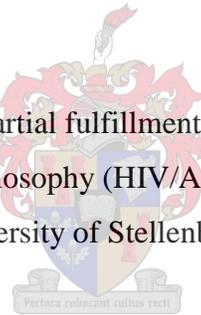


**DESCRIPTIVE STUDY OF HIV/AIDS-RELATED STIGMA EXPERIENCED BY
PEOPLE LIVING WITH HIV/AIDS (PLWHA) IN HEALTHCARE SETTINGS
OFFERING FAMILY PLANNING AND/OR HIV SERVICES IN KAPIRI-MPOSHI,
ZAMBIA**

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Assignment presented in partial fulfillment of the requirements for the
Degree of Master of Philosophy (HIV/AIDS Management) at the
University of Stellenbosch



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March 2012

DECLARATION

By submitting this assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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January 2012

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SUMMARY

Few results are available describing the experiences of people living with HIV/AIDS in health care setting in Zambia. Describing and understanding the experiences of people living with HIV/AIDS (PLWHA) in health care settings would allow the Zambian health system to improve health interventions to maximally benefit the PLWHA. The objective of this study is to describe experiences of PLWHA while accessing HIV and family planning services (health care settings) in Kapiri-Mposhi, Zambia from the time they were diagnosed with HIV to 2011.

A cross-sectional descriptive study of experiences of PLWHA was conducted while accessing HIV and family planning services (in a health care setting) in Kapiri-Mposhi, Zambia from the time they were diagnosed with HIV to 2011. Data was collected from a convenient sample of 100 PLWHA attending HIV and/or family planning services on the dates of interviews by administering a questionnaire. Data was analyzed using descriptive statistical methods and presented in figures and tables in the text.

PLWHA still experience stigma and discrimination in health care setting related to: disclosure of their HIV status without consent, being coerced into taking an HIV test and being denied services, including family planning services. More education is needed for the health care workers in order to reduce HIV-related stigma and discrimination.

OPSOMMING

Weinig inligting is beskikbaar aangaande die persoonlike belewenisse van MIV/VIGS pasiënte (verkort as PLWHA) in Zambiese sorgenhede. Die studie stel dit ten doel om kennis en insig te bekom betreffende die ervarings van pasiënte met die gesinsbeplanningsdienste in Kapiri-Mposhi in Zambië. Die studie fokus op die pasiënte se beskrywing van hul ervarings met die siekte, asook die behandeling ontvang in die sorgenhede sedert hul eerste diagnose tot en met 2011.

‘n Deursnee profiel van die pasiënte se ervarings met gesondheidsdienste is bekom deur persoonlike onderhoude te voer met ‘n gerieflikheidsmonster van een honderd pasiënte. Die persone het ten tye van die ondersoek, gebruik gemaak het van dienste by die sorgenhede in Kapiri-Mposhi. Die onderhoude is aangevul deur vraelyste. Die kwalitatiewe en kwantitatiewe inligting is verwerk en waar toepaslik verder deur beskrywende statistiese metodes ontleed en grafies toegelig.

Inligting verkry deur die toepassing van bogenoemde metodes dui op die volgende: Pasiënte ervaar stigma en diskriminasie in die sorgenhede omdat hul MIV-status sonder hulle toestemming bekend gemaak word; hulle voel geforseerd om MIV-toetsing te ondergaan; hulle is van mening dat hulle sekere dienste ontsê word en ook nie behoorlike toegang tot gesinsbeplanning ontvang nie. Die studie dui op die noodsaaklikheid vir beter opleiding van gesondheidsdienswerkers ten einde die ervaring van stigma en die persepsie van diskriminasie behoorlik aan te spreek en uit die weg te ruim.

ACKNOWLEDGEMENTS

The completion of this work has been a long walk for me and everybody involved. It has particularly been tough because I have to change towns, jobs, and countries in the course of doing this work.

I have several times felt like quitting. This painstaking work would not have stood a chance of being completed without the support of my supervisors, the late Mr. Eva Gray and Professor Elza Thomson. My supervisors kept on resurrecting my hopes on many occasions when the mission appeared impossible. I would also wish to acknowledge the tones of encouragement that I received from my daughter, Chisha, my son Izu, and my wife Monica for their support.

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CHAPTER I INTRODUCTION

1. 1 INTRODUCTION

Sub-Saharan Africa remains the most affected by the AIDS pandemic, with more than two thirds (68%) of all people infected living there (UNAIDS, 2008). Estimates show that one in every five adults in the region is infected with HIV and that patients with HIV related illnesses occupy up to 70% of hospital beds (Grimwood, et al., 2003).

Zambia, like the rest of sub-Saharan Africa has not escaped the HIV pandemic. The prevalence of HIV in the general population is 14.3% (Zambia Demographic and Health Survey (ZDHS), 2007). The high burden of HIV in Zambia is accompanied by an equally high prevalence of stigma and discrimination for PLWHA (Nyblade et al. 2003). Cameron (2000) notes one of the most surprising elements of AIDS stigma is its ubiquitous nature even where the epidemic is widespread and affecting so many people such as in sub-Saharan Africa. Malcolm et al (1998) have argued stigma and discrimination relating to HIV/AIDS undermines public health efforts to combat the epidemic. AIDS stigma negatively affects preventive behaviors such as family planning, condom use, HIV test-seeking behavior and care-seeking behavior upon diagnosis, quality of care given to HIV-positive patients, and perception and treatment of PLWHA by communities, families, and partners (Gerbert et al. 1991). Therefore, as many in the HIV/AIDS community note, decreasing AIDS stigma is a vital step in stemming the epidemic (Cameron 2000). Given this situation it is critical that interventions that effectively reduce AIDS stigma be identified and implemented.

Though stigma undermines public health efforts to combat HIV/AIDS, Zambia has not adequately documented the experiences of PLWHA at household, community, workplace and service delivery levels such as health care settings and schools. Data on experiences of PLWHA in health care settings is even scantier. An electronic search for published and unpublished work on experiences of PLWHA in health care settings only yielded one unpublished study conducted in 2009/2010 by the Network of Zambian People Living with HIV/AIDS.

The aforementioned report reveals some troubling results regarding coercion of PLWHA into accepting provider-preferred methods of family planning and/or denial of HIV services for not accepting to be coerced. This study is, however, weak for the following reasons: the investigators are PLWHA and might have been biased towards a defined result, the respondents were asked questions leading to a defined answer, the questionnaires were not interpreted in local languages and finally the sample size in the proposal was reduced during the implementation of the study because of limited funding.

It is against this background that a study to describe experiences by people living with HIV/AIDS in health care settings providing HIV and family planning services in Kapiri-Mposhi, Zambia from the time they were diagnosed with the infection to 2011 is being proposed.

1.2 PROBLEM STATEMENT AND JUSTIFICATION

Although stigma negatively affects HIV/AIDS related outcomes, a limited number of studies in the international body of literature explore the experiences of PLWHA in the context of the health care system (Ramati-Najarkolaei, 2010). Understanding stigma suffered by PLWHA in health care setting is important in designing interventions aimed at reducing the prevalence of dishonor in health care settings. Research suggests that exploring the experiences of PLWHA with the health care system may not only enhance the quality of care that the patients receive, but could also improve the quality of life of PLWHA (Rahmati-Najarkolaei et al. 2010).

One recent cross-sectional study conducted among a sample of 202 PLWHA in Los Angeles County in the USA, demonstrated in a diverse and under-served sample of PLWHA, poor access (self-reported) to medical care is strongly associated with experiencing stigma. Another unpublished study conducted in Zambia (2010) by the network of Zambian people living with HIV/AIDS (NZP+) reveals disturbing findings related to coercing PLWHA to accepting family planning as a condition for accessing HIV treatment (Network of People living with HIV/AIDS in Zambia (NZP+), 2010).

Zambia clearly needs more studies describing experiences of people living with HIV/AIDS in health care setting in order to better position interventions such as family planning, counseling and testing as effective arsenals in HIV prevention.

1.3 RATIONAL OF THE STUDY

This study is informed by detail there is insufficient knowledge/information about experiences of PLWHA in Zambia in health care settings. This study is intended to add to the body of knowledge and information on the experiences of PLWHA in health care settings.

1.4 THE AIM OF THE STUDY

The aim of the study is to describe experiences of people living with HIV/AIDS in health care settings providing HIV and/or family planning services in Kapiri-Mposhi, Zambia from the time they were diagnosed with HIV to 2011.

1.5 OBJECTIVES OF THE STUDY

1. To establish whether people suspected to be living with HIV/AIDS were ever coerced into taking a HIV test
2. To evaluate whether PLWHA were ever denied family planning services on account of being HIV positive
3. To determine whether PLWHA were ever denied any health service/s on account of being HIV positive
4. To describe whether PLWHA were coerced into accepting family planning, including sterilization as a condition for accessing HIV services
5. To determine whether PLWHA were ever denied any service/s for not accepting being coerced into accepting family planning, including sterilization.

