A SOCIOLOGICAL ANALYSIS OF THE NATURE, EXTENT AND COMPREHENSIVENESS OF STIGMA IN PEOPLE LIVING WITH HIV/AIDS IN AREAS OF THE GAUTENG REGION (EKURHULENI, SEDIBENG AND WEST RAND)

By

MAYLENE ELIZABETH MEYER

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SUPERVISOR: DR. DA DU TOIT

CO-SUPERVISOR: MR. HJL ROETS

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DECLARATION

I, Maylene Elizabeth Meyer (with Student Number: 5997178), declare **that *A Sociological Analysis of the Nature, Extent and Comprehensiveness of Stigma and People living with HIV/AIDS in areas of the Gauteng Region (Ekurhuleni, Sedibeng, and West Rand)*,** is my own work, and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references, and that this work has not been submitted before for any other degree at any other institution.

MAYLENE ELIZABETH MEYER **NOVEMBER 2010**

DEDICATION

I dedicate this study to all the members of my family and friends, far and near, dead and alive, mentioned and unmentioned. To my two sons Earl and Che, who I can count on in the hard and good times, you are indeed the apples of my eyes. My gratitude also goes to my aunt Elizabeth April and her son Ricardo April, for their continual support and hospitality.

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ABSTRACT

Besides constituting major obstacle to effectively addressing HIV/AIDS, Stigma has remained among the least understood experiences of PLWHA. Limited knowledge and understanding of HIV/AIDS related S&D has very much contributed to poor implementation and in most cases failure of HIV intervention programmes at national, regional and international levels. Sociological analysis of Stigma in PLWHA lends verifiable insight into the nature, extent and comprehensiveness of HIV/AIDS related Stigma. With 129 participants from Gauteng regions of Ekurhuleni, Sedibeng and West Rand, the study confirms that Stigma and Discrimination (S&D) still thrives, quantifying its magnitude, implications and impacts in the lives of the HIV infected. Inter alia, the findings showcase the complex matrix analysis of emotion and behaviour associated with HIV/AIDS related S&D. Finally, the study offered a comprehensive recommendation on how to address HIV/AIDS related S&D at individual/family, institutional/community and government levels.

Key Terms:

HIV/AIDS; Stigma; Discrimination; Sociological analysis; Emotional Experience; Social context; manifestations; Assessment Scale; Component Matrix Emotion; Component Matrix Behaviour

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LIST OF ACRONYMS AND ABBREVIATIONS

ACORD	Agency for Cooperation and Research in Development
AIDS	Acquired Immune Deficiency Syndrome
ARC	AIDS Related Complex
ARV	Antiretroviral
ART	Antiretroviral therapy
AZT	Zidovudine
CD4	Cluster differentiation 4 (a glycoprotein that is found primarily on the surface of helper T cells; "CD4 is a receptor for HIV in humans" count)
CDC	Centre for disease control
DDC	Dideoxycytidine
DFID	Department For International Development
DRC	Democratic Republic of Congo
FDA	Food and drug administration
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
HIV-1	Human Immunodeficiency Virus Type 1
HIV-2	Human Immunodeficiency Virus Type 2
GRID	Gay related Immune Deficiency
ICRW	International Centre for Research on Women
LAV	Lymphadenopathy-associated virus
MSM	Men who have Sex with Men
PASW	Stats package
PEPFAR	The United states President’s Emergency Plan for AIDS Relief
PLWHA	People living with HIV and or AIDS
SIDA	Swedish International Cooperation Agency
SIV	Simian Immunodeficiency Virus
S&D	Stigma and Discrimination
PASW	Programme used for Statistical Analysis of data
UNAIDS	United Nations programme on AIDS
US	United States
USA	United States of America
UNISA	University of South Africa
WHO	World Health Organization

CHAPTER ONE: INTRODUCTION

1.1 Introduction and Background

Defined by Goffman as an attribute that is significantly discrediting, Stigma and Discrimination (S&D) have been identified as among the major challenges in the fight against HIV/AIDS. Though lots of studies have been conducted on the subject, HIV/AIDS related S&D is still classified as contentious with the public health body of study. Focusing on Stigma as perceived by PLWHA, the chapters of this study provide an insight and helpful basis to measure the nature, extent and comprehensiveness of HIV/AIDS-related Stigma in PLWHA.

Chapter one provides the conceptual framework for conducting the study. It showcases subsections which serve as perimeters and guidelines to the entire process of the study. While the rationale gives the justification upon which the study is considered worthwhile, the goal and objectives section creates the focal perspective to guide the investigations processes and interpretation of the findings. The problem statement reinforces the "what" by asking the necessary question that contextualizes the study. As noted, the study sites were changed from Hillbrow to West Rand, Van der Bijl Park and Ekurhuleni, the reasons of which will be presented in the study site subsection.

Chapter two consists of the literature review on HIV/AIDS related Stigma and Discrimination. It reviews definitions of Stigma and Discrimination in context to the study; the link between Stigma and Discrimination; the causes of S&D and its various manifestations. The chapter also reviews the social processes involved in HIV/AIDS related S&D as a social phenomenon, and the pre-existing conditions associated with it.

Chapter three reflects upon and outlines of the research methodology and the chosen research design, with emphasis on how data was collected and analysed. With a quick highlight on a pilot study, it maps out the sample as well as the processes involved in conducting the project (incl. recruitment of participants, selection of venues, and a discussion of the ethical considerations of the study).

