UNIVERSITY OF THE WITWATERSRAND

MASTERS IN PUBLIC HEALTH (MPH) DEGREE

EXPERIENCES AND PERCEPTIONS OF HIV RELATED STIGMA: A CASE STUDY
OF YOUNG PEOPLE LIVING WITH HIV IN BULAWAYO, ZIMBABWE

A Research Report submitted to
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Masters degree in Public Health
(Social Behavior Change and Communication)

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Date: 22 November 2016
DECLARATION

I Mgcini Sibanda, declare that this dissertation entitled “Experiences and perceptions of HIV related stigma: a case study of young people living with HIV in Bulawayo, Zimbabwe” is my original work. It has not been submitted before for any degree or academic qualification to this or any other University. I also declare that resources and information utilized in this work have been acknowledged in the reference list.

Mgcini Sibanda:                                    Date: 22 November, 2016
DEDICATION

My wife Sitshengisiwe P. Sibanda for her support and undying love.

My daughters, Babongile, Bongiwe-Thembisile, and Banele-Rowena, for never complaining and understanding and allowing me time to pursue my studies.
ABSTRACT

HIV related stigma is a serious public health problem. It continues to be experienced across the globe, impeding access to and scale-up of HIV prevention, treatment, care and support programmes. The fear of stigmatization often prevents young people from getting tested for HIV, disclosing their status, and accessing treatment and care. The purpose of the study was to explore and describe the HIV related stigma experiences and perceptions of young people living with HIV (YPLHIV) (aged 18-24) in peer support groups in Bulawayo, Zimbabwe. The three specific objectives were to identify the types of HIV related stigma experienced by young people living with HIV in peer support groups in Bulawayo; to explore the perceptions of young people living with HIV in peer support groups; and, to compare the HIV related stigma experienced by young males and females living with HIV in the peer support groups. The study is significant because the current HIV/AIDS programmes on stigma and discrimination for young people in Zimbabwe are not informed by empirical evidence. The study used an exploratory cross sectional qualitative research design, using in-depth interviews and focus groups. The following main themes emerged from thematic analysis of 42 YPLHIV narratives were: (1) How participants learn about their HIV status; (2) How the participants perceived their health status; (3) The fear of being stigmatized (4) The perceived main perpetrators of HIV stigma and how the participants reacted to perceived HIV related stigmatization, (5) The support systems available for the YLPHIV, (6) the social spaces where HIV related stigma and discrimination occurs HIV status and acts of discrimination. YPLHIV experienced both perceived stigma (the fear of stigmatization or discrimination) and enacted stigma (actual experiences of negative behaviors, such as discrimination). The female participants felt that they were more stigmatized than young men living with HIV. We recommend the development and implementation of evidence-based HIV related stigma and discrimination gender-focussed training programmes as well as awareness campaigns targeting traditional and religious leaders. The enactment and implementation of policies are needed to ensure a more enabling environment for YPLHIV to feel safe to disclose their status and to access post HIV services without fear of stigmatization and discrimination.
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I would like to thank the following people who contributed significantly to the success of this study:

- My supervisors, Sara Nieuwoudt and Yandisa Sikweyiya who helped me from the initial phase of developing the research proposal, ethics submission up to submission of the final research report. I’m indebted for their academic guidance and support.

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- To Zimbabwe National Network of people living with HIV (ZNNP+) for granting permission to conduct my research and the support during the process of data collection. I will always be grateful for their support.

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- I will forever remain grateful to my siblings and family members for all their sacrifices and support.

And lastly I would like to thank the Almighty God for giving me the strength and grace to carry out this research.
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<tr>
<td>ART</td>
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<td>ARV</td>
<td>Antiretroviral</td>
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<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>IDI</td>
<td>In-depth interview</td>
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<td>FGD</td>
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<td>HTC</td>
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<td>HREC</td>
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<tr>
<td>MSM</td>
<td>Men who sex with men</td>
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<tr>
<td>NGOS</td>
<td>Non-governmental organizations</td>
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<td>PLHIV</td>
<td>People living with HIV</td>
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<td>OI</td>
<td>Opportunistic infection</td>
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<td>OPD</td>
<td>Out patients department</td>
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<td>TB</td>
<td>Tuberculosis</td>
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<tr>
<td>VCT</td>
<td>Voluntary Counseling and Testing</td>
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<td>UNAIDS</td>
<td>United Nations Program on HIV/AIDS</td>
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<td>YPLHIV</td>
<td>Young people living with HIV</td>
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<td>WHO</td>
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<td>ZDHS</td>
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<td>ZNASP</td>
<td>Zimbabwe National Strategic Plan</td>
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<td>ZNNP+</td>
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DEFINITION OF TERMS

For the purpose of this study the following phrases and terms were used to mean the following:

**Felt stigma** was used and redefined as thoughts and behaviors stemming from the person’s own negative perceptions about him-/herself based on his/her HIV status.

**Enacted stigma** in this study refers to actual experiences of discrimination. This may include the experience of rejection, labelling, the exercise of power or control, harassment, punishment, blame, exclusion, ridicule, or resentment. It may sometimes lead to violence against a person living with HIV/AIDS.

**HIV/AIDS-related stigma** refers to all unfavorable attitudes and beliefs directed toward people living with HIV/AIDS (PLWA) or those perceived to be infected, and toward their significant others and loved ones, close associates, social groups, and communities.

**Internal stigma** refers to thoughts and behaviors stemming from the person’s own negative perceptions about him-/herself based on his/her HIV status.

**Labelling** is defined as attaching an identifying or negative term or sign to a PLWA, linking cause of infection to behavior of PLWA or blaming PLWA for their behavior.

**Sexual rejection** is used to refer to a negative response or the refusal by a sexual partner to engage in any form of sexual activity.

**Shame** is defined as a feeling of dishonor, disgrace or condemnation. To be ashamed of oneself refers to one having this feeling of shame.
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CHAPTER 1. INTRODUCTION AND LITERATURE REVIEW

1.0 Introduction

The history of the HIV/AIDS epidemic has been characterized by social responses of fear, denial, stigmatizing attitudes and acts of discrimination against people living with HIV/AIDS (PLHIV), and their family members (Nyblade et al., 2009, UNAIDS, 2007, Link & Phelan, 2001). The available literature on HIV related stigma has shown that stigma acts as a barrier HIV prevention, treatment, and care, including HIV testing services (Kalichman & Simbayi, 2003; Kalichman & Simbayi, 2004; UNAIDS, 2007, UNAIDS, 2010). The fear of HIV related stigma and discrimination is one of the major reasons why people are unwilling to take an HIV test, disclose their sero status and to be initiated to antiretroviral therapy (ART) (Avert, 2011, UNAIDS, 2010). As a result, more people present late for HIV testing, when they have clinically progressed to an AIDS stage of infection, and this impacts negatively on treatment outcomes (Avert, 2011, UNAIDS, 2010).

HIV has been associated with groups that are already socially marginalized, e.g. MSM, sex workers, and young people (UNAIDS,2010). Nyblade et al. (2009) observed that, the history of the epidemic has always been associated with particular groups of people such as men having sex with other men (MSM), people involved in sex work and drug abusers. In their article, Alonzo and Reynolds (1995) observed that PLHIV were stigmatized against because the virus was associated with deviant behavior and perceived to be acquired through a morally unsanctioned behavior.

Historically, the HIV transmission has always been perceived to be infectious, associated with a painful and uncommon form of death popularly known as ‘wasting syndrome’ (Niehaus, 2007) and the condition was negatively viewed and poorly understood by the communities and health care providers (Alonzo and Reynolds, 1995). Globally people mobilized very powerful metaphors that served to buttress and indirectly legitimize HIV related stigmatization (UNAIDS. 2000, Nyblade et al., 2009). These are some of the notable examples of the images that flooded both print and electronic media during the first stages of the epidemic; AIDS was portrayed as death through the imagery like the Grim Reaper and as a punishment for immoral behaviour; HIV/AIDS shown as war and as horror hence PLHIV were perceived as possessed and were feared); and HIV/AIDS as “otherness”, in which the disease is an attribute of those individuals set apart as undesirable (Niehaus, 2007; UNAIDS, 2007). These images together with the negative assumption that HIV/AIDS is a shameful disease provide a strong foundation for stigmatization. The use of stereotypes made a certain group of people to minimize their HIV risk.
perceptions and believe that HIV/AIDS was an attribute of only a certain group of people (Nyblade et al., 2009).

1.2 Country context

Zimbabwe has a young population, about a third of the population are young people between the ages of 10-24 years (Zimbabwe Government, 2012). These young people are faced with numerous challenges, which include unemployment, unintended pregnancies and gender based violence, sexually transmitted infections including HIV infection and HIV related stigma and discrimination (Zimbabwe Government, 2012). Zimbabwe ranks among the top five high HIV burdened countries in the world, with 16.7% of the adult (15-49 years) population estimated to be infected with HIV (Zimbabwe Government, 2014). HIV prevalence is higher among women (15-24) age group (7.3%) than among men of the same age (4.76%) (Zimbabwe Government, 2014). The challenges faced by young people are compounded by their limited access to information and health services (Zimbabwe Government, 2014).

The available literature indicates that over 80% of new infections are transmitted through heterosexual contact (Zimbabwean Government, 2014). The majority of new infections are recorded in the 15-29-year age group (Zimbabwe Government, 2013). The main notable key drivers of the HIV epidemic are low and inconsistent condom use, low male circumcision prevalence (10.3%), concurrent sexual partnerships, intergenerational sex and age mixing, and stigma and discrimination (Zimbabwe Government, 2006).

Generally, the country has high HIV/AIDS knowledge levels (Zimbabwe Government, 2012), as it is estimated that about 80% of the populations are knowledgeable about HIV/AIDS (Zimbabwean Government, 2012). Despite high knowledge levels, HIV and AIDS remain highly stigmatized in Zimbabwe (Zimbabwean Government, 2006). People living with HIV (PLHIV) are stigmatized and discriminated against because of their condition (ZNNP+, 2014). Many young people are reluctant to get tested for HIV and to access HIV/AIDS treatment for fear of being alienated by family and community or losing their partner (Zimbabwean Government, 2006). Those who are aware of their HIV status rarely disclose even to the health care workers, hence they do not have access to appropriate treatment, care and post HIV test support services (ZNNP+, 2014; Zimbabwean Government, 2006; Mukasa, 2008).

As noted earlier, HIV related stigmatization remains a significant barrier in the HIV/AIDS response (UNAIDS, 2010). The fear of HIV related stigma often prevents young people from knowing their HIV status, seeking treatment, care and disclosing their HIV status (UNAIDS, 2010). The Zimbabwe National HIV/AIDS Strategic Plan 2015-18 (ZNASP) identifies stigma and discrimination as two of the socio-cultural factors that drive the epidemic (Zimbabwe Government, 2015). The Government of Zimbabwe
acknowledges that stigmatization on the basis of sero-status remains a major barrier toward universal access to HIV/AIDS services (Zimbabwe Government, 2015). The available literature on stigma and discrimination clearly shows that they impede access and utilization of HIV testing services, treatment, care and psychosocial support for all Zimbabweans, particularly adolescents and young adults (UNAIDS, 2010; Zimbabwean Government, 2006).

In response to the perceived challenges of young people living with HIV (18-24 years), Zimbabwe National Network of People living with HIV (ZNNP+), a non-governmental organization working to empower people living with HIV in the country, organizes support groups for YPLHIV. These groups provide YPLHIV with information on HIV/AIDS, treatment, livelihood skills and further provide a platform for young people to socialize, make friends and share experiences (Zimbabwe Government, 2012). Some of these groups are organized in the townships around Bulawayo, the second biggest city in Zimbabwe, with an estimated population of 653,377 (Zimbabwe National Statistics Agency, 2012). The province has a high adult HIV prevalence with 21.78% (15-49 years) people are estimated to be infected with HIV; of these, 55403 are accessing the ART programme out of 60052 in need of ART (Zimbabwe Government, 2014).

1.3 Statement of the Problem

Many countries in sub-Saharan Africa, including Zimbabwe, have the highest burden of HIV/AIDS epidemic. Despite the high prevalence of HIV/AIDS, very little is known of the prevalence of HIV related stigma among young people living with HIV in these settings. Much of the existing literature focuses on the levels of knowledge of HIV/AIDS, this information has been used to understand the prevalence of HIV related stigma (Aggleton, 2000; Letamo, 2003). The study by Adebajo, Bamgbala and Oyediran, (2003) limited itself on the role of HIV related stigma in the access of and utilization of HIV services in the adult population. However, to date, I am not aware of any Zimbabwean studies that have empirically explored and described the HIV related stigma experiences and perceptions of YPLHIV specifically.

Despite significant progress made by the Zimbabwean government in scaling up antiretroviral therapy (ART), prevention of new HIV infection, and care for YPLHIV, the 2006 Ministry of Health programmatic data indicates that a significant number of YPLHIV still face stigma and discrimination in multiple settings (Zimbabwean Government, 2006). As noted earlier, the available literature indicates that the fear of stigmatization often prevents young people from seeking HIV testing services, treatment, care and disclosing their HIV status publicly (Adebajo, Bamgbala, & Oyediran, 2003, Zimbabwean Government, 2006). The ZNNP+, together with the Ministry of Health and NAC conducted a Stigma
Index survey in 2014. The survey assessed and tracked specific HIV/AIDS stigma indicators among know PLHIV. The survey utilized both qualitative and quantitative research design. ZNNP+ Stigma Index report (2014), indicates that although HIV related stigma has decreased among adults living with HIV, YPLHIV still face HIV related stigma. It has been explained as one of the reasons for low numbers of YPLHIV accessing ART treatment in public health facilities (ZNNP+, 2014). However, the survey did not directly explore and describe the HIV related stigma experiences and perception of YPLHIV.

1.4 Study Justification
The current HIV/AIDS programmes on stigma and discrimination for young people in Zimbabwe are not informed by empirical evidence (ZNNP+, 2014, Zimbabwe Government, 2012). Although a number of studies have been done on stigma and discrimination elsewhere in the region, little has been done to explore stigma experiences of young people living with HIV in Zimbabwe and Bulawayo in particular (ZNNP+, 2014, Bygrave et al, 2012, Campbell, 2005, Letamo, 2003). HIV stigma and discrimination programming needs to be more empirically based and by utilizing existing networks to conduct this study, the findings could become a basis for additional or comparative studies.

1.5 Research Aim and Objectives
The overall aim of the study was to explore and describe the HIV related stigma experiences and the perceptions of stigma among young people living with HIV (18-24) in peer support groups in Bulawayo, Zimbabwe. The following specific objectives guided the study;

- To identify the types of HIV related stigma experienced by young people living with HIV in peer support groups (18-24) in Bulawayo, Zimbabwe.
- To explore the perceptions of young people living with HIV (18-24) in peer support groups in Bulawayo, Zimbabwe, regarding HIV related stigma.
- To compare the HIV related stigma experienced by young males and females (18-24) living with HIV in peer support groups in Bulawayo, Zimbabwe.

1.6 Literature review
This section presents the previous works of different scholars and researchers on stigma and discrimination, particularly among young people living with HIV. The history of stigma is as old as mankind. In 1963, Goffman defined stigma as a term used in ancient Greece, to refer to a sign, or mark, cut or burn in the body that designated the bearer as an individual perceived to be morally defective and to be avoided (Goffman, 1963). In his article, Goffman (1963) referred to stigma as those attributes that are "significantly discrediting and a stigmatized person as one who possesses "an undesired difference"
This could probably explain how the stigmatization attitudes and perceptions towards PLHIV may have been formed and enacted (Lodder, 2004; Malcom, 1998).

The definition and application of stigma as a concept depends on the research discipline. Yuh (2014) posits that, stigma involves attaching labels to a person or group and connecting the label to an undesirable behavior. The labeled individuals are clearly distinct and set apart from the society, as ‘diseased’, different, and usually experience status loss and stigmatization (Yuh et al, 2014; Link and Phelan, 2001).