1.6 METHOD OF RESEARCH:

It was decided a cross-sectional study using quantitative methods would be employed to gain insight into the formulated problem. Cross-sectional studies form a class of research methods that involve observation of all of a population, or a representative subset in the form of a sample at one specific point in time. Cross-sectional studies involve data being collected at a specific defined time. This approach is often employed to assess the prevalence of acute or chronic conditions or to answer questions about the causes of disease or the results of medical intervention; may also be described as censuses. Cross-sectional studies may involve data collection including questions about the past; they often rely on data originally collected for other purposes. There are, however, a possible negative attached to this approach namely, difficulty in recalling past events may contribute towards bias (Saint-Germain, 2010).

1.7 RESEARCH STRUCTURE

Chapter 1 discusses the following sections: Introduction, problem statement, rational of study, Objectives of the study, method of research, and the structure of the study.

Chapter 2 discusses the research methodology in detail

Chapter 3 discusses the study results

Chapter 4 provides the overall study discussion

Chapter 5 discusses conclusions and recommendations

1.8 LIMITATIONS OF THE STUDY

Any research project has certain limitations inherent due to the environment and restricting factors preventing producing a product that is without flaws. The findings of this project may have poor external validity due to the following reasons:

- Kapiri-Mposhi is a small town with a limited population
- The sampling technique was restricted to being convenient,
- Kapiri-Mposhi has a homogenous population of mostly farmers belonging to one ethnic group whereas Zambia is diverse and has many ethnic groupings.

1.9 CONCLUSION

With a population of 13 million people and an HIV prevalence of 14.3%, Zambia is estimated to have up to 1.5 million people living with HIV/AIDS. Studies elsewhere have demonstrated that stigma is a major impediment to the implementation of effective intervention to stop the spread and effects of HIV. Despite the aforementioned facts, few studies are available to describe the experiences faced by people living with HIV/AIDS in health care settings. Knowledge about experiences faced by people living with HIV/AIDS in health care settings could help to better position interventions aimed at halting the spread of HIV/AIDS. This study aims to describe the experiences of people living with HIV/AIDS in Kapiri-Mposhi, Zambia while accessing HIV and/or family planning services using a cross-sectional study design.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

A discussion of the current literature is placed in context on the experiences of PLWHA in health care settings in Africa, Asia, and North America. A review of the theoretical material emphasizes the significance of the status in Zambia in the discipline of the perception people have of HIV/AIDS and the judging them through attaching a stigma.

2.2 DEFINITION OF STIGMA

More than four decades ago Goffman (1963:11) defined stigma as “an attribute that is deeply discrediting” and proposed that a stigmatized person is reduced “from a whole and usual person to a tainted, discounted one”. Siziya et al. (2010) define stigma as a sign of disgrace or shame which originates from ancient practice of branding or marking someone who was thought to be “flawed” or to have behaved badly and therefore ought to be avoided by other members of society. Deacon (2006) constructed a sustainable theory of health-related stigma that brought together both the individual and social dimensions of this complex phenomenon that may facilitate interventions against health-related stigma. Deacon (2006) argues stigma comes up in a social process during which the following occur, namely illness is perceived as controllable or preventable and caused by unidentifiable ‘immoral’ behaviors. These behaviors are associated with certain groups that ‘carry’ the illness which draws on existing social constructs of the ‘other’ who are consequently blamed for becoming infected. These ‘others’ experience status losses from the projection of blame, and may become disadvantaged as a result. The internalization of this ‘blame’ and the perceived ‘status loss’ by stigmatized persons, combined with objective assessments of the infected person’s day-to-day experiences with structural discrimination (institutional practices that disadvantages stigmatized persons), together may create in a stigmatized person’s view point a perception of the health care system as intolerant and inaccessible (Rahmati-Najarkolaei et al. 2010).

2.3 HISTORY OF STIGMA

Stigma is not new to public health, nor is it unique to HIV/AIDS. History provides an unfortunate abundance of examples of ‘prejudice, discounting, discrediting, and discrimination’ directed toward persons who are ill or perceived to be sick (Valdiserri, 2001). Even after the germ theory became widely accepted, discrediting divine wrath, miasma and other incorrect theories of disease, negative attitudes lingered. For example, some persons with syphilis were ‘innocent’; others were not. Often physicians were reluctant to treat patients in the latter category considering them immoral and hence unworthy of care (Brandt, 1985).

2.4 HIV RELATED STIGMA

In 1987 the late Jonathan Mann then director of the World Health Organization (WHO) Global Program on AIDS, identified three phases of the HIV/AIDS epidemic; the epidemic of HIV, the epidemic of AIDS and the epidemic of stigma, discrimination and denial. He noted the third phase is ‘central to the global AIDS challenge as the disease itself’ (Parker and Aggleton, 2002). HIV/AIDS-related stigma and discrimination are most closely related to sexual stigma. This is because HIV is mainly sexually transmitted and in most areas of the world, the epidemic initially affected populations whose sexual practices or identities are different from the ‘norm.’ HIV/AIDS related stigma and discrimination has therefore appropriated and reinforced pre-existing sexual stigma associated with sexually transmitted diseases, homosexuality, promiscuity, prostitution and sexual deviance (Weeks, 1981). Siziya et al (2010) also argue stigma associated with HIV is often based on association of HIV with already marginalized and stigmatized behaviors such as sex work, drug use and same gender sex practices.

2.5 HIV RELATED STIGMA AND GENDER

Men and women may experience different forms and intensities of stigma. For example, among HIV-positive South African adults surveyed, men reported greater self-abasing beliefs and adverse social reactions to their HIV status than women (Simbay, et al. 2007). Conversely, other studies have shown that women are particularly vulnerable to stigma, including violence one of the harshest and most damaging forms of stigma (Nyblade, 2009).

The impact of HIV/AIDS related stigma and discrimination on women reinforces pre-existing economic, educational, cultural and social disadvantages and unequal access to information and services (Aggleton & Warwick, 1999). Promiscuous sexual behavior by women is also commonly believed to be responsible for the heterosexual epidemic regardless of the epidemiological reality. In Brazil for example, where surveillance data have shown high rates of HIV infection among monogamous married women, HIV positive women are still perceived to be sexually promiscuous (Parker & Galvao, 1996).

2.6 STIGMAS IN HEALTH CARE SETTINGS

A renewed global focus on HIV prevention combined with a massive roll out of antiretroviral therapy has focused worldwide attention on the ability of health facilities to deliver critical prevention, care and treatment services to a growing client population. HIV related stigma and discrimination are now recognized as key barriers both to the delivery of quality services by health providers and to their utilization by community members and health providers themselves. Unfortunately, the health sector is one of the main settings where HIV positive individuals and those perceived to be infected experience stigma and discrimination. Studies show that HIV related stigma in this context is pernicious and that its physical and mental health consequences to patients can be damaging. Reducing HIV-related stigma in health settings should be a leading priority for health care managers. Yet little attention has been paid to this issue particularly in low-resource countries grappling with burgeoning HIV epidemics (Nyblde et al. 2009). Rahmati-Najarkolaei and others argue that a limited number of studies in the international body of literature explore the experiences of PLWHA in the context of the health system, though experiences of stigma and discrimination in healthcare settings are widespread. One recent cross-sectional study conducted among a sample of 202 PLWHA in Loa Angels County, US, demonstrated that in a diverse and under-served sample of PLWHA, poor access (self-reported) to medical care is strongly associated with experiencing HIV stigma (Rahmati-Najarkolaei et al. 2010). Research in India has also shown stigma and discrimination against HIV positive people and those perceived to be infected are common in hospitals and act as barriers to seeking and receiving critical treatment and care services (UNAIDS, 2001).

2.7 MANIFESTATION OF HIV RELATED STIGMA

HIV/AIDS related stigma and discrimination take different forms and are manifested at different levels-societal, community and individual-and in different contexts (Malcolm et al. 1998). HIV/AIDS stigma has been frequently documented in the following areas: policy environment, education, religious institutions, employment and workplace, health care system, HIV/AIDS programs and community, family and individual contexts.

2.7.1 Policy

As far as policy is concerned HIV/AIDS related stigma in society is commonly manifested in form of laws, policies and administrative procedures which are often justified as necessary to protect the 'general' population (Kirp & Bayer, 1992). Examples of stigmatizing and discriminating measures include compulsory screening and testing for HIV, compulsory notification of AIDS cases and restriction of right to anonymity, prohibition of PLWHA from certain occupations and medical examination, isolation, detention and compulsory treatment of person (Thomasevski et al. 1992). In HIV/AIDS programs policies may inadvertently 'contribute to stigmatization and discrimination by differentiating between the 'general population' and 'high risk populations,' prioritizing actions to prevent HIV spreading to the former from the latter (Panos, 1996). For example, government expenditure in most Latin American countries does not reflect the fact that HIV/AIDS has a disproportionate impact on homosexually and bisexually active men in these countries (Frasca et al. 2000).

