johnson, 2012, p. 647) Parker and Aggleton (2003), building on the work of Michel Foucault (1977, 1978) and Pierre Bourdieu (1997, 1984) concerning the intersections between culture, knowledge and power and social structures broaden the conceptualization of stigma beyond the individual to include the social system they inhabit (see Bourdieu, 1977; Foucault, 1980) They conceptualise stigma and discrimination as social processes operating within social systems in which historical,

political, cultural and economic forces intersect and interact with societal power structures, consequently producing, reproducing and legitimating social hierarchies of domination and inequality. They argued that,

Focusing on the relations between culture, power and difference in the determination of stigmatization encourages an understanding of HIV and AIDS related stigmatization and discrimination as part of the political economy of social exclusion present in the contemporary world.... The new forms of exclusion associated with economic restructuring and global transformation have almost everywhere reinforced pre-existing inequalities and exclusions. This intensifying interaction between multiple forms of inequality and exclusion offers a general model for an analysis of the interaction between multiple forms of stigma that has typified the history of the HIV and AIDS epidemics (R. Parker & Aggleton (2003, p. 19).

This broader conceptualization of stigma applied to inquiry within the AIDS context provided a framework that enabled theologians to begin engaging the church and challenging the theologies of retribution within the church and confront the unjust exclusion of PLWHIV from church life (see Ackermann, 2002; de Gruchy, 2006a; Dube & Kanyoro, 2004). The result of this engagement was that the churches started responding with theologies of compassion and theologians came up with frameworks for reflection on stigma and discrimination that helped the church to begin moving away from the theologies of retribution. In the next section, I will explore the representations on stigma that emerged in the third decade of the AIDS pandemic and changed the direction of the discourse.

2.6 Theologies of Compassion

Father Richard Bauer (2005), creating a framework for theological reflection on HIV and AIDS related stigma within the church, challenged the church to move beyond rhetorical commitment to compassionate action informed by reflection.

There is an urgent need to build communities that are welcoming, supportive and capable of breaking the silence about HIV and AIDS. Many churches are committed, in principle, to doing this. But it is hard to see how they succeed without some painful soul searching at the level of the institutions themselves, as well as the clergy and members. For churches, truth telling may involve an acknowledgement that they have been party to stigmatization. They may have advocated 'bad theology' or failed to challenge it. They may have condoned a climate of silence and denial at institutional level, diluted or misrepresented the facts in their educational programs, failed to provide strong prophetic leadership, and been responsible for the poor moral example which sometimes exists within the churches themselves (Bauer, 2005, p. 16).

Dube (2005), challenged the clergy to rethink compassion. She redefined compassion, taking it out of the realms of charity to revolution and liberation (Dube, 2005, p. 54) She argued that compassion, if it is genuine, must always move us to actively seek change and to end the pain, suffering and hurting. Churches did heed the call to soul searching and many opened their doors to welcome PLWHIV and started initiatives to respond to the AIDS pandemic within the context of their local churches and related institutions such as schools and hospitals (see Clifford & Aid, 2004).

UNAIDS and WCC convened ecumenical gatherings to bring together theologians, church leaders and practitioners to soul-search and come up with strategies to deal with stigma and discrimination (Patterson, 2003). Warren Parker and Karen Birdsall (2005) in their review of the role of faith based organizations acknowledged the contribution FBOs had made to the global response to the AIDS pandemic, highlighted responses in supporting orphans, provision of medical care, resourcing support groups for PLWHIV, counselling and pastoral care. They concluded that these expressions of compassion and shared humanity by faith communities, particularly churches, would contribute to the mitigation of AIDS-related stigma and discrimination (W. Parker & Birdsall, 2005).

Heath (2005), speaking on behalf of PLWHIV, contended that while the churches' responses may have been compassionate, they had a negative side to them in that they were dominated by a theology of death, helping people die. He challenged the church to consider a theology of life that would help PLWHIV to live with HIV (Heath, 2005) This was a clarion call to engage in more honest discourse that had the issues of PLWHIV at the centre. This turn of events was very critical, especially at a time when side by side with compassionate church responses to the global pandemic, there were still church leaders who were preaching that AIDS was a punishment from God and that using condoms was sinful. The change in discourse to engage a theology of life would come mostly from the community of PLWHIV.

2.7 Changing the Language to Change the Narrative

Noerine Kaleeba, considered one of the heroines of the AIDS pandemic, started the first African support organization in Uganda for people affected by HIV and AIDS when her husband was diagnosed with HIV. Kaleeba (2000) challenged the notion of helping people die by introducing the ethos of living positively with AIDS. She argued that in order for a theology of life to emerge the language had to change and this had to involve all of society. In 'Open Secret,' she elaborates what living positively is about.

The AIDS Support Organization (TASO)'s slogan is 'Living Positively with AIDS', and calls upon everyone in society, infected or not infected to do their part. It calls on those infected to live responsibly with the HIV infection in their blood, to recognize their responsibility to society, the responsibility to retain the amount of virus they have in their blood and not spread it around, by making the effort not to infect others. It calls upon people who are infected to look after themselves better, and preserve themselves until a cure comes. It calls on people who are infected to remain actively involved in society and in social activities within society. It also calls upon the rest of society to support people with HIV infection so that they can fulfil their obligations. It calls on those who are not infected, or don't know whether they are infected, to accept people with AIDS, to recognize that you cannot catch AIDS through casual contact. Acceptance of people with HIV or AIDS within our community is a

very important starting point for dealing with the problem (Kaleeba, Kadowe, Lalinaki & Williams, 2000, p. 21)

Kaleeba, did, within the context of TASO, introduce new language to the discourse around stigma and discrimination. The term 'living positively' was first used in TASO. This was a departure from the narrative of death in the first decade. She also challenged the victim language and called upon PLWHIV to take responsibility and change their attitude towards themselves. She could authentically do that because she had taken care of a husband with AIDS and was affected herself. It was at TASO that PLWHIV stopped being referred to as 'AIDS sufferers', 'AIDS victims' and 'AIDS patients' and became clients. Kaleeba had discovered that PLWHIV could not be treated with dignity if victim and stigmatizing language was still being used. By challenging the death narrative and encouraging PLWHIV to take care of themselves in anticipation of a cure, Kaleeba introduced hope in response to the AIDS pandemic. She also added her voice to that of others who called upon the Ugandan nation to act with compassion towards PLWHIV and their families. The experience of TASO demonstrated that changing the discourse not only changes the narrative but also has a powerful influence in defining reality. PLWHIV came out of hiding, disclosed their status and sought help. The 'leper treatment' PLWHIV were receiving reduced, as knowledge about how HIV infection was contracted became available in the public space. Instead of waiting to die, PLWHIV changed their health seeking behaviour and did what they could to remain healthy. Public awareness campaigns became more sensitive in their messaging. For example, messages such as 'Beware AIDS Kills' were replaced with others that were more life affirming such as, 'If you have AIDS do not despair'.

By his public disclosure of his HIV positive status while still in active clergy service, Gideon Byamugisha introduced a unique aspect to the conversation about AIDS stigma within the Page | 48

church context. A Ugandan theologian and the first African clergy to publicly disclose his HIV positive status, he dispelled the myth that AIDS was outside the confines of the church. It comes as no surprise that his bold declaration, 'our church has AIDS', earned him more critics than friends in church circles. Out of his own struggle of coming to terms with his HIV positive status in a very hostile and judgmental context, Byamugisha developed a theology of life that was not governed by conventional wisdom and arguments but would take the stigma conversation to a whole different level. He challenged church-held positions that were complicating the response to the AIDS pandemic by encouraging a culture of denial based on fear and ignorance. One of his departure points in talking straight to the church was imploring the church to acknowledge that there were high levels of unsafe sex happening within the church community, hence the need for the church to rethink its stigmatizing position on condom use. Departing from the antagonistic perspective in the church at the time that pitted morality against scientific facts about HIV prevention, Byamugisha called on the church to take a more conciliatory approach. He urged the leadership to equip the membership with both the moral values and scientific facts about sexuality and AIDS so that they could better protect themselves. Byamugisha (1998) challenged the church argument that condom promotion campaigns increased promiscuity among young people and in so doing redefined the notion of safer sex.

Advocating for safer sex is not the same as advocating for safer sin. It does not in any way involve approving or condoning those activities deemed by the church as sinful. Sexual sin is sin with or without a condom. Rather a safer sex message is concerned with stopping God's people from killing their loved ones (lawful or not) and from committing suicide (in marriage or outside it) through unprotected sex. I am postulating that condom education, promotion and use are things church leaders can undertake to encourage with a clear conscience, as part of the mission of the church in preventing disease, and promoting life (Byamugisha, 1998, p. xvii)

Byamugisha encouraged the church to take advantage of the agency of PLWHIV instead of isolating them. In his talk at the XIII World AIDS conference in Durban, South Africa, he challenged the notion of 'risk groups' and contended that it contributes to stigmatizing of PLWHIV.

AIDS does not just happen to "other people"; AIDS can happen to any of us. Some of us may blame others in certain supposed "risk groups" who seem to be spreading infection. This is dangerous for everybody. It creates and isolates a group among us who supposedly are different and worse than the rest of us simply because they have become infected with HIV. It encourages people to deny and hide the real consequences. It fails to address the reasons why escaping infections may be or may have been, difficult for some of us. It can sustain a false sense of security among people who are actually or may soon bear the risk of HIV itself in their daily life" (Byamugisha, 2000, p. 29)

Byamugisha's seminal contribution to the discourse on HIV and AIDS as it relates to the stigmatization of PLWHIV rests primarily on the sexuality discussion debate. Using imagery and contexts that the church is familiar with, Byamugisha made connections between responsible sexuality and being one's brother's keeper. He discussed the biblical understanding of freedom in relation to opening up the social space for people to make decisions about their sexuality in ways that would promote life. Thus Byamugisha gave the church language resource tools to engage in dialogue around morality, sexuality and AIDS with a view to promoting life and not from a judgmental framework. Contributions like those of Kaleeba and Byamugisha discussed above, while revealing the potential for the church to be a social supportive space where issues of stigma could be challenged, also exposed the amount of work that needed to be done before that space could completely open up. Parker and Aggleton (2003) address this complexity and warn that detangling the threads of stigmatization and discrimination was not a process to be undertaken lightly because it requires of those who would attempt to do so, to courageously call into question the very structures of equality and inequality in society.

2.8 Stigma and Gender Inequalities

Parker and Aggleton (2003) posit that

Stigma and discrimination operate in relation to social and structural inequalities and are deployed by concrete and identifiable social actors seeking to legitimize their own dominant status within existing structures of inequality. They also explain that the reason eliminating stigma and discrimination has presented such a formidable challenge in the global response to HIV and AIDS is that the process of stigmatization is linked to competition for and the legitimization of social hierarchy and inequality (R. Parker & Aggleton, 2003, p. 18).

Perhaps no social system illustrates the dynamic described by Parker and Aggleton above like the church. The institutional culture of the church is characterised by a long history and tradition of power, hierarchy and inequality. Denise Ackermann (2005) has argued that in propagating a gospel that discriminates against women, the church has also contributed to entrenching the gender inequalities that leave women vulnerable to HIV infection. With regards to influencing the discourse around gender injustices and inequalities in relation to HIV and AIDS related stigma, the work of the Circle of Concerned African Women

Theologians has been very critical (see Ackermann, 2002; Dube, 2003; Dube & Kanyoro, 2004; F. L. Moyo, 2005; Oduyoye, Phiri & Nadar, 2006; Phiri, 2002) Through their research, writings, activities and campaigns they have courageously raised the issues that have contributed to women particularly being the victims of unfair stigma and discrimination.

Teresa Okure (1998), one such African woman theologian, contends that disordered gender relations, is a virus that was more deadly than HIV in that it legitimised the stigmatization and demeaning of women in society.

Ackerman (2005) proposes that an embodied feminist practical theology offers a potentially helpful framework for faith communities in their search for meaningful approaches to dealing with the prevalent HIV and AIDS related stigma in their midst. Ackermann presents feminist

practical theology as critical, self-reflective and possessing a dynamic relationship between theory and praxis that allows for ongoing reflection to creatively inform and transform action (Ackermann, 2005, p. 386). Her argument is that given the complexity of AIDS related stigma, it is critical that any action to counter stigma manages a healthy tension between theory and practice. Ackermann argues that an embodied feminist practical theology is a useful framework in dealing with HIV and AIDS related stigma within faith communities, because it allows for critical reflection on the actions of the community that then feeds into belief and actions. Ackerman's work is also useful for this study because she highlights the multi-layered nature of stigma and discrimination and also explains how stigma is reproduced and legitimized within any social system (Ackermann, 2005). Drawing lessons from the apartheid system, Ackerman observes that stigma never occurs in a social vacuum and rarely acts in isolation. She points out that in the case of HIV and AIDS related stigma, there are other stigmas that are at work to complicate the situation. These include gender, race and social status. According to Ackerman, these pre-existing inequalities and exclusions add layers onto an already complex situation and they have to be carefully analysed to engage in informed action.

One result of this kind of exclusion (multi-layered stigma) is that children, women, the homeless and the jobless who increasingly bear the burden of poverty are further stigmatized. The poor are not only poor because they are lazy but on becoming infected, are now also immoral. Lack of basic necessities and lack of basic education create fertile ground for the reinforcement of stigma. People are stigmatized for situations that they have no control over and then one stigma feeds into another (Ackermann, 2005, p. 389).

Ackerman's reflections are critical to this study in that she draws attention to the importance of the contribution of the collision of culture, power and difference in reinforcing stigma. In the church probably more than any other institution we see the play of these three forces.

Probably that is why the church has been named as one of the perpetrators of HIV and AIDS Page | 52

related stigma and discrimination. Identifying the multiple layers of HIV and AIDS related stigma within the church and naming the factors that perpetuate it is part of the process of eliminating stigma within faith community contexts.

The contribution of the Circle of Concerned African Women Theologians is well-articulated by Musa Dube (2002-2006) in her work on HIV and AIDS research within the context of the Circle (see Dube, 2003, 2005; Dube & Kanyoro, 2004). Dube's inter-disciplinary location in African women's theology, feminist hermeneutics and biblical studies, as well as her ecumenical and critical postcolonial sensitivity, give her a rich platform from which she makes invaluable contributions to the stigma discourse within the church context. She contends that the HIV and AIDS pandemic, and by implication the related stigma, is located within a multiplicity of social pandemics, including poverty, gender inequality, child abuse and discrimination on the basis of sexual orientation. This contention she elaborates on by uncovering the gendered face of HIV and AIDS and providing lenses through which we can better understand the interface between HIV and AIDS related stigma and issues of gender, sexuality, culture, religion, neo-colonial politics and globalization. Her global location thus contributes significantly to locating the conversation within the ongoing discourse on international issues of justice and more specifically gender justice. In his discussion on transforming masculinities towards gender justice, Adriaan van Klinken (2011) considers gender justice to be a theological horizon for the transformation of masculinities in the HIV and AIDS context (van Klinken, 2011, p. 288). The gender justice theology of Isabel Phiri (2002) places the God of justice at the centre of the liberation process from all forms of injustice and oppression. She proposes that the humanity of men and women toward one another hangs on the ideology that they are made in the image of God and of justice and that

until they embody God's justice in their relationships to one another, gender justice will only be a vision or a very far away horizon (Phiri, 2002, p. 77). Dube's work goes to show that AIDS is not about individual morality as had been preached within church circles in the first two decades of the AIDS pandemic. She argues that the structural dynamics of the social locations that people find themselves in have a bearing on their decision-making processes and life choices and hence AIDS is truly a social justice issue. It is this conceptualization of HIV and AIDS that undergirds Dube's theology of life. It is a theology that takes into consideration all the issues and circumstances surrounding the AIDS pandemic. Dube (2003) connects the discourse on stigma and discrimination to the global social factors of disempowerment that recreates and maintains gender inequalities beyond Sub-Saharan Africa. She laments the fact that HIV and AIDS related stigma has to an extent reversed the gains made in the struggle for gender empowerment for four decades (Dube, 2003, p. 19).

2.9 Power, Empowerment, Agency and Stigma

Parker and Aggleton (2003) contend that whereas stigma takes different forms, depending on the context and the actors, a unifying thread is that stigma always serves to support systems of social inequalities and social difference and to reinforce the interests of powerful social actors seeking to legitimize their dominant status. Hence the discourse on power is essential to this study that seeks to understand legitimating factors of moral exclusion of PLWHIV in church contexts, where social hierarchy and power are central to the social order (R. Parker & Aggleton, 2003, p. 17). Michel Foucault (1979, 1980), in his work on the intersections between culture, knowledge and power, explains that within each social system there are regimes of power as well as social controls that manage the relationships between regimes through a subtle socialising process that achieves voluntary subjectification. The purpose of

this process is to ensure that the power status quo is maintained (Foucault, 1979, 1980). It is this cultural reproduction of power that Parker and Aggleton (2003) applied to their conceptualization of stigma. They observed that "stigmatization occurs at the point of intersection between culture, power and difference" (R. Parker & Aggleton, 2003, p. 17). They propose, therefore, that to appreciate the role of stigma as essential to constructing and maintaining social orders, it is important to explore the relationships between the various categories of social actors in a given system. Campbell et al (2005), applying this concept to an empirical study in Ekuthuleni, South Africa, argue that stigmatization is a form of covert psychological policing whereby those who breach power relations of gender, generation, or ethnicity are disciplined and punished (Campbell, Foulis, Maimane, & Sibiya, 2005, p. 813). Fulata Moyo (2005), in a study on the intersections between sex, power and gender, applies the same notion to expose the traditional patriarchal powers within the Malawi church context that were threatening and challenging women's ability to fully experience church in the context of HIV and AIDS (F.L. Moyo, 2005).

The theme of using power in abusive ways has been the most linked to inquiry related to HIV and AIDS related stigma. There is, however, another dynamic that has emerged towards the third decade of the AIDS pandemic. This notion of power is related to the agency of PLWHIV – here is where PLWHIV, 'the oppressed', become agents of their own empowerment. Dube (2003) alludes to it in her reading of the biblical text of the healing of the woman who had a bleeding problem. She, however, cautions that this can only happen if those in power are willing to give it up or at least share it with those whom society has disempowered such as those stigmatized and excluded due to AIDS (Dube, 2003, p. 23) The theme of empowerment is also picked up by Philippe Denis (2014) in a preliminary report

that examines stigma and discrimination through oral histories of select members of the Fountain of Life support group, in Pietermaritzburg, KwaZulu-Natal, South Africa's province with the highest HIV prevalence. Though not in any way representative or the results conclusive, the report does support recurring themes among scholars writing about stigma and discrimination in the fourth decade of the pandemic. Denis points out that even though stigma and discrimination have not disappeared, it has changed and is much lower than in the previous decades. He draws our attention to some of the factors that have influenced this change. Treatment, on the one hand, has reduced the fatality previously associated with the pandemic, but more importantly he alludes to the empowerment of PLWHIV through training, counselling and support groups. The latter, Denis, drawing on Foucault, points out, had enabled the support group members to develop 'technologies of self' which allowed them to express the multi-layered and sometimes contradictory aspects of their experience of HIV (Denis, 2014, p. 296). With their new found confidence, the members of Fountain of Life support group were not only able to comfortably dialogue about painful and sensitive issues but also able to draw on spiritual resources to assign meaning to aspects of their lived experiences with HIV. It is interesting to note that Denis asserts that they were able to do this without falling into the trap of church-induced self-blame and denial. They did not hesitate to distance themselves from their church leaders where necessary (Denis, 2014, p. 296). This is different from the discovery of Campbell et al only three years earlier that PLWHIV internalized a sense of shame and when ill voluntarily isolated themselves and refrained from active participation in church work. "HIV positive church members feared to disclose their status.... They feared that other church members would regard them as having sinned, leading to what they feared would be unbearably hurtful and humiliating responses of blame and judgment" (Campbell et al., 2011, p. 5). These observations are part of the changing face of

stigma and discrimination in the fourth decade of the pandemic. There is movement from the victim discourse towards one of empowerment and agency, hence the imperative need for the church as well to move beyond compassion towards the just engagement of PLWHIV.

Jessica Johnson (2012), in an ethnographic study of several HIV positive women in Chiradzulu, southern Malawi, discusses the agency of PLWHIV from the angle of hope through a matrilineal setting and lifeline that access to anti-retroviral treatment offers. She argues that whereas historically an HIV positive medical result was like handing one a death sentence that led to moral exclusion of the PLWHIV, the advent and availability of antiretroviral therapies has turned that around. HIV positive women in Chiradzulu are now able to take advantage of the social structures within their setting and recover their moral and social standing in the community. Johnson draws on the personal histories of the women to challenge the victim discourse that to date had dominated the public perspectives of PLWHIV and concludes that.

Far from confirming the image of the passive victim, their narratives point to the creative and pragmatic responses of HIV-positive women and the importance of matrilineal land inheritance for the particular ways in which they are positioning themselves as productive members of families and communities, as capable, responsible mothers and grandmothers, and therefore as moral, social persons (Johnson, 2012, p. 633).

Johnson's work is critical to this study in that it helps to demonstrate the movement from a victim-dominated discourse to one of empowerment and of liberated agents with new identities who have carved out for themselves a social space in their communities. She, however, does attribute the change largely to the transformative impact of access to ARVs. Given the importance of access to treatment in changing the life outcomes of PLWHIV I am

going to locate the study in the global public health debate in the global response to HIV and AIDS.

2.10 Global Health Equity, Spiritual Healing and Stigma

In 2003, Lee Jong-wook, the World Health Organization (WHO) director-general at the time, launched the universal access to treatment initiative for PLWHIV, particularly in the developing world. In his global health report that year he bemoaned the health inequalities that scarred the world's health landscape at the time. Among them was that while PLWHIV in the global north had access to the life-prolonging treatments for HIV infection, in Sub-Saharan Africa, the epi-centre of the AIDS pandemic, only 2% of the 4.1 million PLWHIV eligible for treatment had access. The WHO director-general admitted that a world torn apart by such inequalities was in serious trouble. Yet by acting resolutely to correct the injustices, the WHO could do much to improve the collective future of humankind (Jong-wook, 2003, p. 2083). Jong-wook explained that most of the factors responsible for unequal health outcomes such as poverty and low access to education were outside the health sector's jurisdiction. He, however, acknowledged that there was much that the worldwide health community could do to reduce suffering and death among vulnerable groups, hence the commitment to provide 3 million people in developing regions with access to antiretroviral therapy by the end of 2005 (Jong-wook, 2003, p. 2083).

Patterson (2005), articulating the challenges of contextual conceptualization of stigma, explains that the medical perspective tended to focus on the epidemiological aspects of the AIDS pandemic with a very narrow focus on the health-related condition (Patterson, 2005, p. 33). This is reflected in the WHO director-general's argument above where he thinks that poor access to education and poverty are outside the jurisdiction of the health sector. She

challenges public health practitioners to broaden their focus to take into account anthropological aspects that define the various contexts in which stigma is enacted. The helpful distinction between disease and illness proposed by Gerald Arbuckle (2000, p.14) brings clarity to the public health discourse as it intersects with stigma. Using his location as a priest who is also an anthropologist, Arbuckle distinguishes the two concepts based on their construction. He defines disease as a scientifically or medically endorsed breakdown of a physical or biological nature. Illness, he defines as the subjective experience of the individual or the knowledge that one is ill. Arbuckle proposes that the idea of disease is scientifically constructed, while illness is socially constructed and it includes the pain of stigmatization. This distinction by Arbuckle is very helpful in the stigma and discrimination discourse because it is possible to address the medical conditions related to HIV and AIDS and think that stigma has been dealt with (Arbuckle, 2000, p. 14). The constructions of stigma in any given setting have significant influence on strategies to combat it. Instead of polarised constructions, complementary stigma constructions that blend the medical approach but also take into account the systemic and social implication of stigma are more helpful in the global response to end HIV and AIDS related stigma. In this regard, the five years given to achieve zero stigma and discrimination by UNAIDS (G. T. Z. UNAIDS, 2010), seem inadequate to address the social inequalities legitimating the entrenchment of stigma in societal structures such as the church. However, that timespan may achieve significant medical gains with regards to the treatment of HIV and AIDS related conditions.

While the international health fraternity was working towards universal access to ARVs for PLWHIV, another dynamic was developing within the African faith community and it was more pronounced within the churches of Pentecostal persuasion. The dynamic of faith

healing or miracle cures from HIV and AIDS became increasingly popular. This dynamic was not only working against adherence to ARV treatment but was also creating a different kind of moral exclusion. Several studies have been done exploring faith healing and miracles in the context of HIV and AIDS (see Dilger, 2007; Manglos & Trinitapoli, 2011; Woods & Ironson, 1999). In the Tanzania study by Roura et al. (2010), the findings revealed that,

Praying for the sick was a common practice and over one third of respondents said that prayer could cure HIV. Being HIV-positive was often seen as "a punishment from God" and a consequence of sin. As sinning could result from "the work of Satan", forgiveness was possible, and a "reconciliation with God" deemed as essential for a favourable remission of the disease. Several FLs believed that "evil spirits" inflicted through witchcraft could cause the disease and claimed that they could cast "demons" away (Roura et al., 2010, p. 1).

Roura et al. found that most of the participants doubled in both the world of faith and science. While they believed in the power of prayer for total healing, they also took their ARVs because they saw the two as complementary. However, they believed that the spiritual options for healing were superior to ARV treatment and so if they had to choose between the two, they opted to interrupt their treatment (Roura et al., 2010, p. 1) In a Ugandan study carried out within the context of Pentecostal churches (see Wanyama et al., 2007), results showed that 1.2% of PLWHIV on ART discontinued treatment after being prayed for because they believed that they had been healed. The studies focus on the impact of perceived spiritual healing on adherence to ART. Twesigye et al. (2005)'s assessment of a cultic movement called the Movement for the Restoration of the Ten Commandments of God (MRTCG) gives perhaps the most tragic example of this dynamic. Whereas most of the faith healing studies have been done in church communities with a Pentecostal persuasion, the MRTCG came out of the Ugandan Roman Catholic church. The founders attracted devout Roman Catholic believers, mostly PLWHIV, with claims of divine revelations and visions

from the Virgin Mary. They took advantage of a situation where the death toll due to AIDS was high and people were desperate for healing. ARVs were already available but not accessible to all, least of all the rural population, and very expensive.

The Movement leaders rejected the traditionalists' claim that "Slim/Munywenge" was due to "kuroga" (witchcraft) or possession by angry ancestral spirits or demons (emizimu). Instead, the MRTCG's prevention, treatment and cures for HIV/Aids were prescribed in both moral and religious terms. Accordingly, they were prescribed as the strict observation of the Ten Commandments, renunciation of materialism, sins, sex and marriage. Celibacy was demanded of all the Movement's faithful members. Subsequently, MRTCG leaders dissolved existing marriages as a requirement for initiation into this monastic "Mary's Holiness Movement." Exorcisms and prayers for faith healing of some MRTCG members with HIV/Aids-infection were seriously undertaken. Nevertheless, most of these HIV/Aids patients died in the Movement's camps. MRTCG's faith healing rituals, exorcism, and devout prayers failed to deliver God's promised miraculous intervention and healing (Twesigye, Benedicts & Benedicts, 2005).

The concerning factor in the context of this study is that this dynamic is surfacing two new forms of stigma in relation to HIV and AIDS. A resurgence of associations with witchcraft and evil spirits that need to be exorcised and this was a dominant logic in the very early stages of the AIDS pandemic (see Lentz & Majumdar, 2015; Manglos & Trinitapoli, 2011; Morrin, 2013; Seeling, Mavhunga, Thomas, Adelberger & Ulrichs, 2014; Thielman et al., 2014). It leads to sustained denial and PLWHIV move from one church to another looking for healing, instead of being tested for HIV and accessing ART. For those who are prayed for and the healing does not happen, they are stigmatized as not having enough faith.

All the issues raised by the literature point to the need for a new framework of analysis. They all to some extent raise issues of justice, hence the focus of this study, to move beyond compassion towards just engagement. Since justice is a central theme to this study, I will dedicate the remaining section in this chapter to make the case for a justice discourse which

from a research point of view is only beginning to overtly intersect with the conversation on HIV and AIDS related stigma within church circles and theological debate.

2.11 The Case for Addressing Stigma within a Justice Framework

Interrogating the gaps between comparative ethics and HIV and AIDS, Manda (2011) intimates that it was time to develop an appropriate theo-ethical framework for addressing ethics within the HIV and AIDS for faith community contexts. She, however, quickly adds that for this to happen, there was a need to move the conversation from the compassion context that has been the location of faith communities into the more challenging context of justice (Manda, 2011, p. 210). This is a journey that will not be easy for the church because, as Richard Bauer (2005) points out, the church, historically, has been more comfortable with engaging the symptoms and condemning the causes, while failing to explore the structural roots of the issues that concern society, such as poverty (Bauer, 2005, p. 15). The Kairos Document, put together by South African theologians during apartheid, has continued to be a source of inspiration and reflection in developing theologies of justice. Drawing on the Kairos confession, Frits de Lange (de Lange, 2006) calls upon the church to remember that with regards to HIV and AIDS its responsibilities were not just pastoral but also included a prophetic role to expose factors in globalization and gender inequality that were responsible for exacerbating the burden of suffering from the pandemic (de Lange, 2006, p. 263). Kanyoro (2004) argues that making progress in the global response to AIDS required refocusing advocacy and operational work on poverty, ignorance and powerlessness; factors which compromised women's access to health, hence rendering them more vulnerable to HIV infection (Dube & Kanyoro, 2004). De Gruchy suspected that the reluctance of the Christian fraternity to shift from charity and move towards justice in their HIV and AIDS responses

could be because they had unconsciously become co-dependent on the sick as a condition that requires vulnerability for its sustainability. He questioned the faith community's charity framework.

Why is it that the answer to the question about the contribution of religion to health does not also include answers such as 'political pressure for universal treatment', 'the ongoing critique of patriarchy', and the constant agitation for legal protection of People Living with AIDS'? ... The answer seems to lie in our difficulty as people of faith to shift our thinking about health from a framework of charity to a framework of social justice. To shift from a mind-set of 'picking up the pieces' to an engagement with policy, structures and law institutions (De Gruchy, 2006a, p. 4).

I propose that to make greater strides in addressing issues of endemic stigma and discrimination it is imperative that in our responses to HIV and AIDS we transition from a compassion-based to a justice-centric framework of operation. According to de Gruchy, this movement is possible when people of faith dialogue with the public health fraternity. Up until the end of the second decade in the global response to HIV and AIDS, the two spheres preferred to work separately and for the most part saw their roles as significantly different, rather than complementary. De Gruchy proposed to the faith communities they embrace both compassion and justice to effectively respond to the AIDS pandemic. He asserts that the commitment to public health, social justice and confronting unjust structures that cause disease and death, should never be distanced from the commitment to compassionate care. De Gruchy's premise is that for the church, this call to justice was urgent, given that many church leaders in this decade saw engagement with issues of social justice as incompatible with the call to compassion. Yet, in his opinion, it was the engagement with the compassion side of the AIDS response that gave the church credence and moral authority to engage the unjust political, social, religious and economic structures that contribute not only to new

infections but also to the stigmatization and discrimination of PLWHIV (de Gruchy, 2006a, p. 5).