A number of authors have since made improvements on Goffman’s initial theory. For example, Gilmore and Somerville (1994) conceptualized four different stages of stigmatization in relation to sexually transmitted infections. This was an attempt to explain the four processes any stigmatizing response takes. The first stage involves what Goffman (1963) described as the discredited attribute, which can also be described as distinguishing and marking (Link & Phelan, 2001). According to Gilmore and Somerville (1994), the second stage is identifying the PLHIV for targeted discrimination. This means the discriminated individuals must be recognizable in the society with some easily identifiable characteristics which can then be used to label him or her for example, skin rash and weight loss (Greeff et al., 2008; Miller and Rubin, 2007). The target person is perceived as immoral and blamed for their predicament (Visser, 2009; Link & Phelan, 2001). The last stage has to do with how the society responds to the stigmatized individual. The individual may be isolated, insulted, avoided and ostracized (Campbell et al., 2007).

1.6.1 Manifestation of HIV related stigma

According to UNAIDS (2003, 2010), there are three distinct phases of the HIV/AIDS epidemic. These are; first the epidemic of HIV; the epidemic of AIDS; and the epidemic of stigma, discrimination, and denial. The third phase is as central to the global AIDS challenge as the disease itself (UNAIDS, 2010; AIDS 2031 Social Drivers Working Group, 2010). HIV related stigma is pervasive in sub-Saharan Africa. A number of studies done at community level to assess HIV related stigma among PLHIV (Kalichman et al., 2009), and the general population such as national stigma index surveys (ZNNP+, 2014, Aggleton et al., 2000, Kalichman et al., 2009, Visser, Makin, Vandormael, Sikkema & Forsyth, 2009), and health facility based studies (Mopani et al., 2006,) suggest that HIV related stigma is still high in the region.

UNAIDS (2010) posits that HIV related stigma manifests in different forms and contexts, such as the interpersonal level, family, community, workplace, and health facilities. In a study done in Ghana,
Mukasa (2008) identified three different types of stigma; enacted stigma, felt stigma and self-stigma. Enacted stigma refers to the discriminating acts and violation of the rights of those living with HIV or the families of those infected with HIV (Nkansa-Kyeremateng and Attua, 2013; Mukasa, 2008). Felt stigma, refers to how an individual feel about his/her condition and the fear of how of how other people will react when they learn about this condition (Nkansa-Kyeremateng and Attua, 2013; Mukasa, 2008). Felt stigma is the fear of or anticipation of enacted stigma (discrimination) and often impairs the individual’s perception of available support (Nkansa-Kyeremateng and Attua, 2013; Mukasa, 2008; Lodder, 2004). Self-stigma arises out of both enacted and felt stigma and is expressed when an individual internalizes enacted- or felt-stigma in a way that results into devaluation of one’s identity, both socially and at a personal level (Nkansa-Kyeremateng and Attua, 2013; Greeff, 2008; Lodder, 2004; Bharat, Aggleton, and Tyror, 2001; Alonzo and Reynolds, 1995). Some authorities have described self-stigma as a ‘powerful survival mechanism’ used by people to protect themselves from stigmatization. (Greeff et al., 2008; Miller and Rubin, 2007).

HIV related stigma can be experienced at different levels such as individual and societal levels. At the individual level, HIV related stigma takes the form of behaviours, thoughts, and feelings that express prejudice against PLHIV and can also be experienced by persons perceived to be living with HIV/AIDS (Mukasa, 2008). As indicated earlier, HIV related stigma affects a person’s decision to know his/her status, access to treatment, care and disclosure of HIV to family members, friends, and care providers. The resulting social withdrawal or social isolation imparts negatively on the lives of PLHIV (Mukasa, 2008).

At the societal level, HIV related stigma manifests in the form of restrictive laws, policies, norms, and the social conditions of PLHIV and those at risk of infection (Sambisa, 2008). The ZNNP+ Stigma Index study (2014) found that PL HIV, and even those suspected to be infected by the virus, continue to face discrimination at workplaces such security services, social and community programs such as allocation of houses, access to health insurance and basic civil and human rights. For example, in Zimbabwe there is mandatory HIV testing for people who are recruited into the uniformed force such the army, police and prison services and those who test HIV positive are not considered for employment in the uniformed forces (Sambisa, 2008).

For the purpose of this study, the concept felt stigma was used and redefined as thoughts and behaviors stemming from the person’s own negative perceptions about him-/herself based on his/her HIV status (Scambler, 2004). Enacted stigma in this study refers to actual experiences of discrimination. This may include the experience of rejection, labelling, the exercise of power or control, harassment, punishment,
blame, exclusion, ridicule, or resentment. It may sometimes lead to violence against a person living with HIV/AIDS (Scambler, 2004).

### 1.6.2 Causes of HIV Related Stigma

Letamo (2005) and UNAIDS (2000) identified three factors as contributing to HIV/AIDS-related stigma: (a) associated with behaviors that are already stigmatized in many African communities and perceived as the responsibility of the individual, such as sex work, sex between men and injecting drug use that; (b) perceived to be contagious and fear casual contact with an infected individual; (c) associated with an undesirable and painful form of death.

HIV transmission in sub-Saharan Africa is predominantly transmitted through sex, which is widely considered voluntary, and immoral, particularly when it involves young unmarried people or already stigmatized sexual behaviours such as promiscuity, MSM or sex with sex workers (UNAIDS, 2012). These sexual activities are already stigmatized in most African societies, including Zimbabwe (UNAIDS, 2010). Hence, people living with HIV are perceived to be responsible for their health condition and blamed for spreading the incurable and HIV related disease to other people (Herek et al., 2005).

HIV is generally perceived to be contagious and hence the fear of casual contact with an infected individual (Letamo, 2005). The available literature indicates that there is still fear that HIV could be transmitted through ordinary, daily interactions with individuals living with HIV (Ogden and Nyblade, 2005). Examples include contact with an HIV-positive person through simple touch (shaking hands, kiss on the cheek, sitting next to); eating food prepared by or which may have come in contact with those living with HIV and AIDS; breathing infected air; or using objects that someone living with HIV and AIDS had touched (e.g. clothing, bedding, or eating utensils) (Ogden and Nyblade, 2005).

The clinical progression of HIV infection without ART is associated with an undesirable and painful form of death (Letamo, 2005). It is associated with AIDS defining opportunistic infections such as cancers, TB, pneumonia and skin infections. According to Niehaus (2007), the media has shaped people’s perceptions of the HIV epidemic. He argued that, while in the early 1990s AIDS was an imagined disease only read and seen on television, most started to experience the painful realities of the disease beginning in 2000. These first hand and personal experience of seeing and nursing an ill and dying relative became critical in shaping the way people perceived the disease (Niehaus, 2007).

HIV related Stigma, both enacted and perceived, may also arise from the way communities respond and treat individuals with HIV (UNAIDS, 2000; Greeff, 2008). Generally, most people are not comfortable to publicly refer to the virus and the disease by name. Greeff, (2008) observed that the reluctance to mention the name “AIDS” can be seen as a way of denying the existence of AIDS or simple as a mystical
way of coping with the serious threat of HIV/AIDS (Greeff, 2008). The society has coined and introduced terms and phrases such as "a long illness" or "a short illness" that are considered to be culturally acceptable and neutral in the obituary of an individual who dies from AIDS instead of mention of the cause of death (Herck et al., 2005, Greeff, 2008).

HIV/AIDS epidemic has significantly evolved with the advent of ART and with marked improvements in the treatment and management of opportunistic infections. In the early day of the epidemic, HIV/AIDS was perceived as a fatal disease (Lodder, 2004). As such, an HIV positive diagnosis was perceived as an equivalent to dying or a certificate of death (Genberg et al., 2009), and in the eyes of the communities, those who were diagnosed with HIV represented a reminder of death (Lobber, 2004). According to Rosen et al (2010), the successes with ART have led to decreases in the number of people dying from AIDS, and people living with HIV are living longer and more productive lives. However, Campbell et al. (2007) observes that in some communities where ART is available and the outcome of HIV/AIDS not always fatal, people still continue to link HIV/AIDS and the deviant behaviors.

Although still prevalent, AIDS stigmas appear to be declining somewhat in Southern Africa (ZNNP+, 2014, NAFOPHANU, 2013). The results of the national Stigma Index study (2014) in Zimbabwe indicate that HIV related enacted stigma has gone down among adults living with HIV (ZNNP+, 2014). The same study shows that although the reported incidents of discrimination of people living with HIV has gone down, felt/self-stigma is still a major problem, particularly among adolescents and young people living with HIV (ZNNP+, 2014).

1.6.3 Young people living with HIV (YPLHIV)

Joint United Nations Programme on HIV/AIDS (UNAIDS) (2014) observed that AIDS related mortality fell by almost 40% between 2005 and 2013 for all age groups except for young people. AIDS remains the number one killer of young people in Africa (UNAIDS, 2014). The young adults aged 18-24 years constitute one of the most susceptible, yet overlooked, sub-populations affected by the HIV/AIDS in sub-Saharan Africa. An estimated 2.1 million adolescents (10-19 year) were living with HIV (UNAIDS, 2014), more than 80% of them live in sub-Saharan Africa (UNAIDS, 2014). According to UNAIDS (2014), 250 000 new HIV infections were recorded among the 15-19 year olds in 2013, 64% of HIV new infections were among girls. The population of YPLHIV comprise of a mixed group of people who were infected perinatally as well as those infected mostly sexually (UNAIDS, 2014). The YPLHIV born with the virus form the first generation of long-term survivors of HIV in sub-Saharan Africa who have carried the virus since birth. YPLHIV face a myriad of treatment, sexual reproductive health, psychological and
social challenges that the social services and health sectors had not anticipated (Mukasa, 2008; Lodder, 2009; UNAIDS, 2009; UNAIDS, 2010; UNAIDS, 2014, WHO, 2009).

Adolescents and young people living with HIV often experience stigma (UNAIDS, 2010, UNAIDS, 2014). The HIV-related stigma can range from inappropriate and hurtful comments to physical violence (UNAIDS, 2010). In addition to the usual stigma attached to living with HIV, adolescents and young people who were infected perinatally might experience stigma for having a chronic illness, side effects as a result of antiretroviral drugs, for possible stunted growth and cognitive delays, and for poor school performance (Mukasa 2008, Lodder 2009; UNAIDS, 2009; UNAIDS, 2010). The studies done in Botswana and Zambia found that stigma against YPLHIV acts as a barrier to access and utilization of the HIV testing services (Letamo, 2003; Nyblade & Field, 2002; Ogden and Nyblade, 2005). Sambisa (2008) noted that the fear of stigmatization following a positive HIV diagnosis may result in one being hesitant to disclose his/her status or failure to utilizing health and social services (Sambisa, 2008). In Zimbabwe, like any other country with a mature epidemic, adolescents and young adults constitute an increasing number of the PLHIV who are faced with a number of health related challenges (Zimbabwean Government, 2014).

Despite limited literature on YPLHIV in Zimbabwe, the available literature indicates that HIV related stigma impedes access to and utilization of HIV testing services, ART treatment, care and psychosocial support services for all Zimbabweans, particularly children and young adults (Sherr et al., 2007; Zimbabwean Government, 2006; UNAIDS, 2009; Kalichman and Simbayi, 2003; Mbonu et al., 2009).

1.6.4 HIV related stigma experienced at the workplace

A number of studies done in Africa found that a number of PLHIV still face stigma at their workplaces. For example, in Cameroon Jacob et al. (2012) uncovered that more than 23% of their study participants had lost their employment because of their HIV status. The Uganda stigma index research findings also suggest that of the 255 participants, 23% reported loss of employment and income because of their HIV status (NAFOPHANU, 2013). In Zimbabwe, the Stigma index survey revealed that more than twenty percent (20.6%) of the respondents lost their source of income, while 12.1% were denied employment opportunities and 9.1% reported that their nature of work changed or they were refused a promotion as a result of their HIV status (ZNNP+, 2014).

Although there is limited research focusing on HIV related stigma experienced by YPLHIV at workplace, it is most likely that they continue to experience HIV related stigma like adults living with HIV. Enacted stigma at the workplace is experienced when workmates demonize and talk negatively about PLHIV
(Nkansa-Kyeremateng and Attua, 2013; WHO, 2009). In some extreme cases, workmates may openly refuse to associate with PLHIV (WHO, 2009). In some instances, YPLHIV end up opting to voluntarily leave their jobs because of stigma (WHO, 2009). In a number of studies done with PLHIV, show that PLHIV are often faced with threats of imminent loss of employment due to a positive HIV status (ZNNP+, 2014; Nkansa-Kyeremateng et al., 2013).

1.6.5 HIV related stigma experienced in the home setting

In most countries in sub-Saharan Africa, the family is the primary care-giver to sick members. The available literature clearly demonstrates the important role that the family can play in providing psychosocial support and care for PLHIV (Letamo, 2005; Bharat, Aggleton, and Tyror, 2001). However, not all family response is positive. UNAIDS (2000) and Parker and Aggleton (2003) observed that the family may discourage the infected member from disclosing his/her status or seeking help as means of “managing” stigmatization within the wider community. The success of such strategies depends upon the safety nets of the affected household and its ability to provide care and support to its members without falling back on the support from the other community members.

The available literature on YPLHIV’s experiences indicates that stigma is rife. A study conducted by Campbell et al. (2005) in South Africa demonstrated the prevalence of HIV related stigma across age groups. These authors reported that YPLHIV in particular were not comfortable to disclose their HIV status to their parents, because of the fear of being gossiped about. They further reported that some members of the family may hid a sick relative, hence depriving them of treatment, care and support (Campbell et al., 2005).

Strode and Barrette-Grant (2001) found evidence of HIV related stigma among orphaned young people living with HIV in South African households, including of provision of separate spoons, plates and cups and greater expectation of work contribution. These observations were consistent with those made by Clay et al. (2003) in Zambia. In this study, YPLHIV reported withholding of food, receiving harsher punishments and allocation of heavier workloads as some of the maltreatment they were subjected to by the relatives after the death of their parents (Clay et al., 2003).

Generally, men and women experience HIV-related stigma differently, with a moral dimension. Reviewed literature shows that HIV related stigma at the household level is largely gender-based, with females more stigmatized than men (Nkansa-Kyeremateng and Attua, 2013; Parker and Aggleton, 2003). When a couple is HIV positive, the blame is often apportioned to the female partner, regardless of who
first contracted the virus (Chilikwela et al., 2003; Mukasa, 2008). Generally, in most African societies, females are expected to uphold the societal and moral traditions, and the presence of HIV is regarded as evidence of their failure to fulfil this important social function (Nkansa-Kyeremateng and Attua, 2013; Chilikwela et al., 2003; Mukasa, 2008).

In conclusion, the reviewed literature suggests that the intensity of HIV related stigma is likely to vary depending on the age and gender of the young person living with HIV. Although there is dearth in specific literature comparing HIV related experiences of young females living with HIV. Young females are likely to be stigmatized because of the assumption that they contracted HIV because they violated adult norms of sexual debut, while the same society is likely to tolerate the same behaviors from young males (Bhana, 2016).

1.6.6 HIV related stigma faced by PLHIV in the community

PLHIV also face HIV related stigma in their communities (Herek, 2002; Alonzo et al., 1995). Mukasa (2008) observed that some communities fail to see HIV/AIDS as a challenge, but instead PLHIV are seen as the problem. PLHIV are labelled and given derogatory and dehumanizing names which imply uselessness and death (Mukasa, 2008). In the early stages of the epidemic, there were reports of PLHIV being chased out of their communities, and even threats of death (Visser et al., 2009). In a well-publicized case in KwaMashu, in Durban, South Africa, a young woman was killed by members of her community for disclosing that she was living with HIV (Visser et al., 2009).