2.7.2 Service Delivery Level

There are many ways in which HIV-related stigma manifests in health care settings. A study in Tanzania documented a wide range of discriminatory and stigmatizing practices and categorized them broadly into neglect, differential treatment, denial of care, testing and disclosing HIV status without consent and verbal abuse/gossip. Similarly, a study in Ethiopia found common forms of stigma in health facilities were designating patients as HIV positive on charts or in wards, gossiping about patients' status, verbally harassing patients, avoiding and isolating HIV positive patients and referring patients for HIV testing without counseling.

In Indian hospitals stigma and discrimination manifested as health workers informing family members of a patient's HIV status without his or her consent, and doing the following only with HIV-positive patients: burning their bedding upon discharge, charging them for the cost of infection control supplies and using gloves during all interactions, regardless of whether physical contact occurred (Nyblade, et al. 2009). Some researchers have supported the aforementioned conclusions regarding stigma in health care settings; Tirelli et al. (1991) report widespread HIV testing without consent, breaches of confidentiality and denial of treatment and care; Panos (1990) also argues that widespread failure to respect confidentiality by clearly identifying patients with HIV/AIDS, revealing the serostatus to relatives without prior consent or releasing information to the media or police appear to be problems in some health services. Siziya et al. (2010) document that in stigma index survey conducted in Zambia in 2008/2009 HIV-infected female participants were advised by health care workers not to have children and/or to undergo sterilization.

2.8 IMPACT OF AIDS RELATED STIGMA

Stigma and discrimination are one of the key barriers to combating the AIDS pandemic. They result in individuals denying they are HIV-positive, shying away from preventive behaviors and being inhibited in seeking medical treatment out of fear that their health status will be discovered (Impact study, 2003). Sufferers attempting to receive medical treatment may also experience a lack of commitment and mistreatment by health professionals. In addition, stigma and discrimination may cause infected people to lose social and economic support from their families. Fear of being identified as positive and discriminated against discourage individuals from seeking voluntary testing of their HIV status, thus affecting prevention and surveillance efforts. Stigma and discrimination in the health care setting and elsewhere contribute to keeping people, including health providers from adopting HIV preventive behaviors and accessing needed care and treatment. Fear of being identified as someone infected with HIV increases the likelihood that people will avoid testing for HIV, disclosing their HIV status to health care providers and family members or seeking treatment and care thus compromising their health and wellbeing.

Stigma with its potentially devastating consequences on care-seeking behavior represents a major 'cost' for both individuals and public health. Both experienced and perceived stigma and discrimination are associated with reduced utilization of prevention services, including programs to prevent mother to child transmission, HIV testing and counseling, family planning and accessing care and treatment.

In addition, research has demonstrated that the experience or fear of stigma often results in postponing or rejecting care, seeking care far from home to protect confidentiality and non-adherence to medication. Studies in Senegal and Indonesia for example documented men who have sex with men and injecting drug users respectively, often avoid or delay accessing HIV-related services including treatment for other sexually transmitted diseases for fear of public exposure and discrimination by health workers.

Likewise, researchers in Botswana and Jamaica found stigma leads many people to seek testing and treatment services late in the progression of their disease, often beyond the stage of optimal drug intervention. Concealing the use of antiretroviral medications, HIV-positive individuals in South Africa reported grinding drugs into powder and not taking medication in front of others which can result in inconsistent dosing (Nyblade et al. 2009).

2.9 FACTORS CONTRIBUTING TO HIV RELATED STIGMA IN HEALTH CARE SETTINGS

Factors contributing to these stigmatizing and discriminatory responses include lack of knowledge, moral attitude and perceptions that caring for PLWHA is pointless because HIV/AIDS is incurable (Blendon & Donelan, 1988). Rahmati-Najarkolaei (2010) documents the following causes of stigma from a study including 69 PLWHA in Tehran: Fear of being infected and providers' views on homosexuality, drug abuse, prostitution, and adultery.

Research conducted among general populations around the world has revealed three immediately actionable key causes of HIV related stigma in the community setting: lack of awareness of what stigma looks like and why it is damaging; fear of casual contact stemming from incomplete knowledge about HIV transmission; and values linking people with HIV to improper or immoral

behavior. Similarly among health care workers research suggests fear of casual contact and moral judgments contributes to stigma and discrimination directed at clients living with HIV. Studies in Nigeria, Mexico, Ethiopia and Tanzania have found high levels of fear of contagion among health workers, which is related to a lack of understanding of how HIV is and is not transmitted and how to protect oneself in the workplace through universal precautions. In India a study of hospital workers found those who expressed greater agreement with stigmatizing statements about people living with HIV and hospital discriminatory practices were more likely to have incorrect knowledge about HIV transmission. Studies with regard to moral judgments have demonstrated the assumption that people with HIV have conducted themselves in some improper or immoral way contributes to health workers' negative attitudes toward HIV positive people and permeates client-provider interactions. In Nigeria results of a study among nurses and laboratory technicians showed 35% felt that HIV-positive people deserved being infected as punishment for their 'sexual misbehaviors'. Similarly in Mexico three-quarters of health providers surveyed thought people with HIV bore responsibility for having HIV (Nyblade, et al. 2009).

2.10 CONCLUSION

The literature reflect stigma is real and exists at different societal levels such as families, communities, work places, health care settings, HIV/AIDS programs, religious institutions and education levels. In health care settings particularly, the manifestation of stigma include: differential treatment, denial of services, testing and disclosing results without consent, and isolating HIV-infected patients. The literature has identified stigma as one of the key barriers to combating the HIV pandemic and has highlighted factors that account for it such lack of knowledge and poor moral attitudes.

CHAPTER 3 RESEARCH METHODOLOGY

3.1 PROBLEM STATEMENT

Although stigma negatively affects HIV/AIDS-related outcomes a limited number of studies in the international body of literature explore the experiences of PLWHA in the context of the health care system (Ramati-Najarkolaei, 2010). Understanding stigma experienced by PLWHA in health care settings is important in designing interventions aimed at reducing the prevalence of stigma in health care settings. Research suggests exploring the experiences of PLWHA with the health care system may not only enhance the quality of care that the patients receive but could also improve the quality of life of PLWHA.

One recent cross-sectional study conducted among a sample of 202 PLWHA in Los Angeles County in the USA demonstrated that in a diverse and under-served sample of PLWHA, poor access (self-reported) to medical care is strongly associated with experiencing stigma. Another unpublished study conducted in Zambia (2010) by the network of Zambian people living with HIV/AIDS (NPZ+) reveals disturbing findings related to coercing PLWHA to accepting family planning as a condition for accessing HIV treatment (Network of People living with HIV/AIDS in Zambia (NPZ+), 2010). However, this study had the following weaknesses: the principal investigator (the NPZ+) may have had interest in results that demonstrated stigma because the results would be used to lobby for funds to fight stigma, the study methodology was flawed because the questions were ‘leading’ the respondents to an answer and the implementation of the study did not follow the study proposal because of lack of funds.

Zambia clearly needs more studies on the experiences of people living with HIV/AIDS in health care setting in order to better position interventions such as family planning, counseling and testing as effective arsenals in HIV prevention. What are the experiences of PLWHA in Health Care Settings offering FP and HIV services in Kapiri-Mposhi, Zambia from the time they were diagnosed with HIV to 2011 (the time of collecting data)?

3.2 THE AIM OF THE STUDY

The aim of the study is to describe experiences of people living with HIV/AIDS in health care settings providing HIV and family planning services in Kapiri-Mposhi, Zambia from the time they were diagnosed with HIV to 2011.

3.3 OBJECTIVES OF THE STUDY

The objectives of the study can be placed in the following framework:

1. To establish whether people suspected to be living with HIV/AIDS were ever coerced into taking a HIV test
2. To evaluate whether PLWHA were ever denied family planning services on account of being HIV positive
3. To determine whether PLWHA were ever denied any health service/s on account of being HIV positive
4. To describe whether PLWHA were coerced into accepting family planning, including sterilization as a condition for accessing HIV services
5. To determine whether PLWHA were ever denied any service/s for not accepting being coerced into accepting family planning, including sterilization.

3.4 STUDY DESIGN

There are two approaches that can be followed when conducting research a quantitative and qualitative method. According to the quantitative paradigm is a quantification of constructs central role of variables in describing and analyzing human behavior and the central role afforded to control for sources of error in the research process. In contrast qualitative research refer to the generic research approach in social research according to which research takes its departure point as the insider perspective on social action (Babbie et al. 2008).