2.12 Conclusion

The preceding review of literature has revealed that much has been written about HIV and AIDS related stigma and discrimination. Some gaps, however, exist. I will outline five that I find very significant.

Firstly, many of these empirical studies, I would argue, are descriptive and prescriptive. I found very few studies that took a critical analysis approach. The one that stood out from the rest was the study by Johnson (2012). Her ethnographic study is located in the southern part of Malawi and follows stories of women living with HIV in the era of ARVs. Johnson interrogates human rights, public health, gender and culture in the context of HIV and AIDS. The study is interdisciplinary and attempts to engage PLWHIV in a justice framework (see (Johnson, 2012).

Secondly, the discourse on stigma is still happening in discipline silos, even though everyone acknowledges the importance of interdisciplinary dialogue if the reduction of HIV and AIDS related stigma is going to be a reality. While excellent literature from the public health field, social sciences and theology disciplines exist, collaborative studies that brought the three critical disciplines together are few and far between.

Thirdly there seems to be an absence of empirical studies on HIV and AIDS related stigma that have been done with the church as the focus of inquiry in its entirety as a social system in which stigma and discrimination are enacted. Most studies focus on PLWHIV within the church.

Fourthly, the literature is also lacking in action research. Few studies are based on the application of a stigma reduction strategy. There are several prescriptive suggestions with regards to what needs to be done to reduce stigma but there is a lack of evidence with regards to where the proposals have been tested with observable results.

Finally, a good part of the literature reviewed previous literature and these were the most informative sources (see Campbell et al., 2011); (Haddad, 2011); (Mahajan et al., 2008); (Mbonu, van den Borne, & De Vries, 2009). The challenge is that they all came up with similar observations. This is an indicator that there is need for new work and new thoughts, more especially since many of the dynamics have changed with the universal access to ARVs. The gaps in the literature show that stigma and discrimination research within the context of HIV and AIDS remains a researchable area – requiring empirical, contextualized, interdisciplinary and analytical study. To a small extent, this study is a contribution in that direction.

I will end this chapter with the reflection from Grossman and Stangl on the status of the research with regards to global action on HIV and AIDS related stigma. It is a reminder that there is more work to be done and that the conversation continues. This study is one of the continuing threads.

Despite the advances in HIV stigma research, the gap in the evidence based on effective interventions is hampering national governments from integrating stigma and discrimination reduction – critical enablers of the HIV response – into national AIDS plans, and is threatening our collective ability to get to zero. ...To respond to this gap in the evidence base, a redoubling of research efforts to reduce stigma and discrimination across a variety of settings within all populations is needed (Grossman & Stangl, 2013, p. 2).

CHAPTER THREE: Theories, Methodologies and Conceptual Framework

'NEW WINE SKINS'

21 No one sews a piece of unshrunk cloth on an old cloak; otherwise, the patch pulls away from it, the new from the old, and a worse tear is made.²²And no one puts new wine into old wineskins; otherwise, the wine will burst the skins, and the wine is lost, and so are the skins; but one puts new wine into fresh wineskins (Mark 2:21-22: NRSV).

In Chapter One of this study I introduced the contextual landscape within which this study

3.0 Introduction

occurs. I articulated the critical questions and key objectives that have guided inquiry, analysis and theorization. I also introduced theoretical lenses through which the concepts of stigma and discrimination could be understood and briefly described the methodology adopted for the study. In Chapter Two I located the study within the ongoing discourse about stigma and discrimination, using a chronology of literature and the debates that have dominated the discussion in the four decades of the global response to the AIDS pandemic.

In this chapter, I will give a justification for the theoretical frameworks applied in this study. I will outline and discuss these, while drawing linkages to the core components of this study. Like the biblical parable of the admonition to put new wine into fresh wineskins (quoted above), this chapter of my study seeks to explore the use of diverse theoretical frameworks in engaging HIV and AIDS related stigma in Christian church contexts. In Chapter One, I intimated that this study builds on the research agenda proposed by scholars in the field of HIV and AIDS related stigma including: De Gruchy, 2011; Manda, 2011; Patterson, 2005.

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This agenda proposes a broader re-conceptualization of stigma, contextualization of research and calls for interdisciplinary dialogue. Given the complexity of this agenda, we cannot rely on the well-used theoretical frameworks and their limitations to generate new knowledge. The application of fresh wineskins to guide inquiry in this study is in response to the call made by (R. Parker & Aggleton, 2003) to move beyond the limitations of the psychological and behavioural models that tend to individualize and stereotype stigma and discrimination and keep it masked, to something broader. The nature of moral exclusion calls for the use of a theoretical framing and methodology that allows for interrogation of the power structures, provide for inter-disciplinary dialogue and provide appropriate lenses for theological reflection.

I therefore chose to use liberation theology as the over-arching theoretical framework for this study, because of its contextual, inductive, interdisciplinary orientation, as well as its commitment to praxis. Gustavo Gutiérrez's liberation theology, used together with Pierre Bourdieu's social cultural theory applying social theology methodology, provided an appropriate theoretical framing for this study. Together they make up what I consider a 'new wineskin'. I will introduce liberation theology and Bourdieu's social cultural theory and their broad significance to this study and then develop them in the rest of the chapter. I will now explore in greater detail the historical context in which liberation theology was developed and look at ways in which it mirrors the context under study.

3.1 Historical Foundations of Liberation Theology

Liberation theology was birthed on the bedrock of the struggle for justice for the poor and those marginalized by the rich, religious and powerful in the early 1950s and 60s in colonial Latin America. As the church grew in strength, influence and power its leadership developed Page | 67

a 'preferential option' for the wealthy both in alignment, service and action. Consequently, the Christians in the lower echelons of the social and power strata started to rebel against the merging and institutionalized injustice within the church. Official government economic development policies of South American countries were increasingly being designed to favour the rich and alienate the poor, as Clodovis Boff and Leonardo Boff observed of one such program.

This benefited the middle classes and urban proletariat but threw huge sectors of the peasantry into deeper rural marginalization or sprawling urban shantytowns. Development proceeded along the lines of dependent capitalism, subsidiary to that of the rich nations and excluding the great majorities of national populations. This process led to the creation of strong popular movements seeking profound changes in the socio-economic structure of their countries (L. Boff & C. Boff, 1987).

The protagonists of liberation theology were ordinary Christians who were concerned about the decay happening in their churches and knew that they had to engage to change the status quo. They initiated dialogue between the church and the declining society. They started connecting the dots between the Christian faith and the outcries for freedom, justice, transformation and liberation for the poor and marginalized. They reflected on the relationship between the gospel and social justice. They reached across the denominational barriers and formed social movements to challenge the 'establishment' the church had become.

These social movements did not endear themselves to the church leadership hierarchy at the time, partly because of their extensive use of Marxist ideology in social analysis and at times violent nature. On the other hand, the movements were challenging the positions of the church in relation to the wealthy, poor and marginalized. As different sections within the church began to awaken to the social responsibility of the church and began to understand the

true causes of poverty and underdevelopment, they engaged in joint reflection on critical issues. Out of these joint reflections arose what we know today as liberation theology. The refinement and articulation of liberation theology is largely due to the work of the following theologians: Gustavo Gutiérrez, Leonardo Boff, Jon Sobrino, Segundo Galilea, Juan Luis Segundo, Lucio Gera, Emilio Castro, Julio de Santa Ana, Ruben Alves, José Míguez Bonino and Hugo Assman, among others (Clarke & Linzey, 2013).

The historical account of the development of liberation theology highlights another area of its relevance to this study. There is a similarity in the struggle of the privileged clergy in Gutiérrez's day to the struggle of the church leaders in Malawi to confront moral exclusion of PLWHIV head on. Patterson alludes to this dilemma in her articulation of the research gap with regards to the interface between stigma and ecclesiology.

This is partly because it involves asking painful and challenging questions; partly because it is threatening to individuals and institutions to have to question the beliefs and attitudes around which personal or institutional identities are constructed; and partly because stigma is a complex issue that impacts on so many aspects of life and faith that do not at first sight, appear to be connected with HIV or AIDS (Patterson, 2011, p. 351).

Liberation theologians had to ask difficult questions of their churches to address the issues of their time. Likewise, I used the tools that they developed from their processes to ask difficult questions of a similar context, the church, where moral exclusion from meaningful participation in church life is having a dehumanizing impact on PLWHIV.

We will now take a more critical look at the foundational principles of liberation theology and their relevance to the exploration of moral exclusion.

Gustavo Gutiérrez has defined theology as 'critical reflection on praxis' – reflection on the action of the church in the world from a point of faith (Gutierrez, 1970, p. 245). Liberation, Page | 69

on the other hand, implies freedom from any inner or outer encumbrances which inhibit the fulfilment of one's potential (Evans, 1992, p. 138). José Miguez Bonino combines the two aspects to define liberation theology as a process that begins with the marginalized people's experience of participation in the struggle for liberation; progressing to analysis of the realities involved in that struggle in the light of their faith, and culminates in the development of a theological interpretation which in turn strengthens and clarifies their participation in the struggle. This process, argues Bonino, has to occur at several complex, integrated and inseparable levels. The social and political level which depicts the dreams and aspirations of those oppressed and needing liberation is in conflict with those of their oppressors. At the human level liberation is seen as a historical process that enables those oppressed in any manner or form to become masters of their own destiny, as they navigate the waters of social change of their time. This is an aspect that sets liberation theologies apart from other forms of theology. The people are not merely observers but participants in the formation of their own theology. It is not the domain of the elite few but a community of people affected by oppressive situations (Bonino, 1975, p. 521). As R. R. Ruether (1972) described it, the poor and oppressed become the prophetic community, following a process of conscientization in the Freirean sense of self-liberation. Gutierrez argues that liberation theology does not stop at a critical reflection of the world but is committed to being a part of the process of transforming that which is unjust. He contends that liberation theology is "a protest theology in relation to any dehumanizing situation and joins the struggle of the oppressed to work towards a more just society" (Gutierrez, 1988, p. 12). From Gutiérrez's framework I will isolate four founding principles for liberation theology. First, is a preferential option for the poor – an interpretation of the Christian faith out of the suffering, struggle and hope of the poor. Second is the recognition that genuine liberation theology arises out of the struggle of

the oppressed. Thirdly, liberation theology acknowledges the structural nature of oppression and hence the commitment to critique society and the ideologies sustaining it. Finally, it is committed to work for justice and hence to critique the activity of the Christian faith community from the perspective of the poor (Gutierrez, 1988). I will first take a look at the core components of liberation theology and then explore in greater detail its relation to moral exclusion.

3.2 Liberation Theology: A Critical Reflection on Praxis and Justice

Right from the outset, liberation theologians were committed to an ongoing process of reexamining revelation and tradition with the aim of isolating the social and liberating dimensions implicit in both sources of truth. Liberation theology hinges on praxis informed by theory. Liberation theology has a bias for informed action on behalf of the oppressed and marginalized to mitigate those oppressive situations. Litonjua puts it very succinctly,

The theological task for liberation theology demands orthopraxis, the dialectical unity of action and reflection: the oppressive reality and liberating practice confront and challenge the traditional understanding of the Christian message, the perennial symbols of the Christian Faith; renewed theological understanding and revitalized Christian symbols, in turn, further illumine and inspire the hope of the liberation struggle (Litonjua, 2012, p. 25).

For the early liberation theologians, the greater aim was to ensure that the truth emanating from both tradition and revelation would be relevant to the contexts of oppression in which they were operating and that it would be a function in the liberation process. Thus developed the hallmark three stage cycle of liberation theology: seeing, judging and acting. I will now expand on the three stage cycle of liberation theology.

3.3 Liberation Theology's Three Stage Cycle

The three stage cycle of liberation theology has come to be known as the "see, judge, act" methodology. Seeing refers to the process of analysing one's reality or experience with a view to better understand the root causes of the situation in question. Judging is considered the theological reflection stage in that it seeks to relate the information gleaned in the seeing stage to faith. Acting on the other hand focuses on what can be done about the situation and that is why it is referred to as the pastoral stage. Liberation theology begins with the facts, and then onto theory and action. Liberation theology links reality, theory and practice through a process of critical reflection.

The study of moral exclusion within local church contexts is as complex as the oppressive situations that gave birth to liberation theology. There is a need to look below the surface to truly see what it is within the church structures that legitimize persistent moral exclusion of PLWHIV from church life. There is a need to reflect theologically on the results of the 'seeing' process. On the other hand, reflection without a commitment to influencing praxis would be an injustice to PLWHIV. This study is committed to contributing to a new way of 'seeing'. Engaging at these three levels is not something that can be done through one discipline. It requires the incorporation of human and behavioural sciences, such as social work, sociology, psychology, anthropology and economics, as essential and integral aspects of the theological reflection process. A combination of liberation theology and social cultural theory provides for that process and hence its relevance to this study.

3.4 Preferential Option for the Poor and Justice

Liberation theology recognizes the inviolable need by everyone for liberation from any kind of oppression, be it political, economic, social, sexual, racial or religious, to mention but a few. According to the proponents of liberation theology, freedom is the central theme.

Justice and freedom are meant for all and should not be considered the privileged domain of a few elite oppressors.

Four decades into the AIDS pandemic, a cure is still elusive and the social aftermath of the pandemic is far from over. The 2011 UNAIDS Political Declaration on HIV and AIDS, in alignment with this liberation theology principle, makes the following observation.

We recognize that close cooperation with people living with HIV and populations at higher risk of HIV infection will facilitate the achievement of a more effective HIV and AIDS response and emphasize that people living with and affected by HIV including their families should enjoy equal participation in social, economic and cultural activities without prejudice, and discrimination and that they should have equal access to health care and community support as all members of the community (UNAIDS, 2011).

This study is about justice. As I observed in Chapter Two, the early discourse on HIV and AIDS within church circles refused to acknowledge that it had anything to do with justice. It was relegated to the medical and public health domain, the responsibility of the medical professionals. However, today, stigma and discrimination are recognized as human rights issues and are included as some of the factors on the UNAIDS score cards used to measure progress on the Global AIDS response. The justice foundations of the liberation theology framework in this study lends relevance to its choice as a theoretical lens for inquiry.

Liberation theology is contextually, methodologically and analytically relevant to the study of moral exclusion of PLWHIV as a dehumanizing social construct. It is contextually relevant because it was born out of oppressive social situations within the church, much like the focus

of this study, which is moral exclusion of PLWHIV within a church context. It is methodologically relevant because the process of liberation theology allows for the engagement of power structures from a faith perspective with a view to liberation. This study is an exploration of moral exclusion as a journey moving beyond compassion towards just engagement, a study that requires the engagement of the structures within the church context. It is analytically relevant because liberation theology allows for the use of social research tools to interrogate power structures within social systems. Exploring moral exclusion in this study is about fundamentally interrogating the power structures within the local church settings. In the next section of this chapter I will outline Pierre Bourdieu's social cultural theory and its relevance to this study.

3.5 Pierre Bourdieu's Social Cultural Theory

Bourdieu's social cultural theory analyses the mechanisms of reproduction of social hierarchies using a methodological framework that primarily consists in three elements: the field, the doxa and the habitus. (Bourdieu, 1977). The field is a system of social positions structured internally in terms of power relations. A cultural field is comprised of a series of institutions, rules, rituals, conventions, categories, designations and appointments which constitutes an objective hierarchy, and which produce and authorize certain discourses and activities. But a field is also constituted by, or out of, the conflict which is involved when groups or individuals attempt to determine what constitutes capital within that field and how that capital is to be distributed. The doxa, on the other hand, refers to deep founded, unthought through beliefs taken as universal truths that inform action. The doxa consists in a set of core values and social discourses which a field articulates as its inviolable, foundational principles viewed as inherently true and necessary for normal life functions within a

particular cultural field. Habitus refers to a system of lasting acquired schemes of perception, thought and action. The habitus expresses, on the one hand, the way in which people 'become themselves' – develop attitudes and dispositions – and, on the other hand, the ways in which those individuals do life. The concept of the habitus helps us understand that our ability to perceive or think and hence act along a given trajectory is partly historically conditioned by our environment (Bourdieu, 1977).

3.5.1 Symbolic Systems and Symbolic Violence

A key concept that comes out of Bourdieu's social cultural theory is that of symbolic systems and their ability to reproduce inequalities. For purposes of this study I took into consideration symbolic power and symbolic violence. Symbolic systems have codes with deep structured meanings that are used by different social groupings to order and understand the world they inhabit. These codes are therefore ascribed a social integration function (Swartz, 1996). The downside of symbolic systems is that while they provide a cognitive integrative function, they have great potential to become instruments of domination. It is this aspect of symbolic systems that was critical for this study. According to Bourdieu, symbolic power resides not in the force of ideas but in relation to social structure. It is defined by a determinant relationship between those who exercise this power and those who undergo it. The transition from symbolic power to symbolic violence happens insidiously. It is a process where those dominated or oppressed accept as legitimate the terms and conditions of their domination. In so doing, they give consent to the dominating authority to continue along the same trajectory. Bourdieu concludes, therefore, that every power which manages to impose itself as legitimate by concealing power relations which were the basis of its force adds to the

oppressive and dominating influence of those power relations (Bourdieu, 1973). This is how systems of domination become legitimatized.

Bourdieu's theory was essential to this study because of his vision of sociology as an engaging process of exposing structures that underlie the physical and cognitive practices of people (Bourdieu, 1977). One of the assumptions underlying this study was that the reason moral exclusion of PLWHIV has been a persistent obstacle in making progress around the global response to AIDS is the existence of structures in society that legitimize it. Bourdieu's theory was critical in analysing what those structures are and how the power dynamics operational in those systems impact on moral exclusion (Bourdieu, 1989).

In the rest of this chapter I will show how the liberation theology framework and Bourdieu's social cultural theory engage with the identified gaps as well as core research aspects of the study, namely: the agency of People living with HIV, local church structures, and power relations. In Chapter One of this study I introduced the proposal by Steve de Gruchy, Gillian Patterson, Parker, Aggleton and Birdsall for a new research agenda. According to these scholars, the discourse on HIV and AIDS related stigma and discrimination had several glaring gaps that needed to be addressed. One was the methodological challenge. Second was the need for a broader conceptualization of stigma and discrimination to interface with cultural power structures. Thirdly was the gap related to the absence of inter-disciplinary dialogue to inform discourse.

3.6 Agency in Liberation Theology

Gustavo Gutierrez argues that if theology is to liberate, it has to come from a different source.

He asserts that such theology does not come from the traditional non-believers but rather

from what he calls 'non persons' [sic]. In the context of this study, this would refer to the morally excluded, because they are affected by HIV and AIDS.

Those whom the prevailing social order does not acknowledge as persons: the poor, the exploited, those systematically and lawfully stripped of their human status, who hardly know what a human being is. Non persons represent a challenge, not primarily to our religious world but to our economic, social, political and cultural world. Their existence is a call to a revolutionary transformation of the very foundations of our dehumanizing society (Litonjua, 2013, p. 87).

The recognition by liberation theology of the importance of the agency of the marginalized is of critical significance to this study. Albert Bandura, in his social cognitive theory, defines agency as that ability in human beings to rise above their environment and its limitations, shape their life circumstances and influence the directions their lives take. He rejects the notion that people are purely products of their environment. He argues that contrary to popular thought, people create the social systems which consequently order and influence their lives (Bandura, 2006).

3.7 Liberation Theology as Methodology

For this study, it is difficult to draw the line between theory and method because the methodology used to carry out the study, social theology, derives from liberation theology. Segundo (Juan Luis Segundo, 1976, p. 9) describes the liberation theology process as what has become famed as the 'hermeneutic circle'.

First, there is our way of experiencing reality, which leads us to ideological suspicion. Second there is the application of our ideological suspicion to the whole ideological super structure in general to the theology in particular. Third there comes a new way of experiencing theological reality that leads us to exegetical suspicion, that is the suspicion that the prevailing interpretation of the bible has not taken important pieces of data into account. Fourth we have our new hermeneutic, that is our new way of interpreting the fountain head of our faith (Scripture) with the new elements at our disposal (Juan Luis Segundo, 1976, p. 9).

Litonjua crystallizes the hermeneutic thrust of liberation theology thus, "to critically reflect on the present, to critically reclaim the past and to critically create the future (Litonjua, 1998, p. 45). Liberation theologies are contextual but they all share the same methodology. While realities that give birth to the different theologies may differ, they all share the same process. The oppression of women gave birth to feminist theology, slavery birthed black theology while the ills and aftermath of colonization was one of the forces behind African theology. It would be erroneous to consider liberation theologies as franchises of the same brand. Liberation theologies, however, can be treated as members of the same family, each with their unique features given that they are all founded on certain fundamental elements. As Jose Miguez Bonino points out, "Liberation theologies are contextual in the sense that they consciously and explicitly address a particular historical and social situation and relate to it their theological interpretations" (1996: 521). One such theology is 'Social Theology'. This study used the social theology methodology as the framework of analysis. The social theology framework is appropriate to situations that seek to understand social phenomena from a theological perspective. The social theology framework, like all liberation theologies, allows for critical assessment of social situations, not circumventing the issues of structure, power and justice. It allows for an engagement between the world and theology, doing so with credibility. Since this study sought to address moral exclusion, a social phenomenon that is influenced by social and cultural power structures within a religious context, I found the use of social theology very appropriate. Steve de Gruchy, in 'Tentative Reflections on Religion, Rationality and Research in Social Theology,' outlined the social theology

methodology in four critical steps. These are: faith commitment, social analysis, theological

reflection and strategies for action (de Gruchy, 2006b). These critical steps, derived from the methodology proposed by liberation theology, are detailed below.

3.8 Social Theology Methodology

3.8.1 Stage One: Faith Commitment

The "pre-rational" decision that influenced my undertaking of this study is that I am a Christian developmental social worker working in the area of HIV and AIDS within a religious context. Liberation theology advocates for incarnational experiences with the poor as critical in developing solidarity with the poor. In this study, the poor refers to PLWHIV who are morally excluded from meaningful church involvement because of their HIV status. The incarnational experience that has greatly influenced my solidarity with PLWHIV has involved losing five siblings to AIDS and raising children who are HIV positive. I realize more and more that I need to engage in critical theological reflection and let this inform my praxis, refresh my compassion and energize my relationships. In working with local church leadership over the past fifteen years in the areas of HIV and AIDS, I have discovered that it is easier for clergy to make responsive changes if they are theologically founded. This has driven my desire to propose a theological framework for reflection on moral exclusion. Reflecting on the deaths of my siblings brings me to that place where I want their deaths to count for something. As I support my children to handle moral exclusion at school and at church and help the institutions that are part of their lives respond differently, I need to engage socially and theologically with the issues.

3.8.2 Stage Two: Social Analysis and Pierre Bourdieu's Social Cultural Theory

For the social analysis stage of the framework, the study applied the tools of Pierre Bourdieu's sociological cultural theory. Earlier in this chapter, I outlined the key components of the theory and its significance to this study. In this segment I will discuss a key aspect of the social cultural theory that is central to this study. To Bourdieu, sociology was a means of combating symbolic violence. This study considers moral exclusion as a form of symbolic violence. Bourdieu's work is very useful to this study in that it is committed to methodical holism. This methodology requires that social structures be given primacy in social analysis because people's behaviour, practices, choices and actions are greatly influenced by the social structures of which they are a part and the same structures shape their ability to form dispositions and capacities for action.

An underlying assumption of this study is that moral exclusion is legitimized by dominant social hierarchies and structures within local church ministry settings. This theoretical framework was a useful tool in uncovering the social hierarchies and structures that legitimize stigma and discrimination in the context of the study.

3.8.3 Stage Three: Theological Reflection

De Gruchy (2006b) presents the third step in the methodology of social theology as theological reflection on the outcomes of the social analysis. The theological reflection section of this study was done with the support of tools that were developed by the Catholic Church in framing their vision for social justice. Historically, the Roman Catholic Church has played a significant role with regards to social justice and action. Consequently, the Catholic Church has developed theological resources for dealing with issues of justice and social response. In Malawi, the Catholic Church is a highly respected voice when it comes to issues

of HIV and AIDS and is often looked to for leadership because they were among the first to respond strategically to the pandemic. The current strong leaning towards ecumenical cooperation in addressing HIV and AIDS within the major denominational churches renders the Catholic social justice framework an invaluable tool of ecumenical relevance. The local churches within the Tubepoka Network in Chitipa are from different denominations, including Catholic, Evangelical and Pentecostal orientations. The churches are committed to learning together and to work together for the transformation of their local communities. The use of the Catholic social justice framework as an aid in developing a theological framework to explore moral exclusion within the church context will be embraced.

The relevance of the Catholic social justice framework to this study is that it lends itself to ethical analysis with a strong alignment to practical solutions. The tools used have their origins in liberation theology and intersect with the pillars of Bourdieu's social cultural theory. The tools referred to here are the principles of dignity for the person, the common good, preferential option for the poor, structural sin, and subsidiarity. I will outline these principles in relation to their application to this study.

3.8.3.1 Human Dignity

A strength of Catholic social teaching that is critical for this study is its conceptualization of human dignity. Diverting from modern liberal individualism, the Catholic social justice framework recognizes the inviolable nature of individual human beings but also affirms the inherent social nature of people. In Catholic social teaching, human dignity is a cornerstone of social justice. Since this study is about PLWHIV finding their place within a social system, this principle is a very useful tool of analysis.

3.8.3.2 The Common Good

The principle of the common good refers to the totality of a human being (emotions, intellect, dreams, perceptions, capabilities) in relation to their meaningful participation in their community. Describing the principle of the common good, Cahill draws attention to the social nature of people and their interdependent existence in communities. She observes that each social system can either enable or impede the just participation of its members in community life. It is her summary argument below, however, that is central to the purpose of this study.

Every member of society has a right of participation in the common good, claiming rights and fulfilling responsibilities; the ultimate purpose of the common good to enhance the wellbeing of every single member of society, as well as society as a whole. The common good includes both the material and social aspects of human flourishing (Cahill, 2000, p. 288).

3.8.3.3 Preferential Option for the Poor

Earlier in this chapter, I discussed the preferential option for the poor in the broader sense of liberation theology. Cahill presents the case for affirmative action on behalf of those morally excluded in the AIDS pandemic as a duty not only of human justice but of Christian love. She argues that those who have historically suffered from exclusion have a right to preferential compensation in access to social goods (Cahill, 2000, p. 289). This study explores the place of affirmative action within church contexts on behalf of PLWHIV.

3.8.3.4 Structural Sin

In the first decade of the HIV and AIDS pandemic, attention was drawn to individual sin as a major factor in the spread of HIV infection. By the third decade, AIDS was recognized as a justice issue whose spread was also attributed to various structural agents in society. In her thesis on AIDS, Justice and the Common Good, Cahill posits that the structures of poverty,

gender discrimination, and exploitative economics significantly contribute to the spread of HIV infection. In Catholic social teaching, these are referred to as 'structures of sin'.

Another dimension of structural sin that Cahill discusses that is pertinent to this study is well captured in her assessment below.

Structural sin does not refer to impersonal forces beyond human control, but to the concrete acts of individuals who introduce these structures, consolidate them, and make them difficult to remove, allowing them to grow stronger (Cahill, 2000, p. 291).

This study explores the presentation of these structures in local church contexts, their impact on human dignity and the right of PLWHIVs to just participation in church life.

3.8.3.5 Subsidiarity

The principle of subsidiarity is more aligned to the praxis side of liberation theology. It also provides a good transition to the fourth stage of the social theology methodology used in this study. Subsidiarity is about corrective measures to address the imbalances and inequalities in society resulting from injustices such as moral exclusion of PLWHIV. Cahill cautions that such initiatives are most effective when they nurture networks of collaboration and accountability in a spirit of solidarity, building partnerships that empower people to improve their own situations (Cahill, 2000, p. 293).

There are several points of intersection between Bourdieu's cultural theology theory and the Catholic social justice framework. This adds to the weight of importance of this methodology as a tool for theological reflection in this study. These relationships help provide integral cohesiveness in analysis. I have captured these intersections in the table below:

<u>Table 3.1: Intersections between Bourdieu's Social Cultural Theory and Catholic Social</u>
Justice Framework.

Bourdieu's Sociological Cultural Theory	Catholic Social Justice Framework
Commitment to methodical holism which	The consideration of structures that place people living with
gives social structures primacy in social	or affected by AIDS at risk as structural sin that needs to be
analysis.	addressed.
The reproduction of social hierarchies is	The importance of the common good principle to ensure
influenced primarily by systems of social	that communities provide structures that facilitate the just
positions structured internally in terms of	cooperation of all persons regardless of their assigned social
power relations.	position in society.
The importance of recognizing symbolic	The principles of human dignity and subsidiarity which
violence, where through processes of	affirm the inherent social nature of people as well as their
imposing particular ways of perception, the	inviolable value and hence the importance of making room
oppressed or dominated begin to recognize an	for individual's human agency in the process of program
unjust social order as just.	development.

Moral exclusion is an issue of ethics and justice. It is about dehumanizing power structures. While Bourdieu's theoretical framework provides social analytical tools to understand stigma and discrimination through societal structures, the Catholic framework for social justice is an excellent theological reflection tool for examining and determining practical implications for dealing with moral exclusion in a church setting. This brings us to the last stage in social theology methodology.

3.8.4 Stage Four: Strategies for Action

The fourth stage in social theology methodology is about praxis. The vision and mission of liberation theology demands a commitment to action – action to overcome poverty,

dismantle and replace the unjust structures of domination and oppression to bring about emancipation and freedom of the poor and oppressed (C. Boff, 1987). While it is beyond the scope of this study to develop programmatic initiatives to redress moral exclusion of PLWHIV from church life – since I am using a liberation theology framework that lays great emphasis on praxis, it is critical that I discuss this phase of social theology methodology, albeit briefly. Litonjua mentions four specific steps needed to realize the activist or political dimension of this commitment. First, there is a need for careful analysis of the sources of injustice. Second, there is a need to avoid collusion with the forces responsible for injustice. Third, there is a need for carefully planned and concerted action to challenge the injustice. Fourth there is a need to design realistic alternatives to the unjust structures (Litonjua, 2013).

While action strategies to deal with moral exclusion is beyond the ambit of this study, I developed a liberative hermeneutic of missional justice for praxis on moral discrimination which can also be applied to any situation of injustice. Also, the framework for theological reflection on moral exclusion developed by this study will provide a tool that can be used by students of ecclesiology and church leaders in their journey from compassion towards justice.

In this chapter I sought to demonstrate the relevance of Bourdieu's social theory used in combination with liberation theology as a theoretical and analytical framing for this study. In the next chapter I will focus on the specific research methodology which I employed for this study.

3.9.1 Conclusion

This study was about exploring the experience of PLWHIV in their struggle for just engagement with their churches. In this chapter I sought to demonstrate the relevance of Bourdieu's social theory used in combination with liberation theology as a theoretical and analytical framing for this study. Given that the end goal of liberation theology is freedom towards increasing agency for the marginalized, it is an appropriate framework to use for this study. I have discussed the foundational principles of liberation theology and how they intersect with the study of moral exclusion. However, it is important to point out that it is in the methodology rather than content that the liberating aspects of liberation theology are best brought out. It is for this reason that part of the chapter was dedicated to a detailed discussion of liberation theology methodology as it was applied to this study. In the next chapter I will discuss the methods, designs and strategies used to produce the data in this study.