1.6.7 Stigma and discrimination faced by PLHIV at health facilities

Although there are limited published studies on HIV related stigma towards YPLHIV in health facilities, the existing literature on HIV related stigma indicates that health workers discriminate against PLHIV in health facilities (Kafuko, 2009; dos Santos et al., 2014). In a study done by Kafuko (2009) in Ghana, some health workers were reported to be rude towards PLHIV and lack respect for PLHIV. This obviously has a potential to affect the quality of care that PLHIV receive. Although most of the research on HIV related stigma focus on the attitudes of the health workers, it is imperative to note that health institutions may also stigmatize against PLHIV (dos Santos et al., 2014). This happens when there are institutional rules and policies that violate the dignity and rights of PLHIV, such as mandatory HIV testing in the name of provider initiated HIV testing and the lack of mechanisms to protect the HIV status of PLHIV (Kafuko, 2009). For example, in Zimbabwe, HIV testing is routinely offered in all health facilities to all patients who present at a health facility (Zimbabwean Government, 2013). Most health
facilities have HIV testing counselling (HTC) daily targets; hence it is likely that some patients are coerced by health workers into taking an HIV test.

Consistent with the global literature, the findings of a study done by the Ministry of Health and Child Care at Mpilo Central hospital in Bulawayo, Zimbabwe, indicate that the betrayal of confidentiality were the most reported acts of stigmatization by health workers (Zimbabwe Government, 2004). The patients reported lack of privacy and that the health workers disclosed their HIV-status without their consent. To avoid stigmatization, some patients elected did not share their HIV-status in health care facilities. These factors have the potential to negatively impact on access to HIV testing services, treatment, care and psychosocial support for PLHIV (Zimbabwe Government, 2004).

In conclusion, the health worker stigma may be even worse among young people than for other groups living with HIV as there may be more shame, for young people, about seeking care because having HIV may be an indication of being sexually active- a part of human experience that is often forbidden for young people due to moral and religious objections.

1.6.8 Effects of HIV related stigma on PLHIV
The HIV related stigma creates serious barriers to effective HIV response (Avert, 2011). UNAIDS (2010) notes that HIV related stigma has significant implications for HIV testing services, ART treatment, care and psychosocial support, as it reduces a person’s willingness to know his/her HIV status, to share his/her status with significant other, to use condoms and to access health care. This has serious implications for all the HIV strategies aimed at reducing the spread of HIV (UNAIDS, 2010). This view is supported by Mukasa (2008) who observes that HIV related stigma breeds an atmosphere of ‘fear and denial’, where people are scared to openly disclose their statuses. Historically, HIV/AIDS has been treated as an attribute for a particular group of people. Hence, HIV related stigma has the potential to create a low risk perception among the traditionally ‘not at risk groups’ because they do not identify with a particular high risk group the tendency is to discount the risk of getting infected (Avert, 2011).

There is an ever growing body of literature which demonstrates that HIV related stigma affects the utilization of HIV testing services, ART treatment and care services (UNAIDS,2010, Prince et al., 2006). Pardasani et al. (2010) observe that HIV related stigma has become a powerful deterrent to individual’s health seeking behaviours and self-determination. The fear of being seen in health care centres offering HIV services, fear of sharing their HIV status to health care workers and the long waiting hours at ART clinics hinder effective utilization of available HIV management and care services (Prince et al., 2006, Avert, 2011, Bwambale et al., 2008).
Most YPLHIV are unable disclose to their HIV status to sexual partners and even to family members because of fear of HIV related stigma (UNAIDS, 2009). Due to fear of stigmatization some households may be discouraged from registering infected young person in ART and care programs, and further limits access to information, and psychosocial support (UNAIDS, 2009, Zungu-Dirwayi et al., 2004).

As mentioned above, HIV related stigma remains a major barrier in access and utilization of HIV testing services, treatment, care and psychosocial support (Holzem and Uys, 2004).

1.6.9 International commitments in reducing HIV/AIDS Stigma and Discrimination

Following the United Nations Special Session on HIV/AIDS in 2001, governments from around the globe including the Zimbabwean government, agreed upon goals and strategies to address the needs of young people made vulnerable by HIV/AIDS. Most governments have committed to protect the rights and dignity of YPLHIV. Some of them have enacted policies and guidelines which attempt to create an enabling legal environment to encourage young people to access HIV testing services (UNAIDS, 2012). These initiatives are essential in facilitating the universal access to comprehensive HIV prevention, treatment and care, and to reduce the impact of the epidemic (UNAIDS, 2012).

The statement of commitment from the governments is an acknowledgement that HIV related stigma is still an issue in the HIV/AIDS response. In most African countries, women and girls continue to face gender based violence that expose them to HIV, and limits their access to information on sexual health and reproductive health (UNAIDS, 2012). Although there are no specific laws that discriminate against young people living with HIV in Zimbabwe, the enactment of laws which criminalize same sex among MSM and sex workers in Zimbabwe, Malawi, Uganda and Zambia, have the potential to drive these subpopulations underground (UNAIDS, 2012, Avert, 2011). This serves only to increases their susceptibility to HIV epidemic, as well as to HIV related stigmatization (UNAIDS, 2012, Avert, 2011).

In line with this, UNAIDS (2012) recommends that every country should design sensitive national HIV programmes that realize basic human rights and access to justice in the context of HIV. PLHIV should not be seen as vectors of the epidemic but as partners in the HIV/AIDS response (Bharat et al., 2001). Moreover, authors have argued that such programmes should build capacities of communities and mobilize communities to effectively participate in programme development and participation (Bharat et al., 2001).
This chapter presented a review of literature related to HIV/AIDS stigma and the various types of HIV-related stigma. Also, it was shown that HIV related stigma was largely due to fear of HIV/AIDS, inaccurate information about its transmission modes and inadequate knowledge about HIV/AIDS. Furthermore, focus was also on the possible options for eradicating HIV/AIDS stigma. The next chapter focuses on the study research methodology.
CHAPTER 2. RESEARCH METHODOLOGY

2.0 Introduction
This chapter presents the research methodology. It describes the research study design, the study population, the sample recruited, and data collection, including the instruments employed. In addition, the chapter provides a discussion on the ethical considerations, the researcher's role, data management, and analysis procedures.

2.1 Research Design
The study design refers to a plan that guides the researcher in the process of data collection, its analysis and interpretation of the findings (Kato, 2002). The study reported in this research report was an exploratory cross-sectional qualitative study that used in-depth interviews (IDIs) and focus group discussions (FGDs) with YPLHIV (18-24) in peer support groups in Bulawayo, Zimbabwe. This study design was found to be particularly useful in exploring and describing in-depth the study population's experiences and perceptions of HIV related stigma.

2.2 Population
The study population was young people (aged 18-24) living with HIV and attending peer support groups in Bulawayo, Zimbabwe. The study purposively recruited the study participants from a peer support group first, through their involvement in the HIV peer support group, it was safe to assume that these young people were aware of their HIV positive status, second the peer support groups are the only structured group of young people living with HIV on HIV treatment and attended weekly HIV peer support group meetings outside the health facility. During the study period, there were fifteen support groups of YPLHIV in Bulawayo, with an average of 12 members in each group.

2.3 Study Sample
A purposive sampling procedure was used to recruit participants for this study. In purposive sampling, a researcher uses knowledge of the population to purposively select units (participants), because they are either critical or typical cases (Reave, 1992). In this study, the following criteria was used to purposively sample the study participants; the gender and age of the participants, as well as the period attending peer support groups in Bulawayo high density townships. I recruited a mix of male and female YPLHIV aged 18-24, who had been attending the weekly peer support groups for more than 12 months.

To be eligible, the YPLHIV had to be between the ages of 18 and 24. Only those who had been attending peer support groups for more than twelve months in Bulawayo high density areas were included in the study. In this study I was interested in exploring and describing the YPLHIV’s lived experiences and
perceptions regarding HIV related stigma. Therefore, I restricted my study to those who had known their HIV status for more than twelve months, as those with more recent diagnoses may not yet have come to terms with their identities.

To gain access to support group members and also to gain the trust and confidence of the YPLHIV, I worked closely with officials from ZNNP+ who are the custodians of all the support groups and networks of PLHIV. They introduced the research team to the prospective participants, prior to data collection. During the initial engagement with YPLHIV, I introduced the study to the prospective participants and explained the purpose of the study, procedures involved, benefits and risks of participating and participants’ rights, and invited them to participate in the study. Those young people who showed a willingness to participate in the study were given a study information sheet to read on their own, and appointments were made to further discuss the content of the information sheet and seek their informed consent. A total of 42 YPLHIV gave written consent to participate and no refusals were recorded in the study. Table 1 shows the number and gender of the YPLHIV who participated in the IDIs and FGDs.

Table 1. Final study sample by data collection method

<table>
<thead>
<tr>
<th>Sex of participants</th>
<th>Focus group discussions</th>
<th>In depth interviews</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>12</td>
<td>8</td>
<td>20</td>
</tr>
<tr>
<td>Females</td>
<td>12</td>
<td>10</td>
<td>22</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td>18</td>
<td>42</td>
</tr>
</tbody>
</table>

2.4 Data Collection

To collect the data, IDIs and FGDs as data collection techniques we used. Considering the sensitivity of HIV related stigma, the principal researcher (a male in his early 40s) conducted the IDIs and FGD with male participants and an experienced female research assistant conducted IDIs and FGD with the female participants. Prior to data collection the study objectives, aims and the data collection tools as well as the research ethics were clearly explained to the female research assistant in order for her to have a better understanding of the study.
2.4.1 In-depth interviews

IDIs are described by Reave (1992) as a systematic process that seeks to record and document responses coupled with exploring the deeper meaning of the responses. Twenty-four IDIs (twelve males and twelve females) with YPLHIV were initially planned for this study. As stated above, during the data collection period I did not experience any refusals from the participants who were approached and requested to participate in the study. There was an overwhelming positive response from the YPLHIV in support groups who were eligible and willing to participate in the study. This I attribute to the fact that most of the YPLHIV had been in peer support groups for more than twelve months and empowered with psychosocial initiatives; supportive counselling and information shared in the peer support groups. They were confident, articulate and willing to share their lived experiences as YPLHIV. In the end, 18 in-depth interviews (eight males and ten females) were conducted. Although new ideas were still emerging the data collection was stopped, due to limited budget and time.

The interviews were offered in English and IsiNdebele languages depending on the participants' choice and comfort. Most participants were comfortable in using both languages, which ensured a better comprehension of the questions. Written informed consent was obtained from each participant for participating in the study, as well as for audio recording of the interviews, before the interview began. To ensure privacy, the interviews were conducted in counselling rooms in the community centres where participants usually hold their support group meetings. All interviews were audio recorded and their durations were between 45–60 minutes.

An interview guide (Appendix A) guided the IDIs with YPLHIV. The English version of the interview guide was translated into isiNdebele (the language spoken in Bulawayo) by the researcher and back translated by the research assistant to ensure accuracy of translation. The questions in the interview guide were designed to answer the study objectives. In order to create rapport, the interview started by soliciting participants' basic demographic questions, which included the age, the highest level education attained, and whether they have shared their HIV status with anyone. The interview covered the following issues; how one learnt about his or her HIV status, living with HIV, types of HIV related stigma experienced by YPLHIV, how YPLHIV perceive HIV related stigma, comparison of HIV related stigma experienced by males and females living with HIV, social spaces where HIV related stigma occurs, perceived perpetrators of HIV related stigma and disclosure of HIV status.

The data collection process continued until the respondents expressed no new information related to HIV stigma experiences emerged from the interviews. Before closing the IDI, the information gathered from
each interview was rephrased and summarized for the participants, this was meant to ensure that the obtained information correctly reflect the views and sentiments of the respondents.

All the interviews were audio-recorded and transcribed after each session. Briefing sessions were done daily with the research assistant to compare field notes and share experiences. This was useful because it informed the information and details to be collected in subsequent interviews.

2.4.2 Focus group discussions

FGDs are planned discussions which are carefully designed to gather information on attitudes, affections and perceptions on a particular field of interest utilizing the experts of an experienced facilitator (Reave, 1992). The FGDs were used to explore peer dynamics and norms around living with HIV. Two FGDs were conducted with YPLHIV who did not participate in the IDIs. These young people were recruited from each peer support group, one for males and another for females (with 12 participants for each FGD).

Each discussion took approximately an hour and it used a FGD guide (Appendix B), with probes to ensure that specific topics were covered. However, the guide also allowed the participants to engage each and explore issues under discussion. The topics for discussion in the FGD guide were arranged according to the study objectives. These included the following; different types of HIV related stigmatization experienced by YPLHIV, perceptions of HIV related stigma in different social spaces, fear of stigmatization, perceived support systems, perceived perpetrators of HIV related stigma, comparison of HIV related stigma between females and males, attitudes of the members of the community towards YLPHIV, and possible interventions to respond to HIV related stigma.

The two group discussions were audio-recorded, and field notes were also written to capture non-verbal cues. With the permission of the participants, I took the notes for the female FGD and the research assistant took the notes for the male FGD. The FGDs continued until new information on HIV stigma emerged from the discussions. In order to ensure that the obtained views reflected those of the participants, each topic was summarized for the respondents before ending the discussion.

2.4.3 Data Management and Analysis

The data analysis forms an important step in the research process, and on how a researcher arrives at findings (Saunders et al., 2012). Before analysis, the data had to be converted to text from audio files. The audio recordings of the FGDs and IDIs conducted in IsiNdebele were first transcribed and translated into English by the principal researcher and female research assistant.
In preparation for coding the transcripts, first, three transcribed interviews were independently read by the principal researcher and the two supervisors. From an initial read of three transcripts we identified codes (both inductive and deductive) that were used to develop an initial code book. The initial code book was shared with the supervisors, who shared their feedback on how to further develop the codebook. The principal researcher and the research assistant using the modified code book, then separately coded the remaining 16 transcriptions paying particular attention and recording any emerging new codes. In order to ensure that the correct categories were assigned, each interview was read at least four times. The differences that emerged were resolved by engaging and discussion with the two supervisors.

The data were analyzed manually using word documents. The codes were grouped into categories. The themes which emerged from the analysis were identified following the principles of thematic analysis. The relationships between themes were discussed with supervisors. Themes that were found to be relevant and answering the research question are presented in chapter three, illustrated with verbatim quotes.

2.4.4 My Position as a researcher in the study

My research report explores the HIV related stigma experiences and perceptions of YPLHIV in Bulawayo (Matabeleland). As an IsiNdebele native speaker, I have a lot in common with my study population, and I see myself as an indigenous-insider. I believe that I have a duty towards the wellbeing and growth of my community especially after having lived, studied and worked most of the time in this region.

My public health studies have introduced me to social behavior change discipline and my humanitarian work experiences have led me to work with key affected populations. My twelve years experience as an advocate in the area of HIV/AIDS programming gave me an insight into the difficulties and challenges faced by the people living with HIV, particularly YPLHIV. Having experienced the death of several people I knew to AIDS, including my own relatives because of fear, shame, stigma and depression, I became passionate about HIV related issues which gave grounds for my research on social aspects of HIV.

My religious background influences my perspective about HIV. I feel it is a Christian obligation to contribute to the spiritual comfort, emotional wellbeing and happiness of those infected with HIV as they need my love and support. Churches traditionally have always been perceived as haven for refuge.
As a 43-year-old male, interviewing young males living with HIV, an awareness about my position was quite important to enable the respondents to freely share their genuine perspective on the subject. Therefore, I had to ensure they felt free to express whatever they wished to share or not. I engaged the services of a female research assistant to assist me to interview female participants. This proved to be effective because most female participants could easily identify with a female researcher and freely volunteered their life experiences and perceptions of HIV related stigma.

My twelve years of experience working with the people living with HIV prepared me for the experiences of interviewing YPLHIV. I went into data collection fully cognizant of the sensitive nature of the subject matter. However, I must admit that I was humbled by the levels of courage, emotional maturity demonstrated by the young males living with HIV who freely and enthusiastically volunteered their lived experiences of HIV related stigma. I felt privileged to have been given a rare access to the participants' social world, to the meanings they attach to them and experiences related to being young people who live with HIV. The exercise was emotionally enriching for me.

Every interview presented a unique situation for me and every interview was a step into unknown territory. What I learnt is that it is important for one to be alert to changes in the dynamic of the interview and in the participants' demeanor always. I learnt that creating rapport and trust with study participants was key in data collection, before the interview began, and I found it helpful to spend more time trying to put them at ease by having a general discussion before beginning the interview. Taking time over the introductory information about the purpose of the study findings was particularly useful. I assured the participants that I am interested in everyone's views and experiences, hence there were no right or wrong answers.