Cross-sectional studies form a class of research methods that involve observation of all of a population, or a representative subset in the form of a sample at one specific point in time. Cross-sectional studies involve data being collected at a specific defined time. This approach is often employed to assess the prevalence of acute or chronic conditions or to answer questions about the causes of disease or the results of medical intervention; may also be described as censuses. Cross-sectional studies may involve data collection including questions about the past; they often rely on data originally collected for other purposes. There are, however, a possible negative attached to this approach namely, difficulty in recalling past events may contribute towards bias (Saint-Germain, 2010).

This study chose a cross-sectional descriptive study to establish whether PLWHA and accessing family planning and HIV services in Kapiri-Mposhi, Zambia from 2000 to 2011 (the time of collecting data) were: Ever coerced into taking an HIV test, coerced into accepting family planning, including sterilization as a condition for accessing HIV services, and ever denied any service/s for not accepting being coerced into accepting family planning, including sterilization.

3.5 DESCRIPTION OF STUDY SITE

The research was conducted in Kapiri-Mposhi is a small town in Zambia, located 185 km north of Zambia's capital city, Lusaka. The town is endowed with good road and railway communication that links the town to the rest of the country. The main commercial activities in Kapiri-Mposhi are agriculture, trading and the service industry. Kapiri-Mposhi has a population of 35,000 people; however, the town has an adult HIV prevalence rate of 17.5% which is higher than the national average of 14.3% (Zambia Health and Demographic Survey, 2007). Kapiri-Mposhi is served by one government hospital and several health centers. The choice of Kapiri-Mposhi as the study site was determined by it was one of the two sites (the other one being Lusaka) in which the Network of People Living with HIV/AIDS in Zambia (NPZ+) had conducted the Stigma index study about PLWHA. PLWHA attending HIV services in Kapiri-Mposhi District

3.6 SAMPLING AND SAMPLE SIZE

Kapiri-Mposhi district hospital and the nearby satellite clinics have 509 PLWHA attending HIV and family planning services on their register. It was not be feasible to conduct interviews with all the 509 PLWHA because of time constraints and paucity of resources. A preferred confidence level of 95% and a confidence interval of ± 10 was considered and a convenient sample of 80 PLWHA was interviewed by administering a questionnaire.

3.7 SOURCES OF DATA

A standard questionnaire was administered to the respondents by a qualified researcher. Christensen et al. (2011) indicate a questionnaire is a self-report data collection instrument that is completed by a research participant; measure opinions ad perceptions and provide self-reported demographic information. The questionnaire constructed for this study project consisted of pre-coded questions requiring a yes, no or I don't know answers and the participants were expected to indicate their choice of answer. There were also questions requiring explanations where it was expected the responded reacted to open-ended statements (Annexure 1). The questionnaire was the main vehicle used to capture the responses of the participants and this provided data to be analyzed. Ensuring the participants understood the questions and statements a pre-test was conducted by selecting 5 PLWHA as pilot to ultimately ensure validity before the entire sample of 80 respondents were exposed to the questionnaire.

3.7.1 Type of Data collected

The following type of data was collected from the participants to enable the researcher to gain answers in view of the problem statement:

1. Number of PLWHA accessing family planning and/or HIV services in Kapiri-Mposhi, Zambia who were interviewed
2. Duration in years since each person living with HIV/AIDS had known that he/she was infected with HIV
3. Reason/s for delaying testing for HIV

4. Number of times that the PLWHA had come into contact with the health care system for HIV and/or family planning services.
5. Number of PLWHA who were coerced into doing an HIV test by a health care worker
6. Number of PLWHA coerced into taking a family planning method on account of being HIV positive
7. Number of PLWHA denied a family planning method on account of being HIV positive
8. Number of PLWHA denied any other service on account of being HIV positive
9. Number of PLWHA whose HIV status had been revealed to other people by a health care worker without consent

3.7.2 Reliability of data

An effort was made to verify the responses from the participants in the study by requesting them to explain their responses to ensure what they said are actually what they meant to say (was applicable with the open-ended questions). Further the respondents were asked more than one question on the identified variables of interest in the study. The questionnaires were administered in a local language to ensure all participants felt comfortable and had the ability to express themselves and create understanding.

3.7.3 Data cleaning

Data was imported onto an electronic excel spreadsheet for descriptive statistical analysis. After entering data on the spreadsheet, verification of the data was checked for entry errors (completeness and appropriateness) by using the sort function in excel, which made it easy to identify data gaps and entries that appeared inappropriate. Whenever a gap was noted the questionnaires were cross checked to verify the entries and in the event of mistakes corrections were made to ensure the authenticity of the recorded data.

3.7.4 Data analysis

Descriptive statistics was the choice of analyzing the data collected from the responses of the participants.

According to Babbi et al. (2008) descriptive statistics are used to summarize data under study; some summarize the distribution of attributes while other the association between variables. Christiansen et al (2011) indicate in descriptive statistics the goal is to describe or summarise the research data. This gives the researcher the opportunity to make sense of the data and to make the key characteristics easily understandable to those reviewing the research.

The descriptive statistics of interest in this study were the measurement of the central tendency for specific experiences by PLWHA:

- Mean – the arithmetic average
- Mode – the most frequently occurring number for a variable
- Median – the center point in a set of numbers that has been arranged in ascending or descending order

Completing the presentation of the equation related to descriptive statistics the dispersion of data using frequency tables and/or graphs and calculation of ratios will be utilised.

3.7.5 Guidelines for presentation

- Duration in years living with HIV/AIDS: A graph was created in excel to show the number of PLWHA per number of years that PLWHA had been living with HIV/AIDS. This was done to show the dispersion (distribution) of PLWHA per interval in years living with HIV/AIDS.
- Reason for delaying testing for HIV: A graph was created in excel to show the number of PLWHA per reason for delaying testing for HIV. This was done to show the dispersion (distribution) of PLWHA per reason for testing for HIV late.

- Number of times PLWHA had come into contact with the health care system: A graph was created in excel to show the number of PLWHA per number of contacts with the health care system. This was done to show the dispersion (distribution) of PLWHA per number of contacts with the health care system.
- Decision to test: A graph was created in excel to show the number of PLWHA per person/individual who made a decision to test for HIV (health care worker, family member, or patient). This was done to show the dispersion (distribution) of PLWHA per who made a decision for testing for HIV.
- Coercion to start family planning: The proportion of PLWHA coerced into accepting a family planning method on account of being HIV positive was computed.
- Denial of family planning services: The proportion of PLWHA denied a family planning method on account of being HIV positive was computed.
- Denial of any other services: The proportion of PLWHA denied any other service/s on account of being HIV positive was computed.
- Disclosure of HIV status: The proportion of PLWHA whose HIV status had been disclosed without their consent was computed.

3.8 ETHICAL CONSIDERATIONS

The ethical concerns surrounding the conduct of psychological research may include, *inter alia*, honesty, objectivity, integrity, openness, confidentiality, competency and legality. Ethics in social research is related to positivists and interpretive data that are collected and analyzed with careful attention to their accuracy, fidelity to logic, and respect for the feelings and rights of research participants; one of the four criteria for evaluating research problem areas *and* formulating research questions out of the problem areas (Grinnell et al. 2011).

The main ethical issues associated with this study will be the details about individual patients-getting to unauthorized persons and coercing respondents to be part of the interviews.

Respondents were not coerced into being part of the interview. As a matter of procedure, informed consent was required for participating in interviews. Further, there were no identifiers on the data collecting tools (questionnaires).

It is envisaged the results/findings of the study will have the following benefits:

- The findings will add to existing knowledge on HIV-related stigma and discrimination in Zambia
- The findings will stimulate further research in the field of HIV-related stigma.
- The findings will inform interventions to reduce stigma and discrimination

The study did not have any risk/s of physical injury because the only intervention was interviews with the study population.

3.9 LIMITATIONS OF THE STUDY

Any research project has certain limitation inherent due to the environment and restricting factors preventing producing a product that is without any flaws. A limitation of this project is the findings may have poor external validity because Kapiri-Mposhi is a small town with a limited population. Due to the situation of the setting a convenient sample with the participants had to be chosen. The country is diverse in geographic setting but most of all there are many language groups and it may not be feasible to generalize the findings for the country as a whole.

3.10 CONCLUSION

The research methodology aims to generate and analyze data on the experiences by people living with HIV in health care settings in Kapiri-Mposhi, Zambia from the time they were diagnosed with HIV to the time of data collection in 2011. The study has employed a cross sectional design and conveniently sampled 80 people living with HIV/AIDS. The data has been analyzed with descriptive statistics to yield the results will provide a vehicle to make ultimately recommendations that will enable to pave the road for the future in this particular part of the world.