CHAPTER FOUR: Research Design and Methods

The product of the interpretive bricoleur's labor is a complex, quilt-like bricolage, a reflexive collage, a set of fluid, interconnected images and representations. The interpretive structure is like a quilt, a performance text, a sequence of representations connecting the parts to the whole (Kincheloe, 2001).

4.0 Introduction

This study was empirical in nature and located within a critical research paradigm, using the following research methods: in-depth interviews, focus group discussions and participant observation. I define myself as a bricoleur qualitative researcher which influenced my decision to use an inter-disciplinary approach to my methodology. Kincheloe, borrowing from the French meaning of a handyman or bricklayer, describes the bricoleur approach to research as an interdisciplinary process whereby disciplinary boundaries are crossed and the analytical frames of more than one discipline are employed by the researcher. She argues that,

The researcher as bricoleur-theorist works between and within competing and overlapping perspectives and paradigms. The interpretive bricoleur understands that research is an interactive process shaped by the personal history, biography, gender, social class, race and ethnicity of people in the setting. Critical bricoleurs stress the dialectical and hermeneutic nature of interdisciplinary inquiry knowing that the boundaries between traditional disciplines no longer hold (Kincheloe, 2001, p. 683).

Given the complex nature of this study I used inter-disciplinarity in the context of Kincheloe's understanding. Exploring moral exclusion of PLWHIV from church life required a critical reading of their experiences. I worked back and forth across several disciplines including: social work, theology and development, psychology and gender studies. That is why my methodology defies 'hegemonic colonization' by any particular discipline boundary but rather uses what Pinar describes as a 'hybrid of interdisciplinary

constructions, integrating and melding of several disciplinary perspectives into new methodological synthesis. This approach appreciates the reality that "knowledge frontiers rest in the liminal zones where disciplines collide, what has come to be called as that scholarly world with faded disciplinary boundary lines" (Pinar, 2001, p. 698).

The methodology I have used in this study is as bricoleur in stance as is my theoretical framework that favours melded integration of liberation theology, social theology and Pierre Bourdieu's social cultural theory and the Catholic social justice framework. Like the complex social situations that gave birth to it, the liberation theology discipline incorporates the human and behavioural sciences not merely as referral disciplines but rather as integral aspects of theological thinking. Social theology on the other hand allows for critical assessment of social situations allowing for the engagement between the world and theology. Pierre Bourdieu's social cultural theory draws heavily on structuralism as a body of theory and system of analysis which informs practices in academic fields such as linguistics, anthropology, cultural studies, Marxism and psychoanalysis. Hence the metaphor of the quilt as applied by Kincheloe, gives a graphic description of the methodology that this study applied to answer the research questions and achieve the derived objectives articulated in chapter one.

4.2 Research Approach

As already mentioned, this was a qualitative empirical study located within a critical research paradigm. I used the following research methods: in-depth interviews, focus group discussions and participant observation. Guba & Lincoln (1994, p. 110) provide three distinctives of the critical paradigm that are pertinent to this study. First is an ontology that is

based on historical realism. Secondly, epistemologically the critical paradigm is transactional and subjective and finally the method of inquiry is dialogic and dialectical.

4.3 Research Design and Methods

The research design used in this study followed the sequence of the social theology methodology. It was predicated upon the basis that I have worked in the communities to be studied for over five years, have very strong relationships with the church leadership and I have operational literacy and fluency in the local languages, and that I was able to make use of a team of field assistants. This enabled me to plan an extensive process that had operational support (see 4.6. below).

As already asserted, for this study it was difficult to draw the line between theory and method because the methodology used to carry out the study, social theology, derives from liberation theology. Juan Luis Segundo (1976, p. 7) describes the liberation theology process as methodology in what has become famed as the 'hermeneutic circle'. Others (see Bontekoe, 1996, p. 5) have defined it as the 'hermeneutic spiral'. This is a process that begins with critical understanding of our experiential reality, that causes us to be suspicious of the ideologies operational within that reality. Second we apply the developed ideological suspicion to the ideological superstructure of our reality in general but with more poignant attention to the theology in particular. This results in a new way of experiencing theological reality. The third level in the methodology is a function of our suspicion that the dominant theologies undergirding our experiential reality are interpretations that have not taken the total reality of our context into account. The fourth stage in the hermeneutic circle is the development of a new hermeneutic, a new way of seeing, interpreting and appropriating reality.

Gadamer asserts that the hermeneutic circle has no closing but rather goes on in a spiral, with dialogue happening back and forth all the time between the parts of the system and the whole (Gadamer, 1975). He also introduces the notion of 'fusion of horizons', referring to the understanding that happens when the different parts of a system are in dialogue, creating an environment that potentiates birth of new meaning (Stern, 2003, p. 844). Gadamer deduces that when the historical and current horizons fuse, and new meanings are birthed, they bridge the gap between what is familiar and that which is not, thus building a bridge to the future. This hermeneutical concept is critical to this study because it is about movement from a framework of compassion towards one of justice in the engagement of PLWHIV in the church context. Given the challenges involved, bridges need to be built between the new horizons to enable change to happen. Hence the appropriateness of the application of social methodology to this study. Liberation theology has a hermeneutic thrust that Litonjua crystallizes as the ability "to critically reflect on the present, to critically reclaim the past and to critically create the future" (Litonjua, 1998, p. 45). De Gruchy (2006b) adapts the hermeneutic circle principles to propose a social theology methodology. This he outlines in four critical steps namely: faith commitment, social analysis, theological reflection and strategies for action. I have used the diagram below to outline the methodology and show how the hermeneutic circle processes align with the social theology methodology.

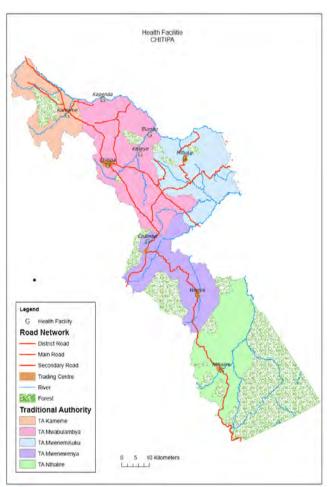
Figure 4.1 Schematic Overview of the Research Methodology Used in the Study

	Research design: Data Production Strategies	Research Methods and Instruments
(i) An embodied faith experience.	(1) The motivation to carry out the study. A reflection on my life story and how it intersects with the study.	
(ii) Social analysis (Application of ideological suspicion leading to exegetical suspicion.	 (2) Literature review – i.e. situating the research in the wider scholarly debate, and reflecting the contribution of the study to ongoing dialogue. (3) Field work – Empirical study – primarily qualitative methods. Multi-method approach using a range of instruments, providing for triangulation of findings. 	(a) Research instruments: Interview guides, focus group discussion guides, observation schedules. (b) Identify study populations using purposive sampling.
Theoretical Frames (1) Social Cultural T Bourdieu		(c) PLWHIV: (c1) Participant observation (c2) Focus group discussions (c3) In-depth interviews (d) Church leaders/pastors
		(d1) Participant observation (d2) Focus group discussions (d3) In-depth interviews (e) Write up research, analyse and present findings in academic format.
↓	(4) Theoretical engagement with research findings using Bourdieu as the framework – and with others that might be helpful: Foucault	
(iii) Theological analysis Application of exegetical suspicion	(5) Liberation theology alongside Catholic framework for social justice	
(iv) Action strategies	(6) A new hermeneutic	

4.4 Geographical Context

Figure 4.2: Map of Chitipa District

The study is located in the Chitipa District of Malawi. It is the most northern district in the



Tanzania. Its remoteness and border location make it vulnerable to high levels of HIV infection, because of the movement of people across the borders.

To ensure that the sample was representative, I made sure that I spread the zonal selection across three geographical divisions of the district. As the map in Figure 4. illustrates, Chitipa District is divided into five traditional authorities. I could not get to all the zones due to financial constraints. I therefore chose my sample from three

out of the five traditional authorities (TAs): Nthalire, Mwaulambya and Kameme. Nthalire Zone is in the southern corner of the district. It was also critical to the study because it has an interesting cultural make up. It borders Zambia and therefore brings together a combination of Zambian and Malawian cultural influences and culture is one of the constructs that my study uses to analyse the structural injustices that impact on local church based stigma and discrimination. Mwaulambya is the largest traditional authority and represents the central

region of Chitipa District. Also four of the zonal networks in the Tubepoka Churches

Network are located in this TA. I therefore chose two zones out of this Traditional Authority.

TA Kameme represents another critical geographical location and that is why it was included in the sample. It borders with Tanzania and the local churches in that this location draw much from the Tanzanian traditions, while the cultural traditions in the area have some influence from Tanzanian tribes in the Songwe area. The study participants were evenly distributed between 5 zonal networks from the three traditional authorities.

4.5 Sampling

The participants in this study were selected using the purposeful sampling technique. This is where participants are intentionally included in the sample on the basis of their ability to provide the information required by the study. Patton argues that purposeful sampling is one of the core distinguishing attributes of qualitative inquiry. According to him, the power of purposeful sampling lies in selecting information-rich cases from which one can learn a great deal about issues of central importance to the purpose of inquiry. It is these, argues Patton, that yield insights and in-depth understanding rather than empirical generalizations (Patton, 2002, pp. 272-273). Picking up on the 'rich case' concept, Marshall observed that people are not equally good at observing, understanding and interpreting their own and other people's behaviour. Some people are 'richer' than others and more likely to provide insight and understanding for the researcher (Marshall, 1996, p. 523). The qualitative nature of my study warranted the use of purposive sampling in the choice of traditional authorities, zonal networks, local churches, support groups, PLWHIV and church leaders to be included in the sample. I have worked with the TCN for over 10 years in various capacities as I indicated in the introduction to this study. I therefore had good foreknowledge of the context of study.

This made it possible for me to purposively select participants for the sample with the assurance that they had the capability to provide the responses necessary for data production in line with the research questions. For example I knew which churches had support groups and therefore I was able to include support groups that fit my study criteria.

4.5.1 The Church Sample

All the local churches included in the study sample were selected by virtue of being active members of the Tubepoka Church Network (TCN) in the Chitipa District of Malawi. In spite of its remote location, TCN is very strong and committed to a vision of transforming their communities. A successful study in Chitipa District will hopefully provide inspiration and a learning space for other church networks in the district and country. Tubepoka means we are in this together in the Lambya language, spoken widely in Chitipa District. The network has a membership of about 200 local churches from 16 different denominations, organized in 10 zones that are spread across the district. Its denominational component includes: Church of Central African Presbyterian (CCAP); Assemblies of God (AOG), African International Church (AIC), Baptist Church, Pentecostal Holiness Association (PHA), Last Church of God, New Apostolic Church (NAC), Last Church of Malawi, Pentecostal Holiness Church, Lutheran Church, Moravian Church, Roman Catholic Church (RCC), Seventh Day Adventist Church (SDA), Church of African Presbyterian (CAP) and African Church. With such a variety of local church traditions, it provided a very rich context to explore structural injustices across a spectrum of traditions. Given that local churches are very much a product of their geographical localities; a district-wide network provided a rich cultural context for the study of the factors that influence stigmatization of PLWHIV, since each regional network would bring a different perspective to the study. The zonal networks I included in

the study were purposively selected to be part of the sample, based on how active they were in the development programs of the TCN and on the basis that they were meeting regularly to learn together within the Tubepoka Churches Network. From each of the five zonal networks included in the sample (see 4.4 above) I selected two churches to participate in the study. The churches were purposively selected based on the following criteria. Firstly, they had an active ministry to PLWHIV and more specifically a support group for PLWHIV that was at least three years old. Secondly, the church was a role model, was respected by the others in the network, and was looked up to for leadership and guidance. Table 4.3 shows the breakdown of the purposive sample.

TABLE 4.3: Distribution of Participating Local Churches by Traditional Authority and Zone

Traditional Authority	Church Zonal Network	Participating Local Church
Mwaulambya	Chitipa Central Namatubi	Lufita Assemblies of God Church
		Living Waters Church
	Katakwisakene	Chipakama AIC
		Kaseye Roman Catholic Church
Kameme	Illanga Njerengwa	Njerengwa AIC
		Chisankwa Anglican
	Chitipa Northwest Kameme	Nkhangwa CCAP
		Kameme PHA
Nthalire	Nthalire	Kapirinkhonde CCAP
		Mubanga AIC

4.5.2 The PLWHIV Sample

As discussed above all the participants in the study were purposively selected, based on their ability to contribute to the central inquiry of the study. HIV and AIDS related stigma is a sensitive topic and so I had to be sensitive to ensure that the PLWHIV included in the sample were comfortable enough to talk about their experiences. In Patton's terminology they had to be 'rich' in order for me to build a good critical portrait of their experiences with moral exclusion in the church. PLWHIV in the TCN are organized in what is called support groups. In these groups the PLWHIV meet regularly to support each other and it is here that they learn how to cope with their HIV status. They learn new skills and also look at ways in which they can reach out to their communities. These groups are hosted by churches. So it was from here that the participants were drawn for the sample. The sample of PLWHIV to participate was purposively selected from 5 AIDS support groups. One support group was selected from each of the participating zones, based on the fact that they had been in existence for at least three years with a membership of over 10 PLWHIV. The support group also needed to be meeting regularly, at least once a month, and needed to have an active program schedule. Support groups were also selected to participate in the study based on the fact that they were hosted by a local church that was a member of the Tubepoka Church Network. All members of the support group were invited to be part of the participant observation sessions because these happened within the natural context of the support group. For the focus group discussions, 20 volunteers were invited to attend from each group based on the fact that they had done their HIV test, knew their status, had disclosed to the group and were comfortable talking about their experiences. For the in-depth interview, I purposively selected 3 leaders from each support group. These were the leaders of the groups. My decision was based on the fact that they had been recognized by their peers as possessing the

leadership qualities needed to run their groups. Therefore, since I was looking for PLWHIV who were articulate and confident enough to discuss issues of moral exclusion, they were best placed to do so. They were already doing it within their communities and churches. All participants in the study participated voluntarily, based on their perception of their ability to provide the required information. Since the participants are from different denominations, church representation was taken care of.

The table below summarizes the sample of PLWHIV that participated in the study.

Table 4.4 Breakdown of the PLWHIV Sample

PLWHIV Demographics							
Category	Support Group	Designation	Code	Age Group	Gender	INT 1	INT 2
PLWHIV	Lufita SG	PLWHIV 1	LSG#1	30-40	Female	26/03/2011	27/06/2013
PLWHIV	Lufita SG	PLWHIV 2	LSG#2	50-60	Female	26/03/2011	27/06/2013
PLWHIV	Lufita SG	PLWHIV 3	LSG#3	40-50	Female	26/03/2011	27/06/2013
PLWHIV	Chinunkha SG	PLWHIV 4	CSG#4	20-30	Female	23/03/2011	22/06/2013
PLWHIV	Chinunkha SG	PLWHIV 5	CSG#5	30-40	Male	23/03/2011	22/06/2013
PLWHIV	Chinunkha SG	PLWHIV 6	CSG#6	30-40	Female	23/03/2011	22/06/2013
PLWHIV	Chipakama SG	PLWHIV 7	CPSG#7	30-40	Male	29/03/2011	20/06/2013
PLWHIV	Chipakama SG	PLWHIV 8	CPSG#8	30-40	Female	29/03/2011	20/06/2013
PLWHIV	Chipakama SG	PLWHIV 9	CPSG#9	30-40	Female	29/03/2011	20/06/2013
PLWHIV	Chisankwa SG	PLWHIV 10	CKSG#10	40-50	Male	27/03/2011	26/06/2013
PLWHIV	Chisankwa SG	PLWHIV 11	CKSG#11	30-40	Female	27/03/2011	26/06/2013
PLWHIV	Chisankwa SG	PLWHIV 12	CKSG#12	30-40	Female	27/03/2011	26/06/2013
PLWHIV	Nthalire SG	PLWHIV 13	NSG#13	50-60	Male	20/03/2011	18/06/2013
PLWHIV	Nthalire SG	PLWHIV 14	NSG#14	30-40	Female	20/03/2011	18/06/2013
PLWHIV	Nthalire SG	PLWHIV 15	NSG#15	40-50	Female	20/03/2011	18/06/2013

4.5.3 The Church Leader Sample

To have a good understanding of the theologies that undergird persistent exclusion of PLWHIV from church life, participating church leaders had to have a good grasp of the teachings and traditions of their church. At the same time their churches had to be involved in response to the AIDS pandemic at a local level. 30 church leaders participated in the study. 2 leaders were invited from each of the local churches participating in the study to be participants. Both leaders were members of the core leadership team of the church, but not the lead ministers, pastors or reverends and they had to represent both genders. For the indepth interviews, I opted to include the lead ministers of all the churches in the sample.

Table 4.5 Breakdown of Participating Church Leaders' Sample

Traditional Authority	Church Zonal Network	Participating Local Church	FGD	IDI
Mwaulambya	Chitipa Central Namatubi	Lufita Assemblies of God Church	2	1
		Living Waters Church	2	1
	Katakwisakene	Chipakama AIC	2	1
		Kaseye Roman Catholic Church	2	1
Kameme	Illanga Njerengwa	Njerengwa AIC	2	1
		Chisankwa Anglican	2	1
	Chitipa Northwest Kameme	Nkhangwa CCAP	2	1
		Kameme PHA	2	1
Nthalire	Nthalire	Kapirinkhonde CCAP	2	1
		Mubanga AIC	2	1
			20	10

4.6 Data Production Strategies

4.6.1 In-Depth Interviews

An in-depth interview is an interactive conversation with the purpose of generating information about a given social situation occurring in as natural a context as possible. According to Legard et al., in-depth interviews need to be flexible in structure and interactive if they are to generate data that is naturally constructed. They also propose that to allow for the generation of data that has depth, the researcher has to employ the use of probing techniques to go beneath the surface and explore the meanings beneath the given answers (Legard, Keegan, & Ward, 2003, p. 141). To get a better understanding of the experience of PLWHIV with moral exclusion, I needed to do more than interact with them in the context of focus group discussion and observing them within their natural environments. There are aspects that cannot be observed. For example, I observed a church service at one of the participating churches where PLWHIV had been given opportunity to make a presentation on HIV prevention as part of the church program for that day. The women were happy, they danced and sang and taught. I had, however, observed that they wore a different uniform from the other women who also performed. I could not observe how they felt or what they thought. The interview gave me an opportunity to access the emotions and thoughts linked to that experience. The interviews were also helpful in getting access to information related to the past. For example, it is through the in-depth interviews that I was able to understand how the experiences of PLWHIV with moral exclusion had changed with regard to access to ARVs.

I interviewed all the 15 PLWHIV who were part of the study in 2011 and did follow-up interviews with them in 2013. The reason I did two sets of interviews was because the

increased access to ARV's had significantly impacted various aspects of the global response to HIV and AIDS. I wanted to find out if that had had any impact on their experience with stigma in the church context. In total I conducted 30 in-depth interviews with PLWHIV. The average interview length was one hour, though in some instances the interviews ran over by between 15 and 30 minutes. I requested for one hour, but let the participants know that I was flexible depending on how much they wanted to tell me that would help me represent their stories as accurately as possible. Generally speaking, the interviews with the female participants went longer than the male participants. For purposes of anonymity, I gave each participant a code that did not have their name but included a support group ID to help me link the information from both interviews. All the interviews happened in the local churches that host the support groups and they were close to the residences of the PLWHIV, which was helpful for me to connect aspects of their responses to contextual factors in their home setting. I used an interview schedule and to record the responses I took notes, but I also had a research assistant to help me take notes so I could have a backup. Demographics of the PLWHIV interviewed are broken down in Table 4.6 following.

Table 4.6: Demographics of Interviewed PLWHIV

Category	Support Group (SG)	Designation	Code	Age Group	Gender	INT 1	INT 2
PLWHIV	Lufita SG	PLWHIV 1	LSG#1	30-40	Female	26/03/2011	27/06/2013
PLWHIV	Lufita SG	PLWHIV 2	LSG#2	50-60	Female	26/03/2011	27/06/2013
PLWHIV	Lufita SG	PLWHIV 3	LSG#3	40-50	Female	26/03/2011	27/06/2013
PLWHIV	Chinunkha SG	PLWHIV 4	CSG#4	20-30	Female	23/03/2011	22/06/2013
PLWHIV	Chinunkha SG	PLWHIV 5	CSG#5	30-40	Male	23/03/2011	22/06/2013
PLWHIV	Chinunkha SG	PLWHIV 6	CSG#6	30-40	Female	23/03/2011	22/06/2013
PLWHIV	Chipakama SG	PLWHIV 7	CPSG#7	30-40	Male	29/03/2011	20/06/2013
PLWHIV	Chipakama SG	PLWHIV 8	CPSG#8	30-40	Female	29/032011	20/06/2013
PLWHIV	Chipakama SG	PLWHIV 9	CPSG#9	30-40	Female	29/03/2011	20/06/2013
PLWHIV	Chisankwa SG	PLWHIV	CKSG#10	40-50	Male	27/03/2011	26/03/2013
		10					
PLWHIV	Chisankwa SG	PLWHIV	CKSG#11	30-40	Female	27/03/2011	26/06/2013
		11					
PLWHIV	Chisankwa SG	PLWHIV	CKSG#12	30-40	Female	27/03/2011	26/03/2013
		12					
PLWHIV	Nthalire SG	PLWHIV 13	NSG#13	50-60	Male	20/03/2011	18/06/2013
DIWIIIV	Nthalire SG		NICC#14	20.40	Famala	20/0/2011	18/04/2012
PLWHIV	nuianie 5G	PLWHIV 14	NSG#14	30-40	Female	20/0/2011	18/06/2013
PLWHIV	Nthalire SG	PLWHIV	NSG#15	40-50	Female	20/03/2011	18/06/2013
12,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,		15	1,55,115	.0 50	1 ciliuic	20,03/2011	10,00,2013

The interviews for the church leaders were not very easy to schedule because I had to try and fit them into the time frame of my regular visits to the field sites. Knowing how busy the church leaders were, I requested for one hour of their time and the average length of the interviews was 1.5 hours and in two cases we went on for 2 hours. I conducted a total of 10 church leaders' interviews. Table 4.7 shows the demographics of the church leaders that were interviewed.

Table 4.7 Demographics of Interviewed Church Leaders

Category	Church	Designation	Code	Age Group	Gender	INT 1
Church L	Church A	Leader A1	LAGCL#A1	50-60	Male	26/06/2012
Church L	Church B	Leader B2	LWCL#B2	30-40	Male	26/06/2012
Church L	Church c	Leader C3	CACL#C3	40-50	Male	25/06/2012
Church L	Church D	Leader D4	KCCL#D4	40-50	Male	25/06/2012
Church L	Church E	Leader E5	NACL#E5	30-40	Male	18/06/2012
Church L	Church F	Leader F6	CACL#F6	50-60	Male	18/06/2012
Church L	Church G	Leader G7	NPCL#G7	50-60	Male	20/06/2012
Church L	Church H	Leader H8	KPCL#H8	30-40	Male	20/06/2012
Church L	Church I	Leader I9	KPCL#I9	50-60	Male	23/06/2012
Church L	Church J	Leader J10	MACL#J10	40-50	Male	23/06/2012

I found that with the in-depth interview there was greater freedom of expression than even the focus groups. The in-depth interview process was also very helpful for me because I needed to construct narratives out of the participant information as part of my data analysis. There were things I had observed in both the focus group discussions as well as the participant observation sessions that were unclear and at times even contradictory. I needed to seek clarification in a safer environment and I was able to do that during the interviews.

The interviews also aided me in contextualizing responses to my study. I personally conducted the interviews to ensure confidentiality and win leadership and key participant confidence. One thing I had to constantly be aware of is the power paradox between myself and the people I was interviewing, given that I had a working relationship with them.

Ribbens cautions researchers about the power paradox at play within the interview situation between the researcher and the interviewee. According to her,

The particular paradox that is worrying about in-depth interviews is that you give the interviewee the power to control the interview itself, and yet as a result they put themselves very much in your hands by exposing themselves in a one-sided relationship. When you come to depart, you take their words away, to be objectified in an interview transcript. In the end you are very powerful in this style of interviewing and the absence of the questionnaire may obscure this all the more (Ribbens, 1989, p. 587).

Because I was aware of it, I declared it to the participants at the beginning of the interview. I gave them the freedom to only tell me what they were comfortable to share and not feel obligated to respond to any question. I assured them that their responses would not affect our working relationship. I also found that taking time to explain the purpose of my study was very helpful in making them feel included. They felt proud that their stories were going to be written about and that they would help in teaching other people about stigma and discrimination. They found it difficult to comprehend why they should remain anonymous when they had already disclosed their HIV positive status to their families, communities and churches. Another challenge related to in-depth interviewing is the intrusive nature of the process, especially when probing for clarity.

4.6.2 Focus Group Discussions (FGD)

Kitzinger defined focus groups as a form of group interview that capitalizes on communication between a researcher and purposively selected participants in order to Page | 103

generate data. The researcher, using a series of open-ended questions, encourages participants to explore issues of importance to them in their own vocabulary, generating their own questions and pursuing their own priorities (Kitzinger, 1995b, p. 299). FGD's are a natural qualitative methodology of data production that are structured after the nature of people as social beings with an innate desire to connect and deliberate over issues with others (see Colucci, 2007).

I conducted the focus group discussions for the PLWHIV in 2011. This was after a full year of interacting with each support group for a minimum of three meetings. I facilitated a total of five focus group discussions – one for each of the 5 support groups. I used a FGD guide adopted from Escalada & Heong (2011) to record the data generated from the discussions. Included in the guide were semi-structured questions, covering four thematic areas derived from my research questions. These included: experiences with stigma and discrimination within their church and community, HIV and AIDS prevention, treatment, and economic livelihood support. The participation by group is recorded in Table 4.4 earlier.

I conducted the FGD for church leaders in 2012 as part of a training for church leaders that was related to HIV and AIDS. 20 leaders participated, 2 from each of the churches participating in the study. The FGD guide for the church leaders covered thematic areas that had issues from the FGD with PLWHIV and my research questions and objectives. We covered three basic thematic areas: the role of the church in combating HIV and AIDS related stigma and discrimination; supporting PLWHIV and preventing the spread of HIV infection.

The interactive and flexible nature of the PLWHIV FGD encouraged the participants to talk to one another and ask questions, as well as share stories and very useful examples. At times it was as if I was absent from the group and they were self-facilitating. This occurred very

naturally for PLWHIV because they knew each other and were used to working together. Encouraging a process like this to happen, says Kitzinger, is particularly useful for exploring people's knowledge and experiences and can be used to examine not only what people think but how they think and why they think that way (Kitzinger, 1995b, p. 299). I found the focus group discussion with the church leaders was not as free as the one with PLWHIV. There was more censorship and I found that leaders with clerical collars and those with higher education tended to be given more license to contribute than others. I found that I had to do more deliberate facilitation with the church leaders' FGD than with the one for PLWHIV. The PLWHIV FGD's were characterized by a lot of laughter, jesting, sharing of stories, use of idioms, proverbs and teasing. On the other hand, the church leaders' FGD had more arguments and seriousness. Kitzinger advises that in conducting focus groups it is critical to tap into the various forms of communication that people use in day to day interaction such as anecdotes, jokes, and arguments. Her rationale for this is that people's knowledge and attitudes are not entirely encapsulated in reasoned responses to direct questions (Kitzinger, 1995b, p. 299). I found this very true for all the FGD's I conducted, both with PLWHIV and with church leaders. Some of the information, such as group norms, cultural beliefs and dominant attitudes, I gathered more from the data generated in the process of members talking to one another in the process of the discussion than as direct responses to the guiding questions I provided. This study used Pierre Bourdieu's sociological cultural theory to analyse the structural nature of stigma and discrimination within church HIV and AIDS programming. Bourdieu analyses the mechanisms of social hierarchy reproduction within naturally occurring social fields. I found the focus groups very helpful in my study in putting this to the test. All my focus group discussions were conducted as part of naturally occurring events to make then as contextually natural as possible. Group norms and values were

evident as the group started interacting with each other around a given topic. The FGD methodology was very helpful to my study because it is very inclusive and does not discriminate against participation on the basis of literacy levels, as is the case with methods such as self-administered questionnaires. The majority of the participants in my PLWHIV sample had very low literacy levels but the group dynamics of the FGD provided safety for them to freely explore, clarify and express their ideas, as well as contribute to the discussions without feeling intimidated. Given the sensitivity of the study topic, the FGD's provided several advantages in the data production process. Even those participants who were at first afraid to get into the discussion because they were unsure of their contribution, were able to build up on each other's thoughts, ideas and contributions. Within the group contexts, it was easier to stimulate fresh thinking, generate new ideas and increase the depth and breadth of discussion. Wong accords the high quality data FGD's are able to generate to this dynamic (Wong, 2008). In the way I set up the FGD's there was room for debate, disagreement and constructive criticism; this made it easier to discuss some of the contentious issues such as doctrine and church traditions. Even in situations where information was censured by some prominent church leaders, such as issues with regards to condom use and prevention, and treatment options for PLWHIV, it was helpful to know what the dominant logic was within the church context and why. On the side of the PLWHIV, the FGD around issues of sexuality was accentuated with jokes, idioms, proverbs and song lyrics. This opened up the conversation and we were able to generate data on what would otherwise have been a very embarrassing subject to discuss. Colucci proposes that for more reflective participants, adding exercises on the agenda of FGD may be one way of drawing them out, in that it helps them focus on the core study topic (Colucci, 2007). I applied this to one of the FGD. When I was discussing issues of treatment options for the PLWHIV, we held the FGD in a herb

garden raised by one of the support groups. In the garden were several herbal treatments for various opportunistic infections common to PLWHIV. As part of the process I required that different members explain to me the role of the various plants and why they were important to them. We started off very well, until we came to plants that were believed to improve sexual performance. There was giggling that went through the whole group and then eventually there was a unanimous vote for a particular gentleman to do the explanations. He used idioms, jokes and anecdotes, many of which I had to ask someone in the group to decipher for me. There were many such plants in the garden and each time we came to one the pattern was repeated. It was very clear that issues of sexuality were primarily relegated to the male domain and there were generally accepted group rules and rituals as to how they should be discussed. That particular FGD was the best patronized and animated. Everyone participated in the discussion.

Focus groups were very helpful in highlighting attitudes of people living with AIDS as well as church leaders with regards to stigma and discrimination. It was during focus groups that I discovered the language that was used to describe stigmatizing experiences was 'Kutsala', the same word used to mean isolate, leave behind, leave alone or ignore. I learned that certain knowledge and words were censured. You did not use words like 'sex' in a group setting. When the need arose, you deferred to the biblical term of 'knowing' to be more politically correct. Condom use was still referred to as 'eating a sweet in its wrapper'. The sexual urge was referred to as 'strength', an attribute associated with men.