When conducting IDIs and FGDs it is highly desirable to audio record the interviews and also to take notes. I was anxious at the beginning of the data collection regarding the audio recording of the IDIs and FGDs. I thought the participants were not going to consent to it or be comfortable with it. What I learnt is that as long as you provide a clear, logical explanation about its value, reassures about confidentiality and clearly explain what will happen to the tapes and transcripts, it is unlikely for a researcher to experience challenges. I also appreciated the fact that one has to be comfortable with the operation of the audio recording equipment, checking that it works before and immediately after the interview and having enough spare batteries on hand is essential. I encountered a minor challenge with the recorder with my first interview. The recorder had a malfunctioning record switch. Thankfully, this did not affect the quality of the interview because I had a spare recorder.
I was taught the basic tenets of conducting IDIs which openly encourages researchers to summarize interviewee's responses particularly at the end of each topic to ensure that one has properly captured the views of the participant and also to signal that you are moving to a different topic. However, what I realized is that sometimes it is difficult to capture the full meaning relayed by the participant in a short summary and attempting to do so may seem patronizing to the participant. It also prevents the smooth flow of the interview.

I am currently working as a National programme officer with Zimbabwe National Network of People living with HIV. This worked in my favour to gain access to the support group members (study population). I am strongly convinced that my familiarity with the study participants enabled IDIs and FGDs to be positive and empowering experiences, for myself and YPLHIV. The participants developed trust and confidence in me hence they were able to comfortably share their lived experiences during IDIs and FGDs. It was a personally enriching experience.

2.5 Ethical Considerations

Ethics define the right and wrong conduct in research. Saunders et al. (2012), defines research ethics as the principles that regulates the behaviours of the researchers and the participants. These include deliberate attempts to protect the participants against harm, protect their privacy, informed consent, confidentiality, and anonymity (Saunders et al.2012). I conducted this study in partial fulfilment of the Master in Public Health (MPH) degree requirements. The protocol was approved by the University of the Witwatersrand’s Human Research Ethics Committee (HREC) (Appendix C). In Zimbabwe, permission to conduct this study was given by ZNNP+, who are the custodians of support groups of YPLHIV. I did not encounter any challenges in securing permission from ZNNP+, probably because the organisation had recently (2014) conducted a HIV/AIDS Stigma Index survey and had a keen interest in tracking and seeing the levels of self-reported HIV related stigma among young people living HIV, and also because I am an employee of the same organization.

During recruitment, the purpose of the study of the study was explained to all the prospective study respondents in order for them to make informed decision on whether or not to participate in the study. All the necessary ethical implications of participating in the study were clearly explained to the respondents with the aid of information sheets (Appendices D and E). the respondents who agreed to take part in the study were requested to sign a consent form. The consent form for the IDIs (Appendix D) stated that the information given will be treated confidentially, and no names or any form of identification will be used that will link the participants to the information they provide in the study. In the case of the FGD, the information sheet and consent form (Appendix E) clearly indicated that the researchers could not guarantee
that other respondents who participated in the group discussion would maintain confidentiality. However, the importance of confidentiality was emphasized to group members before the start of the discussions. Both information sheets and consent forms categorically stated that their participation in the study was voluntary and that respondents could withdraw, even during the interview or discussion process. No participant withdrew their consent or stopped their participation in the IDIs or FGDs.

Separate written consent was sought for audio recording the IDIs and FGDs (Appendices F and G). I did not provide any monetary compensation to the participants for their participation in the study, and this was communicated to the respondents before their enrolment in the study. All the consent forms, audio recordings and study material are kept in a safe and secure place and are to be destroyed two years after the publication of the study findings or six years after the study if the findings are not published.
CHAPTER 3. STUDY FINDINGS

3.0 Introduction

This chapter presents the findings of the study, which are based on the data collected through IDIs and FGDs with YPLHIV and attending HIV peer support groups in Bulawayo, Zimbabwe. The findings are presented according to the study aim and objectives, highlighting themes that emerged for each. The overall aim of the study was to explore and describe the HIV related stigma experiences and perceptions of young people living with HIV (18-24) in peer support groups in Bulawayo, Zimbabwe. To meet this aim, different types of HIV related stigma were explored, along with perceptions of stigma, and a comparison by gender.

A total of 42 YPLHIV participated in this study. Most YPLHIV who participated in the study had completed secondary education, with the exception of a smaller number who were forced to abort their education after the death of their parents. Most participants indicated that they had told an immediate member of their family and peer support group members about their HIV status. The respondent described how they learnt about their HIV status, how they dealt with an HIV positive result, and HIV diagnosis is perceived in their communities or homes and their reactions to stigma. Eight main themes emerged from the data: HIV status (opportunistic infections, involuntary testing, ARVs side effects, family hid HIV status); Perceived health status (self-image); fear of stigmatization (self-isolation, non-disclosure, avoidance); perceived perpetrators of HIV related stigma (learners, friends, Churches, family); reaction to perceived HIV related stigma (self-isolation as a copying strategy); support systems (home, church); social spaces where HIV related stigma and discrimination occurs (home, church, school, community); and acts of discrimination (name calling, rejection, violence). These are discussed and illustrated with quotes. To protect the identities of the study participants, their names have been replaced by pseudonyms.

3.1 How youth learned about their HIV status

Respondents who participated in the IDIs were asked how they learned about their HIV status, and how they dealt with an HIV positive diagnosis. The reason for asking this question was to contextualize the different ways young people learn about their HIV status. Most participants narrated a long history of suffering from different opportunistic infections such as TB and meningitis, and being in and out of hospitals. Maria (female 19) who had known her HIV status for more five years said:
I have been through a lot myself. When I was growing up, I was always a sick child. I used to cough; body rash, had headaches and suffered from weight loss due to poor appetite. So, one day my grandmother encouraged me to go for an HIV test, because she was worried that I was not getting better, always sick and not responding to treatment. (IDI, female 21)

Another participant, Pride (male 20) shared a somewhat similar experience. He said:

I have been ill since I was young. I have been in and out of hospitals suffering from different ailments. What I can clearly remember is that in 2006. Yaa it was in 2006, I was treated for TB. I was admitted at XX hospital; I was coughing continuously and vomiting. I lost a lot of weight. I stayed there for more than two months, because the doctors were saying I wasn’t responding to treatment. They started giving me injections every day. I had given up, because I thought that I was going to die. (IDI, male 20)

Thulani (male 18) also narrated how he suffered from opportunistic infections before he learnt about his HIV positive status:

...been in and out of hospital suffering from many illnesses...I suffered from meningitis in 2003 and I was taken to X hospital, that’s where I got tested for HIV. I was found HIV positive. In 2004, I was started on ARVs at X OI clinic. I was later transferred to XX OI clinic in 2009. (IDI, male 18)

Some participants indicated that they learned about their HIV status when the health care workers pressurized the family to disclose to the YPLHIV. Tom (male 20) described how his parents hid his HIV status from him. He said;

My parents used to tell me that, I am asthmatic. One day I went to the clinic to collect my medication and the nurse at the clinic asked me whether I knew what the medication was for. I told her it was for asthma. I saw her face change, and I got suspicious that something was wrong with my health. I never suspected that I was different from anyone in my family. (IDI, male 20)

Only two participants reported being taken for an HIV test by the parents and learnt about their HIV status. Most respondents reported that most parents of YPLHIV are faced with a dilemma on whether, how and when to disclose the HIV status of a YPLHIV.
In Zimbabwe there is limited support to empower parents and/or guardians of YPLHIV to deal with issues of disclosure, hence disclosure of a person's HIV is not coordinated and clumsily handled, with potential psychological consequences to the YPLHIV. In the majority of cases described by the participants, the issue of disclosure was left till late, when the YPLHIV started to question the caregivers on the medication he/she was taking and why he/she looked different from other young people. This was summarized by James (male 20), when he said:

*I started to take medicine from the local clinic. When I completed TB treatment I continued taking white tablets. After almost six months, I asked my parents (uncle and aunt) what the tablets were for. They didn't tell me the truth. They lied to me and they said it was drugs for headache, because I used to suffer from headache. I got suspicious, and I suspected that they were hiding something from me. I suspected that I had AIDS. I kept on asking questions and eventually they told me that I was HIV positive. They assured me that all will be well and my uncle told me not to worry a lot. He also explained to me how I contracted the virus. (IDI, male 20)*

### 3.2 Types of HIV related stigma

The majority of participants experienced felt stigma (the fear of being stigmatized) and enacted stigma (the negative experiences, such as discrimination). The notable example of felt stigma was fear of telling someone else about the HIV status, self-withdrawal from social events, or reluctance to be involved in intimate relationships, in anticipation of resultant discrimination. Indeed, data suggest that some of the respondents elected not to disclose their HIV serostatus or to isolate themselves. Enacted stigma included actual experiences of stigmatization and took the form of avoidance, rejection, gossip, and verbal insults perpetrated by school mates, family and church members and friends.

#### 3.2.1 Felt Stigma (and Self Stigma): Fear and avoidance

One of the most profound themes that emerged from the data was fear of stigmatization. This was expressed by all of the participants. Most respondents were aware of HIV-related stigma and the possibilities of being stigmatized, because they had observed other people being stigmatized in their communities. Consequently, they were scared of being stigmatized. Jabu (male, 24) described fears that he perceived as the most common among YPLHIV, he said:
Stigma is a big issue here. Those young people who are positive find it difficult to disclose their HIV [status] because of fear of rejection. Most of us here in the support group haven’t disclosed our status to our girlfriends. It is not easy to tell your girlfriend that you are positive especially when you don’t know her status...even your prospects of being employed are very limited, most employers would prefer someone whose status is unknown than a young person known to be HIV positive. Generally, we are not given a chance in this community to prove our worth. (FDG, male 24)

In ability to disclose one’s HIV status outside the family was a salient and significant subtheme of felt stigma, with fear or anticipated stigmatization as the major reasons. Friends, classmates, church members and other members of the community constituted the most frequently mentioned groups of people to whom the participants were reluctant to disclose their HIV status. Thulani (male, 18) expressed fear of disclosing his HIV status to friends because he perceived them as uninformed about HIV issues and harbouring negative attitudes towards PLHIV. He remarked:

I cannot tell them about my status. They will make funny out of me. Most people do not understand about HIV. I do not see any reason why I should disclose my status to anyone other than my relatives. (IDI, male 18).

These sentiments were also shared by John (male, 20), in his own words:

...friends do not have correct information on HIV; they will not understand how I got infected with HIV. I have heard the way they talk about people living with HIV. They say nasty things about people with HIV. If they get to know that I am positive, they will not play with me. (IDI, male 20)

Due to anticipated stigmatization or fear of being stigmatized, some participants engaged in sexual sorting. They indicated that they have resorted to seeking out only HIV positive partners within the support groups or opportunistic infections (OI) clinics. Jabu (male 24) explained:

... personally, I hardly go out anymore.....It is not easy to come out in the open about your HIV status if you are young. There is a lot to lose by disclosing. You risk being rejected and isolated by friends, and if you have a girlfriend she can end things between the two of you. (FGD, male 24)
Mavis (female 20), contributing in a FGD, narrated she is seized with fear on a daily basis, about uncertainty regarding her health as a YPLHIV. Her main worry is fear of being stigmatized when others find out about her HIV status, specifically, fear of gossiped and rejected by significant others. Her fear of stigmatization was so intense that she openly indicated that she was not willing to be involved in new intimate relationships. The following extract illustrates her sentiments:

I'm not in a relationship at the moment. I was seeing this guy at college and he was interested in me. I asked him whether he was serious that he loved me, and he said, “Yes”, then I told him that I was HIV positive. He went silent and confused for a while. Since then, I have not seen and spoken to him. He avoids me and doesn't take my calls and respond to my chat messages. (FGD, female 20)

Some participants appeared to have internalized HIV related stigma such that they expected to be ostracized because of their HIV status. For example, Ben (male 23) mentioned that he is not yet ready to disclose his HIV status to his sexual partner as he feared that the partner might tell others about his HIV status. He posited:

My girlfriend is immature. She will not understand. She will break up with me. I do not want her to know because she will spread it to the whole community. When I am ready, I will take her to the New Start centre for counselling, and testing. It is not easy. I love her so much; I do not want to lose her. (FGD, male 23)

Similarly, Amkela (male, 21) reflected on the fear of disclosure and said:

There is more to lose than gain if you tell people about your status. People will reject you, treat you like a dog or even harass you because you’re HIV. (FGD, male 21)

As indicated above, the majority of the participants were aware of the possibilities and negatives consequences of being stigmatized and rejected by others. Most of them were afraid of being hurt. Hence, some participants perceived the need to withdraw from social activities and functions to protect themselves from stigmatization. Due to felt stigma some participants felt forced to avoid public dealings and social interactions. For example, for some participants the fear of stigmatization was so strong such that they disengaged with their communities and some reported that they were no longer willing to start new intimate relationships.
Some of the YPLHIV were not comfortable to be seen at the health facility and identified as HIV positive. Njabulo (male 20), narrated the challenges faced by the YPLHIV at the health facilities providing ARVs, mentioning that the health facilities use colour coded client identifiers and records for all HIV positive patients. When YPLHIV come for either their pill refill or clinical consultation they first collect ‘colour coded patient records’ before joining the rest of the patients in the waiting area. This, according to Njabulo, enables others to identify or perceive those carrying the colour coded patient records as having HIV. He said:

...the OI clinics use ‘green book’, this book has become known to be a book given to someone living with HIV. Even when you are referred to the OPD for other services, you are expected take the green book with you, Eiish liyamakisa (it marks you out). Most young people when they are queuing for the pill refill, they usually put it [green book] under their shirts. They don’t want to be seen holding it. I know some guys who send other people to collect drugs for them due to fear. (FGD, male 20)

Some participants reported that some of their peers have since stopped taking their medicine due to fear of stigmatization. Incidents of death, purported to be due to ART non-adherence, were also reported among YPLHIV. This view concurs with that of Themba (male 24), who said:

...there are a number of young people who have issues with green book. I lost a friend last year. He died. He stopped taking the drugs. When he was decentralized to XXX clinic, he stopped collecting the drugs because he was scared that people from the hood will see him. (FGD, male 24)

3.2.2 Self stigma, self image and, perceived health status

During the IDIs and FGDs, what was visible in the bodies of a number of participants were physical marks, such as disability or scarring from skin infections, which were largely attributed to HIV related illness. Such physical marks may have a particular impact on the young person’s sense of self. Specifically, this may have a negative psychological impact on the self-image of YPLHIV. Indeed, a number of participants indicated that their physical appearance makes it more difficult to accept their HIV status. Evans (male 19) year old male reflected on his situation:

I am different from other people. I am disabled and have these (pointing to skin warts). People know these are associated with the disease [HIV]. I have seen how people look at me some times.
Even in public places some boys avoid sitting next to me. Like this other day, at a workshop. I came in late and I sat next to this XX school girls.... they changed places and moved to sit away from me. It hurts when people treat you like that. (IDI, male 19)

Although all participants had known their HIV status for over a year, some were still clearly grappling with the realities of being HIV positive and what that identity meant beyond any physical marks. For example, Lisa (female 19) reflecting on her situation explained that:

...it's not easy living with HIV. I sometimes wish I could be normal. I don't see any future as someone living with HIV. My living has limitations and worse still I am also disabled. When people look at me, they treat me like a charitable case, they treat me with pity. I can't freely date like other girls of my age. When someone ask me out, usually I think he is doing out of pity, not because he loves me. (FGD, female 19)

This observation was also confirmed by Dorcas (female 24), who narrated the challenges faced by many female YPLHIV in particular those who place great value on establishing a family and having children. She said:

...To be honest with you, there are some days when I just cry and wish I was not HIV positive. I feel this disease has cheated me of my future. I won’t be able to marry, enjoy and have children just like other people. The fact that I will survive on drugs the rest of my life scares me a lot. HIV has changed my life, my goals and aspirations. I’m now sensitive on the way I conduct myself in public. When people stare at me, I sometimes think they know something about my status or there is something wrong about me. I have lost confidence in myself. Although I’ve accepted my HIV status, I don’t want any one in my life right now. (FGD, female 24)

3.3 Perceived sources of stigma – over simplified perception of modes of HIV transmission.

Most participants interviewed in this study reported that their communities lack an appreciation of different modes of HIV transmission. They reported that their communities are quick to conclude on the mode of transmission (mainly that it was through sexual intercourse), when they encounter an individual living with HIV, and that they do not appreciate that some people were born with an HIV infection. Sihle (female 22) contributing to a discussion, said:
...most people are judgmental. They do not have information on HIV. They still hold negative views about people with HIV. They believe that young people with HIV got it because of mischief. Most people do not understand that someone can get infected from her mother and live to my age. It's so pathetic. Some people are cruel. They give HIV positive people bad names... (FGD, female 22)

The participants lamented the judgmental attitudes held by the adult members of the community and an over-simplistic and moralistic understanding of HIV transmission. Most YPLHIV indicated that they did not contract HIV through sexual contacts, but suspect that they were born with the virus. This was clearly summed up by a male participant who said:

Most of us were born with the virus; it's not our fault. People must understand that we didn't apply to be like this. People must stop this negative attitude against young people living with HIV. We want to live normal lives like everyone else. We are people, with rights also. (FGD, male, 23).