CHAPTER 4

REPORTING OF RESULTS

4.1 INTRODUCTION

A discussion highlights the experiences of eighty (80) HIV positive adult patients attending the Kapiri-Mposhi District Hospital in Zambia since they were diagnosed with the infection. Results discussed hereafter relate to the number of people living with HIV/AIDS interviewed together with the duration in years during which the PLWHA had been living with HIV/AIDS. Reasons individuals gave for delaying HIV testing and then to be informed of their status quo. The study required responses to indicate the number of times the PLWHA had come into contact with a health care system. On the negative side whether the PLWHA were ever coerced by a health care worker to take an HIV test and whether they had ever been forced into accepting a family planning method on account of their status. Because of their HIV infections have the PLWHA were ever denied family planning or any other services. A sensitive aspect for everybody is the disclosure to relatives an individual's HIV status.

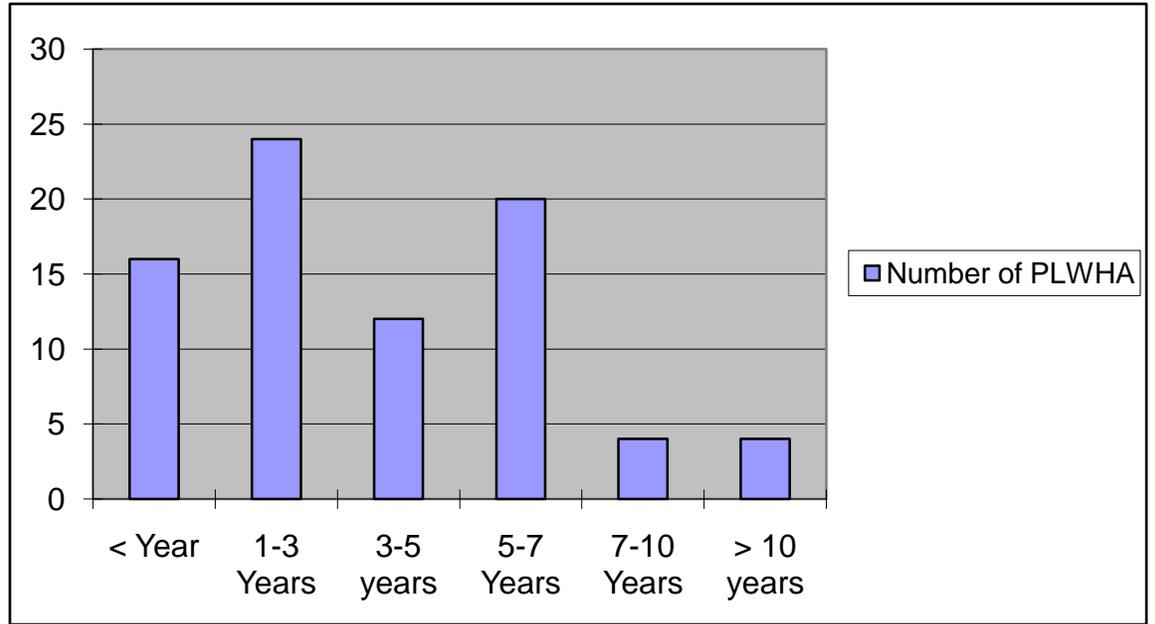
4.2 DISCUSSION OF RESULTS

The results will be presented in a logical format of the eighty (80) participants following the chosen guidelines.

4.2.1 Duration in years living with HIV/AIDS

Those living with AIDS for more than one year were represented by 64 (80%) (Figure 4.1).

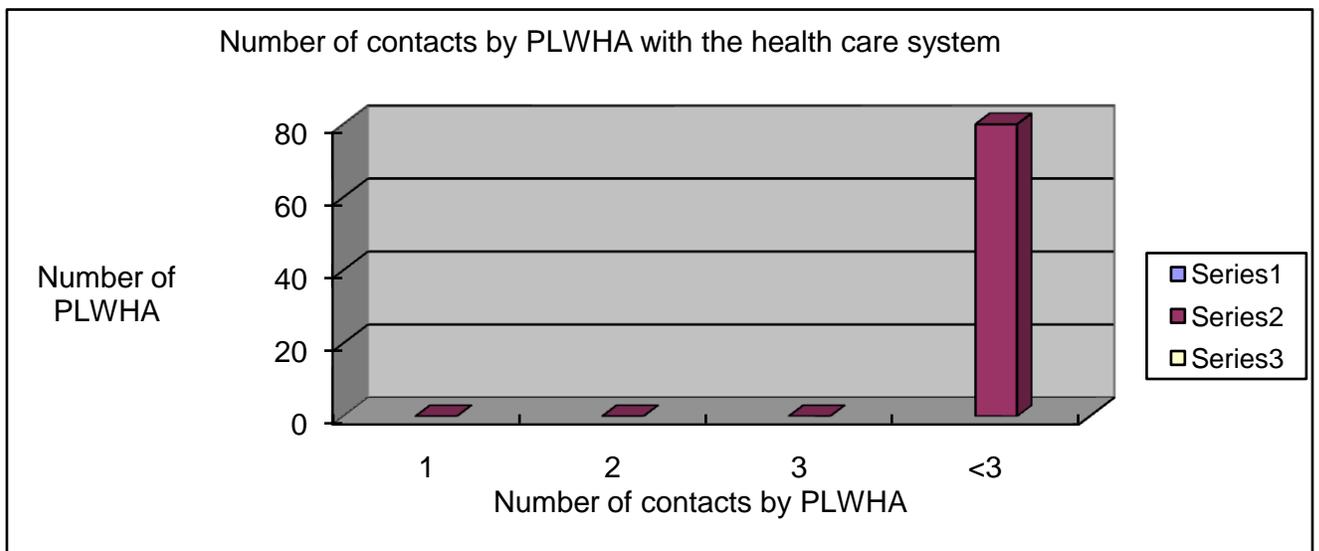
Figure 4.1
Duration during which the PLWHA have been living with HIV



4.2.2 Number of contacts with the health care system by PLWHA for HIV/AIDS and/or family planning services

The total sample indicated they had come into contact with the health care system more than three times for HIV and/or family planning services. They all reported they had come into contact with the health care system many time (countless times) for family planning and/or HIV services (Figure 4.2).

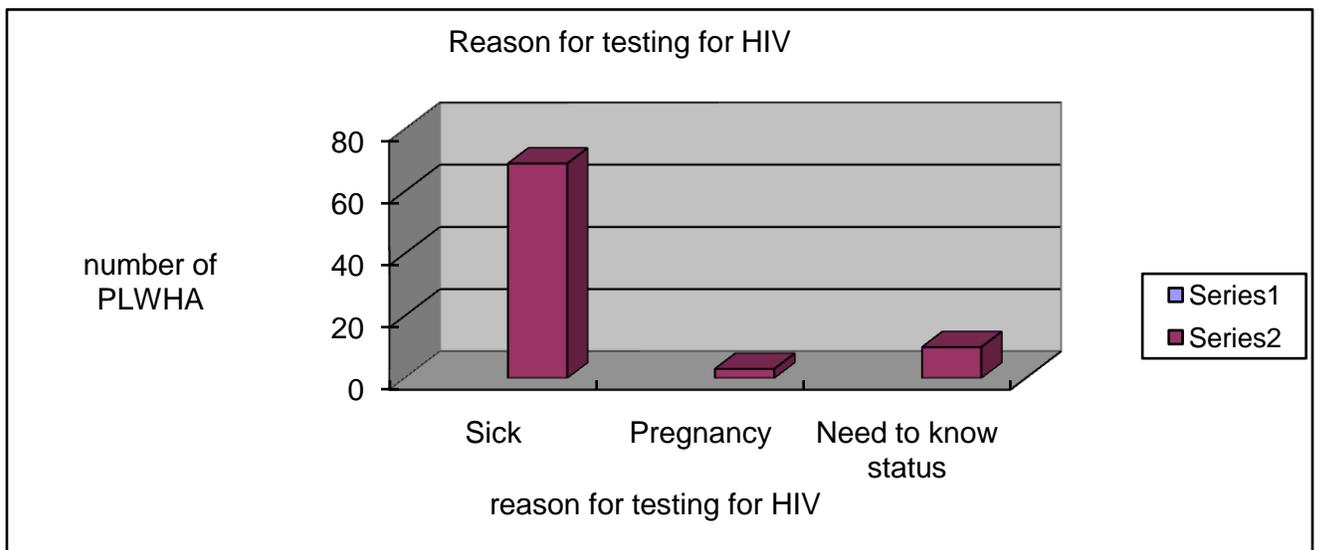
Figure 4.2
Number of contacts by PLWHA with the health care system



4.2.3 Reason for testing for HIV

A total of 69 (84%) tested for HIV on account of being sick, 3 (4%), were pregnant and tested as part of the prevention of mother to child transmission of HIV (PMTCT) program and 8 (10%) tested because they merely wanted to know their HIV status (Figure 4.3).