In the focus group for church leaders which was conducted as part of a pastoral training workshop and church leaders training, the group dynamics were very interesting. We could not get into the herbal treatment issue much because one of the Pentecostal church leaders

objected very vehemently that encouraging the growth of herbal gardens as a treatment option for People living with HIV was asking people to go back to a life of witchcraft. According to this particular church leader, Christians had been redeemed from witchcraft when they received the message of the gospel and discussing herbal treatment was returning to that past. Nobody challenged it. There was silence and a nodding of heads. The subject had been censured. Bourdieu's concept of the habitus asserts that our history and environment condition us to think and develop dispositions and attitudes that make us perceive along a given trajectory. Here is a church leader who was told by missionaries that all things his ancestors used to treat illness were evil and when he speaks as an authority in a leaders' gathering it is accepted as operational truth. That partially explains the perception of support groups by some church leaders as places where witchcraft is practiced and why People living with HIV are excluded from church leadership positions.

FGD were not without challenges. Kitzinger (1995a, p. 300) points out that the disadvantage of FGD' is that the articulation of the group norms may silence the individual voices of dissent. This was more evident as we have discussed above in the church leaders' FGD on issues of HIV and AIDS prevention and condom use, as well as treatment options for PLWHIV. For example, the Roman Catholic Church in Malawi has been encouraging the rediscovery of African remedies for different ailments. However, the dominant logic within church circles is that the use of such treatments is the same as witchcraft. So the members of the Roman Catholic churches who participated in the study did not disagree when the topic was censured. The other example was in PLWHIV FGD. The men were very few in most of the groups and yet when it came to issues of sex and sexuality, the women were silent and deferred to the men. This is why the in-depth interviews were very helpful. I was able to

discern the individual voices of dissent from the group norm. Wong (2008, p. 260) also contends that a fundamental disadvantage of FGD is that they are susceptible to bias as the group and individual opinions can be swayed by dominant participants or by the moderator. Whereas there was a bit of this in the church leaders FGD, it could not be sustained in the FGD for the PLWHIV.

4.6.3 Participant Observation

Of all the methodologies I used in my research, perhaps the one I found most informative was participant observation. Becker and Greer define participant observation as a qualitative research methodology where the observer participates in the daily lives of people under study either openly or covertly in some disguised role, observing things that happen, listening to what is said and questioning people, over some length of time (Becker & Geer, 1957, p. 28). This qualitative research methodology is considered to provide the most complete form of data in that it allows the researcher to gather data that is naturally generated. It is a complementary methodology in that it provides a yardstick by which we can measure the quality of data we have gathered through our other methodologies. Often I found that participant observation was not just a data collection method but crossed over into analysis. As Jorgensen (1989, p.16) asserts, ultimately the methodology of participant observation aims to generate practical and theoretical truths about human life grounded in the realities of daily existence. It is in this context that I used participant observation for this study.

Participant observation was critical to my study for a number of reasons. I declared in my introductory chapter, I am not a neutral researcher but rather a privileged subject who has ongoing engagement with the research context. The other reason is that a critical analysis of social structures requires for one to go deeper into the social system to where the real issues

are. I therefore had to find a way of engaging more with People living with HIV and be an active participant in the life events within which stigma and discrimination occurs. I found in the interview process that there were issues that participants were not comfortable to talk about. Interestingly, they would act out the same issues in skits and if you asked them questions in the context of a play they would openly discuss the same issues. A classic example is negotiating for safer sex in the context of their sexual relationships. That was such a difficult subject for the women in my study, yet they would boldly act out the importance of condom use in a community education drama. I attended support group meetings for people living with AIDS; I spent time with people living with AIDS as they carried out their community awareness programs; I attended church services where PLWHIV were making presentations; I participated in memory book creation events for support groups. They proudly showed me their group gardens and I spent a day being educated about herbal medicines and their role in patient treatment. I participated in fundraisers for office space for support groups. I participated in church leadership training seminars that focused on HIV and AIDS.

Participant observation has often been dismissed as 'merely immersing oneself in a situation and having insights' and therefore not scientific enough to be used in the academy as a reliable way to test and/or formulate a hypothesis. In his critique on the problems of Inference and Proof in Participant observation, Becker calls upon qualitative researchers to make an effort to attempt greater formalization and systematization in order that qualitative research may become more scientific and less an artistic kind of endeavour (Becker, 1958, p. 660). I applied Becker's recommendations to this study.

For my participant observation exercise, I asked questions of the participants seeking to understand what I saw and observed. I observed the relational dynamics between People living with HIV and others in their communities such as church leaders, fellow church members and fellow support group members. I observed for repeated patterns and triangulated them with data from other methodologies. I listened for common and unique language. I found that when I interviewed People Living with AIDS in the context of their activities, they were less guarded and saw me less as an outsider. They took my curiosity as a genuine desire to understand their context. One of the things that I appreciated about gathering data through participant observation is that the participants did not treat me like I was present. I blended in and disappeared and this gave me a vantage point to observe critically. Watching the drama skits and listening to the songs gave me more insight into the language that PLWHIVs used with themselves. They took less offense when they cautioned each other against multiple sex partners, for example, but took offense when church leaders stood in the pulpit and accused them of spreading the virus in the community now that they were healthy from taking ARVs. To an extent, I concur with Becker and Greer that participant observation trumps all the other sociological research methodologies, in that the rich experiential context it provides for the researcher gave me greater awareness of unexplained facts I gathered through the interviews and FGD. Exposure to the participants in my study in their natural context improved my sensitivity to the possible implications of and connections with data previously gathered and drove me to explore different dimensions of my research questions.

The challenge I had with participant observation is that so much data was generated and since I did not always take my pen and paper to record, organizing the data after all the significant

events was always a challenge and I am sure there is a lot that I did not capture effectively in my post event notes and narratives. In participant observation questions are often raised about the informant observer equation. Becker wonders whether we can say with a high degree of certainty that participants in research situations where the researcher is a participant observer will behave in the same way or give the same responses as they would if the researcher were absent (Becker & Geer, 1957). I was able to deal with this bias in my study in several ways. Firstly, I declared my subjective stance as being a research participant as much as I am the researcher. On the other hand, I was careful to watch out for the frequency and distribution of the emerging themes I had isolated at the various events I was a part of. I took the time to compare the repeated patterns with the information that I gathered from interviews and focus group discussions. Making these linkages and connections made it possible to produce what I believe is a credible body of data and not merely researcher insights biased by inference.

4.7 Data Analysis

My data analysis process was divided into seven stages outlined below:

- Stage 1: Developed an analysis framework.
- Stage 2: Identified emerging themes from data.
- Stage 3: Grouped the narratives from all the data production strategies by emerging themes.
- Stage 4: Gave data codes to prominent data quotes.
- Stage 5: Triangulated the data from all the three data production strategies.
- Stage 6: Analysed the data through Bourdieu's social cultural theoretical lenses.
- Stage 7: Reflected on the data through the framework for social justice.

4.7.1 Stage 1: Analysis Framework

With my research questions and objectives as the guides, I developed an analysis framework to help me better organize my data and make sense of it so that I could use it to respond to the questions that my study set out to answer. I super-imposed the data onto the table and I did it separately for the two sets of data, the one from PLWHIV and that from the church leaders. (See Table 4.8 below). Since this study is located within the critical research paradigm, I made sure that there was room in my analysis framework for new categories to emerge that were outside the scope of my study but emerged from the data.

Table 4.8: Data Analysis Planning Framework

Data Analysis and Triangulation Framework					
Data Production Strategy	Participant Observation Sessions	Focus Group Discussions	In-Depth Interviews		
Data Format	POE Narratives	FGD Narratives	Interview Schedules		
THEMATIC CATEGORY					
Experiences of PLWHIV with moral exclusion, stigma and discrimination	Emerging themes and data codes	Emerging themes and data codes	Emerging themes and data codes		
Social constructions of the moral exclusion of PLWHIV from church life	Emerging themes and data codes	Emerging themes and data codes	Emerging themes and data codes		
Theological explanations for the moral exclusion of PLWHIV from church life	Emerging themes and data codes	Emerging themes and data codes	Emerging themes and data codes		
Liberative resources within the church context	Emerging themes and data codes	Emerging themes and data codes	Emerging themes and data codes		
New categories	Emerging themes and data codes	Emerging themes and data codes	Emerging themes and data codes		

4.7.2 Social Analysis and Theological Reflection

The liberation theology framework has three critical lenses that are the overarching framework for my analysis and enable me to engage interdisciplinary dialogue as a core characteristic of the analysis. The first lens is an interpretation of the Christian faith in the light of the struggle of the poor. For my study this analytical aspect used the voices of the people living with AIDS to give expression to that interpretation. The second lens requires a critique of society and the ideologies sustaining it. The methodology I brought to bear on this analysis involved taking the data as organized in the triangulation conceptual framework, super-imposing Bourdieu's social cultural theory and interrogating the data from a structural perspective. Each data category was looked at in the light of the field, the doxa and the habitus. The third lens of the liberation theology framework requires a critique of the action of the church and of Christians from the angle of the poor. The Catholic framework for social justice provided an excellent tool for this exercise. Given that it directly mirrors the liberation theology tenets; it was very easily super-imposed on the data for the interdisciplinary dialogue. This dialogue alongside the literature review, especially the work of Gillian Patterson, Parker and Birdsall, Rankin and Williams, is what produced a deeper cultural, social reading of HIV and AIDS related stigma within the contexts of the local church as presented in the next chapter.

4. 8 Research Credibility

4.8.1 Triangulation and Crystallization

To balance validity and reliability while maintaining a commitment to rigour in data production and analysis, I applied the triangulation and crystallization strategies. Flick (2009, p. 445) has defined triangulation as the use of complementary methods, theories, data Page | 114

or investigators in research to get a broader understanding of the issue while compensating for any one-sidedness or distortion that may result from one individual theory, method, data base or researcher. Building on the geometrical concept of triangulation, Richardson (2000, p. 934) argues that given the multi-dimensional nature of the world, crystallization should be adopted as a more accurate measure of reliability and validity of qualitative research. The use of the crystal metaphor introduces a broader perspective to qualitative research. I have endeavoured to explore the moral exclusion of PLWHIV from church life using a multidimensional approach. This runs through the whole study right from the conceptualization of stigma, to the application of a multi-disciplinary inquiry that brings together social science and theology. The theoretical framing of the study brings together liberation theology alongside social cultural theory. At the methodological level I used mixed methods of data production including participant observation, FGD, and in-depth interviews. All of these dimensions came together to reflect integrity and competence, demonstrating the legitimacy of the research process I adopted for this study. According to Aroni et al. (1999), this is the means by which rigour is achieved. Lincoln (1995, p. 287) maintains that the attributes of rigour are woven through the entire research process and that it is their operationalization through innovation, creativity and transparency that creates excellent quality in a study. By using a multiple methodology approach both to data production and analysis in studying a complex and multi layered phenomenon such as stigma and discrimination, I was able to limit the impact of the biases and limitations of any one methodology on the data generated. Conversely, this allowed leveraging of the strengths and advantages of any one methodology in strengthening those of another. These were discussed in greater detail in the data production strategies section.

The processes of triangulation and crystallization gave me a more vivid picture of the interrelationships between the experiences of PLWHIV with moral exclusion, the structural make up of moral exclusion and the theological representations that undergird moral exclusion. All of these were informed with data generated from the various strategies. I used the framework in Table 4.8 to study these relationships, and I found it very helpful in establishing validity and reliability in the analysis process. As Flick (2002) maintains, the combination of multiple methodological practices, empirical materials, perspectives, and observers in a single study is best understood as a strategy that adds rigor, breadth, complexity, richness and depth to any inquiry. That is what this study was about.

4.9 Ethical Considerations

In their study on ethical considerations in qualitative research, Orb, Eisenhauer, & Wynaden (2001, p. 93) conclude that ethical principles are a useful guide in addressing issues arising from qualitative research in order to meet the goals of the research as well as maintain the rights of the research participants. Drawing on the work of Capron (1978), they isolate three areas of ethical consideration for qualitative researchers, particularly those engaging with health-related research. These are: autonomy, beneficence and justice. Since this study has health leanings and is also about justice, I find their principles helpful in discussing the ethical considerations that were critical in carrying out this study. Lincoln (1995, p. 287) suggests that the standards for quality in interpretive social science are also standards for ethics.

4.9.1 Autonomy

Autonomy is about ensuring that the rights of the participants in the study are respected and upheld. According to Orb et al. (2001, p. 95), these include the right to be informed about the study, the right to freely decide whether to participate in the study, and the right to withdraw at any time without penalty. Through the informed consent forms, I made sure that the purpose of the study was well explained and that I was properly introduced to the participants. I also spelt out their rights in the informed consent form. Before I participated in the structured events or carried out the FGD and the in-depth interviews, I spent unstructured time with the participants to earn their trust, get to know them and explain in person the purpose of the study and solicit their interest to participate in the study. Given that I have a working relationship with the participants, I assured them that if they chose not to participate or to drop out of the study at any time, they would not be penalized. Fortunately, the study was spread over a period of four years and nobody was penalized for their lack of interest in participating in the study. The challenge with autonomy in this context of PLWHIVs is the impact on the extended family of the participant. Whereas I could not be totally sure that the participants had complied, I nevertheless required that they let their families know about their participation in the study. They all assured me that they had already disclosed their HIV status to their families, churches and communities and so they did not think that there would be any negative impact on their families.

4.9.2 Beneficence

Beneficence is about the obligation of the researcher to ensure that the research while preventing harm of any kind does well for the participants. This, according to Orb et al., (2001, p. 95), also involves safeguarding against potential harm that could come to the

participants in the event of publication of the results of the study. At the beginning of the study, I explained to the participants that the data generated in the study would be published and so would their responses. I also included it in the consent form. Participants were given the freedom not to share anything that they would not like published even under a pseudonym. To ensure participant confidentiality and anonymity, I used coded pseudonyms that cannot be traced back to any of the participants. Even for the churches, to protect the positions they shared about their theological representations, I coded their responses. This did present a challenge because to give accurate portraits of the experiences of PLWHIV with moral exclusion required giving thick descriptions and there is a limit to how much one can disguise and yet remain accurate. It was even more difficult when it came to the FGD and interviews with the church leaders. Theological representations were often linked to particular churches and denominations. Given that the sample was purposively selected and care was taken to make it representative of the denominations that make up the network, I had to take extra care in determining descriptors; otherwise it would have been possible to trace positions back to specific churches.

4.9.3 Justice

The ethical principle of justice requires that fairness is observed and that there is no exploitation and abuse of participants. Orb et al. (2001, p. 96) discuss the importance of recognizing the vulnerability of the participants but at the same time acknowledging their contributions. This is a difficult balance to achieve, especially with the requirement to ascertain confidentiality and anonymity. This is an example of a situation where the principle of beneficence comes in conflict with that of justice. For the PLWHIV in my study, this presented a conflict. They were proud of the fact that they could tell their story but did not

understand why their names could not be used yet their families and communities were aware of their HIV status and their commitment to make a difference through educating others. So while I did listen to the voices of PLWHIV and told their stories as accurately as I could, knowing very well that some of the truth is lost in the translation process, I wrestle with that feeling of having done injustice by not recognizing specific people for their unique contributions. There are times when the data gathering process crossed into meal times or coincided with other obligations. I provided lunch for PLWHIV considering that most of them are on ARV medication and require proper nutrition. On a few occasions, I had scheduled meetings at times where the participants had a conflict with time. I always deferred to their preference. For example, during the planting season, meetings would be cancelled if they had been scheduled in the morning hours.

4.9.4 Ethical Considerations and Power Dynamics

I obtained ethical clearance to conduct this study from the University of KwaZulu-Natal. Karnieli-Miller, Strier, & Pessach (2009, p. 279) discuss that qualitative inquiry is committed to democratizing the research process by allowing greater disclosure and authenticity between the researcher and participants. They are both co-creators of the data with the participants as the experts. This concept aligns well with the liberation theology framework where the oppressed are the theologians. As the oppressed are empowered to become agents of their own liberation they become the theologians. In the context of the study I did not have much of a challenge in deferring to the PLWHIV in the data production process. Where the conflict arose was in listening to the theological representations by the church leaders rationalizing moral exclusion of PLWHIV. I had to time and time again come back to Karnieli-Miller et al., 2009, warning that neither my power position, nor my skills gave me

license or afforded me supremacy to perform a judgmental data analysis. The parameters and tools of the critical research paradigm were a great help in pulling me away from the judgmental stance. I find the wisdom by Karnieli-Miller et al. (2009, p. 286)a great reminder with regards to ethical considerations in qualitative research like mine – that my primary moral research obligation is to the participants and their welfare, which can be achieved only through non-judgmental writing and analysis – a journey I am just beginning, with still a lot to learn. It is to the embodied storied narratives of the experiences of PLWHIV with moral exclusion that we now turn to in the next chapter.

4.10 Conclusion

In this chapter, I discussed the research design as well as the methods and strategies for data production and analysis applied to this study. The multi layered complexity of this study, its empirical nature and its location within the critical research paradigm influenced the choice of a research design that was a hybrid of inter disciplinary constructions. The bricoleur research stance I adopted as a researcher gave me freedom to work inter-disciplinarily as well as across disciplinary boundaries. This was critical to the study because it favoured the critical melded integration of liberation theology, social theology and Pierre Bourdieu's social cultural theory. Thus, allowing for each discipline to bring its unique contribution to the research process. The multi method approach applied allowed for the triangulation of results from the three data production methods of in-depth interviews, focus group discussions and participant observation sessions. Rigour across the research process was thus ensured and credibility ascertained. The result of this research design and approach was the production of high quality data as well as a rich theoretical engagement with the findings.

Chapter five presents the first part of these findings, the storied narratives of the experiences of PLWHIV with moral exclusion.

CHAPTER FIVE: Embodied Storied Narratives of the Experiences of PLWHIV with Moral Exclusion

If we are going to counter stigma and deal with HIV and AIDS in a responsible manner theologically, the place to start is the lived experience...Praxis must be done in the interests of those who experience stigma, it must be collaborative, and it must be culturally sensitive to different ways of experiencing reality (Ackerman, 2005, p. 48)

5.0 Introduction

Bonino argues that what sets liberation theologies apart from other forms of theology is their placement of the oppressed as participants at the nexus of theology formation, thus becoming masters of their own destiny (Bonino, 1975). It is therefore imperative for this study that as I attempt to construct a theology of de-stigmatization that PLWHIVs are placed right at the centre through their lived experience, as Ackerman advises in the quote that introduces this chapter. Bauer (2005) affirms that PLWHIV are invaluable to any initiative aimed at addressing stigma and need to be fully engaged in all aspects, for not only are they the "wounded healers" of our time but they are also the best possible strategy for changing attitudes and removing fear (Bauer, 2005, p. 17).

Hence the purpose of this chapter is to present critical portraits of the experiences of PLWHIV with moral exclusion as storied narratives. The study involved 66 participants in the focus groups, over 100 were part of the participant observation sessions discussions and 15 were interviewed in-depth. I am going to profile 6 participants. I have selected these 6 stories to represent all the PLWHIV who participated in the study. They have been selected on the basis of the representativeness of their stories. While no story is exactly the same as

another in that each experience is unique, there are some common threads that run through the stories and I have attempted to draw them out in the analysis, albeit not exhaustively.

In the next section of this chapter I will describe the ways in which PLWHIV experience moral exclusion within the church context, as told to me during the in-depth interviews. In some cases, the portraits are presented as descriptions of what I observed during participant observation events. Life stories are an essential element in dealing with stigma. According to Ackerman (2005), telling stories is critical to claiming one's identity. Instead of having one's identity subsumed under the label of being 'an HIV positive', speaking and being heard affirms both dignity and identity. Narrative has a further function: the very act of telling our stories helps us to make sense of situations that are often incomprehensible (Ackerman, 2005, p.48).

The dilemma I found myself in as a researcher in my context is that in order to obtain ethical clearance for the research, I had to maintain anonymity of the participants and I therefore had to respect this. However, in doing so, by using pseudonyms, I subsume their identity and am not sure that I am affirming their dignity and identity. Suffice it to say that all of the PLWHIV in my study have disclosed their HIV status to their families and in their communities. Their status is known in their communities because they are also community educators. They did not mind me using their real names. However, for ethical integrity I will use pseudonyms for the narratives I use.

The data and narratives were produced over a period of 5 years, from 2009 to 2013. I had multiple contacts with the participants in this study over that period of time. Therefore, before I relate the experiences of PLWHIV with moral exclusion within their churches, it must be noted that the concept of moral exclusion has evolved, developed and been adapted

in this period. Herek (2002) predicted that the forms of stigma would change with the changing social profile of the AIDS pandemic. He was right to a certain extent, but given the fact that most of the stigma is layered, the outward expressions of exclusion may have changed, yet there are ways in which the structural forms are still intact (Herek, 2002). That is what this study addresses. The fact that many local churches in the Chitipa network continue in the fourth decade of the pandemic to refuse discussions on HIV and AIDS in their churches bears testament to this.

In narrating their stories of moral exclusion, the participating PLWHIV in this study often divided it into two phases, before 2009 and after 2010. This is because of a number of contextual factors ranging from the increase in funding for the global response to the AIDS pandemic, universal access to ARVs, the church shift in its position on responding to the HIV and AIDS pandemic, to the Malawi response embracing the faith communities as part of the national response. All of these reasons were alluded to in the background to this study and so I will just briefly outline them here in setting the context for the stories of the experiences of PLWHIV.

Firstly, the increased funding for the global response to AIDS, particularly from the Global Fund for AIDS, TB and Malaria and PEPFAR, made it possible for high-prevalence countries such as Malawi to scale up the national response to HIV and AIDS (Dietrich, 2007). Secondly, the global rollout of universal access to ARVs for PLWHIV resulted in Malawi launching the treatment campaign in 2004. Gradually rural communities, including Chitipa, were added to the treatment grid around 2007 (see Ferradini et al., 2006; Kober & Van Damme, 2004). Thirdly, recognizing that stigma and discrimination were undermining the global response to the HIV and AIDS pandemic, UNAIDS, the body responsible for

coordinating the response to AIDS, introduced a new five year agenda to guide the global response from 2011 to 2015. This was codenamed "Getting to Zero: Zero New HIV Infections, Zero Discrimination, and Zero AIDS-Related Deaths." This helped to renew the global commitment to counter stigma and discrimination (see G. T. Z. UNAIDS, 2010).

Fourthly, the global church was mobilised through the WCC ecumenical initiative on HIV and AIDS in Africa that prioritised reduction of stigma and discrimination on the churches' priority list. This gave birth to various international initiatives. For Africa, perhaps the most significant one was the UNAIDS-sponsored theologians' workshop in Namibia in 2003. The outcome of this workshop was a framework for theological reflection on HIV and AIDS related stigma. This provided a framework for faith communities to engage with stigma and discrimination (see I. UNAIDS, 2005) Finally, on the Malawi local scene, the establishment of a technical working group on HIV and AIDS for Faith Communities provided a platform for churches to engage with the AIDS pandemic and be resourced and equipped to do so from an informed perspective, instead of being reactionary. A ground-breaking event organised by the group was the ecumenical 'Breaking the Silence' workshop in 2003, that challenged the churches to deal with stigma and discrimination in their midst. Following these local initiatives, a national mobilization process was initiated that included the churches in Chitipa which are part of this study (see Trinitapoli, 2006; Willms, Arratia & Makondesa, 2004).

All the above initiatives combined to influence the churches in Chitipa to begin to open up the religious space and get involved in the national response to HIV and AIDS. They also influenced the availability of ARVs to PLWHIV who were at the time beginning to get organised in support groups. Hence the influence in the storied narratives of the reference to before 2009 and after 2011. I will now present these narratives.

5.1 Myness: A Portrait of Gendered Exclusion

Myness (not her real name) is 41 years old. She is the chair of her support group and definitely its life. She exudes confidence and vitality. A few minutes in her presence and you have no doubt that she is a woman with a vision and on a mission. Yet beneath this confidence is a very complex story of loss, exclusion, disillusionment and triumph. She hopes that in the end the good in her story will triumph over the not so glamorous. This is her story.

I grew up in a good family. My parents went to church and they made sure we all went as well. That is me and my three brothers and two sisters. I was the oldest. In my time we did not go very far in school. I wanted so much to go to school but my parents felt it was a waste of money to pay for me to go to school since I was going to get married soon and sit at home to raise my children like my mother had done and my grandmother. Deep within me there was a desire like a fire to go farther than my mother did. However, I could not go against the wishes of my parents. So when they found me a husband at the age of 18 I got married. He was a good man, a provider and a Christian. He had his own house and I moved in and started working in the garden. It all started off well, we were going to church and I was happy. After our first child my husband decided to start growing tobacco as a way to increase our household income. As a Christian I had problems with it because I thought it was not right to grow something that caused death. From what I can remember, the problems started after the first tobacco harvest. While during the growing season we all worked together as a family, once the tobacco was ready for market, he shut me out of the process. He went alone to sell the tobacco and so I do not know how much he made. He started coming home late and then he started drinking and at times he would not even make it home. Even though I knew that we were making more money than before, our life at home did not change. When I would ask for money for things at home I would be screamed at and asked if I thought money grew on trees.

He stopped coming to church and I would go alone with our son. It was the only place where I felt happy and I connected with other women. We sang, studied the Bible together and prayed for each other. We would go out into the community to do different projects. I became very active in our women's guild because it helped me forget about my problems. I talked to some of my close friends about my situation and they told me that it was normal and I would get used to it. All I had to do was pray, be a good wife and take care of my child. By 2005 things were terrible in addition to the drinking, my husband started going out with other women he met at the drinking place. I would hear the rumours on the village even if none talked to me directly. Then I got pregnant with our third child in 2006. I was so sick; I thought I was going to die. After I gave birth I could not get better and my daughter also was in and out of hospital. One of my neighbours suggested that I visit a singanga (traditional healer). She suggested that my husband's girlfriends wanted me dead and I needed to protect myself. Even that did not help.

I went to visit my parents and told them about my situation, they advised me to go to the hospital and get tested for HIV. My test came out positive and then a nightmare I would rather forget took over my life. Sickness, hunger, loneliness, I was shunned by the women in our church group. The hospital was far away, we had no money my husband left me for another woman because I according to him I was not a real wife anymore. My son was taken to his grandmother because I was too sick to look after him. I longed for death because what I had was not a life.

Then in 2007 a lady came to visit me. She said she was a volunteer from one of the churches. She told me about AIDS and encouraged me to join the support group for PLWHIV which was meeting at their church. I was not so sure I wanted any associations with any church after the way I had been treated by the women at my church. However, out of options and I was longing for human connection and so I went. It was the best decision I made and it saved my life. These have been the best years of my life. I have been trained as a leaders, I have learned so many things. My friends have stood by me in ways my husband never did. In sickness and in health. In poverty and in plenty, what I have now may not seem much but believe me it is plenty when I remember the nightmare years. I have learned to accept my condition and live with it.

When the ARVs became available in 2011, our lives were transformed. You look at me now. Now that we are not sick often our focus has changed. We have a savings initiative and now I am beginning to buy things in the house that I used to beg for. I like my home. These days I smile more than I cry. I love the new church. They allow us once in a while to do things at church. There is one thing though that does not make sense to me. They said they needed leaders to help out with some ministries at church. I volunteered and I felt qualified because of all the training that NAPHAM had given us. At first I was told that I was not a full member. So I did the membership lessons and I became a member. The second time I was not sure why they would not let me. I asked one of my friends who had been longer at the church. She told me that even though I did not have the symptoms of AIDS, I was still HIV positive and that would be difficult for the leaders to overcome and also that since my husband had left, my marital status was not clear and all the people in leadership seemed to have proper marriages. She said though that it was her thinking but she was not sure why they would not let me lead. Our support group is going well and the church can learn from us but they do not seem interested. Can I tell you a secret though? I hope that I get married again and have another child; there is a part of me that still feels empty. But also I know the church will look at me differently if I get properly married in church. What gives me hope is that in some churches they are beginning to allow PLWHIV to lead. For example Tifness (PLWHIV, Myness)

Tifness (not her real name) narrates her experience laughing out loud.

When I look at myself today I cannot help but laugh. I now lead the women's guild at my church and am also the church treasurer. Who would have thought that Tifness would one day stand up and lead the same women who called her names and rejected her when she was sick? You know the way they

talk about lepers in the Bible and how they had to shout unclean as they approached people. That is how I was made to feel in the early days, like I was so unclean that I could never lead (PLWHIV, Tifness).

5.1.1 Symbolic Power and Social Capital

Moral exclusion is not an isolated phenomenon that arises in a social vacuum. Rather like stigma as Ackerman posits, "it is deployed by concrete social actors who seek to legitimize their own dominant status and therefore operates on a religious and political economy of exclusion, often at the point of intersection between culture, power and difference" (Ackerman, 2005; Ackermann, 2005, p. 46). The portrait of gendered exclusion described in Myness' story attests to this fact. Ackerman contends that excluding PLWHIV from using their gifts, abilities and potential by rendering them unacceptable not only hurts the people but it also cripples the church and renders it ineffectual (Ackermann, 2005, p. 393). Bourdieu proposes that "to change the world, one has to change the ways of world-making" (Bourdieu, 1989). Borrowing Bourdieu's concept, I would like to propose that the same applies to changing unjust social orders like the one that excludes Myness from being the leader she can be in her church. The story of Tifness, though one among many of exclusion is reason to hope. Bourdieu presents symbolic power as the force behind world making. Tifness's story is a result of her exercising symbolic power to challenge an unjust system. Symbolic power is a compound of symbolic capital, social authority and symbolic efficacy. Through her leadership position in the support group, she earned social authority, she demonstrated the ability to lead a group of people through challenges and struggles to one of a team of people with the ability to exercise collective efficacy and change their lives. In recognition of that the church credited her with leadership positions, beginning with smaller roles. Each time she proved herself, she earned more symbolic capital, the currency of recognition. The

leadership training Tifness got in the support group increased her symbolic efficacy, the ability to effectively communicate a vision founded in reality. Bourdieu points out that symbolic power is one of consecration and revelation (Bourdieu, 1985, p. 23) Eventually Tifness accumulated enough currency and she was asked to lead the women's guild. While this was a long journey, her story shows that the same currency that creates social orders, can be used to un-make them.

5.2 Petrina, a Portrait of Spiritual Exclusion

I can remember my confirmation and first communion like it was yesterday. The white dresses and the ribbons in our hair. We were all like little angels. We had gone through several weeks of catechism lessons and we had been tested and considered ready for confirmation and our very first communion. The Bishop came and we all had to go to the big church at the parish and join with all the young people from our district. Even though we did not have much for that day my parents bought us special dresses on market day and after church we had special food. In addition to the kondowole (cassava meal) we had rice and goat stew. I think because it was my happiest childhood memory, the Holy Communion part of the service is my favourite. That is when I feel like I have gone to church.

This experience all changed for me when my husband died after a long illness and my life changed forever. When my husband got a job at the Kayelekera Uranium mine we were very happy. He had been looking for a job for a long time. What I was not prepared for was that he would come home only one week every six months. The rest of the time they lived in camp-like structures close to the mine. When he got sick he said it must be something he had inhaled. It was only after his death when I went to collect his benefits that I learned the truth. My husband had died of AIDS and I needed to go and be tested. I had heard about AIDS. Some of my relatives had suffered with it. But I never ever dreamed that it would come so close. We were good people, we went to church, I was a faithful wife. What happened? But those are questions the answers to which I will forever speculate about. I have my suspicions but that is what they are. Only suspicions. I prefer to remember my husband differently.