3.4 Enacted Stigma: Discrimination, exclusion, rejection, being chased away, verbal abuse and loss of intimacy

One of the questions asked to the participants sought to explore and understand how participants experienced HIV-related stigma in their communities, homes, health facilities, churches and schools. Although some participants expressed that in recent years there seems to have been a reduction in levels and acts of stigmatization and discrimination in their communities, most participants still expressed fear in disclosing their status due to past experiences.

The most salient themes under enacted stigma were; acts of discrimination, social spaces where acts of discrimination occur, and the major perpetrators of stigmatization and discrimination. Participants reported that the main acts of discrimination included verbal abuse (name calling by derogatory terms, insulting), gossiping, rejection, being chased away from home, and denial of opportunities. As reported by the participants, HIV-related stigma was most prevalent in churches, schools (particularly boarding schools), and community and to some extent at home. The main perpetrators were reported to be church members, neighbours, sexual partners, friends, school mates, relatives and siblings.

Betty (female 23) contributing to a discussion described a situation of a young person living with HIV who got chased away from home by her own relatives after disclosing her status. She remarked:
I heard of a girl in... who was chased away by her uncle after testing HIV positive. This girl used to go to town attending night clubs. The uncle was now blaming her and calling her names.

(FGD female, 23)

Participants reported that some parents and relatives were hesitant to invest in the lives of YPLHIV. Some YPLHIV were denied opportunities such as educational advancement. They indicated that priority was given to the HIV negative siblings. Pride (male, 20) explained:

...my grandmother told me that, she did not have money to send me to school. Other children of my age in the family continued with school. I guess they thought that I was going to die soon. They did not want to waste their money on me.

Participants narrated stories of intimidation and verbal abuse (insults) that young people endure in their communities because of their HIV status. Busi (female 23) narrated her ordeal in the hands of young men in her community who were aware of her HIV status. She described derogatory words that were used to describe her. The young men in her community used the words like “hot-stove” and “red-robot” to describe YPLHIV. She said:

...like this day when I was going to the shops and I met a group of boys, you know boys will always say nasty things to girls. If you decide to keep quiet, they start to call you with all sorts of names. Such as, ‘you’re nothing, but a hot plate stove. (IDI, female 23)

This was buttressed by another participant, Bongie (female, 23), who also narrated how she was verbally abused by a group of young men from her neighborhood. In her own words:

“I was called by demeaning names by males from the hood such as ‘yistofu’ (red-stove), ‘ungene red robot’ (passed a red robot, heading for a crash), “ngupiki iyeza” (death is imminent)” (FGD, female 23).

These acts of discrimination were also reported within the family set up. Evans (male 19) described how things changed when he disclosed his status to his relatives. He narrated how the living arrangement changed. He was allocated separate utensils and sleeping arrangements. He said:

...But after an HIV test it became worse. I was allocated my own plates, spoons and cups, and they were put aside and not washed together with other plates. Sometimes I will soil myself, my clothes were washed separate from the rest. I have been called all sorts of names. I guess it is worse for people like me. (IDI, male 19)
Some YPLHIV reported that they were rejected by their sexual partners, friends and families probably because people thought that they deserved the disease (because of their promiscuous behavior) or that HIV transmission is limited to sexual intercourse or casual contact. The YPHIV were perceived moral as either “guilty” or “innocent” depending on how the individual is perceived to have contracted HIV. This “othering perception” dismisses YPLHIV as “promiscuous”, “sinful” or “irresponsible”, hence justifies the stigmatization of YPLHIV. In relating her experiences, Dorothy (female, 19) said:

I have lost a number of important people in my life. Some started distancing themselves...they no longer hang out with me. Even at school, some avoid sitting next to me. (IDI, female, 19)

When contributing to the FGD, Charity (female, 21) reported that most people in her community see HIV as an attribute, a condition for certain individuals. She said:

Most people see HIV as an attribute. Being HIV positive says a lot about your character and your morals. Hence most parents discourage their own children from hanging with us. (FGD, female, 21)

Ntombi (female, 18) described how she was asked by a church member to “ask for forgiveness from God” because she had transgressed. She noted:

People still hold negative attitudes towards those infected with HIV. One day, a girl from the main church choir asked me to confess my sins. When I asked her, what sins? She said since I have been sleeping around I should confess my sins to the church elders. I was really hurt. I don’t sleep around; I was born with the virus. (FGD, female, 18)

Some respondents reported that their sexual partners ended the relationship after learning that they were HIV positive. For example, Lolo (female, 20) described how her boyfriend ended their relationship after she had shared her HIV status to him. She describes the impact this had on her life:

Three years ago, there was a boy who was interested in me and after some months I told him that I was living with HIV, he stopped seeing me. He even changed his phone numbers. This really affected me because I was hoping for a happy future with that boy. (FGD, female 20).
The rejection by boyfriends after disclosing their HIV positive status was commonly reported by the female participants. Mable (female, 18) also lamented the loss of a boyfriend after disclosing her status. She said:

*My boyfriend broke up with me when I told him that I am HIV positive. He just became cold to me and told me that he cannot continue with me. I was so hurt and I still regret ever telling my status. I told myself, I will never date anymore.* (IDI, female 18)

Some participants reported that most people in their communities do not expect young people living with HIV to be in intimate relationships. Lucky (male, 23) described how his relationship with an HIV negative girlfriend was stopped by the mother of his girlfriend. He said:

*Personally I have experienced stigma. I was going out with this girl at church. One day her mother saw us walking home together. Apparently her mother knew I was on treatment and I was still struggling to disclose my status to her. My girlfriend’s mother was angry that I was going out with her daughter. She told me to stop seeing the girl because I will infect her. I was embarrassed because there were other girls from church. The whole community got to know that I was positive that day. She was talking on top her voice for everyone to hear. The girl broke up with me on that very day. I was hurt and embarrassed. Even up to now she doesn’t talk to me. I stopped going to church on that very day.* (FGD, male 23)

This was also supported by Buhle (female, 19) who expressed that most people in her community do not approve YPLHIV to be in a sexual relationship. This complicates the prospects of YPLHIV getting into intimate relationships. She remarked:

*...when you’re known to be living with HIV, most people don’t expect you to be in a relationship, it’s like we are sick and not capable to get into any relationship. They would start to say nasty things about us. Saying we are spreading the disease.* (FGD, female 19)

The participants who did not experience HIV-related stigma and discrimination reported that they had carefully chosen the people they disclosed their HIV status to in an effort to avoid discrimination. They noted that most people in their communities are not informed on HIV related issues. Furthermore, they stated that most people perceive heterosexual transmission as the only mode of HIV transmission. The participants reported experiencing an extra layer of community disapproval; in addition to general
disapproval of pre-marital sexual intercourse among young people, they faced being perceived as vectors of the disease. Thulani (male 18) noted that:

*Generally, in this community most people don’t have enough information on HIV and AIDS. Some still believe that HIV can only be transmitted through sex and that it is for naughty people. When people see someone with HIV they usually pass nasty comments, suggesting that he is immoral and unclean. HIV positive people are still called by bad names here. Personally I can’t say I have faced any challenges because most people in this community don’t know that I am HIV positive.* (IDI, male 18)

### 3.5 Forced disclosure of HIV status (involuntary disclosure)

The past experiences of involuntary disclosure of HIV status and the gossip that resulted from this seemed to enforce a culture of silence around HIV. Most YPLHIV found it difficult to disclose their HIV status and to trust other people with their status fearing that there could be breach of trust and confidentiality. Indeed, some participants reported to have had experienced situations where people they disclosed to went on to disclose their status to others without their permission. Loice (female, 19) narrated how her close friend betrayed her trust by disclosing her HIV status without her consent. She said:

*...my best friend went behind my back and told my boyfriend at school that I am HIV positive. She started spreading rumours about me. I stopped going to school for a while, because people at school were saying nasty things about me.* (IDI, Female 19)

Betrayal of trust was also reported even among family members. Chipo (female, 22) narrated how her sister disclosed her HIV status to her intimate partner’s mother without her consent. She remarked:

*...I was going out with this guy. Everything was ok between us; he knew my HIV status and didn’t have issues with it. But it was one day when my cousin went and told his mother, that her son was dating an HIV positive girl. That’s when hell broke loose. His mother failed to appreciate that an HIV positive person can be in a relationship with someone who is HIV negative. She went around the township saying nasty things about me. She said her son had failed her by dating a corpse.* (IDI, female 22)

Nozipho, a 24-year old female participant related how she was emotionally hurt by involuntary disclosure of her HIV status without her consent by her relative.
I once experienced a situation where my aunt disclosed my status without my consent. She told my best friend's mother that my friend should stop coming for sleep-over at my place because I was HIV positive, I will infect her. I was so hurt. (FGD, female 24)

3.6 Gender and HIV related stigma

In the IDIs and FGDs participants were asked to share their experiences on whether and how HIV-related stigma experienced by young males was comparable to that experienced by young females. A majority of YPLHIV reported gendered experiences of HIV related stigma, with a moral dimension which affects women more than men. Susan (female, 24) observed that:

Women and girls are treated differently than boys. If you are a girl and you are living with HIV people usually associated it with prostitution. HIV is always associated with a person who sleeps around. It is also not easy to get married if you are girl and known to be living with HIV. Girls are unfairly treated. When you are a girl and HIV positive most people think that you are sleeping around, which is not the same thing with boys. (FGD, female 24)

The differences in the experiences of stigma between males and females can be explained, in part, by the dominant social views and norms that are rooted in patriarchy and constructions of gender in this setting. Most participants reported that in their community a man is expected to be control of the intimate relationships and women are expected only to comply. Men feel that they have an entitlement to have sex with other women and expected their sexual partners to remain faithful to them.

This observation was buttressed by Evans (male, 19) who narrated the challenges that young women living with HIV encounter in a conservative male dominated society. He argued and said:

I am not sure but I think girls experience more stigma than boys... I think it is worse for girls. There are more social expectations from girls than boys. Women and girls are expected to be pure and faithful. When one gets infected with HIV, it is like that person would have broken social trust and norm. The society will judge her harshly. Generally, it is expected for boys to be naughty; hence it is not a big issue if one gets infected with HIV. That is what I think. Therefore, most girls find it difficult to disclose their status. (IDI, male 19)
The participants described the deep-seated heteronormative attitudes held by their communities, that is, communities require different genders actively participate in heterosexually defined behaviors, any transgression is punished or negatively sanctioned. Contributing to the group discussion, Betty (female, 23) described the different social expectations, taboos and sanctions imposed on women and girls by the society. She remarked:

*Most people think that HIV is only transmitted through sleeping with boys. A boy is usually expected to sleep with more than one girl before he gets married, but girls are expected to be virgins when they get married. When people see and hear that you are HIV positive they run to conclude that you slept around a lot, not knowing that some of us we got HIV from our mothers. It is unfair real. Girls do not have the same rights like boys.* (FGD, female 23)

Nomusa (female, 23) described the negative perception held by her community regarding young females living with HIV. She reflected on the limited information the general members of the community have on the modes of transmission. She said:

*Most people do not have correct information about HIV... some think that sex is the only way of getting infected. Worse still if you’re a woman, people will always think you’ve loose morals. You sleep around with boys.* (IDI, female 23)

Betty (female 23) lamented the problems faced by young women living with HIV in their communities. She observed that:

*People think that HIV positive girls are prostitutes. If you’re a woman and you’re living with HIV you’ve to prove yourself all the time. It’s difficult for us.* (IDI, female 23)

### 3.7 Support system available for YPLHIV

Closely related to the study interest in stigma were descriptions of support that YPLHIV accessed. Most participants reported that they received psychosocial support from family members and the peer support groups for YPLHIV. Most participants indicated that they got medical support from their local clinics, some participants received education, information and counseling support from the community based AIDS service organizations, and no one mentioned getting support from the churches. A number of participants reported that their family members supported them in accepting their HIV positive status,
and that some family members were their treatment supporters. Some participants indicated that they had only disclosed their status to the family member because of the anticipated emotional support. Loice (female, 19) a female participant noted that her grandmother was her pillar of strength when she learnt of her HIV status.

*She told me that I was not the only person to be found with HIV and everyone in the neighborhood is HIV positive and encouraged me to take my medicine every day, correctly. She became my pillar of strength and treatment buddy... accompanied me to the clinic to collect my drugs. She attended the entire adherence counseling sessions at the clinic with me.* (IDI, female 19)

This was further buttressed by Tom (male, 20) who narrated the psychosocial support he received from his mother. He said:

*I totally lost all the confidence, I felt useless and empty. Suddenly life lost meaning. If it wasn't for the support that I got from my mother, I was going to stop coming to school.* (IDI, male 20)

Given that they were all recruited from a peer support group, it was not surprising that the peer support groups were mentioned by a number of participants as a source of support outside the family setting. Dorothy (female, 19) described how the peer support group helped her to copy with her HIV status. She remarked:

*I used to feel empty and worthless. Wherever I go, I felt like people were looking at me and could tell that I was HIV positive. I was afraid that I will die. Joining the support group really helped me to understand HIV issues and also to realize that I am not the only one living with HIV.* (IDI, Female 19)

3.8 Chapter summary

This chapter discussed the findings of the study. Here it has been argued that two forms of stigma, felt and enacted were experienced by YPLHIV. The main perpetrators of HIV-related stigma were family members (especially if parents were deceased), friends, sexual partners, churches, schools, and health institutions. The main acts of stigmatization and discrimination included self-stigma, gossip, verbal abuse, rejection, and self-isolation. Over simplified and generalized heterosexual HIV transmission was reported as the main cause of stigmatization and discrimination. Participants reported being rejected and ostracised by others, often because of fear of casual transmission of HIV or being perceived as immoral and dirty.
Self-stigma, negative self-judgments resulting in self-blame, shame, and feeling of worthlessness were also reported in the study. In this chapter it was also shown that HIV related stigma included not wanting to share utensils, clothes or play with YPLHIV, and some YPLHIV were deprived basic rights like education. Finally, the study showed that females and males living with HIV perceived and experienced HIV related stigma differently. These findings highlight the challenges experienced by YPLHIV in Bulawayo, Zimbabwe.
CHAPTER 4. DISCUSSION

4.0 Introduction

The present study aimed to explore and describe YPLHIV's experiences and perceptions of HIV-related stigma in Bulawayo, Zimbabwe. Through thematic analysis of data drawn from semi-structured IDIs and FGDs, the study provides an account of how HIV related stigma manifests itself and how it is perceived and handled by YPLHIV in peer support groups in Bulawayo, Zimbabwe. In this chapter, the findings are discussed in terms of broader empirical evidence that has been reported by various researchers regarding HIV-related stigma. The study limitations in terms of data collection and design are also discussed in this chapter.