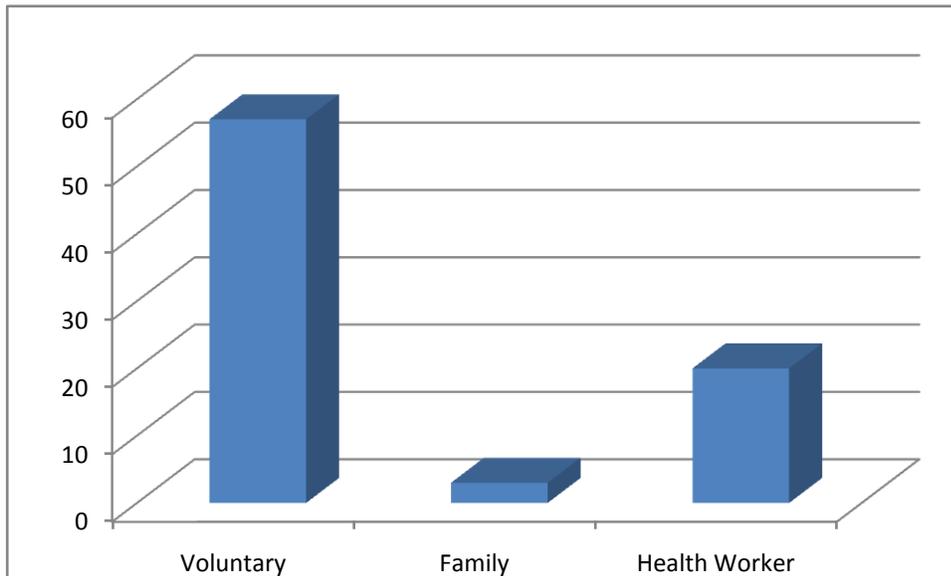
Figure 4.3
Reason/s for testing



4.2.4 Decision to take an HIV test

A decision to take an HIV test voluntary was represented by 57 (71%) (on their own and/or after being provided with information by a health care worker), 3 (4%) had been coerced by family members and 20 (25%) had been coerced into testing by a health care worker (Figure 4.4).

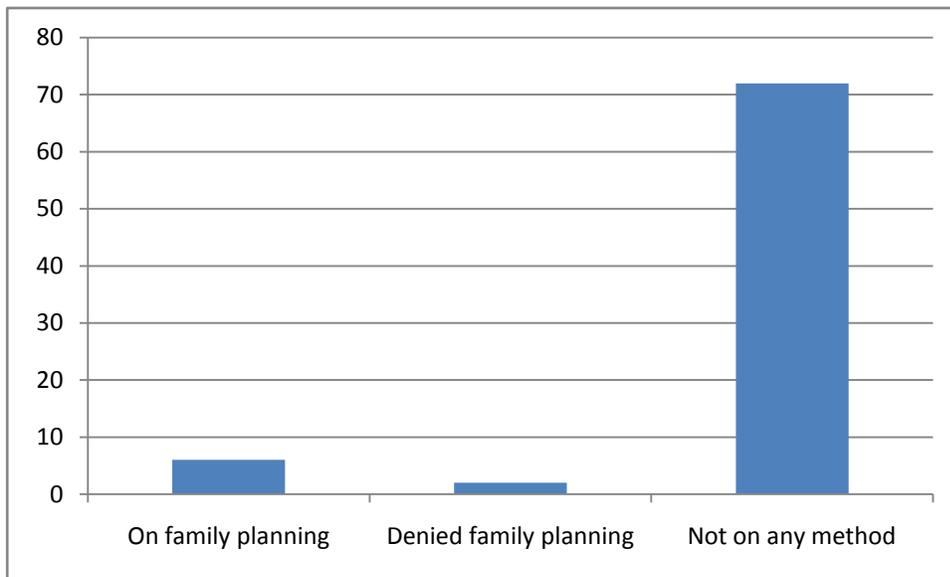
Figure 4.4
Decision to test



4.2.5 PLWHA on Family Planning method and those denied

The respondents indicated only 6 (7.5%) were on a family planning method; with four being on Depo-Provera and two on oral contraceptives. There was no person living with HIV/AIDS sterilized. Two persons reported they had been denied a family planning method on account of being HIV-positive in between 1995 and 2000 (Figure 4.5).

Figure 4.5
Family planning denied



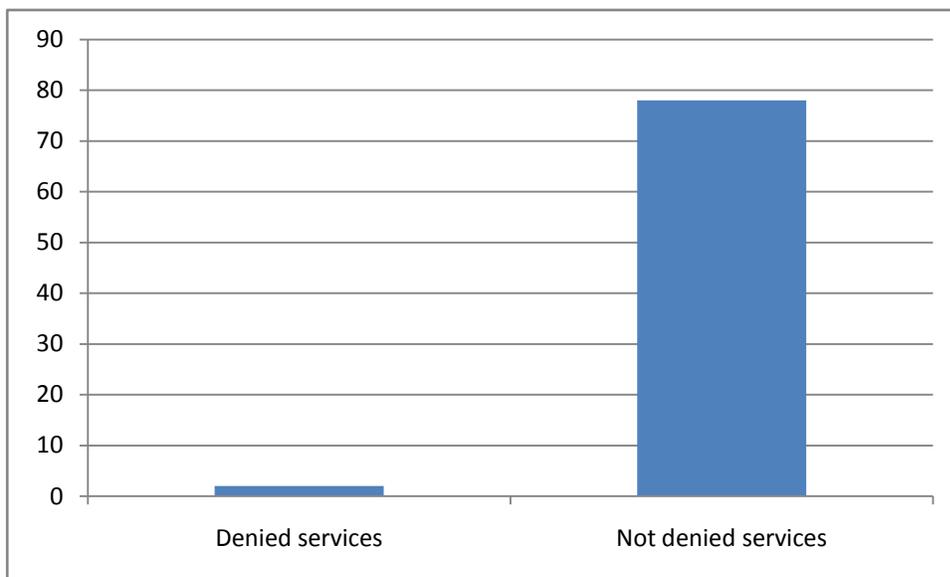
4.2.6 Number PLWHA coerced into accepting a family planning method

The respondents indicated none of them had ever been coerced into accepting a family planning method on account of being HIV positive (Figure 4.5).

4.2.7 Number of PLWHA denied other services on account of being HIV-infected

Two individuals had been denied further services on account that they needed to do an HIV test before being provided with additional services. One person living with HIV/AIDS said, “A nurse at our local clinic said she would not provide me with any services unless I tested for HIV”. This happened more than ten years before the interview (Figure 4.6).

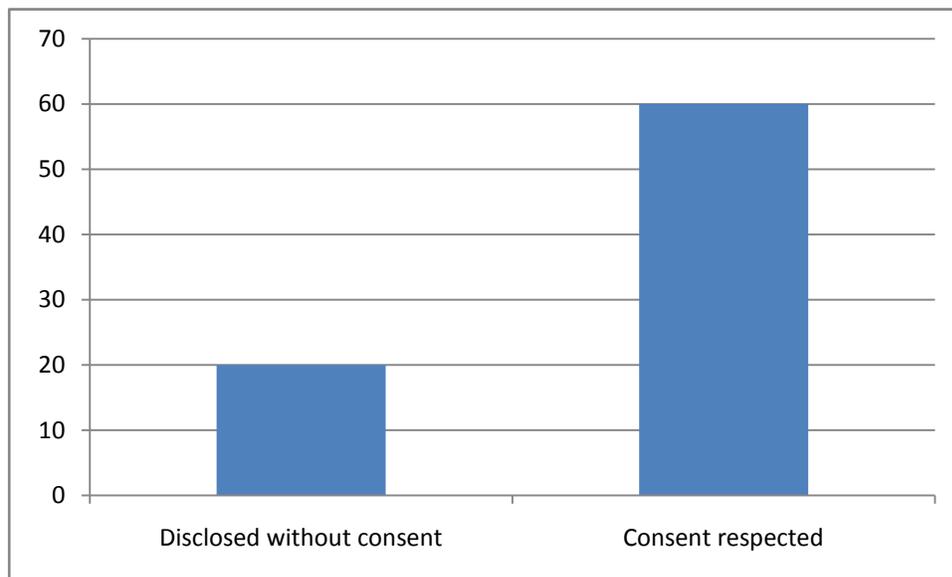
Figure 4.6
PLWHA denied services



4.2.8 Disclosure of HIV tests

An ethical principle was violated when 20 (25%) disclosed health care workers had disclosed their HIV positive status to their relatives without their consent (Figure 4.7).