I went through hell after the funeral. My husband's family who had been good to me before came and took everything we had and claimed that they would come for the children after the mourning season and look after them. They never did. What saved our lives was that we had a home and the mine would only give my husband's benefits directly to me. At first they were insisting that a male relative from my husband's side needed to be present as well. When I explained to the person in charge what my husband's family had done, he was more understanding and waived the requirement. That is what

helped me take care of the children in those early months. I was so angry at God that I stayed away from church for a long time. Finally, when I felt that life was going out of me, I went back to church and I chose to go on communion Sunday which happened once every two months when the ordained reverend came to our church. He was responsible for 10 other churches and so we only have communion when he comes to our church. I was so unprepared for the comments on my favourite aspects of the service. One woman said, 'They want to kill us by sharing the cup with us?" I had listened to the communion liturgy all of my life and for once after the Reverend read I Corinthians 11, I did not want to go for communion. Especially the part which says that the reason some of us are sick is because of taking communion when we should not. I felt excluded. Was everyone looking at me? Maybe they were not but that is how I felt. From then on I avoided participating in Holy Communion. I felt that my HIV positive status was a sentence that I carried for life. A sentence which attributed to me a permanent guilt. Since I joined our support group, I feel different but I must confess I still hesitate to partake of communion even though things are a little bit different now (PLWHIV, Petrina).

5.2.1 Holy Communion, Unconditional Acceptance or Moral Gatekeeping?

Forrester positions the Eucharist (Holy Communion) as having an important formative role in the church both to individual and the community. He asserts that

The communion table is an open invitation to all where deeply entrenched suspicions, divisions, and hostilities were overcome. Where Jew, Gentile, rich, poor, weak and strong come together and experience a new and challenging depth of community. When the poor are despised, the sacrament is invalid. In the Eucharistic sharing the divisions of the world are challenged and a better way is shown. The Eucharist involves a commitment to sharing with the needy (Forrester, 1997, p. 382).

Ideally one aspect of church that PLWHIV would be most comfortable with is Holy Communion, a table to which they are invited and accepted unconditionally. Welker (2000) laments the fact the Holy Communion is no longer a feast of reconciliation but rather an anxiety-producing means of moral gatekeeping. This sheds some light on Petrina's feelings of ambivalence with regards to participating in the sacrament after her HIV positive diagnosis. Welker laments the sad irony that the feast of unconditional acceptance of human beings by God and among each other is misused for intra-human moral control (Welker, 2000).

5.3 Pedulo and Tyness, Portraits of Social Exclusion

I know that I am responsible for my wife's death while she was having our third born. I know because she died of AIDS and a broken heart. I brought AIDS into our home and that is a pain and regret I will take with me to the grave. I know God forgives and I need to forgive myself but how can I when I never had a chance to apologise to my wife. Eech Eech. There is so much I could tell you about my story but if I did then we would be here until the chickens and the cows come home. What I will talk about today is my current heartache. I want to get married again. Am a changed person. I have learned from my mistakes. Maybe if I get married again and start a new life with someone who will work with me to raise my children, I may learn to forgive myself. Why can't my pastor do this for me. I will tell you why getting married in church is important to me.

You see I was raised by very godly parents. I actually tried to be the kind of son they could be proud of and I think I was succeeding until after my form four, my cousin who had left for South Africa came home and told me about the opportunities in Jozi. Against my parents' wishes, I decided not to go to college and I went to South Africa. I was making good money and I was living the life with my cousin. We would come home every Christmas and bring gifts for the family and give the old people money. We even managed to repair our grandparent's home and built a home for my parents. All before I was 25. Wow!!!! I guess I did something good. Then I started going out with the girls. No commitment just clean plain old fun. Or was it. Now in hindsight not really. My dad always told us about stupidity often hurrying ahead of wisdom and that we had to watch out. I thought I was very street smart. Now I know my father was right. My life is a witness to that.

On my 25th birthday my parents advised me that if I had decided not to continue with school, at least I should settle down and start a family. My mother joked about the fact that she needed to see some grandchildren before she went the way of our ancestors. So I told them to find me a wife. Find one they did and she was an exceptional woman. I debated about staying home and getting a job there but my skill level was so low and besides I was making good money in Jozi, but it was not the kind of place I wanted to raise my family. The crime, the violence, I could take but I loved where we grew up and I wanted to raise my family there. After we got married, I convinced my wife to stay home while I returned to Johannesburg. Instead of coming home at Christmas I came home every month end and spoiled her. We had two beautiful children. I was, however, addicted to my old lifestyle even though I tried to change after I got married.

Then the tragic phone call that my wife had passed on while having our third born prematurely, the baby had not survived. My family had not wanted to worry me but my wife got very ill in the last two months of the pregnancy and when she went to the hospital they ran the tests and found her HIV positive. She did not want to break the news over the phone and was waiting to tell me when I got home at the end of the month. She did not make it. When I came for the funeral, I did not go back to

Jozi, I aged in a few months, I knew I was going to die soon and so I decided to spend what I thought were my last days with my children. My parents were heartbroken. My in laws, I could not even face. What had I done? I had taken their beautiful daughter and because I allowed my stupidity to hurry past my wise side, she was dead as well as our child.

While I was drowning in my sorrow and inconsolable a friend who had heard about the support group I am a member of came to visit and invited me to attend. It was like I was thrown a life line. Look at me now. In all respects brand new, except for the pain and regret in my heart that wells up every time I see my children. They had an amazing mother. Because of the support group now I have reason to hope that I can have a second chance at life. The ARVs have helped to stabilize my health. I even forget that I am HIV positive. I have even rediscovered my childhood faith. I know that if I had kept going to church my life would be different. So that is why I want to get married and not anywhere but in church. I want to start right the next time round. I want my children to have the same opportunities I had as a child. However, I cannot do it alone. I want to do it with a companion. I shared my dreams and hopes with my pastor and he crashed them. He reminded me of how I committed adultery. He reminded me that even though I was well I was carrying a virus that kills people in my body and I could pass it to the person I marry and to the babies she would give birth to. He made me feel like a serial killer. He told me that marriage was a sacred sacrament and God takes its violation seriously. You tell me, is it so bad to want a second chance? There is a part of me that thinks God understands me and approves and my pastor has it wrong. But then I also know what I did and maybe my pastor is right (PLWHIV, Pedulo)

Pedulo's dilemma is also echoed by Tyness (not her real name) below.

Our HIV status does not change our humanity. We want to love and be loved. We want to get married and have children. We want to participate. Why do they call us murderers simply because we want what everybody wants? My husband left me when I tested positive. I looked after myself, got on treatment, took care of my children. But I am lonely and I need companionship beyond my children and support group. When I told my pastor about my desire he asked me why I wanted to kill somebody else. That if I pass on the AIDS virus to someone else it is like shooting them with a bullet. He told me that the Bible says that marriage is holy and it needs to be kept that way (PLWHIV, Tyness).

From the above portraits of exclusion it is clear that whenever the church wants to exclude a group of people from anything without having to explain why, all that has to be done is add the word, 'Holy', in front of it. One level of just engagement that PLWHIV are crying out for is with regards to marriage. There are as many perspectives on marriage as there are

religions and cultures. The church could open up and provide that space where all members can dialogue about marriage and its implications for its membership in the context of HIV and AIDS.

5.4 The Habitus and Doxa of PLWHIV

Bourdieu's social cultural theory defines a socialization process called the habitus. He defines the habitus as "a system of schemes of perception and appreciation of practices, cognitive and evaluative structures which are acquired through the lasting experience of a social position" (Bourdieu, 1989, p. 19) The end result of this process of socialization according to Bourdieu is the doxa, sets of universally held beliefs that agents assent to and accept as true and just, often without knowing or understanding (Bourdieu & Eagleton, 1992). The dilemma that Pedulo and Tyness are experiencing above is a function of a habitus framed by moral values defined from a biblical narrative informed by Greco-Roman and Jewish traditions. Consequently their doxa is that marriage is only proper if it happens in the church. Implicitly any marriage that does not happen in church is stigmatised. So when the barriers to get married "the church way" become too complicated, PLWHIV decide not to go "the church way." Some of these unions also have complicated legal implications for them, especially in the event of death of one of the spouses. They do not have legal cover and families take advantage of those situations to "grab" property.

5.4.1 Uniformed Moral Exclusion

As part of the data production process for this study, I participated in a local church service of one of the participating churches. I was invited by the support group for PLWHIV hosted by

that particular church because it was the women's day of prayer and the women would be in charge of the whole service. Below is the account of my observation.

As the service started we were all encouraged to stand up by the woman leading the service. She was wearing a white blouse and a blue skirt. She had a blue turban on her head and a blue sash on her waist. She looked very distinguished. The singing started and other women dressed like her came filing into the church and closely behind them were the members of the support group. They were dressed differently than the first group. In my mind I thought the women in white and blue must be the choir and the PLWHIV must be the drama group. They were all wearing the same chitenge (the Malawian traditional cloth), blue t-shirts and turbans on their heads of the same chitenge cloth as their skirts. They looked stunning. They sang the same song as they filed in dancing and animating the song, 'Amai tigwile ntchito za mulungu iti tidzatope', 'women, let us do the work of God and we will not grow weary'. The service proceeded and in due course women were called up to make presentations. The women in blue and white presented several songs. The PLWHIV were also called up and they sang some songs as well and acted a drama on AIDS. After the service I was curious to find out about the distinctions of the different women's uniforms. I asked the leader of the PLWHIV support group to explain it to me. This was her explanation.

Much as we would also like to put on the Women's Guild uniform, for most of us it will never happen. First of all you have to be properly married in church, most of us are either not married or our husbands left us or we are cohabiting with people we are not married to because there are so many barriers if you want to get married in church and then the traditional marriages become complicated with lobola because of our HIV status. So we can admire it only from afar. Some of our friends had it before their marriages went bad but now they cannot wear it because you have to be given permission to do so, but they prefer not to ask because of the judgemental attitudes within the women's guild. You can participate in the women's ministry but you would not be given the uniform. They do not want the uniform associated with PLWHIV because it is considered holy. The white blouse stands for holiness. Each part means something but that is the only one I know what it means. The most painful is when we attend funerals and sometimes it is or our friends and we still cannot dress in the uniform. That is when we feel most excluded. Funerals are very important to us to stand in solidarity with our friends who have left us. So when you are not in uniform you cannot sit next to the coffin or do the final maluwa ceremony (flowering the grave). They take over because they are considered the official church representatives. We have our chitenge uniform and we love that at weddings. But when we are part of church functions we do not want to stand out as different (Participant Observation Event, Women's Day of Prayer)

5.4.2 Symbolic Power and Symbolic Violence

Bourdieu's social cultural theory discusses symbolic systems and their ability to reproduce inequalities. He asserts that symbolic systems have codes with deep structured meanings that are used by different social groupings to order and understand the world they inhabit. These codes are therefore ascribed a social integration function (Swartz, 1996). The problem with symbolic systems is that while they provide a cognitive integrative function, they have great potential to become instruments of domination. This is the case of uniformed exclusion described above. According to Bourdieu, "symbolic power resides not in the force of ideas but in relation to social structure. It is defined by a determinant relationship between those who exercise this power and those who undergo it. The transition from symbolic power to symbolic violence happens insidiously. It is a process where those dominated or oppressed accept as legitimate the terms and conditions of their domination. In so doing, they give consent to the dominating authority to continue along the same trajectory. Bourdieu concludes therefore that, "every power, which manages to impose itself as legitimate by concealing power relations which were the basis of its force adds to the dominating influence of these power relations." (Bourdieu, 1973) This is how systems of domination become legitimatized.

5.5 Kambalame, a Portrait of Economic Exclusion

In Chitipa District, the context of this study, financial institutions are only located at the boma, the district centre. People who live in the outlying areas have no access to banking services. It does not make sense for one to travel 100 kilometres to go and bank their money. The money they spend on the travel alone could contribute to their life savings. Participants Page | 135

in my study are mostly farmers by profession. They have no collateral to access credit facilities in case they wanted to improve their livelihoods. So what most rural communities do is that they establish their own financial services in the form of saving circles. Here the rural poor are able to save and borrow. It is through these savings circles that they also get some extra income. The rural poor trust their friends from church because they know that they are bound by an ethical code that will not let them cheat or run away with their members' money. Kambalame relates the following story:

So when Opportunity Bank in Malawi started a lending program in our area we were excited, we were very excited. After the information meeting we even got more excited. At last an opportunity to raise capital for all of our small business ideas and to expand our farms so that we could become food secure. We fulfilled most of the criteria. We knew each other very well because we have been working together for a long time. We knew who could be trusted and who could not be. We had a strong spiritual foundation we had built up through the support groups' Bible studies and prayer times. We knew what was at stake and so we had a very different work and commitment ethic. We thought everyone would want us in their group; well we were in for disappointment. When the group formation phase for the loan groups started, we discovered that someone had gone around telling people not to include us in their groups.

We were devastated. We were treated like we were going to die tomorrow. No one wanted us to be in their group. But we do not blame them, before ARVs we knew our deaths were so close. They did not want us to be in their groups. They said that what if we died before we repaid the loan, then they would be left with the burden. When we suggested that we form our own group they refused to give us the loan because they said we were bad risk. It was like we would not win. You know that proverb, 'amene akutamangitsa, amakuwonesa njira (The one who chases you away, shows you the way)? They showed us the way. Look at us now. We started our own savings club. We have improved our homes, built a meeting place in our community and even helped pay school fees for a student. Maybe sometimes it is good to be discriminated against. Personally both my daughters have finished form 4 and no one in our family has ever gone that far. My son was admitted to Mzuzu technical college and now I am working hard to make sure that when the term starts I will have money for him to go. You know what, I am glad we were excluded because maybe now we would be strapped in debt due to interest, like some of our friends on the village are. We are better off than most of them who sent us away. It is difficult not to gloat sometimes (PLWHIV, Kambalame).

5.5.1 Emerging Agency through Collective Efficacy

Bandura argues that people's shared beliefs in their collective efficacy influences the types of futures they seek to achieve through collective action (Bandura, 2000, p. 76). The storied experiences of PLWHIV reflect this dynamic. The collective agency that has emerged from the support groups has enabled them to creatively fight back against moral exclusion in ways that have transformed their lives and changed their life options for the better. Together they have overcome opposition and reduced their vulnerability to social and cultural pressures. Together they have reached for and attained horizons that they only dreamed of before. One participant, a widowed single parent, proudly told me how one term she was the only parent who paid her daughter's high school fees for the whole year at the beginning of the year. Another struggling father talked about donating iron sheets for his church's building project, in spite of the way they had treated him. Another one with the support of her group was able to resist being married off to her dead husband's brother who was an alcoholic. She was sent away empty-handed with her children and now after being out of school for a year, all three were back in school and one was studying to be a nurse. The motivational commitment of the participants to life and the future is formidable and all of them agree that they could not have done it without the group. I asked participants if they would disband as support groups when AIDS got eradicated and in every situation I got a resounding 'NO'. They used many metaphors, stories and proverbs to explain why. Two stood out very graphically. One was the image of the fire. They explained that when you have a good fire going each log is contributing its little flame to keep the collective fire going. If you take one log from the fire and put it on the side, it will burn for a while but eventually it loses its flame. They said we do not lose our flame when we are with the group. They gave me examples of their members who had dropped out, lost their flames and some even died. One participant commented that

it took a life-threatening illness to help her find true community and achieve her life dreams. She said now she truly appreciated the power and truth of Ecclesiastes 4:9-11; it was the reason she was alive.

Two are better than one, because they have a good return for their labour: If either of them falls down, one can help the other up. But pity anyone who falls and has no one to help them up. Also, if two lie down together, they will keep warm. But how can one keep warm alone? Though one may be overpowered, two can defend themselves. A cord of three strands is not easily broken (Eccl 4:9-11, NIV)

Bandura concludes that "life will always have new social realities and each will open up new opportunities and with them constraints. Nevertheless, the ability of people to navigate the new social realities, take advantage of the opportunities therein and overcome the constraints, will partly depend on their sense of efficacy to bring their collective influence to bear on those new realities" because cords of multiple strands are strong and not easily broken (Bandura, 2000, p. 78).

5.6 Failess and Nyamusukwa: Portraits of Cultural Exclusion

Another form of exclusion was at church celebration meals. Failess (not her real name) narrates:

You know in our church, we always celebrate with food. We usually do not give everyone a plate because we are very many. We put food on one plate and relish on another and then you sit in a circle and share. Before things changed we were discriminated. Nobody wanted you in their circle. Sometimes they would leave the food for you. You would want to pretend that it does not hurt but it did. When we took our children it was better because we would share with the children. However if the function was for adults only, that is when you felt the isolation. It is not nice to eat by yourself. You have no one to talk to. But now we all eat together, things have changed (PLWHIV, Failess).

The participants would also be excluded from the opportunity to contribute ufa (maize flour) for church. This was Nyamusukwa's (not her real name) experience.

At my church, usually when we have a function we contribute in kind since usually we do not have money. For example if there is a funeral in the community, the women from the church would carry ufa, firewood, vegetables and contribute to the meal that would serve the mourners. If I wanted to contribute ufa, my fellow women would tell me it was ok. They would pretend like they are feeling sorry for me since I needed the ufa. But so did everybody else. I knew I was being discriminated against because when I offered to bring firewood, nobody said it was not ok (PLWHIV, Nyamusukwa).

5.6.1 The Injustice of Non-Participation

In Malawi, the church is very connected with the community and often the lines are blurred.

The moral exclusion of PLWHIV does not end when church ends. It often follows them into the community where they live. Rankin et al made a very accurate description of the pervasive nature of HIV related stigma.

HIV/AIDS related stigma directly hurts people who lose community support due to real or supposed HIV infection. In the community, the entire family may be sanctioned because one member is ill. In an impoverished society where there are no safety nets of public service, the results can be ominous for everyone (Rankin, Lindgren, Rankin, & Ng'oma, 2005).

When people are cut off from their church community and their home social community they are left truly alone. The word used for stigma and discrimination in all the Malawian local languages used in Chitipa is the same, 'kutsala'. The term connotes being cut off, to be left behind, to be excluded, to be ignored, eliminated, not counted or considered. That is the position the church relegates PLWHIVs to when they are morally excluded from participation in the life of their church. Probyn (1996) underscores the importance that belonging has for one's social well-being. He argues that to be socially included in the life-shaping activities that happen in any social space enhances one's sense of feeling valued. It is to have a sense of 'insideness and proximity' to others (Probyn, 1996, p. 355). Funerals and church feasts are part of the social-cultural fabric of many African communities and Chitipa is no exception. Denying PLWHIV the opportunity to participate is not only immoral but it is

unjust social exclusion. Participation in life-shaping activities and ceremonies is an important aspect of social justice.

5.7 Authentic Community through Solidarity: A New Way of Being Church

As I listened to the stories of the PLWHIV in the study a theme started emerging, that of authentic community. The emerging patterns were very similar to those recorded in the accounts of the early church in sacred biblical literature. In particular, the second chapter of Acts in the Bible. This passage is quoted below.

⁴²They devoted themselves to the apostles' teaching and to fellowship, to the breaking of bread and to prayer. ⁴³Everyone was filled with awe at the many wonders and signs performed by the apostles. ⁴⁴All the believers were together and had everything in common. ⁴⁵They sold property and possessions to give to anyone who had need. ⁴⁶Every day they continued to meet together in the temple courts. They broke bread in their homes and ate together with glad and sincere hearts, ⁴⁷praising God and enjoying the favour of all the people. And the Lord added to their number daily those who were being saved (Acts 2:42-47; NIV).

I can draw a number of parallels between the narratives of the PLWHIV and the biblical passage above, which is an account of what was happening between people of faith in the beginnings of the church. The participants talked about supporting each other to ensure that they were compliant in taking their ARV treatment. They worked in each other's gardens to ensure that everyone had a good harvest. When one of their number was too weak to come to the support group meeting they went and visited them. They saved their money together and loaned it out to each other so they could improve their livelihoods. They worked hard and encouraged each other to make sure that their children completed school. They instructed each other on how to live well so they could live longer. Their sense of unity and concern for one another parallels that depicted in the Acts 2 passage above. It took PLWHIV being

excluded from the community in their local churches for them to discover authentic community. Yet by definition, a local church is a community of believers. As churches grow bigger, one of the first things that is lost is the sense of community. So instead of AIDS ministry being restricted to PLWHIV doing the same things they did at the beginning of the pandemic, visiting the sick, teaching communities about HIV and AIDS, they could become social spaces within the local churches where authentic community is modelled and taught for the rest of the local church community. De Gruchy (2006), reflecting on the concept of support groups for PLWHIV, describes them as an emerging ecclesiological structure that is defining new ways of being church (De Gruchy, 2006a, p. 2).

5.8 We are Living and not Dying of AIDS: A Theology of Life

One program that Malawi has put in place to help the poor to grow enough food is the agricultural inputs subsidy. Community members register with their chiefs and are assessed according to the level of need. When the agricultural season starts, coupons are given to the farmers and then they use these to access fertilizer and seed for their gardens. Churches also participate in verifying that the people on these lists are in need of support. One of the forms of exclusion for PLWHIV that still exists is in relation to this very program.

Harry (not his real name) has experienced this. He had been assessed and approved but when the time came for coupon distribution he was left out. I asked him why he thought they left him out and this was his response.

For some people in our community we are dying of AIDS because we carry the HIV virus in our bodies. It does not matter that we are compliant with our ARV treatment, we are strong, we serve in our communities and some of our gardens even look better than theirs. It seems we cannot overcome the death branding that was associated with the pandemic in its early years. Others in our community treated us better when we were very sick and bed ridden. Now that we are well without any signs of

AIDS, they do not seem to know how to deal with us. Sometimes I feel like there are people at my church who wish that ARVs had never been discovered. At times I feel like screaming, I am alive, do not talk about us like we are dying tomorrow (PLWHIV, Harry).

Local churches are a product of their communities because that is where the membership lives and that is where their attitudes and values are formed. The local churches that were part of his study were all very comfortable with the mercy and compassion side of the ministry to PLWHIV. They are genuinely struggling with what their role then should be in the lives of PLWHIV now that they are no longer bed ridden – now that they are healthy and able to take care of themselves and their children. They do not know how to transition to the "just engagement" side. One leader was not very happy about the availability of ARVS. According to him, they made PLWHIV better and now they were back to their old habits of promiscuity and spreading the virus. "Now you cannot tell who is sick and who is not. Before you were able to tell", he said. De Gruchy ponders whether the reason we struggle with the new portraits of PLWHIV, healthy, not sick, with an amazing agency, relates to an identity crisis for the church with regards to its HIV and AIDS ministry response. He wonders if the church has not become co-dependent on sick people, so that like the spouse of an alcoholic, our reason for existence actually requires the 'other' to be vulnerable (De Gruchy, 2006a, p. 4) Dussel et al (1985) contend that whenever liberationist action favours the poor and oppressed, it is condemned by the powerful few who benefitted from the inequality the action challenged. They contend that more often than not, the oppressed who claim their rights are often criticised, named as violators of human rights and persecuted (Dussel, Martinez & Morkovsky, 1985, p. 180). This is the attitude reflected by the church leader who is not happy that PLWHIV have access to life-giving medicines that are transforming their experience.

5.9 Conclusion

In this chapter I set out to present critical portraits of the experiences of PLWHIV with moral exclusion. I presented them as embodied storied narratives. I presented them categorically as portraits of moral, social, cultural and economic exclusion. For analysis I drew out the themes that emerged from these narratives as I brought them in conversation with liberation theology, Bourdieu's social cultural theory and Bandura's social cognitive theory. I discussed the concepts of symbolic power, symbolic capital, social capital, symbolic violence, collective agency, solidarity and authentic community as a new ecclesiology. Key themes that emerge from these embodied narratives of exclusion include the following, not in any particular order.

Moral exclusion does not occur in a social vacuum but is a function of concrete social actors that operate at the intersection between culture, power and difference. That is why moral exclusion is easily legitimated in social structures. Another emerging theme is the double edged nature of moral exclusion. Like any other form of oppression, moral exclusion not only hurts the excluded but also renders the church an- ineffective agent in the fight against any form of social injustice. The doxa of PLWHIV in church contexts which often manifests as internalised stigma is a function of the habitus resulting from a socialisation process mostly informed by Greco-Roman and Jewish traditions. These traditions are difficult to challenge because they bear a lot of resemblance to the African traditional cultures undergirded by patriarchy. In the next chapter, I will discuss the theologies that undergird these forms of moral exclusion within the church context.

Liberation theology distinguishes itself from other theologies by placing the oppressed at the centre of the theology formation process not as observers but as the core participants who

become masters of their own destiny, as they navigate the waters of social change of their time. This distinguishing feature is illustrated in the narratives in this chapter and is the redemptive hope of the storied narratives. The PLWHIV live out a theology of life and remind their communities that they are living with HIV and not dying of AIDS. They learn to use symbolic power and social capital once used to exclude them to unmake the unjust social structures that kept them excluded. Using the collective efficacy acquired through the support groups and newly found agency, PLWHIV fight back against moral exclusion, reduce their vulnerability to social and cultural pressures thus changing their life options for the better. Perhaps the most powerful front against moral exclusion has emerged unintentionally. Through the support groups, PLWHIV are living out community that is being considered as a new and more authentic way of being church. For a situation to exist and persist for a long time, there has to be underlying, nurturing conditions allowing it to thrive. Likewise the forms of moral exclusion of PLWHIV in church contexts discussed in this chapter have legitimating root factors. In the next chapter I will explore the theological positions in the church that undergird the forms of moral exclusion of PLWHIV as derived from the data narratives from church leaders.

Chapter 6: Theological Perspectives that Undergird Persistent Moral Exclusion of PLWHIV

The Church is holding onto the temple model which is defined by sacred places, sacred texts, sacred men and sincere followers. The temple model grants extraordinary power to sacred men in sacred places who determine the meaning of sacred texts (Andy Stanley, North Point Church Sermon February 1 2015).

6.0 Introduction

In chapter five I presented the portraits of moral exclusion of PLWHIV within the church contexts in Chitipa. In this chapter I endeavour to critically discuss the theological presentations, arguments and positions that undergird the forms of moral exclusion discussed in the previous chapter as presented by the church leaders who were part of the study. I also bring these representations to dialogue with liberation theology, the Catholic framework for social teaching and justice and the literary discourse that couches this study. A more comprehensive Catholic framework for social teaching and justice is built upon ten principles (see Byron, 1998). However, for purposes of my study I have focused on the principles of structured sin, human dignity, human equality, common good, association and participation, because they are the ones that align with the responses of the church leaders who participated in the study. I also recognize that some of these principles would be interpreted and used differently by Catholic social activists and other scholars. I have contextualized the principles to my study and for each principle I have endeavoured to explain how I am using it.

Andy Stanley, a 21st Century American theologian and pastor of one of USA's mega churches, made the comment quoted at the opening of this chapter as part of his sermon on the need to "rebrand" the church and make it less resistible. For purposes of my analysis of Page | 145

the theologies that undergird the persistence of moral exclusion in the church I have extended his metaphor of the temple model into a framework I use to categorize the various theologies. Below is my rephrased version of Andy Stanley's metaphor:

The church is holding on to the temple model which grants extraordinary power to sacred men in sacred places, wearing sacred garments, to interpret sacred texts in sacred language, preside over sacred feasts and uphold sacred traditions. [The bold italics are mine.]

6.1 Of Sacred Men and the Injustice of the Structural Sin of Patriarchy

Myness' account of her experience with exclusion presented in chapter 5 was very characteristic of positions held by churches in Chitipa in the early days of the AIDS pandemic. It is still the situation in some of the churches that were part of this study. PLWHIV were excluded from leadership opportunities. This would happen regardless of the qualifications or giftedness of the PLWHIV. The majority of those denied opportunities to lead in their churches were women. While the more common grounds presented were moral, there is a deeply rooted theology about leadership that is upheld by most churches that participated in the study. I raised this with the church leaders in the focus group discussion while we were focusing on leadership and below is the response from one of the church leaders. I will call him Church leader #1.

Leader #1: Everything we do in our church is based on the rules and regulations that God has given us in the Bible. In our church we believe in the infallible nature of the Bible. It is the word of God divinely inspired and given to us for right living, instruction as well as correction of error. One of the criteria for membership to the network is belief in the authority of the Bible according to 2 Timothy 3:16 which tells us [he opens his Bible and reads the text to me]

¹⁶ All Scripture is God-breathed and is useful for teaching, rebuking, correcting and training in righteousness, ¹⁷ so that the servant of God may be thoroughly equipped for every good work (2 Timothy 3: 16-17, NIV)

I know our friends in America and Europe are changing things but we are not just going to change our holy church traditions simply because they (American and Europeans) have got lost and are disobeying the word of God. When we are choosing leaders these are the passages we follow.

An elder must be blameless, the husband of but one wife, a man whose children believe and are not open to the charge of being wild and disobedient. 7 Since an overseer is entrusted with God's work, he must be blameless – not overbearing, not quick-tempered, not given to drunkenness, not violent, not pursuing dishonest gain. 8 Rather he must be hospitable, one who loves what is good, who is self-controlled, upright, holy and disciplined. 9 He must hold firmly to the trustworthy message as it has been taught, so that he can encourage others by sound doctrine and refute those who oppose it. 10 For there are many rebellious people, mere talkers and deceivers, especially those of the circumcision group. 11 They must be silenced, because they are ruining whole households by teaching things they ought not to teach – and that for the sake of dishonest gain (Titus 1: 6-11, NIV)

Here is a trustworthy saying: If anyone sets his heart on being an overseer, he desires a noble task. 2 Now the overseer must be above reproach, the husband of but one wife, temperate, self-controlled, respectable, hospitable, able to teach, 3 not given to drunkenness, not violent but gentle, not quarrelsome, not a lover of money. 4 He must manage his own family well and see that his children obey him with proper respect. 5 (If anyone does not know how to manage his own family, how can he take care of God's church?) 6 He must not be a recent convert, or he may become conceited and fall under the same judgment as the devil. 7 He must also have a good reputation with outsiders, so that he will not fall into disgrace and into the devil's trap. 8 Deacons, likewise, are to be men worthy of respect, sincere, not indulging in much wine, and not pursuing dishonest gain. 9 They must keep hold of the deep truths of the faith with a clear conscience. 10 They must first be tested; and then if there is nothing against them, let them serve as deacons. 11 In the same way, their wives are to be women worthy of respect, not malicious talkers but temperate and trustworthy in everything. 12 A deacon must be the husband of but one wife and must manage his children and his household well. 13 Those who have served well gain an excellent standing and great assurance in their faith in Christ Jesus. 14 Although I hope to come to you soon, I am writing you these instructions so that, 15 if I am delayed, you will know how people ought to conduct themselves in God's household, which is the church of the living God, the pillar and foundation of the truth (1 Timothy 3: 1-15, NIV)

You will notice all of those passages talk about men. Men who have proved they can lead by first of all taking care of their own homes as heads of their households. It is not that we do not recognise women. They have their place too. Paul tells us that they have to keep quiet and simply support their husbands. Besides they have other places where they serve such as children's Sunday school, hospitality, and women's guild. We even have special Sundays when we allow them to lead the whole

service such as mothers' day and women's day of prayer. So to answer your question, our model of leadership comes straight out of this holy book.

[He holds the Bible up and shakes it in his hand as he closes his remarks. He receives a round of applause from the rest of the church leaders participating in the focus group].