Like other studies done in the sub-Saharan region, the study findings revealed two major forms of HIV related stigma among YPLHIV, felt and enacted stigma (Zimbabwe Government, 2014; Nyblade et al., 2009; Ngozi et al., 2009; Gomo et al., 2006; Ferrand et al., 2007; Parker & Aggleton 2003). The study adds to a growing body of evidence that suggests that the majority of the YPLHIV experience felt stigma (i.e. the fear of stigmatization or discrimination) and enacted stigma (actual experiences of negative behaviors, such as discrimination). In this study, the YPLHIV in Bulawayo experienced rejection; gossip, verbal insults, and ostracism perpetrated by intimate partners, fellow church members, school mates, family members, friends and general members of the community. As a result, YPLHIV reportedly withdrew from social events, and were reluctant to be involved in intimate relationships, in anticipation of stigmatization and discrimination. As reported in other studies most of the HIV related stigma took place at home, schools, church and in their communities (Nyblade et al., 2009; Ngozi et al., 2009; Gomo et al., 2006).

4.1 Forms of HIV related stigma

4.1.1 Felt Stigma (and Self Stigma)

Consistent with other studies done else, (Nkansa-Kyeremateng and Attua, 2013; UNAIDS, 2010, Nyblade et al., 2009, UNAIDS, 2009) the findings from the current study showed that YPLHIV still face significant HIV related stigmatization which affects access to treatment, care and psychosocial support and other social aspects in their daily lives. Those who did not experience discrimination, had carefully chose the people they shared their sero status to in order to avoid stigmamization.

Like other studies on felt stigma (UNAIDS 2010, Nyblade et al., 2009), YPLHIV in Bulawayo expressed fear of disclosure of their HIV status. Most of them expressed unwillingness to disclose their HIV status
to anyone outside their family. Most participants elected not to disclose their status to people outside their families, because disclosure of HIV status was not seen to be beneficiary and carried a lot of risk. This finding reflects existing knowledge. For example, the unwillingness to their HIV status by the YPLHIV was a salient theme in a research of young people from developed countries where none disclosure is viewed as a social coping mechanism (Fielden et al., 2010). Furthermore, findings of the current study are consistent with those of other studies (Maman et al., 2001, Okoror et al., 2007, Miller and Rubin 2007 and Greeff et al., 2008) which showed that the fear of stigmatization, of the confidant disclosing their status to others without their permission, and the fear of rejection were the major barriers to disclosure of HIV among YPLHIV. However, support for some of the young people who disclosed their positive status particularly to relatives was encouraging, it could be indicative of shift in the levels of tolerance against PLHIV, reported in other studies (Zuch et al., 2011, Gilbert et al., 2009).

As discussed in the findings, even before considering issues of disclosing to others, YPLHIV had to learn about their own status. For most participants, this was not through testing, but by accident. Further, the majority of the participants reported that they were negatively affected when they learnt about their status through accidental disclosure. This is consistent with the observations made by Mbonu et al. (2009) and UNAIDS (2009) that those parents or guardians who wait to disclose the HIV status of children who are perinatally infected until their children are teens often experience negative consequences, such as rejection. Mbonu and colleagues (2009) recommend early disclosure of HIV status to the young person, to ensure that the YPLHIV are fully informed of their health status and are in position to make informed decisions regarding their actions and sexual choices. This view is consistent with the provisions of the Zimbabwe Treatment literacy manual (2015), which indicates that young people who know of their HIV status tend to cope better with their illness and can participate in their own treatment (Safaids, 2015). According to this logic, knowing their HIV positive status can be empowering and improve their sense of self-esteem, and confidence and reduce anxiety (Safaids, 2015). The same document indicates that keeping the information from a young person that they are infected with HIV can lead to poor development of coping strategies and inability to accept ones’ status (Safaids, 2015).

Disclosure of ones’ HIV status is beneficial from a public health point of view (UNAIDS, 2010). It facilitates access to psychosocial support, ART treatment and care services (Paxton et al., 2002). Notwithstanding such benefits, it is important to note that there can also be negative consequences and Zimbabwean public health policy provides for the voluntary concealment of one’s HIV status. AIDS is not a notifiable medical condition hence disclosure is left at the discretion of the infected individual. Apart from a few who reported to have disclosed their status to others, the present study found that a majority of participants chose not to share their HIV status because they anticipated stigmatizing
attitudes. These findings are consistent with observations made by Nkansa-Kyeremateng and Attua (2013), Sambisa (2008), and Campbell et al. (2005), that fear of stigmatization reduces the likely of accessing HIV testing services, ART treatment, care and psychosocial support and disclosure of HIV status to significant others. Given that our study findings came from a group of youth who had known their status for a year or more and were members of a peer support group, demonstrates the pervasive power of felt stigma, beyond the immediate health context.

4.1.2 Social withdrawal and self-exclusion

Consistent with findings reported in other studies done is sub-Saharan Africa (UNAIDS, 2009; Sambisa, 2008, Kalichman and Simbayi, 2003; Mbonu et al., 2009), the current study findings showed that as a result of anticipated stigmatization or fear of being stigmatized some participants avoided forming new intimate relationships. Some participants engaged in sexual sorting, i.e. engaging in intimate relationships only among the HIV positive youth accessing the peer support groups or health facilities providing ART for young people. This is encouraging and is indicative of how HIV related stigma was changed into some form of solidarity and active resistance. It is imperative to note that unlike several HIV related stigma research focused on the individuals who had just tested for HIV and got a positive diagnosis this study was done with YPLHIV already in peer support groups, who have known their HIV status for more than a twelve months and most of them taking ARVs. The study provides an insight into a form of resilience by YPLHIV in face of social challenges such as stigma and discrimination and how YPLHIV seem to have coped and adapted to living with HIV after an HIV positive diagnosis.

4.2 Enacted Stigma: Discrimination, exclusion, rejection, being chased away, verbal abuse and loss of intimacy

In this study, YPLHIV were asked to describe scenarios where they encountered stigmatization. Most participants did not report personal experiences of enacted stigma, and this could be attributed to the fact that some participants selectively disclosed their status to close relatives and friends. Notwithstanding this, gossip, not being treated with respect, and keeping a distance from people perceived or known to be HIV positive were the most reported forms of HIV stigmatization reportedly experienced by YPLHIV in Bulawayo. This observation is consistent with the available literature on enacted stigma (Zimbabwean Government, 2013; Visser et al., 2009; Kafuko, 2009). Visser et al. (2009) and Kafuko (2009) claim that many individuals reduce the opportunity for enacted stigma in order to protect themselves from discriminatory actions. For example, people living with HIV may conceal their HIV status in anticipation of negative attitudes and treatment. To the extent that they are successful in “passing” as non-infected (Goffman, 1963); such individuals may limit the amount of enacted stigma prevalent in a society or
community at least in the short term (Visser et al., 2009; Kafuko, 2009). This strategy seemed to be very much in evidence among the YPLHIV in this study.

Two major sources of stigmatization were identified: there are the fear of getting HIV infection due to poor risk perception of how HIV is transmitted; and presumptions regarding how one got infected with HIV. The fear of contracting the virus, both sexual and casual, was one of the salient themes that emerged from this study. Some participants reported incidents of discrimination based on their HIV status. Some participants reported that they were rejected by their sexual partners after disclosing their HIV status. A similar finding has been reported in a number of studies in Southern Africa (Prince et al., 2006; Zungu-Dirwayi et al., 2004, Mfecane, 2012). Fear of contagion referred to any behavior that shows a fear of close or direct contact with an individual perceived to be living with HIV. Consistent with the available literature, findings of this study showed that the most prevalent forms of possible contagion that were reportedly feared by family members of YPLHIV and other community members included getting into contact with either the person infected with HIV or using the same utensils used by him/her, coughing and sitting next to an infected young people (Zimbabwe Government, 2013; Visser et al., 2009; Kafuko, 2009).

Furthermore, in line with findings of other studies, (Nkansa-Kyeremateng and Attua, 2013; Greeff, 2008; Lodder, 2004; Bharat, Aggleton, and Tyror, 2001), gossiping or talking about an HIV positive person behind her/his back was ranked very high among the responses. Like other studies on HIV-related stigma (Nkansa-Kyeremateng and Attua, 2013, Bharat, Aggleton, and Tyror, 2001), YPLHIV were hurt when those close to them were spreading rumours about their HIV positive status. This is contrary to the provisions of the Zimbabwe National Policy on HIV AIDS (1999). The policy says that disclosure of the individual’s status is strictly voluntary and should be of benefit to the individual in terms of support.

4.2.1 Social spaces where HIV related stigma occurs

In order to deepen understanding of the HIV related stigma experienced by YPLHIV, this study sought to explore which and how social spaces enable or sustain HIV related stigma. This will assist in developing context specific anti-stigma interventions. The findings of this study provide support to existing research that HIV-related stigma and discrimination may occur in a variety of contexts. For example, Parker et al. (2002) observed that HIV-related stigma and discrimination manifest in a number of social contexts, including within the family set up, communities, schools, workplaces, health care settings and the church. The same was found here.
Increasing empirical evidence emphasize the significant role of members of the family in providing psychosocial support to the infected individual. (Ngozi et al., 2009; Greeff et al., 2008; Okoror et al., 2007). However, findings of this study clearly show that not all family members respond positively and supportively when a member of the family discloses his or her status or is known to be living with HIV.

In the previous chapter, data were presented showing that some participants experienced stigma and discrimination within the family setting. Data revealed that some family members and caregivers discouraged the YPLHIV from disclosing their status to other people in the community, including health care providers because they were embarrassed and concerned about their family being associated with a disease like HIV. Finding of this study suggests that this may have negative health outcomes for those infected with HIV. This finding receives support from Mukasa (2008) and Okoror et al. (2007) who argue that the family’s efforts to ‘manage’ stigmatization within the wider community may have negative implications on the health of the person living with HIV. Families may attempt to shield an infected member of the family from the community by keeping him or her within the house, limiting his or her ability to access care and treatment.

While HIV related stigma has reduced over the years, recent studies still report isolated cases where people living with HIV get stigmatized by the health workers (Holzemer et al., 2009, Greeff, 2008, Mopani et al., 2006, Zimbabwe Government, 2004). Some notable examples are those of withdrawal of treatment, breach of confidentiality and forced testing (Greeff, 2008, Kalichman, 2003). All patients registered for ART in Zimbabwe have a color coded patient-book. The findings of the present study revealed that YPLHIV are not comfortable to be seen holding the ‘green books’ by other patients. One serious implication of this discomfort with color coded patient-book, as reported in this study, was that some young people reportedly stopped taking their medication or deliberately missed their clinic appointments due to fear of being seen holding the ‘green’ record books. These findings are consistent with the available literature which note that YPLHIV may isolate themselves from community events as a means of self-preservation (Greeff, 2008). Unfortunately, the withdrawal from the society can extend to avoidance of health care, social functions, employment opportunities, and intimate relationships (Sikweyiya et al., 2014). In an effort to address this health system problem, in Zimbabwe it is now a recommended standard practice to integrate the ART services into the mainstream primary health care services (ART guidelines, 2013), as such patients on ART now receive their treatment together with other patients, and the client’s ‘green’ record books are now kept in the consulting rooms in some health facilities.
The role of religion and cultural norms in HIV response is well documented. Authors have commented that religious institutions have played both a supportive and detrimental role towards YPLHIV (Mfecane, 2012, Bhana, 2016, Mbonu et al., 2009; Miller & Rubin, 2007). As Ngozi and colleagues (2009) argue, traditionally the church is the last place a religious person clings to in times of great difficulty and suffering, as such churches are well placed to offer varying forms of support for YPLHIV. Some authors argue that, broadly, the churches have significant influence and can play a cardinal role in facilitating HIV stigma reduction initiatives (Ngozi et al., 2009; Otolok-Tanga et al., 2007).

However, the findings of this study have shown that some YPLHIV in Bulawayo experience stigmatizing attitudes and discriminatory acts by fellow church members. And in this study it has been shown that being stigmatized by church members may have devastating emotional effects on YPLHIV. The stigmatization of YPLHIV by church members may stem from traditional church values which, as observed by Nkansa-Kyeremateng and Attua (2013), promote religious teachings that are consistent with the type of male-dominated conservative sexual moralities. Similarly, other authors have argued that the religious leaders preach that unmarried people should not engage in premarital sex and rather exercise abstinence until they get married (Ngozi et al., 2009; Otolok-Tanga et al., 2007). Therefore, a young person living with HIV becomes a convenient example of God’s punishment to “transgressors”. As such, as shown by data presented in the previous chapter, YPLHIV who are active church members may be discouraged from disclosing their HIV status or even stop attending church (Otolok-Tanga et al., 2007).

4.2.2 Causes of HIV related stigma- over simplified perception of the modes of HIV transmission, social judgment and fear of infection through casual contact.

The characteristics of the HIV epidemic, oversimplification and misunderstandings about its etiology underpin the forms of stigmatization described by participants in this study. Most participants in the present study identified the main underlying causes of HIV-related stigma as first, the unrealistic fear of infection from casual transmission of the disease caused by limited knowledge, insufficient and inaccurate understanding and knowledge of how HIV is transmitted. Secondly, the placement of blame and accusation of moral wrongdoing on those infected with the virus.

These findings are consistent with those of several studies conducted in sub-Saharan Africa. For example, Ogden and Nyblade (2005) identified ignorance and inaccurate information on how HIV is transmitted as contributing to stigma. Indeed, in the current study, some participants indicated that family members took unnecessary ‘prevention’ measures, such as isolation from other household members or separate eating utensils. YPLHIV reported that some fellow church members refused to share a seat with them in the church. This emanated from a belief of social transmission, such as getting infected through sharing of
utensils, food, clothes and toilets) that was once widely thought to be the most practical and feasible preventative measures available (Mfecane, 2012, Herek, 2002). These measures were perceived as discriminatory by YPLHIV who participated in this study. This view is further buttressed by Mfecane (2012) and Herek (2002), who observed that HIV related diseases share some commonalities with other diseases that are highly stigmatized, such as its perception to be a life threatening disease which is highly infectious and incapacitates the individuals in the advanced stages of the disease.

Although some participants noted a reduction of stigma among some segments of the population, HIV infection remained stigmatized. The main perpetrators of the HIV related stigma were the community members. For example, HIV has always carried a lot of stigma particularly among the conservative traditional and religious communities (Coleman, 2012), largely because of the assumption people who get infected are associated with “deviant” lifestyle (sex workers and men who have sex with other men) (Ogden & Nyblade, 2005, Bhana, 2016). Most participants spoke of this negative association and the difficulty it presented them.

### 4.3 Gender and stigma

All the participants in the present study reported that girls and boys living with HIV experience stigma and discrimination differently. Females living with HIV reported more stigma than males. They reported that members of the society verbally insulted them, insinuating that they were morally loose and were involved in prostitution. This is consistent with available literature which suggests that the society is more tolerant of men infected with HIV than women living with HIV (Bhana, 2016, Mfecane, 2012, Nkansa-Kyeremateng and Attua, 2013; Jewkes and Morrell, 2010, Parker and Aggleton, 2003).