Figure 4.7
Disclosure of HIV status without consent



4.3 CONCLUSION

The results of this study, though limited by the study confines show that PLWHA in Kapiri-Mposhi, Zambia experienced stigma in form of being coerced into taking an HIV test, delaying testing for HIV for fear of stigma, denial of health services, including family planning and HIV services, and disclosure of HIV status without consent. The study has also demonstrated the PLWHA were not fully aware of their rights.

CHAPTER 5

DISCUSSION

5.1 INTRODUCTION

A discussion regarding experiences of PLWHA is highlighted while receiving HIV/AIDS and/or family planning services in Kapiri-Mposhi, Zambia from the time they were diagnosed with HIV to the time the interview/s in 2011. The primary results of interest include:

- Total number PLWHA interviewed
- Period in years that the PLWHA interviewed had been living with HIV/AIDS
- Number of contacts that the PLWHA had had with the health care system for HIV and/or family planning services since knowing that they had HIV infection
- Reason/s for testing for HIV
- Who took the decision for testing for HIV (person living with HIV/AIDS, the relative to the person living with HIV/AIDS or the health care worker)
- Denying PLWHA a family planning method on account of being HIV infected
- Coercing PLWHA to accept a family planning method on account being HIV-infected
- Denying PLWHA any other services on account of being HIV-infected, and
- A health care worker disclosing the HIV status of PLWHA without their consent.

5.2 DISCUSSION OF STUDY RESULTS

Once the research project has been placed in context by going through the different phases of eliciting responses from participants, analyzing the data and placing the result in figures together with explanations it is deemed necessary to lead a discussion on the findings.

5.2.1 Duration in years living with HIV/AIDS

A total of 80 PLWHA were interviewed and 64 (80%) had been living with HIV/AIDS for more than one year. This implies the vast majority of PLWHA interviewed had a reasonable chance of coming into contact with the health care system which would allow them to share valuable experience (if any) related to HIV stigma and discrimination.

5.2.2 Number of contacts with the health care system providing HIV/AIDS and/or family planning services by the PLWHA

The sample of 80 respondents had come into contact with the health care system more than three times for HIV and/or family planning services. They all reported they had come into contact with the health care system many times (countless times). Because all the PLWHA interviewed had come into contact with the health care system countless times, it was likely that a proportion of them would have experienced HIV related stigma and/or discrimination if at all it ever existed in health care setting providing HIV and/or family planning services.

5.2.3 Reason for testing

The 80 people interviewed 69 (representing 84%) had tested for HIV on account of being sick. This finding is consistent with other observations and studies on the main reason for people testing for HIV in health care setting; it is usually because they are feeling unwell or say they are sick. For example an assessment on HIV testing conducted in San Francisco in 2006 revealed majority of those who delayed HIV testing received their first positive HIV test in a medical setting (2007: HPPC Needs Assessment HIV Prevention Council). They received testing due to illness or disease-related symptoms. Another study, a cross country analysis based on the people living with HIV stigma index in Asia by a consortium of organizations namely UNAIDS, Global Network of People Living with HIV/AIDS (GNP+), International Community of Women Living with HIV/AIDS, and the International Planned Parenthood Federation also demonstrated that high percentages of respondents tested because they had symptoms related to HIV.

5.2.4 Reason/s for delaying HIV testing:

Late testing for HIV is typically defined as receipt of an initial positive HIV test one year or less before the diagnosis of AIDS. The 69 PLWHA who had reported late for HIV testing, the main barrier cited was fear of being discriminated against by either a family member or a health care worker. This finding consolidates other findings on why people do not test early enough for HIV. Stigma and discrimination is the single most important reason why voluntary testing and counseling services in sub-Saharan Africa do not attract many clients. The voluntary HIV testing and counseling services in Zambia, which cover the whole country with easy access, has only been able to test 12% of the population as a result of stigma and discrimination (National AIDS Council of Zambia, 2011).

5.2.5 Decision to take an HIV test

A decision to take an HIV test voluntary was represented by 57 (71%) (On their own and/or after being provided with information by a health care worker), 3 (4%) had been coerced by family members and 20 (25%) had been coerced into testing by a health care worker (Figure 4.4). These results shows despite an increase in awareness among health care workers and the PLWHA that HIV testing should be voluntary; some health care workers still compel their clients to do an HIV test. According to a 2011 report on HIV-related stigma in Egypt, the health care sector was consistently identified by people living with as a major source of stigma and discrimination. A study quoted in the report found denial of care, breach of confidentiality, non-consensual testing, poor quality of care, gossip and blame were all frequent features of Egypt's health care system. Another report by the American Centre for Reproductive Rights (ACRR) commented: "women are subject to coercive practices and violations of informed consent and confidentiality in testing for HIV" (Awiti, 2009). Another study in Nigeria on the attitude of health care workers towards PLWHA found 14% of health care workers reported never obtaining consent before doing an HIV test on their clients (Reis et al. 2012).

5.2.6 Denial of a family planning method

The respondents indicated only 6 (7.5%) were on a family planning method; with four being on Depo-Provera and two on oral contraceptives. Two persons reported they had been denied a family planning method on account of being HIV-positive in between 1995 and 2000 by a health care worker (nurse). The significant findings are that the two people living with HIV/AIDS denied family planning methods on account of being HIV positive experienced this rejection more than 10 years before the interview and the attending health care worker was a nurse. The most obvious reason for denial of family planning occurring during the early phase of the HIV epidemic could be that good education on the needs and rights of people living with HIV/AIDS had not yet filtered through in the minds of health care workers. A 2012 study conducted in Nigeria regarding the attitudes and practices of health care workers towards patients with HIV/AIDS revealed that providers who reported less adequate training in HIV treatment and ethics were more likely to report negative attitudes and practices across the different health professionals surveyed (Reis et al. 2012).

5.2.7 Denial of other services on account of being HIV-infected

Two individuals had been denied further services on account that they needed to do an HIV test before being provided with additional services. One person living with HIV/AIDS said, “A nurse at our local clinic said she would not provide me with any services unless I tested for HIV”. This finding is very consistent with several other finding where health care workers withhold services to people suspected to be HIV-infected until such persons accept to take an HIV test. Even people with a confirmed HIV status are also at times denied health services on account of being infected with HIV. In Nigeria, 9% of health care workers interviewed reported refusing to care for HIV/AIDS because of fear of being infected by HIV (Reis et al. 2012).

5.2.8 Disclosure of HIV tests

An ethical principle was violated when 20 (25%) disclosed health care workers had disclosed their HIV positive status to their relatives without their consent.

This finding is consistent with many other findings where health care workers tend to disclose their clients' HIV status without consent under the guise that this would protect unsuspecting family members and health care workers. In a Nigerian study on attitudes of health care workers towards PLWHA, 91% all respondents agreed that staff and health care workers should be informed when a patient is HIV-positive so that they can protect themselves; 57% believed that relatives and sexual partners of patients with HIV/AIDS should be informed of the patient's status even without consent; 38% reported giving confidential information to a patient's family member without the patient's consent and 53% had observed the behavior (Reis et al. 2012).

CHAPTER 6

RECOMMENDATIONS

6.1 INTRODUCTION

This study has shown that HIV related stigma still exists among the PLWHA and within the health care system. The study has also demonstrated that HIV-related stigma and discrimination has a profound effect on the epidemic's course. Recommendations are made that would assist in reducing HIV related stigma in Zambia.

6.2 RECOMMENDATIONS FOR POLICY

The aim for conducting research is to solve a problem that has been formulated. A research project is completed in the first instance when data is collected from chosen respondents, analyzed and displayed in tables or graphs and then ultimately interpreted. The value of research is contained in the recommendations made to enable action that can be taken to add value to society.

6.2.1 Legal/policy framework

The prevalence of HIV-related stigma in Zambia and health care settings in particular can be reduced by promulgating a law that addresses the rights of people with disabilities, including those living with HIV/AIDS. These laws could be operationalized by devising policies and guidelines for health care workers on how to provide services to PLWHA.

6.2.2 Education of Health care workers

Though the study did not necessarily interrogate the etiology of HIV related stigma perpetuated by health care workers, other studies have argued that lack of understanding of the pathophysiology of HIV/AIDS, ignorance of the rights of PLWHA, and beliefs that HIV is a disease contracted through mischief by health care workers are responsible for the stigma endured by PLWHA in health care settings.

For example, a stigma report of the Egyptian Health Ministry of 2011 found physicians and nurses were often reluctant to provide people living with HIV health services due to lack of knowledge about the infection; doubts to the effectiveness of prevention measures; moral stigma against illegitimate sex; fears of being stigmatized; misconception about care and treatment of HIV-infected patients, and the generally negative connotations associated with HIV/AIDS (Global HIV/AIDS news 2011).