Link and Phelan (2001) are convinced that considering a multifaceted, multilevel approach to stigma, one should choose interventions that either produce fundamental changes in attitudes and beliefs, or change the power relations that underlie the ability of dominant groups to act on their attitudes and beliefs (Link & Phelan, 2001, p. 381) For churches in general and particularly for the African churches, changing the patriarchal system that dominates power relations within leadership structures and hence influences attitudes such as those expressed by church leader # 1 above is going to be a very long and complex undertaking. This is due to the fact that power relations are deeply rooted within the nexus of society within which they operate, as was observed by Foucault (see Foucault, 1982). Oduyoye also argues that it is very difficult to separate African culture and religion because they are so intricately intertwined. Patriarchy is part of the fabric of many African cultures. It is even harder to address when it is perceived as God ordained because it is legitimized in the sacred texts such as the Bible as leader #1 asserts. Ruether observes that,

Most human religions including Christianity in most of its historical practice has functioned to sacralise the social status quo. They have taken the social hierarchies of gender, class and ethnicity to be divinely given. They have pictured the heavenly world as a divine mirror image of this human social world. To obey God is to accept one's social station. The ruling classes are seen as agents of God (Ruether, 2001, p. 41).

The Stanley (2015) concept of 'sacred men' that is alluded to by Ruether above is what is expressed in the sentiments by Church leader #1 above. Ruether makes an interesting assertion that has implications for the new-found agency of PLWHIV, particularly the women. She says that Christian prophetic tradition is not short of amazing female leaders.

However, "the memory of women's participation is continually erased or re-interpreted according to male interests" (Ruether, 2001, p. 45). The new found agency of the PLWHIV is an opportunity for them to, as Ruether suggests, "shape the tradition by which the story of their accomplishments will be told", remembered and carried on. While this is already happening to a certain extent within the feminist theological circles, it is yet to happen for PLWHIV. For just engagement to happen it will take "a transformative re-conceptualisation of power within the church." Phiri and Bongmba (2012) suggest that this process begins with the recognition and affirmation of truth that God is the source of all power and that he bestows this on all people, men and women alike, for their use to ensure the wellbeing of all humanity and creation (Phiri & Bongmba, 2012, p. 266) The catholic social framework of justice is cognizant of the role of structural sin in legitimizing the moral exclusion from church life. I will describe structures of sin as the institutionalized patterns of decision making that promote oppression and inequality. The church patriarchal theology of leadership is one such structure. Cahill (2000) cautions that structural sin does not refer to impersonal forces beyond human control, but to the concrete acts of individuals who introduce these structures, consolidate them, and make them difficult to remove (Cahill, 2000, p. 291). We need to name the patriarchal theology of leadership in the church for what it is, an unjust structure that contributes to the persistent moral exclusion of PLWHIV from full participation in church life.

6.2 Of Sacred Places and the Sin of Hoarding the Common Good

In chapter 5 I observed and confirmed through the interviews with PLWHIV that the majority of support groups, while theoretically hosted by local churches, were not holding their meetings on the church premises. Most were meeting in community centres, homes of other

PLWHIV or they had constructed their own premises in the community. The PLWHIV talked of a time when they were allowed to meet in the church but that over time, the leadership was uncomfortable with them carrying out their activities in the church and so to avoid unnecessary conflict they had opted to finding alternative venues where they felt freer to carry out their activities during meetings. In an interview with one of the church leaders who hosts a support group, I got the response below. For purposes of confidentiality I will call him Leader #2.

Leader #2: You know there are not many passages in the Bible where Jesus is angry but one time was when he entered the temple and found people selling all sorts of things. He chased them out and overturned their tables. Let me show you in case you think I am making it up. I know you young people these days do not read the Bible. Do you even know where the book of Matthew is? [He chuckles.] You might start opening at the beginning of the Bible. Here it is, let me read it to you.

¹² Jesus entered the temple courts and drove out all who were buying and selling there. He overturned the tables of the money changers and the benches of those selling doves. ¹³ "It is written," he said to them, "'My house will be called a house of prayer,' but you are making it 'a den of robbers (Matthew 21:12-13, NIV).

So you see why we just cannot allow anybody to come and do whatever they want on our church premises. Most especially these People living with HIV. We do not have enough elders to police them every time they come here to make sure that they do not desecrate our sanctuary. You want God to break down our churches the same way he upset the temple? Hehe. Have you seen what kind of activities the PLWHIV do? Do you know what they talk about and the language they use? Have you seen their sketches? I understand that some of them even discuss the use of traditional medicine, condoms and other such things which we do not allow in our church. We don't want them to pollute the house of God. It is a house of prayer and worship to a holy God. That is why we advised them to find a place in the community where they can meet, but not in the church. You know some of them are not even Christians but they attend those group meetings. What will people think when they hear that such things are happening at our church. You want them to stop respecting us? No, we will not allow that to happen. We have to respect the house of God.

Cahill (2000) asserts that people are social beings who interdependently exist in communities providing structures that either facilitate or impede their just cooperation. She defines the

principle of the common good as "embracing the sum total of conditions of social living where people are enabled to achieve integral perfection and flourish materially, socially and spiritually" (Cahill, 2000, p. 288) (Paraphrasing Catholic Church, Gaundium et spes, § 26) The principle of the common good is central to the Catholic framework of social justice. While more commonly used in reference to access material resources that are necessary for human flourishing, in the context of this study, the church physical structures as social spaces that comprise part of the common good are critical for PLWHIV to carry out their activities that contribute to their growth and development. Refusing support groups of PLWHIV to meet in the church space because the temple is considered a holy place that would in essence be defiled if meetings of PLWHIV take place there is moral exclusion and unjust. This is particularly so since they are members of those churches and contribute financially and otherwise to the work of the church. It is also denying PLWHIV the opportunity to partake of the common good so they too can achieve integral perfection and flourish in their environments. This kind of moral exclusion also keeps them on the margins of the church and therefore it is unjust and legitimises stigma and discrimination within church structures. It also raises questions of the feasibility of creating a liberative inclusive space where the just engagement of PLWHIV can be realised. If sharing the physical space is not feasible, is the church ready to open up the rest of the theological space for just engagement?

6.3 Of Sacred Feasts, Holy 'Uncommunion' and Equality

I have chosen to call this section holy 'uncommunion' because the practice and sharing of communion as highlighted by the experiences of PLWHIV has become one not of coming together but of experiencing exclusion, as is reflected in Tryness' story in chapter 5.

All the Christian churches that were part of my study serve and share communion as one of the church sacraments. In most of the rural-based churches, communion is served on very rare occasions because it has to be done by an ordained priest. The shortage of ordained clergy in the rural churches often means that one ordained minister is responsible for over 10 smaller congregations and will visit them on a circuit plan. It means, therefore, that a church will be served communion maybe once every two months, or once a month. Communion is therefore treasured by these congregations. For the church members communion is very central to the expression and experience of their faith.

All the churches that were part of the study also consider the Bible as the sacred text upon which their beliefs are founded. The practice of communion is derived from the Bible and the liturgy used is derived from there as well. There are two biblical texts that all of the churches in the study use in their communion liturgy. These are 1 Corinthians 11:20-34 and Luke 22:7-20.

⁷Then came the day of Unleavened Bread on which the Passover lamb had to be sacrificed. ⁸Jesus sent Peter and John, saying, "Go and make preparations for us to eat the Passover." ⁹ "Where do you want us to prepare for it?" they asked. ¹⁰He replied, "As you enter the city, a man carrying a jar of water will meet you. Follow him to the house that he enters, ¹¹ and say to the owner of the house, 'The Teacher asks: Where is the guest room, where I may eat the Passover with my disciples?' ¹²He will show you a large room upstairs, all furnished. Make preparations there." ¹³They left and found things just as Jesus had told them. So they prepared the Passover. ¹⁴When the hour came, Jesus and his apostles reclined at the table. ¹⁵And he said to them, "I have eagerly desired to eat this Passover with you before I suffer. ¹⁶For I tell you, I will not eat it again until it finds fulfilment in the kingdom of God." ¹⁷After taking the cup, he gave thanks and said, "Take this and divide it among you. ¹⁸For I tell you I will not drink again from the fruit of the vine until the kingdom of God comes." ¹⁹And he took bread, gave thanks and broke it, and gave it to them, saying, "This is my body given for you; do this in remembrance of me." ²⁰In the same way, after the supper he took the cup, saying, "This cup is the new covenant in my blood, which is poured out for you (Luke 22: 7-20, NIV).

²⁰When you come together, it is not the Lord's Supper you eat, ²¹ for as you eat, each of you goes ahead without waiting for anybody else. One remains hungry, another gets drunk. ²²Don't you have homes to eat and drink in? Or do you despise the church of God and humiliate those who have nothing? What shall I say to you? Shall I praise you for this? Certainly not! ²³For I received from the Lord what I also passed on to you: The Lord Jesus, on the night he was betrayed, took bread, ²⁴and when he had given thanks, he broke it and said, "This is my body, which is for you; do this in remembrance of me." 25In the same way, after supper he took the cup, saying, "This cup is the new covenant in my blood; do this, whenever you drink it, in remembrance of me." ²⁶For whenever you eat this bread and drink this cup, you proclaim the Lord's death until he comes. ²⁷Therefore, whoever eats the bread or drinks the cup of the Lord in an unworthy manner will be guilty of sinning against the body and blood of the Lord. ²⁸A man ought to examine himself before he eats of the bread and drinks of the cup. ²⁹For anyone who eats and drinks without recognizing the body of the Lord eats and drinks judgment on himself. 30 That is why many among you are weak and sick, and a number of you have fallen asleep. ³¹But if we judged ourselves, we would not come under judgment. ³²When we are judged by the Lord, we are being disciplined so that we will not be condemned with the world. ³³So then, my brothers, when you come together to eat, wait for each other. ³⁴If anyone is hungry, he should eat at home, so that when you meet together it may not result in judgment. And when I come I will give further directions (1 Corinthians 11: 20-34, NIV)

The biblical texts that are used for communion are all an expression of an invitation to come and share in a meal as an affirmation of community and belonging to the same faith. The first communion as presented in the biblical gospel texts was an ordinary meal that Jesus shared with his disciples and encouraged them to share in the same practice in remembrance of him. As the church became an institution the practice of communion also took on a very formal nature. The word 'Holy' was added to it. To be holy refers to being set apart or separate for special purpose. Unfortunately, for those who feel excluded it also translates as being left out. Instead of being about sharing ordinary bread and wine or the equivalent of the staple food and drink, there are now specific elements that are considered sacred, to only be used during communion. Instead of a shared meal to which all the followers of Jesus are invited, in most churches you have to go through a ceremony such as confirmation for the Protestants and first communion for the Catholics in order to qualify to participate in

communion. Even after confirmation or first communion, every time one is going to partake of communion, they have to go for confession first as in the Catholic Church. In some of the churches, couples that are living together and not legally married in church are excluded from communion. Other church traditions will exclude from communion people whose spouses are of a different faith from theirs. All these exclusions carry their own stigma and so for most PLWHIV they layer onto those pre-existing stigmas.

Pieris, reflecting on a theology of communion proposes that the Eucharist is a celebration of the incarnation of Christ and hence symbolic of a very physical event. He argues that spiritualizing communion, to the point of excluding others in the name of them not being holy-worthy, [italics mine], is to deny the embodied reality of communion (Pieris, 2000). In support of Pieris' proposition, Patterson (2005) argues for an incarnational faith, whose founding sacrament is the Eucharist, to celebrate the human body. She, however, recognizes that before this can happen, there is a need to overcome the hurdle of all the negative body associations that have dominated the discourse on HIV and AIDS. She concludes by calling for theological reflection on HIV and AIDS related stigma to face up honestly to the effects of negative Christian constructions of the body (Patterson, 2005, p. 9).

To a certain extent, a theology of communion as practiced in the churches that participated in the study is unjust in that it violates the principle of human equality. Byron (1999) conceptualizes this principle as:

Deriving from the essential being of dignity possessed by people. That while differences and talents are part of God's plan, social and cultural discrimination in fundamental rights are not compatible with God's plan. That treating as equals equally is one way of defining justice, also understood classically as rendering to each person his or her due. That underlying the notion of equality is the simple principle of fairness (Byron, 1999, p. 12).

The lived experiences of PLWHIV with regards to participating in communion in their local churches reflect a compounding of their feelings of exclusion. The churches are yet to create just spaces where all their members, including PLWHIV, can challenge the unjust structures that legitimize moral exclusion, even when it is immorally couched in church traditions that have not been reflected upon.

6.4 Of Sacred Garments that are Barriers to Full Participation

In the year 2000, I was facilitating a workshop for church leaders on HIV and AIDS. The purpose of the workshop was to help the churches come up with meaningful ways to strategically respond to the HIV and AIDS pandemic in their midst. To co-facilitate, I invited a friend, Reverend Gideon Byamugisha, a priest living openly and positively with his HIV status, to share his story with the group. He challenged the group with his story and shared of how his own church made a brave stand to respond to the HIV and AIDS pandemic and by asking him to head up the HIV and AIDS initiative of the church. During the break I was approached by a group of clergy who thanked me for introducing them to this powerful speaker. They, however, expressed concern that he had spoken so openly about living with HIV while wearing a clerical collar! In other words they were fine with him speaking about his HIV positive status, as long as he was not wearing his clerical collar, which they regard as the sacred symbol of church leadership. They even asked if he could remove the collar for the subsequent sessions! These church leaders had gathered for precisely the purpose of wanting to respond to the HIV pandemic, and yet even before they started they were unconsciously being held back by their own prejudices with regards to sacred garments. Sacred garments are not relegated to the priestly domain. As per my observations of the Women's day of prayer activities in one of the churches participating in the study, they are often a medium of

exclusion of PLWHIV. Since I wanted to understand the significance of the uniform, I asked one of the leaders to explain this to me and her response is given below. I will call her Leader #3.

Leader # 3: The blue and white is a special uniform and not everyone gets to wear it. It is for those who have been properly married in the church. After the wedding, the women leaders call the wife and she is given some special teaching. This includes among other things her role as wife, mother and a servant of the church. We encourage her to join the women's guild. When we think that she is ready we organize for the induction ceremony and we consider this sacred. That ceremony is inducting the woman of God into the army of God. The induction ceremony involves dressing up the woman in the Mothers' Union uniform and giving her a Bible. The uniform is symbolic and it is her reminder that she is wearing the armour of God as described in Ephesians 6:10-18. I will read it for you because this is our induction passage for all Amai a Myano (Women's Guild).

¹⁰ Finally, be strong in the Lord and in his mighty power. ¹¹ Put on the full armor of God, so that you can take your stand against the devil's schemes. ¹² For our struggle is not against flesh and blood, but against the rulers, against the authorities, against the powers of this dark world and against the spiritual forces of evil in the heavenly realms. ¹³ Therefore put on the full armor of God, so that when the day of evil comes, you may be able to stand your ground, and after you have done everything, to stand. ¹⁴ Stand firm then, with the belt of truth buckled around your waist, with the breastplate of righteousness in place, ¹⁵ and with your feet fitted with the readiness that comes from the gospel of peace. ¹⁶ In addition to all this, take up the shield of faith, with which you can extinguish all the flaming arrows of the evil one. ¹⁷ Take the helmet of salvation and the sword of the Spirit, which is the word of God. ¹⁸ And pray in the Spirit on all occasions with all kinds of prayers and requests. With this in mind, be alert and always keep on praying for all the Lord's people (Ephesians 6: 10-18, NIV)

We wear the uniform on special occasions and ceremonies where we need to identify ourselves as the 'Amai a Mvano' from our church. It is our sign of solidarity and community. The men also have their own group called the Fathers' Union. You also have to be properly married in church to be inducted. However, in their case they do not have a uniform.

Every women's church group in Malawi has a uniform that is worn at special occasions and is considered sacred. Henderson and Gilman (2004) describe the significance of the different pieces of the Presbyterian Church uniform as,

Consisting of a black skirt that means we are living in a dark sinful world, a white, long-sleeved blouse testifying that we have accepted Christ as our light, a white headscarf signifying that we are striving ahead in light, a white belt to strengthen us for the journey and a badge depicting an open Bible and a cross. The uniform is consecrated at a special religious ceremony and is therefore considered sacred. The wearing of the uniform carries with it the responsibility of representing Christ and the church. Consequently, the women wear their uniforms only on specific designated occasions, for example during Holy Communion, evangelism campaigns, and special church services or women's gatherings, when preaching; when visiting the sick, bereaved and needy; and during funerals to name a few (Henderson & Gilman, 2004, p. 26).

Excluding women living with HIV from the social space of the women's group in essence takes away from their social core and is therefore unjust. Byron (1998) includes the principle of participation as one of the building blocks of Catholic social teaching. He articulates this as,

The right to be actively involved in society, seeking together with others the common good and well-being of ALL. Without participation, emphasizes Byron, the benefits available to an individual through any social institution cannot be realised. He concludes that the human person has a right not to be shut out from participating in those institutions that are necessary for human fulfilment (Byron, 1999, p. 9).

In the case of PLWHIV the church uniform excludes them on a number of fronts. On the spiritual front, they are treated as outsiders to that sacred space. Even on the day when women are supposed to come together in solidarity, as in the service described above, they are separated by sacred clothing, whose purpose is to unite women. They cannot participate fully in women's evangelistic campaigns because they would not be able to wear the uniform. It also means that that they would be excluded from preaching opportunities at church. On the social and cultural level, while they can attend the funerals, they would be excluded from the meaningful ceremonies performed by women that are reserved for women. Phiri (1997) discusses how sometimes women's spaces can play the dual role of solidarity and exclusion. Whereas churches are considered as appropriate social spaces where stigmatizing attitudes

and practise can be appropriately addressed (see Campbell, Skovdal, & Gibbs, 2011), they can also be alienating spaces for women who are living with HIV. For women, social spaces such as the church women's group are symbolic as well as interactional. This is because it is here, as Latane, Liu and Sibley conclude, that social representations, shared knowledge and meanings, social identifications as well as recipes for living, are constructed and reconstructed as they network and interact with others (Latané & Liu, 1996; Liu & Sibley, 2004).

6.5 Sacred Traditions that War against the Principle of Association

In chapter five in the portrait of social exclusion, I portrayed the struggle PLWHIV experience with regards to their desire to marry or remarry in the church, using Pedulo's story. The negative attitude of the clergy with regards to the desire of PLWHIV to marry or remarry is undergirded by a theology of marriage that is informed by doctrinal positions deriving from Jewish traditions as well as the Greco-Roman cultures in which the Bible was written and translated. Lawler gives an explicit description of this theology.

Since the fourth century, and Augustine, the Catholic Church has insisted that there is a sacrament in marriage between Christians. That the marriage between Christians is as much a sacrament as the big sacraments of Baptism and the Eucharist. In Catholic tradition, a sacrament means an outward sign of an inward grace instituted by Christ. A sacrament is a prophetic symbol through which the Church, the body of Christ proclaims, reveals and celebrates in representation the action of God called grace. Marriage between Christians is therefore a two tiered reality which on one level proclaims, reveals and celebrates the intimate communion of life and love between a man and a woman. On another more profound level, it proclaims, makes explicit and celebrates the intimate communion of life and love and grace between God and God's people and between Christ and Christ's people, the Church (Lawler, 1993, p. 14).

With the above position as the foundation, Christian churches have gone on to develop theologies of marriage using biblical narratives. The narratives shared by all the churches in the study were the three below: Genesis 1:22, Mark 10:1-12 and Ephesians 5: 22-33.

God blessed them and said, "Be fruitful and increase in number and fill the water in the seas, and let the birds increase on the earth (Genesis 1:22, NIV).

Wives, submit to your husbands as to the Lord. 23 For the husband is the head of the wife as Christ is the head of the church, his body, of which he is the Saviour. 24 Now as the church submits to Christ, so also wives should submit to their husbands in everything. 25 Husbands, love your wives, just as Christ loved the church and gave himself up for her 26 to make her holy, cleansing her by the washing with water through the word, 27 and to present her to himself as a radiant church, without stain or wrinkle or any other blemish, but holy and blameless. 28 In this same way, husbands ought to love their wives as their own bodies. He who loves his wife loves himself. 29 After all, no one ever hated his own body, but he feeds and cares for it, just as Christ does the church — 30 for we are members of his body. 31 "For this reason a man will leave his father and mother and be united to his wife, and the two will become one flesh." 32 This is a profound mystery — but I am talking about Christ and the church. 33 However, each one of you also must love his wife as he loves himself, and the wife must respect her husband (Ephesians 5: 22, NIV)

1 Jesus then left that place and went into the region of Judea and across the Jordan. Again crowds of people came to him, and as was his custom, he taught them. 2 Some Pharisees came and tested him by asking, "Is it lawful for a man to divorce his wife?" 3 "What did Moses command you?" he replied. 4 They said, "Moses permitted a man to write a certificate of divorce and send her away." 5 "It was because your hearts were hard that Moses wrote you this law," Jesus replied. 6 "But at the beginning of creation God 'made them male and female.' 7 'For this reason a man will leave his father and mother and be united to his wife, 8 and the two will become one flesh.' So they are no longer two, but one. 9 Therefore what God has joined together, let man not separate." 10 When they were in the house again, the disciples asked Jesus about this. 11 He answered, "Anyone who divorces his wife and marries another woman commits adultery against her. 12 And if she divorces her husband and marries another man, she commits adultery (Mark 10: 1-12, NIV)

With the above biblical narratives as their point of reference, the Christian churches have operated from a theology of marriage that defines marriage as being a permanent union between a man and a woman that involves separation from their own families to form a new

unit based on love and submission, fidelity and faithfulness with primary purposes of procreation and companionship. These theologies though are being challenged and reconsidered in contemporary societal contexts and the advent of HIV and AIDS has greatly influenced these debates. Kelly (1998) contends that a reinterpretation of marriage is being driven by the HIV and AIDS pandemic. He argues that,

As sexual persons, created in God's image, it is the inseparable connection between life and love that we must respect, rather than the unitive and procreative significance which are both inherent to the marriage act. Our loving relationships must be life-giving and in a relational and social sense (Kelly, 1998, p. 134).

PLWHIV find themselves in situations of abandonment or abusive relationships, as was discussed in a portrait in chapter 5. However, when they approach their churches for counsel, they are reminded of the indissoluble nature of the marriage sacrament and that God hates divorce. Moyo (2005) questions whether divorce could be not be considered a viable solution for issues of marital conflict in Christian marriages (F. Moyo, 2004). Perhaps it is Kelly (1998) who best wrestles with the conflict at the centre of the traditional theology of marriage in the Christian church context that represents the struggle of PLWHIV who are navigating marital questions. He articulates this dilemma experienced by PLWHIV thus,

It has also been claimed that this quality of relationship focus throws light on the problem of marriages which have broken down because the relationship took on a destructive quality. Are Christians obliged to stay in a relationship which is destroying them as persons? Does such a catastrophic deterioration of quality if irremediable, indicate that there is no longer any real marriage at all since, in terms of interpersonal love, the relationship has ceased to exist? Why should not the partners be able to experience the life giving healing of a new loving relationship, if the opportunity presents itself? (Kelly, 1998, p. 135).

A cornerstone of the catholic framework for social justice is human dignity – the belief that every human being is made in the image of God and therefore has inherent value, worth and

dignity, irrespective of their race, gender, economic or social status. I would like to add here that this also applies regardless of their marital status. The implication of this foundation is that people are to be valued above institutions, even those institutions that are considered sacred, such as marriage. Cahill (2000) reflects that traditional societies, Christian and otherwise, usually understand individual identity and worth primarily in terms of social roles. She proposes the need to strike a balance that considers the individual as having inviolable value in themselves, while strongly affirming the inherently social nature of the person (Cahill, 2000, pp. 286-287). A balanced theology of marriage would include PLWHIV, as opposed to the traditional one that further alienates them and keeps them morally excluded and stigmatized.

The injustice in the theological arguments that church leaders use to prevent PLWHIV from getting married in church not only violates the principle of human dignity but that of association as well. In agreement with Cahill, Byron emphasizes that Catholic faith tradition views the person as not only sacred but also social. Hence the organization of all human relationships will directly affect the capacity of individuals to grow in community. He underscores the importance of association with others in families and social institutions as fundamental to fostering growth, protecting dignity and promoting the common good, enabling human beings to achieve their fulfilment (Byron, 1999, p. 9).

6.6 Of Sacred Texts and Sacred Interpretations that Promote Injustice

A common thread that runs through all of the theologies that undergird the moral exclusion of PLWHIV from full participation in church life discussed above is that they are all rationalised with biblical texts. In almost every situation of moral exclusion experienced there was a biblical justification used. All the exclusion was rationalised from scripture. Un-

contextualised interpretations will sustain the discriminatory teachings on sin, punishment and sexuality. Bauer (2003) points out that we can trace through history instances where churches have used the Bible for purposes of exclusion (Bauer, 2005, p. 12). Similarly, Dube (2010) laments the readings and interpretations of the Bible in the early days of the HIV and AIDS pandemic which were done within an unconstructive moral religious framework. She points out that these initial stigmatizing biblical interpretations capitalized on biblical texts that tended to equate illness with disobedience, impurity and God's punishment (Dube, 2010, p. 224). Chitando (2007), while affirming the centrality of the Bible to African Christianity, also points out how in the early days of the AIDS pandemic, theological rigidity and intellectual aridity influenced the church to read the Bible in ways that were not life-affirming. He cites how:

Many Christians turned to passages like 'For the wages of sin is death' (Romans 6:23) to account for the suffering and death of people with AIDS. Other readers utilized the Deuteronomistic view of history in which Yahweh rewards good and punishes evil. Thus initial reading of the Bible generated stigma and discrimination toward People living with HIV. They also provided the theological framing for the church response... HIV became a manifestation of humanity's sinfulness. The epidemic [sic] was interpreted as fulfilling the curses cited in Deuteronomy 28:27, which include God sending incurable diseases to an apostate people. HIV was read as a signifier that the end of the world was drawing near (Luke 21:5-28). The failure to develop a vaccine to cure HIV has been taken by some as confirming God's punishment of a stubborn and sinful generation (Chitando, 2007, pp. 9,21).

It is possible to conclude that these unconstructive readings of the Bible were only characteristic of the early years of the AIDS pandemic and are now history. In my interviews with PLWHIV, I discovered that there are a group of churches in Chitipa that still operate from this position of theological rigidity and will not even allow HIV and AIDS to be mentioned in their pulpits or health education lessons to be conducted on their premises. For these churches the opportunity has eluded them to rethink their theology and become more

relevant, taking advantage of the Kairos moment the AIDS pandemic has given the church. The danger is that they command large followings of people and where silence dominates, stigma thrives and moral exclusion is legitimised.

Liberation theology calls for the reading of the Bible from the perspective of the poor, marginalised, oppressed, discriminated against and morally excluded. The readings and interpretations of the Bible in the early years of the AIDS pandemic do not reflect this principle at all. A number of theologians have advocated for a re-reading and reinterpretation of the Bible in ways that are more life-affirming within the HIV and AIDS context (see Chitando, 2007; Dube, 2010; Nadar, 2003b; West & Zengele, 2006). Dube (2010) goes further to advocate for what she calls a liberative and combative biblical hermeneutics. She posits this approach to biblical studies as seeking to combat the oppressive conditions, structures and perspectives that aid the spread of HIV and AIDS while denying quality care for PLWHIV (Dube, 2010, p. 225). According to Dube, "liberative HIV and AIDS hermeneutics are war instruments for the establishment of justice for PLWHIV".

6.7 Conclusion

In this chapter, I discussed the theological positions that undergird the moral exclusion of PLWHIV from full participation in church life, using the metaphor of the temple model and the framework of the catholic framework for social teaching and justice derived from liberation theology. I used Andy Stanley's temple model as a framework for my discussion and expanded it to include sacred men, places, feasts, garments, traditions and texts. A disclaimer here is that Andy Stanley would probably apply this model differently but my use of it does not depart significantly from his broad application. Through the sermon series "Brand New", he advocates for a rethinking of the way we "do church" if more people are Page | 163

going to find it attractive. Continuing the re-branding analogy, I will use the next chapter to examine the theological resources that are existent within the church context to contribute to the liberative and combative hermeneutic proposed by Dube above, that would address the injustices perpetrated by the theologies discussed in this chapter and instead create an environment that is more inclusive and allows for the just engagement of PLWHIV in church life.

Chapter 7: Liberative Theological Resources for Overcoming Moral Exclusion

One midsummer night there was a serving girl who had been to a dance somewhere and was on her way home. Just as she was walking along with her thoughts miles away, she met a big ox on the road. The poor girl was frightened, of course, but when she couldn't figure out any way to avoid it and couldn't see any living person to help her in any other way, she grabbed the ox by the horns and stood clinging to it all night long, just like that. She didn't dare let him go, either – instead they just stood where they were. After some time had passed the sun came up, and then the girl saw she was standing holding a big kettle which was full to the brim with gold coins [Al, Dalarna. Collected in 1933 by Enar Persson from Karin Holstr6m. Printed in Klintberg 1972:266].

7.0 Introduction

In the previous chapter I discussed the theologies that undergird moral exclusion of PLWHIV from participation in the church and their connections to structures of injustice. Like the serving girl in the Swedish fable quoted above, the discourse on HIV and AIDS related stigma in the church context has come to that fork in the road. It is time to move beyond compassion towards justice. However, the church is wrestling with a seemingly big ox that is halting progress – its own theological representations as presented in chapter six. The current global HIV and AIDS research context greatly influenced by increasing access to treatment has ushered in a new dawn for discourse. From within its own polity, the church has access to theological resources, its own kettle of gold coins, which have the power to move the discourse on stigma and discrimination into the justice space. In this chapter I will interrogate theological resources within the church context for liberating theologies with potential to confront the unjust structures unearthed in the previous chapter and create an environment that allows for the just engagement of PLWHIV.

In chapter six, the data showed that all theological positions that undergird exclusion of PLWHIV in the church were supported by biblical texts and by those in church leadership. It is primarily for this reason that the bulk of resources discussed in this chapter derive from the Bible. Secondly, the Bible is a theological resource that is used, respected and revered by all of the churches that participated in the study. It is also an accessible resource in that it has been translated into the local languages. Bauer (2005) offers some very sound guidance for anyone that would attempt to reclaim destignatizing readings of the Bible. First Bauer suggests that the following points need to be taken into consideration in using biblical texts for justice purposes.

- Scriptures themselves were written in particular contexts, at different times and they reflect the social locations of the authors.
- When we choose texts to support stigma, we are often refusing to acknowledge our own social context and the cultural traditions that have shaped our views.
- The two consistent themes of scripture are God's love and God's justice, by which God seeks to redeem creation and humanity.
- Since God's abiding concern is for our wellbeing or fullness of life, no passage from scripture should be used to diminish this in any other human being (Bauer, 2005, p. 13).

"Readings of the Bible must be Christ-centred and linked to the context in which we find ourselves. We need to acknowledge insights, now available to us which were not available to the biblical authors and previous generations of people studying or reading the Bible. These include the findings of modern biblical scholarship, and the relevant anthropological and sociological research on biblical themes. They also include insights gained from contextual theologies and from a deepening understanding, within the church, of issues of social justice" (Bauer, 2005, p. 13).