In some African societies women are wrongly seen as the vectors of STIs, and in some cases are referred as ‘women diseases’ (Nkansa-Kyeremateng and Attua, 2013, Parker and Aggleton, 2003, Chilikwela et al., 2003). Together with old deep seated traditional myths about blood, sex, and transmission of infections, these perceptions provide a convenient narrative to further stigmatize HIV positive women. (Bhana, 2016; Chilikwela et al., 2003). Interestingly, while females tend to be ‘blamed’ for acquiring HIV, males are often forgiven by family and society (Jewkes and Morrell, 2010; Letamo, 2005; Parker and Aggleton, 2003). Regrettably, by apportioning blame to people infected with HIV, the communities can absolve themselves from the responsibility of looking after the inflicted individuals (Chilikwela et al., 2003). These ideas were echoed by participant in the current study, particularly when questioned about how males and females may experience stigma differently.
The study findings support the observations made by Bhana (2016) and Campbell et al. (2005), who argued that stigma serves as an effective form of ‘social psychological policing’ by punishing those individuals who transgress the social norms on gender and age of sexual debut. Young people, particularly girls, are not expected to engage in sexual activities outside marriage (Parker and Aggleton, 2003). According to Bhana (2016), Jewkes and Morrell (2010) sex among African young men is an expression and celebration of masculine status and virility, while it is considered damaging and an assault to young women’s virtues. In most African cultures ignorance of sexual matters is considered as a sign of purity (Prince et al., 2006; Zungu-Dirwayi, et al., 2004, Skovdal et al., 2011). In a study conducted in Kwa-Zulu Natal to assess the teenage sex cultures, Bhana (2016) observed that whilst virginity is idealized until marriage, young males emphasize male sexual entitlement in their desire to have sex with virgins. This is further bolstered by the most religious teachings that discourage extramarital unions. The sexual activities outside the marriage are perceived as ‘sinful acts’, hence AIDS is regarded as God’s punishment for those who acquire HIV (Mfecance, 2012; Ngozi et al., 2009; Otolok-Tanga et al., 2007). Hence any young person infected with HIV is perceived to have contracted it through sexual contact. Such a narrow narrative has the potential to hinder community based interventions to address HIV infections.

4.4 Effects of HIV related stigma

The study findings provide important insights into the effects of HIV related stigma as perceived and experienced by YPLHIV in Bulawayo. The findings suggest that stigma may affect YPLHIV’s access to education. Some participants (especially those orphaned by AIDS) reported that relatives and caregivers were reluctant to invest in their education. As such, some YPLHIV could not proceed with their education after they were diagnosed with HIV as such opportunities were taken away from them. Indeed, the analysis of the data revealed that ostracism, name calling, and rejection of YPLHIV by their peers at school, after involuntary disclosure of their HIV status, were common forms of stigmatization suffered by YPLHIV in Bulawayo. This is consistent with the observations made by Mavhu et al. (2013) in Zimbabwe. These authors noted that YPLHIVs’ childhoods were characterized by frequent ill health and absenteeism from school; hence most guardians are hesitant to pay for their education.

This study has shown that the majority of participants elected not to share their HIV status, even to friends, girlfriends or boyfriends and other household members, due to fear of negative reactions. In line with this, participants reported to have resorted to dating people within the HIV support groups. This is consistent with the findings reported by Sikweyiya et al. (2014) who also found that due to fear of stigmatization that may follow a HIV positive status disclosure, a number of PLHIV sought out partners.
who were also HIV-positive, who they had met in ART clinics or HIV support groups. Peer support groups provide a platform and a social space for psychosocial support and advocacy (Bygrave et al., 2012, Campbell et al., 2005, Paxton et al., 2002). However, that a number of YPLHIV who participated in this study reportedly elected not to disclose their HIV positive status, due to fear of stigmatization, meant that they could not access support from significant others when they needed it.

Although the scope of this study did not explore ART adherence, the study findings indicate that the fear of stigmatization has the potential to disrupt drug adherence, as some young people were reported to have stopped collecting their ART medication due to discomfort of being seen at clinics carrying the green book- which they find stigmatizing. This finding is consistent with that reported in other studies in Zimbabwe (Sherr et al., 2007; Zimbabwean Government, 2006; UNAIDS, 2009; Kalichman and Simbayi, 2003; Mbonu et al., 2009). The available literature shows that the fear of HIV related stigma might lead to delay in HIV testing and also delay entry into treatment and care (Mbonu et al., 2009). In a study conducted by Sherr et al. (2007) in rural areas in Zimbabwe some participants expressed fear of HIV related stigma than HIV and AIDS. Greeff, (2008) noted that YPLHIV may withdraw from society as a self-preservation strategy. However, his self-preservation may result in exclusion from seeking health care services, social functions, employment opportunities, and even intimate relationships (Sikweyiya et al., 2014). In line with this, Skinner and Mfecane (2004) argue that a prime impact of HIV related stigma is that it may push the epidemic underground, forcing people who are infected with the virus into hiding.

4.5 Limitations

There are several limitations to this study. First, as an adult and an employee of the network of PLHIV, there is a possibility that some participants responded to particular questions with the answers that they considered to be the most desirable. As a safeguard measure and also considering the sensitivity of HIV related stigma, the principal researcher (a male in his early 40s) conducted the IDIs and FGD with male participants and an experienced female research assistant conducted IDIs and FGD with the female participants. The female researcher received training on the study instruments and study aims, objectives and research ethics in order for her to have an appreciation on the study.

Second, the findings may not be transferred to other YPLHIV who are not attending HIV support groups or those in a different context and not having access to ART. The study used a sample of YPLHIV who are all involved in a peer support group. It would be important to access young people who do not belong to support groups to determine if there is a difference in how these two groups experience and perceive HIV-related stigma.
4.6 Conclusion

The HIV-related stigma among YPLHIV results from a number of factors which include the mode of transmission, the fact that HIV has got no cure, and the uncertainties of the course of the illness. In this study it has been shown that young men and women are affected and experience stigma differently. Therefore, it is imperative for both the policy makers and programmers to have a better understanding and appreciation of the determinants of HIV-related stigma. The anti stigma interventions should seek to address gender equity at different levels and be sensitive to gender issues. The next chapter presents more specific conclusions and recommendations to this end.
CHAPTER 5. CONCLUSIONS AND RECOMMENDATIONS

5.0 Introduction
This chapter presents concluding remarks on the most salient themes which emerged from the analysis of the experiences and perceptions of young people living with HIV in peer support groups in Bulawayo. The chapter concludes with recommendations that can be used by the respective policy makers, HIV programme managers, health care workers and community health workers and researchers working in this area.

5.1 Conclusion
The study was motivated by the fact that HIV related stigma is a serious public health problem that affects HIV testing services and post HIV care, including access to ART for people living with HIV in Zimbabwe and elsewhere. The fear of stigmatization often prevents young people from knowing their HIV status, accessing treatment and disclosing their HIV status publicly (Letamo, 2003; Nyblade & Field, 2002; Ogden and Nyblade, 2005). In this study, the young people involved were already living with HIV, comprising a distinct group in Zimbabwe's epidemic.

The findings of the current study are significant as the current HIV/AIDS programmes on stigma and discrimination for young people in Zimbabwe are informed by limited empirical evidence. The literature reviewed showed that young adults aged 18-24 years consist of the most prone sub-population, heavily affected by the HIV in sub-Saharan Africa (Mavhu et al., 2013). The main underlying causes of HIV related stigma and discrimination identified in existing literature are ignorance and inaccurate information on how HIV is transmitted, moral judgments, religious and cultural beliefs (Nkansa-Kyeremateng and Attua, 2013; Parker and Aggleton, 2003, Chilikwela et al., 2003, Castro & Farmer, 2005, Maman et al., 2003; Nyblade et al., 2009). Findings of the current study provide support to the literature referred to above.

The study is important in its contribution to the development of framework for understanding how HIV related stigma is perceived and experienced by YPLHIV in Bulawayo. Findings of this study showed high levels of HIV related stigma. The negative perceptions and attitudes towards sex as the only mode of HIV transmission were the major causes of stigma experienced by YPLHIV in Bulawayo. For example, HIV infection among young people was largely perceived to have been contracted through immoral or socially sanctioned behavior.
Indeed, findings of this study suggest that YPLHIV were stigmatized against because HIV and AIDS continues to be perceived as a life-threatening disease, and some people do not want to be associated with a life threatening condition (Niehaus, 2007). Even YPLHIV in this study had difficulty in understanding that being HIV positive is ‘not the end of the world’. Most respondents were unhappy, were concerned about other people’s reaction, felt useless, hopeless and worthless because of their HIV status, despite having access to a support group. This finding clearly shows the crippling and profound effects of both felt and enacted stigma on the lives of YPLHIV. Most participants narrated experiences that showed that YPLHIV in Bulawayo are faced with numerous complex social and health related problems, and these were principally related to HIV related stigma. Finally, the study showed that males and females who are living with HIV experience stigma and discrimination differently. Data in this study suggest that these gendered differences may have religious and cultural foundations, rooted in patriarchy. The anti-stigma interventions should address gender norms and a deeper set of values that make it hard for people to accept PLHIV.

The stigma experienced by YPLHIV is both felt and enacted. The fear of stigmatization was one of the notable themes that emerged from the data. Most respondents were aware of the potential risks of stigmatization and some had experienced acts of stigmatization themselves. Fear of stigma and discrimination resulting from disclosure is a key reason for YPLHIV to isolate themselves, limiting their access to both services and opportunities.

5.2 Recommendations

There seems to be a general consensus that HIV-related stigma undermines access and utilization of HIV testing services, ART treatment, care and psychosocial support services and this impacts negatively on the health outcomes of PLHIV (Nkansa-Kyeremateng and Attua, 2013; UNAIDS, 2010; Mukasa, 2008; Lodder, 2004; Kalichman & Simbayi, 2004; Kalichman & Simbayi, 2003). The following recommendations emanate from the findings of this study and are specific to addressing the concerns raised by YPLHIV.

5.2.1 Anti-stigma Interventions

The study findings support a scaling up of HIV anti-stigma interventions which will increase and improve appreciation of YPLHIV sexual rights and understanding of different modes of HIV transmission, among community gatekeepers, policy makers and service providers. Working through champions and opinion leaders will foster a spirit of community activism and promotion of social support as an essential component of promoting debate and discussion the sexual rights and HIV transmission (Pakachere, 2007).
The YPLHIV's narratives imply that improving knowledge about the routes of HIV transmission and understanding the rights of YPLHIV could assist to curb the stigma that exists due to ignorance, and improve levels of tolerance and acceptance of YPLHIV. The YPLHIV want the right to be sexually active members of the community as young adults, no matter how they were originally infected.

A useful starting point would be to create an enabling environment by opening up community dialogues championed by enlightened community and religious leaders, to unpack how HIV is transmitted, and to challenge popular misconceptions and stereotypes that feed into the template upon which HIV related stigma flourishes. Community based organizations such as Matabeleland AIDS Council, ZNNP+ and Umzingwane AIDS Network should intensify their level of community engagements through structured community dialogues.

In South Africa, the Soul City’s model of social and behavior change utilizes community dialogues and these have proven to be effective in promoting discussion among young people on sexual issues and multiple concurrent sexual networks that exist in the communities (CSA-University of Pretoria, 2006). In Vietnam, where the HIV-related stigma was so strong that most PLHIV were scared to disclose their HIV status, community dialogues led to a significant increase in awareness of stigma, and reduced unrealistic assumptions on getting infected through casual contact with PLHIV (Nyblade et al., 2008). Public personalities should be used to advocate the rights and dignity of YPLHIV and also to influence legislative agenda on HIV rights issues. In the SADC region, for example, the use of statesmen like Nelson Mandela, Festus Mogae, and Desmond Tutu, or Kaunda in Zambia to influence public opinion on HIV/AIDS in general and HIV/AIDS interventions in particular, are typical examples of political interests and commitment by the governments in the HIV/AIDS response (UNAID, 2013).

In developing anti-stigma interventions for young people living with HIV, the most common approach has been to increase knowledge of HIV transmission and reduce misconceptions about the disease. However, the use of specific HIV/AIDS and sexual reproduction education programmes that emphasise the rights of PLHIV is a well-documented way of eradicating stigma (Ogden & Nyblade, 2005). Exposure to edutainment programmes, such as Soul City’s One Love campaign and serial dramas aired on TV or radio with different audiences has been shown to be a powerful approach to influence both attitudes and behaviours (Ogden & Nyblade, 2005). Therefore, there is need for the development of knowledge-based interventions that are gender, age, religion and culturally appropriate in order for them to be accepted across various contexts, which in this case would be interpersonal counselling.
Another intervention which can be considered for the long term impact is to include HIV related stigma training in the curricula of health care and other public servants such as teachers, police officers and social workers. In a study cited by Ngozi et al. (2009) conducted by Knussen and Niven (1999) with health care workers in Scotland found that where staff did not receive in-service training relating to HIV and AIDS they displayed more negative attitudes to PLHIV. Training in HIV and AIDS appears to be an important aspect in the eradication of negative attitudes that health care workers hold. As part of health systems strengthening initiatives the development partners such Organization of Public Health Innovation Development and Southern African AIDS Trust are assisting the Zimbabwean government with in-service training health care workers in line with new changes and development in HIV response (Zimbabwe Government, 2015). The purpose of the in-service training is to orientate the health workers towards a client centred and a rights based service delivery. This will ensure that the health care workers openly advocate for the rights of YPLHIV and deliberative create systems, programmes and social spaces to address issues affecting YPLHIV in a sensitive manner, which is currently missing in Zimbabwe (Zimbabwe Government, 2015).

Training of expert patients and engaging them as volunteers in HIV/AIDS programmes has proven to be effective, in Manicaland province (Mavhu et al., 2013). Africaid an organization that provide ART adherence support to adolescents in Harare, Zimbabwe has demonstrated the impact of peer to peer counselling through their CATs (community adolescent treatment support) (Mavhu et al., 2013). The government should resuscitate the deliberating youth centres by improving the infrastructure and also train interested YPLHIV to become peer counsellors.

The anti-stigma interventions should give greater attention to the gender biased nature of the prevailing HIV-related stigma. Gender focussed anti HIV stigma programmes such as community dialogues to engage the traditional and religious gatekeepers on religious, social norms and views that disproportionately affect women and girls who live with HIV. The anti-stigma interventions should deliberately address the women living HIV self-efficacy to engage men in community dialogues as equal partners.

It is in the public interest to adopting a human rights approach to HIV/AIDS, creating an enabling condition for YPLHIV to enable them to freely seek HIV services and ensure that the service providers are sensitive to the needs of YPLHIV. The dialogues should also aim to solicit the buy-in of the community leaders in championing the rights of YPLHIV in their respective communities. This approach
is in sync with UNDP’s community health systems strengthening initiative which seeks to empower the communities to respond appropriately to the HIV epidemic. For example, the establishment of more peer support groups for YPLHIV in the community and building their capacity to disseminate factual HIV/AIDS messages will create awareness and tolerance of PLHIV in the communities.

5.3 Suggestions for further Study
It is important that longitudinal studies be carried out on YPLHIV to explore whether the stigma subsides over time as young people cope and adjust to their HIV positive status, or as their families learn to accept the HIV status of the young people. Additionally, it could be of value to carry out a research to explore and understand the perceptions of the traditional and religious leaders and of healthcare workers regarding the HIV related-stigma among YPLHIV in Bulawayo and elsewhere in Zimbabwe.
REFERENCES


Kato, S. (2002), *A Study of Research Method* Faculty of Business Administration, Bunkyo Gakuin University, Japan


Mukasa, A. (2008), Stigma and discrimination faced by people living with HIV/AIDS: a review of literature based on attitudes, beliefs and practices, prepared for health communication partnerships


Ogden, J. and Nyblade, L. (2005), Common at its Core: HIV related Stigma, International Centre for Research on Women (ICRW), Washington DC.


Appendix A: Participant Information Sheet (IDIs)

Participant Information Sheet

Study title: Experiences and perceptions of young people living with HIV in Bulawayo, Zimbabwe.

Greeting: Good morning/afternoon.

Introduction:
My name is _________________ and I am a student at the University of the Witwatersrand. I am doing a study for a Masters in Public Health (MPH) degree. As part of the course requirements, I am conducting a research on the experiences and perceptions of young people living with HIV (YPLHIV) in support groups in Bulawayo.

Invitation to participate: I am inviting you to take part in a research study.

What is involved in the study?
The interview will be a talk between you and the researcher where you will be asked to share your views and experiences of HIV related stigma among YPLHIV in Zimbabwe. If you agree to be part of this study, you will be one of about 10 YPLHIV who will be interviewed. You will be interviewed only once and the interview will take about 45 to 60 minutes to complete. If you agree, we will digitally record the interview so that we can capture all the information that you provide.