Another study in Nigeria observed a vast majority of health professionals expressed interest in additional information and suggested education as a way to address discriminatory behaviors by their colleagues (Reis, 2012). Therefore, educating health care workers on HIV addressing the following issues would also be important in reducing HIV related stigma in Zambia:

- a) HIV is not transmitted by casual contact with the PLWHA; there might be fear out there that casual contact might lead to acquiring HIV.
- b) That being HIV-positive may not necessarily imply promiscuity on the part of the PLWHA.
- c) PLWHA has equal rights with those who do not have HIV, including access to reproductive health and family planning services.
- d) Education of the special needs of health services for PLWHA, including the type of family planning methods.

6.2.3 Education of the community

Members of the community also require education for them to fully understand their rights regarding HIV and other services within the health care system.

6.2.4 Expansion of HIV treatment services

Treatment services mean HIV/AIDS is no longer viewed as a death sentence as it was a decade ago. PLWHA with increasing treatment services are now more comfortable to reveal their HIV status to others. Therefore, Zambia should continue scaling up HIV services.

6.2.5 Workplace policies

The HIV/AIDS work place policies have largely not been successful (personal experience) working in the area of HIV/AIDS in Zambia.

Though impact work related fears such as fear of being dismissed on account of being HIV positive, there is a conviction that HIV related stigma in general and in health care setting particularly can be reduced by robust work place policies. Therefore it is recommended there should be a strengthening of the HIV/AIDS work place policies in Zambia.

6.3 RECOMMENDATIONS FOR FURTHER RESEARCH

As noted in the introduction and in the research methodology sections, the study findings contained in this report may have limited external validity due to the following reasons:

- (a) Kapiri-Mposhi is a small town with a limited population.
- (b) The sampling was convenient and thus not everybody was included in the study.
- (c) Kapiri-Mposhi has a homogenous population of mostly farmers belonging to one ethnic group whereas Zambia is diverse and has many ethnic groupings. Therefore, it recommended that further studies with wider sampling be undertaken to collaborate the findings of this study.

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Appendix 1

Questionnaire for PLWHA

Instructions to Interviewer:

The purpose of this questionnaire is to gather information potentially related to stigma and discrimination that may be experienced by people living with HIV/AIDS (PLWHAs) while receiving HIV/AIDS and/or family planning services at Kapiri-Mposhi Government Hospital in Zambia. This interview tool is designed to collect information from *HIV-positive individuals*.

Introduction

My name is Dr George Sinyangwe and I am a student at Stellenbosch University. I am here to collect some information about HIV/AIDS and/or family planning services and would like to ask you some questions about HIV/AIDS and/or family planning services you have received. The results of our discussion and data collection will be used to better understand the current situation in these services and to identify areas that might be strengthened. Thank you for your assistance in helping us better understand the services in this district.

Do you have any questions for me?

Yes No

Do you agree to participate in this interview?

Yes No

Date: _____

Interviewer: Dr. George Sinyangwe _____

Client: Male Female
 Transgender Other/Specify _____

1. **When** did you first learn that you were HIV-positive?

- < 1 year ago
 1-3 years ago
 4-5 years ago
 6-10 years ago
 > 10 years ago

2. What necessitated your testing for HIV?

- I was sick
- It was for employment purposes
- I just wanted to know my HIV status
- I was pregnant

3. In your opinion, do you think you delayed in arriving at a decision to do an HIV test?

- Yes
- No

3.a if yes, what was the main cause of the delay

- Testing services not available
- Not knowing about the benefits of testing for HIV
- Fear of being discriminated against by the family system
- Fear of being discriminated against by the health care system

4. Was the decision to be tested for HIV made by you?

Yes No

4. a) If no, by whom?

- Family members or friends
- Health Service Provider
 - i) Doctor
 - ii) Midwife
 - iii) Nurse
 - iv) Other: _____
 - v) Other: _____

5. How many times have you come into contact with the health care system for health services, including HIV and/or family planning services?

- One
- Two
- Three
- Countless times

6. Has a health care provider ever told you that you must use family planning or a barrier method like condoms in because of your HIV status?

Yes No

6a. If yes, approximately when were you told this?

- < 1 year ago
- 1-3 years ago
- 4-5 years ago
- 6-10 years ago
- > 10 years ago

6b. If yes, who told you this?

1. Doctor
2. Midwife
3. Nurse
4. Community Health Worker
5. Pharmacist
6. Other: _____

6c. If yes, what action did you take in relation to this recommendation on FP methods?

1. Accepted advised method
2. Accepted different method
3. Did not accept any method

6d. 1 If you did not accept any method, did anything happen to you as a result of not accepting a family planning method? What specifically?

7. Has a health care professional ever advised you not to have children because you are HIV-positive?

Yes No

7a. If yes, approximately when were you told this?

- < 1 year ago
- 1-3 years ago

- 4-5 years ago
- 6-10 years ago
- > 10 years ago

7b. If yes, who told you not to have children?

- 4. Doctor
- 5. Midwife
- 6. Nurse
- 7. Community Health Worker
- 8. Pharmacist
- 9. Other: _____

8. Have you been denied family planning services because of your HIV status?

- Never
- Once
- A few times
- Often
- 10. Not applicable

8a. If yes, approximately when were you denied FP services?

- < 1 year ago
- 1-3 years ago
- 4-5 years ago
- 6-10 years ago
- > 10 years ago

8b. If yes, who denied you these services?

- 1. Doctor
- 2. Midwife
- 3. Nurse
- 4. Community Health Worker
- 5. Pharmacist
- 6. Other: _____

8c. If yes, what did you do

- 1. Nothing
- 2. Reported the matter to higher authorities
- 3. Took matter to court

9. Has a health care provider ever told you that you needed to use family planning or barrier methods such as condoms because of your HIV status?

- Yes No

9a. If yes, approximately when were you told this?

- < 1 year ago
- 1-3 years ago
- 4-5 years ago
- 6-10 years ago
- > 10 years ago

9b. If yes, who told you this?

- 7. Doctor
- 8. Midwife
- 9. Nurse
- 10. Community Health Worker

- 11. Pharmacist
- 12. Other: _____

10. Has a health care provider ever told you that you needed to be sterilized because of your HIV status?
 Yes No

10a. If yes, approximately when were you told this?

- < 1 year ago
- 1-3 years ago
- 4-5 years ago
- 6-10 years ago
- > 10 years ago

10b. If yes, who told you this?

- 1. Doctor
- 2. Midwife
- 3. Nurse
- 4. Community Health Worker
- 5. Pharmacist
- 6. Other: _____

11. Have you ever been denied any services on account of being HIV infected?
 Yes No

11a. If yes, approximately when did this happen?

- < 1 year ago
- 1-3 years ago
- 4-5 years ago
- 6-10 years ago
- > 10 years

11b. If yes, who told you this?

- 1. Doctor
- 2. Midwife
- 3. Nurse
- 4. Community Health Worker
- 5. Pharmacist
- 6. Other: _____

Appendix 2

Informed Consent

Protocol Title: DESCRIPTIVE STUDY OF HIV/AIDS-RELATED STIGMA EXPERIENCED BY PEOPLE LIVING WITH HIV/AIDS (PLWHA) IN HEALTHCARE SETTINGS OFFERING FAMILY PLANNING AND/OR HIV SERVICES IN KAPIRI-MPOSHI, ZAMBIA

Purpose of the research study: The purpose of this questionnaire is to gather information potentially related to stigma and discrimination that may be experienced by people living with HIV/AIDS (PLWHAs) while receiving HIV/AIDS and/or family planning services at Kapiri-Mposhi Government Hospital in Zambia.

Introduction of the interviewer: My name is **Dr George Sinyangwe** and I am a student at Stellenbosch University. I am here to collect some information about HIV/AIDS and/or family planning services and would like to ask you some questions about HIV/AIDS and/or family planning services you have received. The results of our discussion and data collection will be used to better understand the current situation in these services and to identify areas that might be strengthened. Thank you for your assistance in helping us better understand the services in this district.

Time required: 20 minutes

Voluntary participation: Your participation in this study is completely voluntary.

Right to withdraw from the study: You have the right to withdraw from the study at any time without consequence.

Confidentiality:

Your identity will be kept confidential to the extent provided by law. Your information will be assigned a code number. When the study is completed and the data have been analyzed, the data will be destroyed. Your name will not be used in any report.

Do you have any questions for me?

Yes No

Do you agree to participate in this interview?

Yes No

Agreement:

I have read the procedure described above. I voluntarily agree to participate in the procedure and I have received a copy of this description.

Participant: _____ Date: _____

Principal Investigator: _____ Date: _____