As I discuss these theological resources, I am going to apply Bauer's invaluable guidance and acknowledge that his framing has influenced my choice of biblical texts as my contextual use of the same.

In their reflexive theory, Bourdieu and Wacquant argue that researchers are not a neutral presence but social actors in their own right (Bourdieu & Wacquant, 1992). As an actor in my own right in this study, I bring to it all the privileges that Bauer (2005) outlines above. I have been a student of the Bible since I was a teenager within an evangelical Baptist tradition. My social work training has given me opportunity to wrestle with issues of social justice. I have been involved in development work with the church and particularly around issues of HIV and AIDS for 15 years. Hence I have a passion for and commitment to the church, locally as an agent of development in marginalized communities. My formal education privilege has exposed me to opportunities for biblical scholarship as well as anthropological and sociological research on biblical themes. The internet age makes study resources available to me. This is my location as I discuss liberating theological resources within the church. It is critical that I embody my location because it constitutes a big portion of my internalized objective environment out of which I make my selection of liberating texts, then analyse and interpret them. As Bourdieu articulates below:

The analysis of objective structures is inseparable from the genesis, within biological individuals, of the mental structures which are to some extent the product of the incorporation of social structures; inseparable from the analysis of the genesis of these social structures themselves: the social space, and the groups that occupy it are the product of historical struggles (in which agents participate in accordance with their social space and the mental structures through which they apprehend this space (Bourdieu, 1990, p. 14).

I am also aware that these privileges and opportunities that have influenced my location are not available to everyone. I therefore own my positions but appreciate that others, also given their location, may take ones that are different to mine. I have selected five liberating church theologies for discussion in this chapter. These are: mission mandate, leadership model,

community paradigm, people ethos and life-affirming culture. These are discussed in the remaining part of this chapter.

7.1 A Liberating Mission Mandate

I submit that the most important liberating theological resource available to the church is a mission mandate which resonates with the justice principle of the preferential option for the poor in liberation theology. This mission mandate in my opinion is articulated in two biblical texts, in Luke 4:17-21 and Isaiah 58:6-12.

¹⁴ Jesus returned to Galilee in the power of the Spirit, and news about him spread through the whole countryside. ¹⁵ He was teaching in their synagogues, and everyone praised him. ¹⁶ He went to Nazareth, where he had been brought up, and on the Sabbath day he went into the synagogue, as was his custom. He stood up to read, ¹⁷ and the scroll of the prophet Isaiah was handed to him. Unrolling it, he found the place where it is written: ¹⁸ "The Spirit of the Lord is on me, because he has anointed me to proclaim good news to the poor. He has sent me to proclaim freedom for the prisoners and recovery of sight for the blind, to set the oppressed free, ¹⁹ to proclaim the year of the Lord's favor."²⁰ Then he rolled up the scroll, gave it back to the attendant and sat down. The eyes of everyone in the synagogue were fastened on him. ²¹ He began by saying to them, "Today this scripture is fulfilled in your hearing" (Luke 14: 17-21, NIV).

I would like to consider the above declaration, made by Jesus at the beginning of his redemptive work to define what his life was going to be about, as the mission mandate of the church. Ideally it should be the same for the church, because if the church is considered as the continuing bodily expression of the redemptive work of God in the world that was started by Jesus, then by default this mission mandate is available to the church as a theological resource. The liberation and justice agenda is articulated as involving proclaiming good news to the poor, proclamation of freedom to the prisoners, recovery of sight for the blind, setting the oppressed free and proclaiming the year of jubilee. This liberation paradigm for mission

also echoes an Old Testament text and I will propose it as another liberating theological resource.

Is not this the kind of fasting I have chosen: to loose the chains of injustice and untie the cords of the yoke, to set the oppressed free and break every yoke? ⁷ Is it not to share your food with the hungry and to provide the poor wanderer with shelter—when you see the naked, to clothe them, and not to turn away from your own flesh and blood? ⁸ Then your light will break forth like the dawn, and your healing will quickly appear; then your righteousness will go before you, and the glory of the Lord will be your rear guard. ⁹ Then you will call, and the Lord will answer; you will cry for help, and he will say: "Here am I." If you do away with the yoke of oppression, with the pointing finger and malicious talk, ¹⁰ and if you spend yourselves on behalf of the hungry and satisfy the needs of the oppressed, then your light will rise in the darkness, and your night will become like the noonday. ¹¹ The Lord will guide you always; he will satisfy your needs in a sun-scorched land and will strengthen your frame. You will be like a well-watered garden, like a spring whose waters never fail. ¹² Your people will rebuild the ancient ruins and will raise up the age-old foundations; you will be called "Repairer of Broken Walls, Restorer of Streets with Dwellings" (Isaiah 58: 6-12, NIV).

Bauer (2003) submits that while the Bible has been used to rationalize stigma and discrimination, there is also within its narrative evidence of people being treated humanely in ways that liberated them from the oppression and marginalization of unjust and discriminatory systems. This opened up options for them to experience life in its fullness. He cites biblical narratives about lepers, Samaritans, women with medical conditions, and people with physical and emotional disabilities. These, though considered outcasts and untouchables by the religious establishment of the day, were welcome in Jesus' company. "He included them, invited them into his circle of friends, touched them and allowed himself to be touched by them. In the end Jesus submitted himself to the ultimate stigmatization of public crucifixion outside the city walls" (Bauer, 2005, p.12).

A liberating ministry model therefore counters stigma, discrimination and exclusion in that its focus is a preferential option for those on the margins and intentionally includes them as

agents in the process of their own liberation. It thus restores their dignity and affirms their worth as human beings worthy of honour, recognition and full participation in life.

7.2 A Liberating Leadership Model

The Bible also offers liberating theological resources in a leadership model that is gendersensitive and undergirded with the values of humility, service and compassion. History is awash with oppressive and patriarchal models of leadership within the church – such as the ones that led to reformation spearheaded by Martin Luther and the conditions that gave birth to liberation theology (see Bainton, 2013; L. Boff, 1988; Gutierrez, 1988; Ogden, 1991; Juan L Segundo, 2002). Even in this study, in chapter six, I presented theologies that undergird the moral exclusion of PLWHIV as expressed by church leadership in Malawi. In the theologies of the clergy of the churches in Chitipa are inherent models of leadership that are oppressive and legitimate the structures of gender inequality. This makes the elimination of HIV and AIDS related stigma and discrimination very difficult. It was such models that Jesus was speaking out against and presenting a more liberating one in Matthew 20: 24-28 and Mark 10:42-45 below

²⁴ When the ten heard about this, they were indignant with the two brothers. ²⁵ Jesus called them together and said, "You know that the rulers of the Gentiles lord it over them, and their high officials exercise authority over them. ²⁶ Not so with you. Instead, whoever wants to become great among you must be your servant, ²⁷ and whoever wants to be first must be your slave— ²⁸ just as the Son of Man did not come to be served, but to serve, and to give his life as a ransom for many (Mattew 20: 24-28, NIV).

⁴² Jesus called them together and said, "You know that those who are regarded as rulers of the Gentiles lord it over them, and their high officials exercise authority over them. ⁴³ Not so with you. Instead, whoever wants to become great among you must be your servant, ⁴⁴ and whoever wants to be first must be slave of all. ⁴⁵ For even the Son of Man did not come to be served, but to serve, and to give his life as a ransom for many."(Mark 10: 42-45,NIV)

This liberating leadership model that Jesus advocates for is echoed by the Apostle Peter in his instructions to church leaders in his day.

1 To the elders among you, I appeal as a fellow elder and a witness of Christ's sufferings who also will share in the glory to be revealed: ²Be shepherds of God's flock that is under your care, watching over them—not because you must, but because you are willing, as God wants you to be; not pursuing dishonest gain, but eager to serve; ³ not lording it over those entrusted to you, but being examples to the flock. ⁴ And when the Chief Shepherd appears, you will receive the crown of glory that will never fade away (1 Peter 5: 1-2).

In Chapter six I discussed the injustice of patriarchal leadership within the church and its complicit role in legitimizing structures of domination and inequality that complicate the response to HIV and AIDS related stigma within church settings. Biblical tradition offers a liberating theology of leadership in the doctrine of 'the priesthood of all believers'. This doctrine recognizes that all Christians are equal before God and can perform priestly duties. The biblical resources that describe these are: Galatians 3: 26-29 and 1 Peter 2: 4, 5, 9 below.

⁴ As you come to him, the living Stone—rejected by humans but chosen by God and precious to him—⁵ you also, like living stones, are being built into a spiritual house to be a holy priesthood, offering spiritual sacrifices acceptable to God through Jesus Christ. For in Scripture it says:.... But you are a chosen people, a royal priesthood, a holy nation, God's special possession, that you may declare the praises of him who called you out of darkness into his wonderful light. Once you were not a people, but now you are the people of God; once you had not received mercy, but now you have received mercy (1 Peter 2: 4,5,9, NIV).

²⁶ So in Christ Jesus you are all children of God through faith, ²⁷ for all of you who were baptized into Christ have clothed yourselves with Christ. ²⁸ There is neither Jew nor Gentile, neither slave nor free, nor is there male and female, for you are all one in Christ Jesus. ²⁹ If you belong to Christ, then you are Abraham's seed, and heirs according to the promise (<u>Galatians 3: 26-29, NIV</u>).

The liberative power of this doctrine is well articulated by Walzer (1984) in his deductions on liberation and separation within the church polity. He argues that,

The art of separation doesn't make only for liberty but also for equality. Religious liberty annuls the coercive power of political and ecclesiastical officials. Hence it creates, in principle, the priesthood of all believers, that is, it leaves all believers equally free to seek their own salvation; and it tends to create, in practice, churches dominated by laymen rather than by priests (Walzer, 1984, p. 320).

I do recognize that patriarchy has cultural as well as religious underpinnings and so effectively dismantling it as a structure of injustice will take action from both spheres. However, when it is legitimized within the church setting it is accepted as divine. The liberating doctrine of a priesthood of all believers where values of humility and service are upheld provides a starting point. The work of reformers such as Martin Luther and liberation theologians such as Gutiérrez offers a hope of what can be done (see <u>Bainton</u>, <u>2013</u>; <u>Gutierrez</u>, <u>2004</u>; <u>Ogden</u>, <u>1991</u>).

7.3 A Liberating Community Theology

In chapter 5 I discussed a model of community that is emerging from support groups for PLWHIV. This model is authentic and liberating, as was evidenced in its impact on those who actively participate as agents within it. I have selected Acts 2: 42-47 to define the liberating community theology of the church. This is a theology based on inclusiveness and it affirms the justice principles of equality: solidarity, association and participation. All of these principles, characteristic of a theology of community, form a powerful force against discrimination of others. The biblical text of Acts 2: 42-47 is a vivid description of this theology in action.

42They devoted themselves to the apostles' teaching and to fellowship, to the breaking of bread and to prayer. 43Everyone was filled with awe at the many wonders and signs performed by the apostles. 44All the believers were together and had everything in common. 45They sold property and possessions to give to anyone who had need. 46Every day they continued to meet together in the temple courts. They broke bread in their homes and ate together with glad and sincere hearts,

<u>47</u>praising God and enjoying the favour of all the people. And the Lord added to their number daily those who were being saved" (Acts 2: 42-47, NIV).

Byron observes that when the principle of participation is in operation, the social space is opened up and agents in that space seek together the common good of all which results in the human fulfilment of all (Byron, 1999). In the Acts 2 account of the early church this dynamic is very evident. Keller (2001) defines liberating community as fellowship that is committed to nurturing relationships, support and accountability. He concludes that in its most authentic form, a liberating theology of community is both counter intuitive and counter-cultural (Keller, 2001, p. 2). Middleton uses the metaphor of a prism to capture this liberating dynamic culture of the church when it is engaged. He says that the church becomes God's multi-sided prism in the world, reflecting and refracting the creator's brilliant light into a rainbow of cultural activity and socio-political patterns that manifests God's reign in the world (Middleton, 1994, p. 25).

7.4 A Liberating People's Theology

The fourth liberating theology accessible to the church that I will discuss is that of a people ethos that affirms human dignity. One Biblical text, 1 Corinthians 12:12-25, uses the metaphor of the body to illustrate this theology.

Just as a body, though one, has many parts, but all its many parts form one body, so it is with Christ. For we were all baptized by one Spirit so as to form one body—whether Jews or Gentiles, slave or free—and we were all given the one Spirit to drink. Leven so the body is not made up of one part but of many. So Now if the foot should say, "Because I am not a hand, I do not belong to the body," it would not for that reason stop being part of the body. And if the ear should say, "Because I am not an eye, I do not belong to the body," it would not for that reason stop being part of the body. If the whole body were an eye, where would the sense of hearing be? If the whole body were an ear, where would the sense of smell be? But in fact God has placed the parts in the body, every one of them, just as he wanted them to be. If they were all one part, where would the body be? As it is, there are

many parts, but one body. ²¹ The eye cannot say to the hand, "I don't need you!" And the head cannot say to the feet, "I don't need you!" ²² On the contrary, those parts of the body that seem to be weaker are indispensable, ²³ and the parts that we think are less honourable we treat with special honour. And the parts that are unpresentable are treated with special modesty, ²⁴ while our presentable parts need no special treatment. But God has put the body together, giving greater honour to the parts that lacked it, ²⁵ so that there should be no division in the body, but that its parts should have equal concern for each other. ²⁶ If one part suffers, every part suffers with it; if one part is honoured, every part rejoices with it. ²⁷ Now you are the body of Christ, and each one of you is a part of it (<u>1 Corinthians 12: 12-25, NIV</u>)).

In this biblical text, theologies of liberation are reflected in the author's recognition of equal honour accorded to all parts of the body, regardless of location. Every part of the body is significant and has a special function that is critical for the body to function properly. He cautions against division or self-aggrandizement and instead encourages solidarity and unity. Commenting on this theological resource, Kim (2013) summarizes the liberative nature of the people ethos in the embodied image of the church thus. Honour is given to all, not by social status but by God's radical love and justice. All are considered equal partners in God's church, creating a community in solidarity. She points out that in such a community, the rest of the body embraces and stands in solidarity with the marginalized, weak and powerless (Kim, 2013, p.26)

Central to this liberating people's theology is the belief that every human being is created in the image of God and therefore is invaluable and worthy of respect and honour. Byron (1999) asserts that the respect for human dignity regardless of race, gender, sex, nationality, religion, social or economic status, is the bedrock of social justice. He further states that this value is the only qualification for inclusion and belonging to the human family and to any community (Byron, 1999). The liberating power of this people's theology is that no one is permitted or given space to treat another badly on any basis, least of all because of their HIV status. The body metaphor can also be a great antidote to stigma and discrimination in that it

demonstrates that all parts of the body are so intricately connected and therefore, it is in the interest of each part to ensure that all the other parts are well and included because their health and wellbeing affects every other part.

7.5 A Liberating Cultural Theology

The last liberating theological resource I will consider is that of a cultural theology that finds expression in life-affirming traditions and sacraments such as the Eucharist. A life-affirming culture opens up the church as a social space where life can be celebrated, where people can develop a sense of unity and solidarity as well as exercise their agency through participation. Shared traditions are a reminder that they belong together. The Biblical basis for this life-affirming culture is the same one that in Chapter 6 was used as the basis to exclude others. 1 Corinthians 11:20-34 and Luke 22: 7-20:

⁷ then came the day of Unleavened Bread on which the Passover lamb had to be sacrificed. ⁸ Jesus sent Peter and John, saying, "Go and make preparations for us to eat the Passover." ⁹ "Where do you want us to prepare for it?" they asked. ¹⁰ He replied, "As you enter the city, a man carrying a jar of water will meet you. Follow him to the house that he enters, ¹¹ and say to the owner of the house, 'The Teacher asks: Where is the guest room, where I may eat the Passover with my disciples?' ¹² He will show you a large room upstairs, all furnished. Make preparations there." ³ They left and found things just as Jesus had told them. So they prepared the Passover. ¹⁴ When the hour came, Jesus and his apostles reclined at the table. ¹⁵ And he said to them, "I have eagerly desired to eat this Passover with you before I suffer. ¹⁶ For I tell you, I will not eat it again until it finds fulfilment in the kingdom of God." ¹⁷ After taking the cup, he gave thanks and said, "Take this and divide it among you. ¹⁸ for I tell you I will not drink again from the fruit of the vine until the kingdom of God comes." ¹⁹ And he took bread, gave thanks and broke it, and gave it to them, saying, "This is my body given for you; do this in remembrance of me." ²⁰ In the same way, after the supper he took the cup, saying, "This cup is the new covenant in my blood, which is poured out for you" (Luke 22: 7-20, NIV).

When you come together, it is not the Lord's Supper you eat, 21 for as you eat, each of you goes ahead without waiting for anybody else. One remains hungry, another gets drunk. 22 Don't you have homes to eat and drink in? Or do you despise the church of God and humiliate those who have nothing? What

shall I say to you? Shall I praise you for this? Certainly not! 23 For I received from the Lord what I also passed on to you: The Lord Jesus, on the night he was betrayed, took bread, 24 and when he had given thanks, he broke it and said, "This is my body, which is for you; do this in remembrance of me." 25 In the same way, after supper he took the cup, saying, "This cup is the new covenant in my blood; do this, whenever you drink it, in remembrance of me." 26 For whenever you eat this bread and drink this cup, you proclaim the Lord's death until he comes. 27 Therefore, whoever eats the bread or drinks the cup of the Lord in an unworthy manner will be guilty of sinning against the body and blood of the Lord. 28 A man ought to examine himself before he eats of the bread and drinks of the cup. 29 For anyone who eats and drinks without recognizing the body of the Lord eats and drinks judgment on himself. 30 That is why many among you are weak and sick, and a number of you have fallen asleep. 31 But if we judged ourselves, we would not come under judgment. 32 When we are judged by the Lord, we are being disciplined so that we will not be condemned with the world. 33 So then, my brothers, when you come together to eat, wait for each other. 34 If anyone is hungry, he should eat at home, so that when you meet together it may not result in judgment. And when I come I will give further directions (1 Corinthians 11:201-34, NIV).

In this segment I would like to adapt the admonition by Nadar (2003) and discern an alternative voice (Nadar, 2003b). Wren (1986) laments the fact that the actual practice of the Eucharist has become so ritualized, privatized and abstracted from its historical basis and communal beginnings that the symbolism has become detached from the reality (Wren, 1986). Willimon (1983) is of the opinion that it should be a major concern that our observance of communion has reached the point of trying to have a meal without having a meal, in what seems to be an unconscious attempt by the church to protect itself from the radical, communal, transforming power of the rite (Willimon, 1983, p. 132). In an attempt to reclaim this liberating theology I will draw on the reflections offered by Wren (1986). He is of the view that examining the original practice of communion may help us discover all the dimensions of the Eucharist which in addition to sharing the wine and the bread include a sharing community moving towards justice (Wren, 1986). Written three decades ago, I found in Wren's reflections a theology that is liberating and an excellent guidepost towards just

engagement. I will summarize his reflections below, focusing on those aspects that are most linked to liberation.

The Last Supper was a real meal, not ritualized worship. The Eucharistic "breaking of bread" in the context of a real meal where the most basic human needs are met was taken for granted in the early church. The Last Supper was a Passover meal. The synoptics describe a Passover meal in which a group of Jews gathered and reminded themselves that they were slaves in Egypt, but God delivered them from oppression. This memory is not poetic fancy, but personal identification. In the Eucharist, we follow Passover precedents by telling the story of God's liberating acts. But our story must move from the safe, uncontroversial past to give thanks for what the Spirit of God seeks to do now. The liberating power of the Eucharist would become more visible if we continued the story beyond exodus, cross and resurrection. A four-dimensional Eucharist is celebrated when the Eucharistic community critiques abuses of political power, resists the powers of death in our world, and stands by the oppressed in their struggles for liberation. The Eucharist is a sharing community meal. From the beginning, celebrating the Eucharist involved sharing goods and possessions. It used to be fashionable to decry the early church's "primitive communism" as naïve and unsustainable. "Communion" is not merely in the words with bread and wine duly shared, but in these together with an open sharing of goods and income. As difficult though it undoubtedly is, to recover this communal sharing in an individualized enterprise culture, such a perspective is at the heart of the Lord's Supper. We are now the body that is to be broken. The risen Christ now calls us his body. For whom are we to be betrayed and "broken" if not for the powerless, excluded ones whom Christ loves? The proper posture for the Body of Christ is not static wholeness but bruised brokenness. Brokenness implies one body that has been broken, offered in unity of purpose. When one part is bruised, the whole body aches. The Eucharist is an unambiguous reminder that the church is called to build itself on relationships of love and mutuality, not power and domination – not for its own self-satisfaction, but as a political witness, as a harbinger of the Kingdom of God (Wren, 1986, p. 839).

In chapter 5 I discussed how PLWHIV often felt unworthy, even when given an open invitation to communion. This they attributed to various church theologies of the Eucharist which are exclusive by virtue of the barriers they set up within the communion liturgy. For example, you can't come because you don't believe, because you don't belong, because you belong to the wrong church, because you haven't joined us, or because you're not old enough. Wren submits that a Eucharist in the spirit of Jesus' scandalous table fellowship will be open to all – including non-members and nonbelievers (Wren, 1986, p. 839). I cannot Page | 177

think of a more practically inclusive theology for countering moral exclusion within the context of a church.

7.6 Towards a Liberative Hermeneutic of Missional Justice for Praxis

I would like to conclude this study by proposing a liberative hermeneutic of missional justice as a framework for praxis by the church to counter persistent stigmatization and discrimination of PLWHIV and pave the way for their just engagement within the life of the church. Given the commitment of liberation theology to praxis, my study would be incomplete without this tool. The liberative hermeneutic of missional justice is not just a framework for praxis, and a tool for countering stigma, it is in many ways the merging of my research journey with a personal life journey as well as reflection on my work experience in HIV and AIDS work within the church come full circle. Doing this study has provided space and framework to reflect on my work in development with churches in the last twenty years and more especially around the global response to HIV and AIDS. This hermeneutic reflects the key lessons I have learned from the study and their implications for any personal development initiatives I may do in the future. I will now elaborate on the four stages of the framework.

7.6.1 Embodied-Storied Narratives of Injustice

The first step is to begin with the storied embodied experience of those experiencing a situation of injustice as opposed to just statistics. As Ackerman (2005) advises,

If we are going to counter stigma and deal with HIV and AIDS in a responsible manner theologically, the place to start is the lived experience...Praxis must be done in the interest of those who experience stigma, it must be collaborative, and it must be culturally sensitive to different ways of experiencing reality (Ackerman, 2005, p. 48).

Beginning with the experience of PLWHIV is affirmation of their dignity and recognition that there are resources within their community that are critical to a sustained action against any injustice towards them. This honours the principle of participation as well as changes the power dynamics between PLWHIV and those that would act on their behalf. Drawing on Foucault's principle that knowledge is power, in this case the story teller, the PLWHIV, holds the greater power. Traditionally it was the development workers who had the statistics and therefore the power. The hermeneutic helps to change that in alignment with liberation theology principles that place the oppressed at the centre of the liberation process, not as observers but as agents.

7.6.2 Critical Inter-disciplinary Analysis of the Structures that Legitimate Injustice

The second step involved embarking on a critical inter-disciplinary inquiry of the structural roots of the issues raised by those experiencing the situation with the assistance of the social sciences. Parker and Aggleton (2003) remind us that,

Stigma and discrimination operate in relation to social and structural inequalities and are deployed by concrete and identifiable social actors seeking to legitimize their own dominant status within existing structures of inequality. They also explain that the reason eliminating stigma and discrimination has presented such a formidable challenge in the global response to HIV and AIDS is that the process of stigmatization is linked to competition for and the legitimization of social hierarchy and inequality (R. Parker & Aggleton, 2003, p. 18).

The importance of inter-disciplinary analysis and dialogue is that it is critical to the unearthing and understanding of those structures because very often they are subtle. Taking into consideration the advice by de Gruchy and Patterson, this phase of the framework allows for inter-disciplinary dialogue to inform the church's understanding of issues such as gender

inequalities and social hierarchies with knowledge and experience from disciplines that are committed to understanding those very structures.

7.6.3 Theological Framing for Missional Action as Concursus Dei

The third step is to interrogate the structural roots of injustice with the help of theological resources to understand and link into the *concursus dei*, the missional mandate for action.

Concursus dei is a medieval concept that means divine accompaniment. Richebacher (2010) describes *concursus dei* as

God's presence and walking with all of creation, calling and leading creation into ever new life. It is God's redemptive activity leading creation towards God's own self-surpassing fullness. The base of concursus dei is a vision of God's unceasing accompaniment with creation, calling and evoking its participation in God's movement as God leads it patiently and persuasively, both in judgement and grace, to its future in God's future (Richebacher, 2010, p. 20).

7.6.4 Collaborative, Sustained Liberating Praxis against Injustice

We are called to engage in liberating praxis that confronts the structures of injustice and provides sustainable solutions and builds the agency of the marginalized for future action. Pienaar has defined liberating praxis as collaborative sustained action for justice liberation and healing, empowered by continuous struggle, hope and passion (Pienaar, 2003, p. 48).

7.6.5 Just Engagement of Liberated Agents

This final stage in the liberative hermeneutic of missional justice is the opening up of the social space so that the previously poor, marginalized or excluded can now exercise their agency as liberated agents in liberating others. I see this piece missing in the liberation theology framework. I would like to submit that our own liberation is not complete until we become active agents in the liberation of others. This is the test of the calibre of our agency.

7.7 Conclusion

I set out in this chapter to explore the liberative theological resources available within the church that have potential for countering stigma, discrimination and the moral exclusion of PLWHIV from full participation in church life. Resources can be deployed to create a conducive environment for the just engagement of PLWHIV within the church. While there are many resources one can draw upon within the church polity, I have particularly selected resources that could be more readily accessible to any church setting that was interested in intentionally pursuing a de-stigmatization agenda. I have also focused on resources that were more directed towards the structures of injustice identified in chapter 6, such as patriarchy, prejudice and social inequality. The liberating theologies of mission, leadership, community, people and culture discussed above provide a framework that the church can use either to pursue an intentional destignatizing culture or measure the extent to which its structures legitimate the moral exclusion of PLWHIV. I would like to submit that to create an environment that enables the just engagement of PLWHIV, the church needs to courageously and intentionally confront structural forms of injustice within its ranks. When the church fails to do this it not only contributes to the delay in getting to zero stigma and discrimination; more importantly it compromises its mission to be an agent of justice in community. I will close with the caution by Schori (2009):

The heart of the church will slowly turn to stone if we think our primary mission work is to those already in the pews inside our beautiful churches, or to those at other altars. We are in cardiac crisis if we think we can close our doors, swing our incense and sing our hymns and all will be right with the world. The heart of the body is mission... Every time we gather, the spirit offers a pacemaker jolt to tweak the rhythm of this heart. The challenge is whether or not the muscle will respond with a strengthened beat, sending more life out into the world...can you hear the heartbeat? Mission, Mission, Mission (Schori, 2009, p. 3).

My hope is that the reflections in this study will be a "pacemaker jolt" that will tweak the heart muscle of the church to challenge it to open up the social participation space within the church and engage in a just manner with PLWHIV so that they can exercise their agency and complete the process of their liberation and enjoy life in all its fullness. Like the Swedish serving girl in the proverbial fable of the 'big ox' may we wake to a dawn and discover that within the church polity is a 'kettle' full of coins, amazing liberating theological resources that can confront moral exclusion.

Chapter 8: Critically Creating a Future of Moral Inclusion and Just Engagement

"To Critically Reflect on the Present

To Critically Reclaim the Past

To Critically Create the Future" (Litojua, 1998:45)

8.0 Introduction

In concluding this study, I would like to borrow the reflective definition of the hermeneutic thrust of liberation theology by Litojua (1998). "To critically reflect on the present, to critically reclaim the past and to critically create the future" (Litojua,1998:45).

This research journey has been long but very rewarding, and in a very literal sense, I have come the full hermeneutical circle. I have had opportunity to critically reflect on the present, critically reclaim the past and critically create the future. I will use this framing in this chapter to reflect on the key findings of this study and their implications, the major contributions the study has made to the academy. I will reflect on my own research journey, consider the limitations of the study and close with proposals for future directions for research.

The critical question this study sought to answer was the extent to which the moral exclusion of People living with HIV (PLWHIV) from full participation in church life impedes the global commitment to eliminate stigma and discrimination and impacts on the church's calling to be an agent of justice in the response to the AIDS pandemic. The study sought to do this by critically portraying the lived experiences of PLWHIV in relation to moral exclusion within an inter-denominational Church Network in the Chitipa District of Malawi.

The storied experiences of PLWHIV were critically analysed through an inter-disciplinary framework of theology and the social sciences to establish if there were linkages between their experiences, theological representations in their churches and structures of injustice in their societies and communities. The study also sought to identify liberating theological resources within the church setting that could become part of a framework for praxis against moral exclusion and facilitating the creation of a conducive environment for the just engagement of PLWHIV so they could fully participate in the life of their churches.

8.1 Critically Examining the Present

The portraits of the lived experiences of moral exclusion within their churches, told by the PLWHIV, revealed that four decades into the global response to HIV and AIDS, stigma and discrimination are still a formidable barrier to zero stigma and discrimination as outlined in the global commitment of "getting to zero." The portraits revealed that the nature of stigma in the church settings takes on moral, social, cultural, spiritual and economic parameters. A critical social scientific reading of the portraits of moral exclusion revealed that the reason moral exclusion was so pervasive and persistent within church settings is because of its structural nature that allows it to reproduce itself with supportive structures such as symbolic power, symbolic capital and symbolic violence. A pleasant revelation from the portraits was that as a result of being excluded, PLWHIV were using their collective efficacy and agency to accumulate social capital bolstered by the solidarity within the support groups. These new authentic communities being created by PLWHIV in the process of fighting against stigma are emerging into what de Gruchy defined as a new way of being and doing church.

8.2 Critically Reclaiming the Past

In order to critically reclaim the past, chapter six of this study examined the linkages that exist between the lived experiences of PLWHIV with HIV and AIDS related stigma and discrimination, and the theologies that undergird them. It established if there were any connections to structures of injustice. Drawing on the justice principles of human dignity, participation, the preferential option for the poor and solidarity, within Catholic social teaching informed by liberation theology, the study demonstrated that the abuse of sacred texts to justify moral exclusion is rooted in structures of injustice. The study discovered that theologies that undergirded moral exclusion were founded on sectarian favouritism, moral policing, patriarchy, gender inequality and prejudice. Consequently, the culture of moral exclusion became part of the identities of the churches and was legitimated through a process of structural entrenchment. The resulting model of doing and being church is what Andy Stanley called the temple model. This temple model is defined by sacred places, sacred texts, sacred men and sincere followers granting extraordinary power to sacred men in sacred places to determine the meaning of sacred texts. To use Bourdieurian terminology, the injustice has become an integral part of the church, field, doxa and habitus. This is so much so that even when the church is being discriminatory sometimes it is not aware and it feels justified. The implication of this is that once stigma is legitimated in faith cultures it is more difficult to deal with, because it is not seen as unjust but as sacred.