Risks of being involved in the study
In the interview you will be asked personal questions that may make you feel uncomfortable at times, and the interview may bring up topics that are difficult to talk about. We do not wish for this to happen. We want you to know that you do not have to answer any question or take part in the interview if you feel the questions are too personal or make you uncomfortable. If you feel uncomfortable at any point during the interview, you can decide to pause or stop the interview at this time — it is completely up to you to decide this and to indicate to me, as the interviewer, that you wish to pause or stop the interview process. Sometimes people want to explore certain issues and experiences in more depth after the interview. In case you need psychological or physical support, such as counseling or advice concerning educational, health or social support, we have developed a list of professional support services in our community (Appendix J). You may consult these services for professional help and we will be happy to share this information with you.

There is a risk that the information you share in this study and your personal details could be known by someone who does not already know your HIV status. However, we have put in place measures to avoid this. All completed interviews and other forms used in this study will be stored in a locked cabinet or
cupboard at the University of Witwatersrand and destroyed after two years of publishing the findings or six years after the study if the findings are not published.

**Benefits of being in the study**
You will not benefit from participating in this study. However, we hope that the process of going through the interview will be an interesting one for you as it might cover some issues that you may not have thought about in detail. We also hope that you will learn from the interview process and from any discussions which may arise from it. However it is hoped that, through you and other young people living with HIV participating in this study, we will be able to produce rich and valuable information that will assist both our national and global efforts to reduce HIV related stigma and discrimination and ultimately improve the lives of all young people living with HIV.

**Participation is voluntary**
Your participation in this study is entirely voluntary. You can choose not to participate and there will be no negative consequences to you and you will not suffer any penalty or loss of benefits to which you are otherwise entitled in your support group. If you decide to participate, you may choose to stop your participation at any time, and you are also free to not answer any of the questions that you are uncomfortable with.

**Confidentiality**
This study is taking every possible step to ensure confidentiality, i.e. to prevent any personal information from being known to people outside the study team. We know that if the information you share in this study would be known by others who are not part of this study, it could lead to problems for you, so we have put in place measures to minimize this risk. We will not write your name on the interview transcript, and we do not write down anything that would allow someone to link the completed interview to you. When we analyze the data, your information will be combined and analyzed together with the information that we will get from other young men and women who will participate in this study.

**Further information**
If you require any further information or have any questions/complaints on the study please contact the chairperson of the Human Research Ethics Committee. Prof Peter Cleaton-Jones at the University of Witwatersrand Tel: 011-717-1234
Appendix B Informed consent form (IDIs)

IDIs - Informed consent form

To be completed by the interviewee and the interviewer.

My name is _______________ I study at the University of Witwatersrand. I am doing a study for a Masters in Public Health (MPH) degree. The purpose of this study is to explore and describe the perceptions and experiences of young people living with HIV (18-24) in support groups in Bulawayo.

I have provided you with an information sheet that describes the purpose of this study and how this information collected from you will be used. The information sheet also outlined what type of questions you will be asked, how we will keep this information confidential and the potential risks involved in your participation in this study.

Before we begin the interview, I would like to make sure that you are voluntarily willing to participate in this study and that you have obtained all the information that you need in order to make an informed choice about your participation.

If you choose to participate in the study, I will ask you some questions about your experiences and perceptions as a person living with HIV, in particular those related to the experiences of stigma and discrimination you may have had. I expect that the interview will take between 45-60 minutes.

With this signature I state that I have read or had it read to me the information sheet and I understand its content. Also:
1. I understand that my participation in this study is entirely voluntary. It is my choice whether to participate or not.
2. I understand that I am free to not answer any of the questions in the interview that I am uncomfortable with, and that.
3. I may stop participating in the interview at any time without any consequences to me.

It has been explained to me that the information collected in this interview will be kept strictly confidential and destroyed after two years of publication of the study findings. Also it has been explained to me that my name will not be written on the interview schedule or appear in any report that will come out of this study, and that my information will be anonymously analyzed together with the information that will be shared by others who will participate in this study.

I freely and voluntarily consent to participate in this study.

Name of research participant: __________________________ Date:____________

Signature of research participant: _________________________________

Name of researcher: ____________________________________ Date:______________

Signature of researcher: __________________________________
Appendix C Audio-recording Consent Form (IDIs)

The reason for audio-recording the interview has been explained to me.
I am aware that I may choose whether to participate or not to participate in the interview and to be recorded.
I am aware that I may stop the interview at any point.
The researcher will take measures to make sure that the recording is kept confidential and safe.
I consent to having the interview audio recorded.

Interviewee:
Name: _______________________________________
Signature: ____________________________________
Date:________________________________________

Researcher
Name: _______________________________________
Signature: _____________________________________
Date: _____________________
Appendix D. In-depth interview Guide

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<td>Interviewer Name:</td>
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1. **ICEBREAKER:** To start with, would you like to tell me more about yourself, family and the people you stay with now.

2. Please share with me how you got to learn that you were living with HIV.

3. How long have you known your HIV status?

4. Please tell me how you have experienced life living with HIV?

5. What have been your experiences of disclosing your HIV status to others, if you have done so?
   - Who have you disclosed to and how were their reactions?
   - How long did it take for you to disclose your status after you learnt that you were living with HIV, and why?

6. Would you say you received the support or reaction you were hoping for from the people you disclosed to? Please explain.

7. Have you ever experienced stigmatization and discrimination because of your HIV status?
   Probes: Where did it (stigmatization and or discrimination) happen?

8. Now please tell me about how you responded to experiences of stigmatization or discrimination.
9. How did being stigmatized and or discriminated against because of your HIV status make you feel? And has there been any change in your situation?

10. (Closure): Is there anything else you would like us to know, which we did not talk about with regards to stigma and discrimination among YPLHIV?

Thank you very much for coming to this meeting and sharing your views with us.
Appendix E- Participant Information Sheet (FGD)

Study title: Experiences and perceptions of young people living with HIV in Bulawayo, Zimbabwe.

Greeting: Good morning/afternoon.

Introduction:
Thank you very much for coming to this group discussion meeting. My name is _________________ and that of my colleague here is _____________________. I am studying at the University of the Witwatersrand (Wits). I am doing a study for a Masters in Public Health (MPH) degree. We are doing a study on the experiences and perceptions of HIV related stigma among young people living with HIV (YPLHIV) in support groups in Bulawayo.

Invitation to participate: We are asking / inviting you to take part in a research study.

What is involved in the study?
The discussion will between you, other YPLHIV and the researcher where you will be asked to share your views and experiences of HIV related stigma among YPLHIV in Zimbabwe. If you agree to be part of this study, you will be one of about 20 YPLHIV who will be interviewed in this. The discussion will take 45 to 60 minutes to complete. If you agree, we will digitally record the discussion so that we can capture all the information that you provide.

Risks of being involved in the study:
The study asks personal questions that may make you feel uncomfortable at times, and it may bring up topics that are difficult to talk about. We do not wish for this to happen. We want you to know that you do not have to take part in the interview or answer any question if you feel the questions are too personal or if talking about them makes you uncomfortable. If you feel uncomfortable at any point during the discussion, you can decide to walk out – it is completely up to you to decide this and to indicate to me, as the moderator that you wish to stop participating in the discussion. Sometimes people want to explore certain issues and experiences in more depth after the interview. In case you need psychological or physical support, such as counselling or advice concerning educational, health or social support, we have developed a list of professional support services that are operating in our community. You may consult these services for professional help and we will be happy to share this information with you.

There is a risk that the information you share in this study and your personal details could be known by someone who does not already know your HIV status. However, we have put in place measures to avoid this. All audio tapes, field notes and other completed forms used in this study will be stored in a locked cabinet or cupboard at University of Witwatersrand and destroyed after two years of publishing the findings.

Benefits of being in the study.
You will not benefit from participating in this study. But we hope that the process of going through the interview will be an interesting one for you as it might cover some issues that you may not have thought about in detail. We also hope that you will learn from the interview process and from any discussions which may arise from it. However, it is hoped that, through you and other young people living with HIV participating in this study, we will be able to produce rich and valuable information that will assist both our national and global efforts to reduce HIV related stigma and discrimination and ultimately improve the lives of all young people living with HIV.

- Participation is voluntary

Your participation in this study is entirely voluntary. You can choose not to participate and there will be no negative consequences to you and you will not suffer any penalty or loss of benefits to which you are otherwise entitled in your support group.

Confidentiality:
This study does not guarantee you confidentiality. The study has taken every possible step to ensure confidentiality, i.e. to prevent any personal information from being known to people outside the study team. We know that if the information you share in this study would be known by others who are not part of this study, it could lead to problems for you, so we have put in place measures to minimize this risk. We will not write your name on the discussion transcript, and we do not write down anything that would allow someone to link the completed discussion to you. When we analyze the data, your information will be combined and analyzed together with the information that we will get from other young men and women who will participate in this study.

- Further information

If you require any further information or have any questions/complaints on the study please contact the chairperson of the Human Research Ethics Committee, Prof Peter Cleaton-Jones at the University of Witwatersrand Tel: 011-717-1234
Appendix F. Informed consent form (FGD)

To be completed by the interviewee and the interviewer.

My name is ______________ I study at the University of Witwatersrand. I am doing a study for a Masters in Public Health (MPH) degree. The purpose of this study is to explore and describe the perceptions and experiences of young people living with HIV (18-24) in support groups in Bulawayo.

I have provided you with information sheet that describes the purpose of this study and how this information collected from you will be used. The information sheet also outlined what type of information you will be asked, how we will keep this information confidential and the potential risks involved in your participation in this study.

Before we begin the discussion, I would like to make sure that you are voluntarily willing to participate in this study and that you have obtained all the information that you need in order to make an informed choice about your participation.

If you choose to participate in the study, you will be part of a group discussing the HIV related stigma as perceived and experienced by YPLHIV. The discussions are expected to take between 45-60 minutes.

Before asking you whether or not you would like to be a participant, I would like you to know that:

1. Your participation in this study is entirely voluntary. It is your choice whether to participate or not.
2. You are free to not answer any of the questions in the discussion schedule.
3. You may stop participating in the discussion at any time that you wish.

The information collected in this discussion will be kept strictly confidential and destroyed after two years of publication of the study findings. This study does not guarantee you confidentiality, however, I will not write your name on the discussion guide, and I will not write down particular details that would allow you to be identified.

Do you consent to participating in the discussion?

Name of research participant: __________________________ Date: ____________
Signature of research participant: _________________________________
Name of researcher: ____________________________________ Date: ______________
Signature of researcher: __________________________________
Appendix G- Audio-recording Consent Form (FGD)

The reason for audio-recording the discussion has been explained to me.
I am aware that I may choose whether to participate or not to participate in the discussion and to be recorded.
I am aware that I may leave the discussion at any point.
The researcher will take measures to make sure that the recording is kept confidential and safe.
I consent to having the discussion audio recorded.

Interviewee:
Name: _______________________________________
Signature: ____________________________________
Date: ________________________________________

Researcher
Name: _______________________________________
Signature: _____________________________________
Date: ____________________________
Appendix H. Focus Group Discussion guide

Ground rules and tape recording

To make it easy to refer to each other during the discussion, please think of a name (not your real name) by which you would like to be called during this discussion – I will call myself ..............................................., and I will stick the name tag on me (as you do it). Please do the same. (Hand out stickers for people to write their names or write the names on stickers for them.) (WAIT UNTIL THIS IS COMPLETED BY EVERYONE)

(ICEBREAKER)
Respondents will be asked to tell other group members what they want to be called (pseudonyms) during the discussion and their hobbies.

(GROUNDRULES)
Before we begin, there are a few things which we must all follow, in order to have a meaningful discussion:

- Because of the need to transcribe the recorded information later, it is important that only one person talks at a time, but one can kindly ask to respond while someone is still talking
- Everyone must be allowed to express their views freely without being interrupted
- At certain times, the note taker may need to check a point with the moderator, to make sure all questions are asked
- Please note, there are no right or wrong answers

1. What do people in this community say about young people living with HIV?

Probes: How does that make you feel?

2. In your view, what is HIV related stigma and discrimination?

3. How have you experienced stigma, if at all?

4. From your own experience as a young person living with HIV, do you thing young women and young men living with HIV are treated differently in your communities, if so why?

5. What support structures are there in this community if someone experiences HIV related stigma or discrimination?

6. From your own experiences or observations, what happens when someone discloses his or her HIV status?

7. We are now nearing the end of our discussion (Recommendations). The views you have shared are extremely useful to us. In your view what do you recommend should be done to address stigma and discrimination among YPLHIV?
8. **Closure:** Is there anything else you would like us to know, which we did not talk about with regards to stigma and discrimination among YPLHIV?

Thank you very much for coming to this meeting and sharing your views with us.
Appendix I: Letter to ZNNP+

1187 Emganwini
P O Nkulumane
Bulawayo, Zimbabwe
7th August 2014

The Executive Director
ZNNP+
28 Divine Road
Milton Park, Harare.

Dear Sir/Madam

Re: Request for permission to conduct an HIV related stigma research in support groups for young people living with HIV in Bulawayo.

This communication serves as a request for permission to conduct an academic research in the above referred study population. I am a Master of Public Health student at the School of Public Health, University of Witwatersrand. As part of the course requirements, I will be conducting a research study to explore and describe the experiences and perceptions of YPLHIV regarding HIV related stigma in support groups in Bulawayo. A total of 30 YPLHIV in support groups will be purposively sampled, of these 10 will be individually be interviewed while 20 will participate in focus group discussions. Due to the sensitive nature of the subject under study, all efforts will be made to ensure confidentiality is maintained. Participation in the study will be voluntary. YPLHIV will be provided will all the necessary information that will inform their participation. Your cooperation on this matter is highly appreciated.

Yours faithfully
Mgcini Sibanda
15th August 2014

To whom it may concern

Re: Permission to conduct an HIV related stigma research in support groups for young people living with HIV in Bulawayo.

This communication serves to confirm that Mgcini Sibanda is a Masters of Public Health student with the University of Witwatersrand (South Africa) and is currently doing a research on HIV related stigma among young people living with HIV in peer support groups in Bulawayo. Please provide him with the support deemed necessary, for any questions regarding this research please do not hesitate to contact the undersigned.

Joseph Muguse

M&E Officer
Appendix J: List of professional organizations

1. Matabeleland AIDS Council (MAC) –
   Address: P.O. Box 1280
   Telephone: +263-9-62370
   Fax: +263-9-61540
   Mobile: +263-11-515310
   Email: danmac@mweb.co.zw
       97a J/Tongogara Street, Bulawayo.

2. New start centre –
   Address: Haddon Sly building, 4th floor, 8th avenue, Bulawayo.
   Phone: 63 268

3. Nkulumane New start clinic –
   Address: Mgoqo Street, Nkulumane, Bulawayo.
   Phone: +263 02639 48 2134

4. Contact Family Counseling Institute,
   Address: Luveve clinic, Luveve Township, Bulawayo.
   Phone: +263 772 809197
Appendix K. HREC Certificate

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M141137

NAME:
(Principal Investigator)
Mr. Mongezi Sibanda

DEPARTMENT:
School of Public Health
Bulawayo Community Centre, Zimbabwe

PROJECT TITLE:
Experiences and Perceptions of Young People Living with HIV in Bulawayo, Zimbabwe

DATE CONSIDERED:
26/11/2014

DECISION:
Approved unconditionally

CONDITIONS:

SUPERVISOR:
Sara Murewa and Yandiswa Shweyile

APPROVED BY:
Professor C. Faidian, Chairperson, HREC (Medical)

DATE OF APPROVAL:
17/12/2014

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and ONE COPY returned to the Secretary in Room 10004, 10th floor,
Senate House, University.

I/We fully understand the conditions under which I/We am/are authorised to carry out the above-mentioned
research and I/We undertake to ensure compliance with these conditions. Should any departure be
contemplated from the research protocol as approved, I/We undertake to resubmit the
application to the Committee. I/We agree to submit a yearly progress report.

Principal Investigator Signature: ____________________________
Date: 25/12/2014

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.
PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I MGCINI SIBANDA (Student number: 741389) am a student registered for the degree of

Masters degree in Public Health in the academic year 2016.

I hereby declare the following:

❖ I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.

❖ I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.

❖ I have followed the required conventions in referencing the thoughts and ideas of others.

❖ I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.

Signature: [Signature]

Date: 30/08/16