8.3 Critically Creating the Future

As a contribution to critically creating the future, the study identified key liberating theological resources that the church can draw on to counter a stigmatising culture. Five of these were isolated in chapter seven of the study. They include liberating theologies of

mission, leadership, community, people and culture. The study demonstrated that the power of these theologies is that they counter stigma and discrimination by creating an enabling environment within which a culture of inclusion, participation and just engagement can be nurtured. As a contribution to the lack of stigma reduction tools, the study developed a liberative hermeneutic for missional justice as a framework for praxis against moral exclusion. These were the key findings that emerged from the study.

I will now highlight the major contributions the study has made to generating new knowledge in the academy. The study has generated new knowledge by contributing to narrowing four research gaps. I have discussed each research gap as well as the contribution of the study to narrowing that gap below.

8.4 Significance of the Study: Narrowing the Gaps

This study sought to contribute to the academy by narrowing four research gaps in scholarship on HIV and AIDS related stigma and discrimination as identified by Manda (2011), de Gruchy (2011), Patterson (2011), Parker, Aggleton and Birdsall (2003). The aforementioned scholars call for the need to pay attention to four critical areas that formed the core of this study. These are the methodological challenge, a shortage of context specific empirical studies, a broader conceptualization of stigma and discrimination to reflect its interface with cultural and power structures and the need for interdisciplinary dialogue to inform discourse. I will discuss how this study has contributed to the narrowing of these gaps.

8.4.1 The Conceptualization Gap

Parker and Aggleton (2003), highlighted the need for 'context specific empirical investigations' that use this broad conceptualization of stigma and discrimination and interrogate its underlying structures (R. Parker & Aggleton, 2003, p. 19).

This study being empirical in nature and done within the church context, using the socially constructed conceptualization of stigma has provided a context specific empirical investigation. Beginning with the storied experiences of PLWHIV within local church contexts in Chitipa District of Malawi, I used a social structural conceptualisation of stigma to provide a critical reading of the portraits of moral exclusion of PLWHIV. I drew on the social science theories of Bourdieu, Bandura and Foucault within the liberation theology framework and identified the social and structural factors contributing to the legitimation of persistent moral exclusion of PLWHIV from full participation in church life. Among the processes linked to the reproduction and legitimation of stigma within the Chitipa Church setting I isolated: gender inequalities, patriarchy, symbolic power, symbolic violence, religious prejudice and moral policing.

8.4.2 The Ecclesiology Interface Gap

Patterson (2011) pointed out the need for research into the interface between stigma and ecclesiology. She called for research that would be courageous to look into linkages between belief systems, teachings, traditions and practices upon which the institutional identity of the church is constructed and the reproduction of stigmatizing attitudes and practices within the church context (Patterson, 2011, pp. 360-361).

This study used an inter-disciplinary conceptualization of stigma to provide a secure base for theological reflection and did it within the local church context in Chitipa District of Malawi as a case study. The Chitipa church context provided the social system that this study uses to explore stigma as a social process involving interactions between culture, power and tradition in a religious institution. It examined church liturgy, sacraments and traditions for theological positions and representations that contributed to the legitimation of stigma within church structures. The study also explored liberative theological resources existing within the church that could be explored in praxis against persistent stigma directed at PLWHIV in the church.

8.4.3 The Justice and Theological Perspective Gap

Lucinda Manda (2011) advocated for the need for research into a theo-ethical framework for addressing HIV and AIDS related stigma to move beyond compassion into the justice sphere. While recognising that much research has been done on the justice perspective within the political and social sciences, Manda's contention was the need for further reflection from a religious perspective (Manda, 2011, p. 210).

This study contributed to the movement of the conversation around the engagement of PLWHIV within the church context from the comfortable zone of compassion towards the more complicated yet critical sphere of justice. I looked at issues of injustice within the church setting. The choice of liberation theology as the over-arching framing for the study provided an excellent platform to look at justice issues around stigma and discrimination from both the social science side as well as the theological discipline.

8.4.4 The Methodology Gap

De Gruchy (2011) pointed out the need for an interdisciplinary theological methodology that would incorporate insights from the social sciences such as sociology, psychology and anthropology to enable the exploration of HIV and AIDS related stigma and discrimination and its relationship to fundamental themes such as gender, poverty, globalization, ecological crises, climate change, African identity, sexuality and racism (de Gruchy, 2011, p. 188)

This study contributed to the narrowing of this gap by using social theology methodology as an inter-disciplinary derivative from liberation theology. This methodology incorporated the use of social science theories, including Bourdieu's social cultural theory and Bandura's social cognitive theory and to a lesser extent Foucault's theory of knowledge and power.

8.4.5 Praxis Tools Gap

I would like to propose that the shortage of evidence-based research, as highlighted by Grossman and Stangl (2012), is indicative of the absence of tools that would enable practitioners to intentionally act against stigma. There is no shortage of prescriptive solutions for the church (see Parry & oecuménique des Eglises, 2008). However, one thing most studies have in common is that they do not show the church how it can implement the good prescriptions. In my discussions with the church leaders I discovered that the issue is not that of a knowledge gap but how to turn that knowledge into action. The liberative hermeneutic of missional justice that has been developed from this study is an attempt to provide a tool that can be used as a framework for praxis to reduce stigma but also as an evaluation framework that can be used to measure if a church is making progress in addressing situations of injustice in their communities.

8.5 Limitations of this Study

8.5.1 Representativeness

This study is not only qualitative but also empirical; those frameworks alone impose their own limitations. Qualitative inquiry is not aimed at representativity but density.

Consequently, in order to get a dense reading of the experiences of PLWHIV I had to limit the number of in-depth interviews that I could conduct. So even if I could have had over 100 amazing stories of PLWHIV that could have provided very rich portraits of PLWHIV, I had to limit my in-depth interviews to 15 and even all the 15 stories could not be included in the study. This I think took away from an even richer study. To make up for this shortage, I included in the study portraits that were as representative as possible of the myriad of experiences of PLWHIV.

8.5.2 Challenging Context

The contextual setting of this study is very remote and there are long distances between places. In my desire to get a sample that was representative I included participants from all the four corners of Chitipa District. These wide distances proved very costly to the process and limited how much I could go back to some of the participants in case I wanted to follow up information. To reduce cost and keep the study empirically credible, I took advantage of some of my work-related field trips to do the follow up.

8.5.3 Reflexive Location

While my reflexive location as a researcher and an insider to the system was a great strength in producing quality data, it also presented some limitations. Sometimes I got carried away during focus group discussions because they also generated a lot of good information for the

programmatic development of the churches network. I often found myself with wads of notes to work through and separate research related content from work related content. Fortunately, I picked this up in the early focus groups and so intentionally added more structure to the later ones to keep them more research focused. While this gave me very good research based data, I missed the spontaneous interaction that generated much useful content for our programs. Another aspect of my location that was a limitation as well as a strength was my limited language proficiency. I am not a native of Chitipa. I have worked long enough in the district to hear the languages and speak some basics but I am not fluent. While for the most part I was able to manage and my limitation made me a keener listener and observer, there were times when I missed the meanings in the interpretation – more especially so in the use of idioms and proverbs and slang. I am sure my portrayal of the lived experiences of PLWHIV would have been much richer if they had all the proverbs and idioms. I made sure I asked lots of questions for clarification where I did not understand to make sure that the stories were as accurate as possible.

8.5.4 Follow Up Interviews with Church Leaders

Being able to connect with the PLWHIV on several occasions gave me excellent opportunities to follow up with questions as the study progressed. It would have been a great addition to the study if I had been able to do the same with the church leaders. However, their schedules did not permit that and some of them got transferred from Chitipa in the course of the study and we lost contact. This to a small extent limited the depth of the data produced with the church leaders. So to reduce the impact of this limitation on the study, where I had opportunity to connect with the church leaders even in an informal setting I took advantage of it.

8.5.5 Time Scope

I carried out this study over a long period of time and while this proved a great advantage to the study, it was not intentionally designed to be longitudinal. Consequently, I was not able to explore in depth the implications of the dynamics that impacted on the changing nature of the stigma and discrimination discourse. While I explored to greater length the impact of universal access to ARV treatment, I did not do it exhaustively. I would also have liked to explore the changing dynamics of the prevention campaigns in the light of access to treatment and how this could impact on stigma. I highlighted a few issues related to this in the public health discourse and HIV prevention discourse in the literature review but did not explore them in depth in the field research. Both of these areas are studies in themselves.

8.6 Proposals for Future Directions for Research

Although this study has contributed to the narrowing of the above mentioned research gaps, all of them are still areas for future research. I will highlight five areas that are closely linked with my study.

8.6.1 Empirical Context Studies on the Impact of Access to ARV Treatment on Stigma

There is a need for more context specific empirical studies on HIV and AIDS related stigma within the context of increased access to treatment. Most of the empirical work was done prior to the declaration of universal access to ARVs. As the literature review revealed, access to treatment is one of the most critical factors in changing the conversation around stigma.

8.6.2 Collaborative Inter-disciplinary Research

While I have greatly appreciated doing an inter-disciplinary study, I had difficulty finding mentors I could learn from. The discourse around stigma and discrimination is still happening in discipline silos. This is despite the acknowledgement by many scholars that interdisciplinary dialogue is critical to the realization of reduction of HIV and AIDS related stigma. Empirical studies that bring theology in conversation with social sciences are still a largely un-researched field.

8.6.3 Church Based Studies

The church is still considered one of the most stigmatizing institutions. However, there are very few studies that have engaged the church institution as the unit of inquiry to put under the microscope. The church is a complex social system in which stigma is not only enacted but unwittingly legitimated through its structures. Context specific studies that are more analytical than prescriptive are greatly needed to provide some fresh perspectives.

8.6.4 Action Research

There are very few studies which are based on the application of a stigma reduction strategy. There are a lot of prescriptive suggestions with regards to what needs to be done to reduce stigma but there is a lack of evidence with regards to where the proposals have been tested with observable results.

In all the research gaps mentioned above, there is a place for fresh ideas and thoughts. There is a greater need to move beyond the reviews of what has already been done to creating new knowledge that is action based, empirical, contextualized, interdisciplinary and analytical.

Therefore, as long as stigma and discrimination continue to appear as a key barrier to progress in the global response to HIV and AIDS, Grossman and Stangl's appeal is still valid.

Despite the advances in HIV stigma research, the gap in the evidence based on effective interventions is hampering national governments from integrating stigma and discrimination reduction – critical enablers of the HIV response – into national AIDS plans, and is threatening our collective ability to get to zero. ...To respond to this gap in the evidence base, a redoubling of research efforts to reduce stigma and discrimination across a variety of settings within all populations is needed (Grossman & Stangl, 2013, p. 2).

8.7 The Liberation of an Activist Researcher

As I reflect on my journey as a researcher, I find that Segundo's summary of the process of liberation describes it very well. I will summarize it below and then go on to relate my own journey of liberation.

First, there is our way of experiencing reality, which leads us to ideological suspicion. Second there is the application of our ideological suspicion to the whole ideological super structure in general to the theology in particular. Third there comes a new way of experiencing theological reality that leads us to exegetical suspicion, that is the suspicion that the prevailing interpretation of the Bible has not taken important pieces of data into account. Fourth we have our new hermeneutic, that is our new way of interpreting the fountain head of our faith (Scripture) with the new elements at our disposal (Juan Luis Segundo, 1976, p. 9).

In the introduction to the study I talked about my own journey as researcher who is engaged with the context. As I have wrestled with the literature grounding this study and spent time with PLWHIV and church leaders I have developed strong suspicions about the ideological foundations that have informed a big part of my journey as an activist. Having grown up in the church, my ideological foundations were greatly influenced by my religious up-bringing. My world growing up was very black and white with hardly any shades of grey. For example, I grew up believing that homosexuality was a sin punishable by God; similarly that making condoms accessible to young people was a way of promoting promiscuity. During

my early HIV and AIDS work I would be very angry at mothers who got pregnant when they knew they were HIV positive. I remember conducting a focus group with HIV positive women at TASO very early in my career and taking them to task about what I described as selfishness. In my '10 commandments' upbringing, it was murder to pass on the HI virus to your unborn child. I admit that now I am embarrassed at some of my foundations. Coming to the end of this study I wonder how much damage I did to the very cause that I was giving my life to. On many counts I was an unwitting perpetrator of stigma and discrimination.

After twenty five years, 10 countries and numerous relationships with PLWHIV from all walks of life, there is more colour in my ideological framework. I have developed an ideological suspicion of theological positions I was raised with.

Segundo describes the second stage in liberation as that of applying the ideological suspicion developed in the first phase to our whole life ideological super-structure but more specifically to our theology. I wish I could say that when I started my academic journey I was very excited. I would be lying. I was what you would call a reluctant researcher. In 2007 I was at cross roads in my life. A number of tragic events had happened in my life and I was questioning a number of things. My sister had been brutally murdered, I had lost an adopted son at only 15 months, I had made a decision to start an adoption process for two young girls I had been parenting for two years one, of whom was HIV positive. The organization I was working for wanted me to move countries and take on a regional leadership position for our organization. It was all too much to take in. My mentor suggested that I take time out and study for a PhD. Being the activist that I am, I thought that was such a waste of precious active time to generate a big book volume that will gather dust on some library shelf. He only managed to convince me by seeing it as an opportunity to reflect on at that point an 18

year, very meaningful career in international development and most of it HIV and AIDS related. He told me that given my passion for the local church in development, it may be a good idea to reflect on what I had done theologically and see if there were life lessons I could consolidate and share them in the form of a doctoral thesis. He encouraged me to consider a discipline that would help me bring my developmental social work background in conversation with theology. So I decided to consider it and chose to be part of the theology and development program.

Since I had been out of school for so long, I decided to attend the late Steve de Gruchy's classes in Public Theology as a way to get me back into the academic world. In one of our first classes he told us that for most of us, the PhD was not our life work. He, however, challenged us to learn a 'new way of seeing'. He encouraged us to suspect our positions and interrogate them, to develop new lenses through which we would not only see but also interpret our world. Those classes were very influential in getting me to the second stage of my liberation.

My theology now is so different to what I came to UKZN with. My acquired ideological suspicions have led me to question my own overall theology. My theology as it relates to issues of justice, sin, agency, sexuality, church, marriage, child bearing and rearing, leadership, women in the church, and community has been reformed and transformed along my research journey. I think I have a richer and more informed theology born out of experiential reflection, suspicion and questioning than the one I started out with that was based on unquestioned loyalty to what I had been taught in my church growing up. I know it has changed because some in my church think I have lost my faith altogether and others think I am a heretic. I know that to a certain extent I have been liberated because now I do not feel

like I have to defend myself like before. I am at a good place theologically and I have also learned that the journey continues; it is not a destination.

The third level of my own liberation has been achieved and tested in the process of carrying out this study. The process of gathering data brought me into conversation with church leaders, People living with HIV and church members at a level I had not done before in my work. As I looked at the information I gathered and looked at it through the lenses of liberation theology as well as social cultural theory and also brought it into conversation with a big body of literature, I came to that conclusion that is characteristic of this third level of liberation. What Segundo describes as, "the suspicion that the prevailing interpretation of the Bible has not taken important pieces of data into account." When we exclude PLWHIV from community because we have decided that they are being punished by God for engaging in sinful sexual relations, we are so far from the truth. Tyness, who was faithfully married to her unfaithful husband, got infected and consequently passed on the infection to her unborn baby during pregnancy, is evidence of how far from the truth we are. When we exclude Max from sharing in communion because he has committed the unforgivable sin, have we understood the invitation to come as we are?

Perhaps the most exciting aspect of my research journey is that I come to the end of it with a new hermeneutic that I will call the hermeneutic of missional justice. My career path seems to be leading me towards a long term engagement with local churches in their mission to transform their communities by addressing issues of poverty and inequalities, that take away from life in all its fullness. The same factors that impact on the church's calling as an agent of justice in the AIDS pandemic are the same ones that will make the church ineffective or effective as transformational development change agents. So I come away from my study

with a new framework of practice that I know will change the way that I work with churches in the future. It is not just about creating programs that deal with poverty and inequality. It is about creating a new consciousness; it is about confronting the structures that legitimize poverty and inequality, even when it means questioning the identity of the very institution that I am trying to serve. I doubt that I will read the Bible the same way. I have a new way of seeing. As a liberation theologian, I believe that in some ways my liberation has come full circle, according to Litojua's summation of the liberation theology thrust. I have been able, "to critically reflect on the present, to critically reclaim the past and to critically create the future" (Litojua, 1998:45). I can say with a fair degree of certainty that I am a liberated transformed activist.

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APPENDICES

APPENDIX 1: INFORMED CONSENT FORMS

INFORMED CONSENT FORM FOR CHURCH LEADERS

Study Title: BEYOND COMPASSION TOWARDS JUST ENGAGEMENT: Exploring Moral Exclusion of People living with HIV in Local Church Contexts in Chitipa District of Malawi

Objectives of the Study

- To describe the face of HIV and AIDS related stigma and discrimination in Chitipa District.
- To study from the roots the socio-economic, cultural and religious ideas, structures and practices that legitimize HIV and AIDS related stigma and discrimination in Chitipa District
- In the light of the findings of the previous two objectives, to propose a theological framework that is contextually appropriate for the churches in Chitipa District to better understand HIV and AIDS related stigma and discrimination.
- Thereupon, to develop practical guidelines that Church programs in Chitipa District can use to combat HIV/AIDS related stigma and discrimination through culturally sensitive, theologically sound and contextually relevant programming.

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Participants Identification Process:

Church Leaders

You have been selected to participate in this study because you fulfil the criteria out lined below.

- 1. You are a leader within your local church.
- 2. Your church is part of the Tubepoka development Initiative Network (TDI)
- 3. You are able to explain what is going on in your church very well.
- 4. Other church leaders in the area respect you very much, look to you for leadership and trust that you will teach them what you learn form this process.
- 5. You express yourself very well in (Tumbuka, Chichewa and or English)

Description of task.

- You will be given a questionnaire that you will fill out and immediately collected by a research assistant.
- If your questionnaire is among the most informative, you may be invited to an indepth interview by the researcher. The purpose of the interview is to get more specific information on HIV and AIDS related stigma from a church leader's perspective. Unlike the questionnaire, the interview will have your details so that we can come up with some profiles of church leaders. The interview will take a maximum of two hours.
- If the researcher finds the information you provide during the interview exceptionally useful to the study purpose, your permission will be sought to profile you in the study. This means that your story will be told and your names, that of your church and your picture will be included in the study. Given that the study is going to be a public document, if you feel uncomfortable about your details being publicly exposed, you have the freedom to turn down the request to be profiled. There are no consequences for your refusal. Alternatively you can give the researcher permission to use your story with different names and change the names of places and not to use your picture.

TIME FOR CONSULTATION BEFORE CONSENT.

You will be given time to read, understand and question the information given before giving consent. This will include time out of the presence of the investigator and time to consult with your friends and/or family.

NO PAYMENT FOR PARTICIPATION

You are participating in this study voluntarily. The purpose of this study is to contribute to the understanding of stigma and discrimination to improve church-based programming for people infected and affected by HIV and AIDS. The study is not being undertaken for commercial purposes. Hence there will be no payment for participation.

DECLARATION Village......Traditional hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project voluntarily, not expecting to be paid for it. - I understand that I am at liberty to withdraw from the project at any time, should I so desire and that I will not be penalized in any way should I choose to do so. I also understand that the results of this study will be published in a public document. I give consent to the researcher to use my details in the study, as appropriately described to - I have consulted with the significant people in my life (family, friends and colleagues) that may be affected by my participation and I have their permission to participate. - I take responsibility for the information I am providing and neither I nor any member of my family or circle of influence will take legal action against the researcher for using my story and the information provided by me in her study. SIGNATURE OF PARTICIPANT **DATE** SIGNATURE OF WITNESS NAME/SIGNATURE OF REASEARCHER DATE

INFORMED CONSENT FORM FOR PEOPLE LIVING WITH HIV.

Study Title: BEYOND COMPASSION TOWARDS JUST ENGAGEMENT: Exploring Moral Exclusion of People living with HIV in Local Church Contexts in Chitipa District of Malawi

Objectives of the Study

- To describe the face of HIV and AIDS related stigma and discrimination in Chitipa District.
- To study from the roots the socio-economic, cultural and religious ideas, structures and practices that legitimize HIV and AIDS related stigma and discrimination in Chitipa District
- In the light of the findings of the previous two objectives, to propose a theological framework that is contextually appropriate for the churches in Chitipa District to better understand HIV and AIDS related stigma and discrimination.
- Thereupon, to develop practical guidelines that Church programs in Chitipa district can use to combat HIV/AIDS related stigma and discrimination through culturally sensitive, theologically sound and contextually relevant programming.

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You volunteered to participate in this study and my understanding is that you fulfil the criteria below.

- 1. You are an active member of your support group.
- 2. You are comfortable talking about your HIV and AIDS status.
- 3. The members of your support group believe that whatever you say will be representative of their experiences and thoughts.
- 4. You are able to express yourself very well.
- 5. You have already had your HIV and AIDS test.

6

Description of Task

- A researcher will take you through a guided questionnaire. He/she will ask you various questions about yourself, your family and your experience with HIV/AIDS related stigma and discrimination. The process will take about one hour. The questionnaire will be anonymous and so your personal details will not be included in the study write up. Please answer as freely and as honestly as possible. You have the freedom not to answer any questions if they are uncomfortable for you for one reason or another.
- If your questionnaire is among the most informative, you may be invited to an indepth interview by the researcher. The interview will take about two hours. The purpose of the interview is to get more specific information on HIV and AIDS related stigma from the perspective of a person living with HIV and AIDS. Unlike the questionnaire, the interview will have your details so that we can come up with some profiles of church leaders. The interview will take a maximum of two hours.
- If the researcher finds the information you provide during the interview exceptionally useful to the study purpose, your permission will be sought to turn your interview into a case study. This means that your story will be told and your personal details and your picture will be included in the study. Given that the study is going to be a public document, if you feel uncomfortable about your details being publicly exposed, you have the freedom to turn down the request to use your story in a case study. There are no consequences for your refusal.
- You have chosen to participate in this study voluntarily. However, if at one point you decide you do not want to be a part of it you have the freedom to withdraw and there are no repercussions for your decision. Alternatively you can give the researcher permission to use your story with different names and change the names of places and not to use your picture.

TIME FOR CONSULTATION BEFORE CONSENT.

You will be given time to read, understand and question the information given before giving consent. This will include time out of the presence of the investigator and time to consult with your friends and/or family.

NO PAYMENT FOR PARTICIPATION

You are participating in this study voluntarily. The purpose of this study is to contribute to the understanding of stigma and discrimination to improve church-based programming for people infected and affected by HIV and AIDS. The study is not being undertaken for commercial purposes. Hence there will be no payment for participation.

DECLARATION I...... of Village......Traditional hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project voluntarily, not expecting to be paid for it. - I understand that I am at liberty to withdraw from the project at any time, should I so desire and that I will not be penalized in any way should I choose to do so. I also understand that the results of this study will be published in a public document. I give consent to the researcher to use my details in the study, as appropriately described to me. - I have consulted with the significant people in my life (family, friends and colleagues) that may be affected by my participation and I have their permission to participate. - I take responsibility for the information I am providing and neither I nor any member of my family or circle of influence will take legal action against the researcher for using my story and the information provided by me in her study. SIGNATURE OF PARTICIPANT **DATE** SIGNATURE OF WITNESS NAME/SIGNATURE OF REASEARCHER

DATE

INFORMED CONSENT FORM FOR CHURCH MEMBERS.

Study Title: BEYOND COMPASSION TOWARDS JUST ENGAGEMENT: Exploring Moral Exclusion of People living with HIV in Local Church Contexts in Chitipa District of Malawi

Objectives of the Study

- To describe the face of HIV and AIDS related stigma and discrimination in Chitipa District.
- To study from the roots the socio-economic, cultural and religious ideas, structures and practices that legitimize HIV and AIDS related stigma and discrimination in Chitipa district.
- In the light of the findings of the previous two objectives, to propose a theological framework that is contextually appropriate for the churches in Chitipa District to better understand HIV and AIDS related stigma and discrimination.
- Thereupon, to develop practical guidelines that Church programs in Chitipa District can use to combat HIV/AIDS related stigma and discrimination through culturally sensitive, theologically sound and contextually relevant programming.

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You were identified by your pastor to participate in this study and my understanding is that you fulfil the criteria below.

- 1. You are a registered or regular attendee of your local church.
- 2. You have enough information about the ministry of your local church.
- 3. You are able to read and write very well in (Chichewa, Chitumbuka and or English).
- 4. You are not in the top leadership of your church.
- 5. You are not afraid to say, tell or write what you think.

Requirements And Expectations For Participation

- You will be given a questionnaire that you will fill out and then it will be immediately collected by a research assistant.
- The questionnaire will be anonymous and so you do not have to fill in your name. Please be as honest as possible in filling out the answers.

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TIME FOR CONSULTATION BEFORE CONSENT.

You will be given time to read, understand and question the information given before giving consent. This will include time out of the presence of the investigator and time to consult with your friends and/or family.

NO PAYMENT FOR PARTICIPATION

You are participating in this study voluntarily. The purpose of this study is to contribute to the understanding of stigma and discrimination to improve church-based programming for people infected and affected by HIV and AIDS. The study is not being undertaken for commercial purposes. Hence there will be no payment for participation.

DECLARATION I..... of Village......Traditional hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project voluntarily, not expecting to be paid for it. - I understand that I am at liberty to withdraw from the project at any time, should I so desire and that I will not be penalized in any way should I choose to do so. I also understand that the results of this study will be published in a public document. I give consent to the researcher to use my details in the study, as appropriately described to me. - I have consulted with the significant people in my life (family, friends and colleagues) that may be affected by my participation and I have their permission to participate. - I take responsibility for the information I am providing and neither I nor any member of my family or circle of influence will take legal action against the researcher for using my story and the information provided by me in her study. SIGNATURE OF PARTICIPANT DATE SIGNATURE OF WITNESS DATE NAME/SIGNATURE OF REASEARCHER **DATE**

APPENDIX 2: INTERVIEW GUIDES

INTERVIEW GUIDE FOR PEOPLE LIVING WITH HIV.Note: This Guide will be used to conduct in-depth interviews with PLWHIV. The guide is very detailed for the reason that some of the interviews will be developed into case studies. The interview will take between one and one and a half hours.

Back Ground Information / Support Group Profile.

- (i) District
- (ii) Church Name:
- (iii) If Support Group has a special Name Indicate it:
- (iv) Number of PLWHIV in the Regular Support Group and their age range.
- (v) Give these details of the people in your support group, Age, Highest school level attained. Indicate if working, self employed or doing nothing. Indicate if PLWHIV is the bread winner or head of his/her family. Indicate number of children and other dependants if applicable.
- (vi) When was the Support Group Formed? Where and how often does the Support Group meet and why?
- (vii) Support Group Leadership, Gender and Positions.

Impact of HIV/AIDS on the Life of PLWHIVs

- 1. Name the 5 most pressing concerns of PLWHIV in your support group.
- 2. How has HIV/AIDS complicated your life and that of your family?
- 3. How does the experience of living with AIDS differ for men and women in your support group? What do you think are the reasons for the differences?
- 4. What Issues put people in your age group at the risk of getting HIV/AIDS? (Group them according to Social, Economic, Cultural and Religious)
- 5. Are the issues you have mentioned in 5 new or old? If they are new issues, have you raised them with anybody? If they are old issues, why do you think they continue to exist in your area?
- 6. What do you understand by the terms Stigma and discrimination?
- 7. Do PLWHIV in your support group experience stigma and discrimination? If so, tell some stories of what has happened to you and explain why you think it happened.
- 8. If you do not mind, please share your worst experience with HIV/AIDS related stigma and discrimination.

HIV/AIDS Related Stigma in Care and Support Programs for PLWHIV

- 9. Was your support group set up and supported by the church? Does your church have a comprehensive program for care and support for PLWHIV?
- 10. If yes, what are the components of the program? If not why do you think not?
- 11. If your church has a care and support program for PLWHIV, is it effective in reducing HIV/AIDS related stigma and discrimination and improving the well being of PLWHIV?
- 12. In what ways do the following institutions contribute to stigma and discrimination of PLWHIV: The community, the Government, the Church and Cultural Traditions?
- 13. Given your understanding of Stigma and discrimination, how do they affect the Care and Support program in your church?

14. What other factors affect the effectiveness of the HIV/AIDS Care and Support program at your church?

Confronting Stigma and Discrimination in Care and Support Programs.

- 15. What do you think needs to be done to address the factors that are affecting the effectiveness of HIV/AIDS Care of Support Programs through the Church?
- 16. If you were to design an HIV/AIDS Care and Support program that respects your culture, recognizes the good values that the church upholds and addresses the issues that contribute to stigma and discrimination of PLWHIVs; how would you put it together? What would be its components? What would be your key messages and how would you phrase them? What would its leadership structure be? How would you know that it is being effective?

INTERVIEW GUIDE FOR CHURCH LEADERSHIP.

Note: This Guide will be used to conduct in-depth interviews by the researcher with church leaders. Interviews will take between one and two hours.

General Background Information.

- (i) District:
- (ii) Church:
- (iii) Name of Leader:
- (iv) Position/Responsibilities in Church:
- (v) Position or Responsibilities in HIV and AIDS Ministry
- (vi) Type of Church Governance:
- (vii) How are leaders recruited, developed and supported in the church system?
- (viii) Is the church system the same one used for the HIV and AIDS Ministry?

Perceptions on AIDS as a Problem in the Area.

- 1. What do you consider as the five major problems in your area?
- 2. Where does AIDS fit in the hierarchy?
- 3. Why do you think AIDS is or is not a major problem in your area?
- 4. What factors predispose or protect people in your area to the risk of HIV and AIDS?

The Church and HIV/AIDS Related Stigma and Discrimination.

- 5. When did your MFL Program start?
- 6. How would you rate the strengths of the various components of the MFL program from strongest to weakest? Give reasons behind your rating.
- 7. Considering the Stigma and Discrimination in your community, what are some of the cultural, social and economic factors that contribute to its existence?
- 8. It has been said that we are either part of the solution or part of the problem. On the issue of HIV and AIDS related stigma and discrimination, where would you put your local church? On the problem side or the solution side? Give reasons for your response. Do you think the church in any way contributes to stigma and discrimination in your community?

- 9. If your answer to 12 is yes, can you name specific ways in which the church contributes to stigma and discrimination? If your answer to 12 is no, can you give reasons why you think so?
- 10. Are there aspects of the HIV and AIDS ministry that contribute to stigma and discrimination? If yes give examples according to four program categories: Leadership; Prevention Program; Care and support for PLWHIV and Orphan Care and Support Program.
- 11. Do you think the presence or absence of stigma and discrimination in the MFL church programs affects their effectiveness? If yes, in what ways?

Confronting Stigma and Discrimination in HIV and AIDS Ministries.

- 12. Considering your responses in the last section, what do you think the church leadership has to do to design HIV/AIDS programs that are culturally sensitive, respect the good values of the church, respond to the issues faced by individuals and families affected by AIDS and eliminate stigma and discrimination? What would these programs look like, how would they be implemented? What would their key messages be?
- 13. What kind of leadership would be needed to effectively run the program you have described in 16? Would your current leadership recruitment, development and support be able to get you the needed leaders? If not, how would your leadership recruitment, development and support processes have to change in order to get you the right leaders for your programs?