Chapter four provides research results, analysis and interpretation. Furthermore, the biographical data from participants, quantitative results, validity and reliability are explained. It also gives a detailed view of the results of the study both qualitative and

quantitative, including the presentation of the development of two measurement scales, which enables the researcher to measure the nature Stigma, both on a behavioural and emotional level when being diagnosed as HIV positive. The statistical analysis forming part of the study is discussed but the reader is required to note that these statistical analyses represent the comprehensiveness surmised to reflect the level required from A DISSERTAION OF LIMITED SCOPE.

Chapter Five consists of the conclusions and recommendations of the research study that provides insight into the key aspects of the research as well as certain recommendations arising from the research findings. As far as possible, recommendations will be consistent with the research objectives as outlined in this dissertation of limited scope.

1.2 Rationale of Study

Besides being one of the greatest challenges to an effective response to the HIV/AIDS epidemic at different levels of intervention, S&D, as spotted by Jonathan Mann cited in Parker et al (2002: 1), has been one of the poorly understood aspects of the HIV pandemic.

Thus, the rationale for undertaking this study is to measure the nature, and comprehensiveness of HIV/AIDS related Stigma among PLWHA using technical a quantitative measurement instrument and with a slight accommodation of qualitative opinions as voiced by participants. Though dated as far back as 1987, Mann's opinion remain substantial when researching on S&D, coupled with the fact that S&D is in most recent studies still identified as a challenge to winning the fight against HIV/AIDS.

Accordingly, HIV/AIDS-related S&D threaten the effectiveness of HIV prevention and care programs, creating a climate that negatively impacts on effective prevention by discouraging individuals from coming forward for testing, and from seeking information on how to protect themselves and others, thus deepening the adverse impact of living with HIV/AIDS[1].

1.3 Goal and Objectives of Study

The goal of the study is firstly to gain an explorative understanding of the nature and

[1] www.heart-intl.net/HEART/Stigma/Comp/ImpactofAIDSdiscrimination.pdf

comprehensiveness of Stigma as it manifests in people living with HIV (PLWHA) and secondly to determine the following using quantitative and qualitative approaches:

- The nature and extent of Stigma endured by PLWHA.
- Barriers arising from Stigma in particular as it may manifest in human interaction in a selected sample of research participants can create in the implementation of HIV/AIDS related interventions.

1.4 Problem Statement

S&D have been identified in a number of studies and evaluative researches as one of the major obstacles to dealing effectively with HIV/AIDS at global, national, community and personal levels. According to the editor of ACORD newsletter, S&D are labeled among the greatest enemies of the fight against HIV/AIDS (2004: 2). For Nyblade and Carr, in a document prepared for DFID by ICRW, Stigma is the central contributor to the HIV pandemic. Cited in Parker et al (2002: 1), Peter Piot, the executive director of UNAIDS, identified Stigma as a “continuing challenge” that prevents concerted action at community, national and global levels. Furthermore, Jonathan Mann in 1987 cited that Stigma has remained among the poorly understood aspects of the HIV/AIDS epidemic (Parker et al, 2002: 1), which begs the question: To what extent has HIV/AIDS related Stigma (and its associated discrimination) been understood across all intervention sectors, a theme which forms the basis of the present discourse.

This research aims to determine and understand the nature, and comprehensiveness of S&D as perceived by PLWHA; the barriers S&D creates for HIV/AIDS infected and affected in the context of implementing intervention strategies and explore helpful options to reduce HIV/AIDS related S&D especially among PLWHA.

1.5 Study Sites

Initially, this research study was planned to take place with Hillbrow as the target location, but considering circumstantial obstacles in obtaining ethical clearance, tight time frame for the study and the difficulty in getting willing participants to make up for the required sample, the following alternative areas were selected:

- West Rand (Evaton, Carletonville, Randfontein),
- Van der Bijl Park (Polokong, Sonder Water),
- Ekurhuleni (Germiston, Thembisa).

These areas are all within the Gauteng province, and are home to predominantly

Black South Africans, mainly within the low socio-economic class. Communities within the areas are mostly poverty stricken, poorly resourced in many basic amenities (such as water, electricity, housing transport, employment, education, food, recreation), and are rife with people living with HIV/AIDS). Worth to mention that the head office of the National Association of People Living with HIV and AIDS (NAPWA), an organization established with the primary purpose as to provide care and support to PLWHA, is situated within this targeted region, Germiston to be precise. Crucial to the study was the collaboration and cooperation from NAPWA assisted in finding willing participants as samples for the study and more, as what will be seen in the findings.

NB: The change of location was notified and confirmed as appropriate by the Sociology Department, UNISA. Following this, the title of this dissertation had to be changed accordingly.

(For more information on the research venues please refer to page 17 Fig. 3: Data collection routes and venues)

1.6 Conclusion

As HIV/AIDS related Stigma has long been recognised as a crucial barrier to the effective prevention and treatment of HIV/AIDS, more needs to be done to fight it. It is significant to see that research studies are on the increase on HIV/AIDS-related Stigma globally and in Sub-Saharan Africa. Stigma remains to have a profound negative effect on those infected and affected by the disease, as reflected in verbal communication of participants in the study.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

Over the last 30 years, there has been enough scientific evidence that human immune-deficiency virus (HIV) causes AIDS (Kalichman, 2009: 1). As at 2007, not less than 33 million people are living with HIV globally.

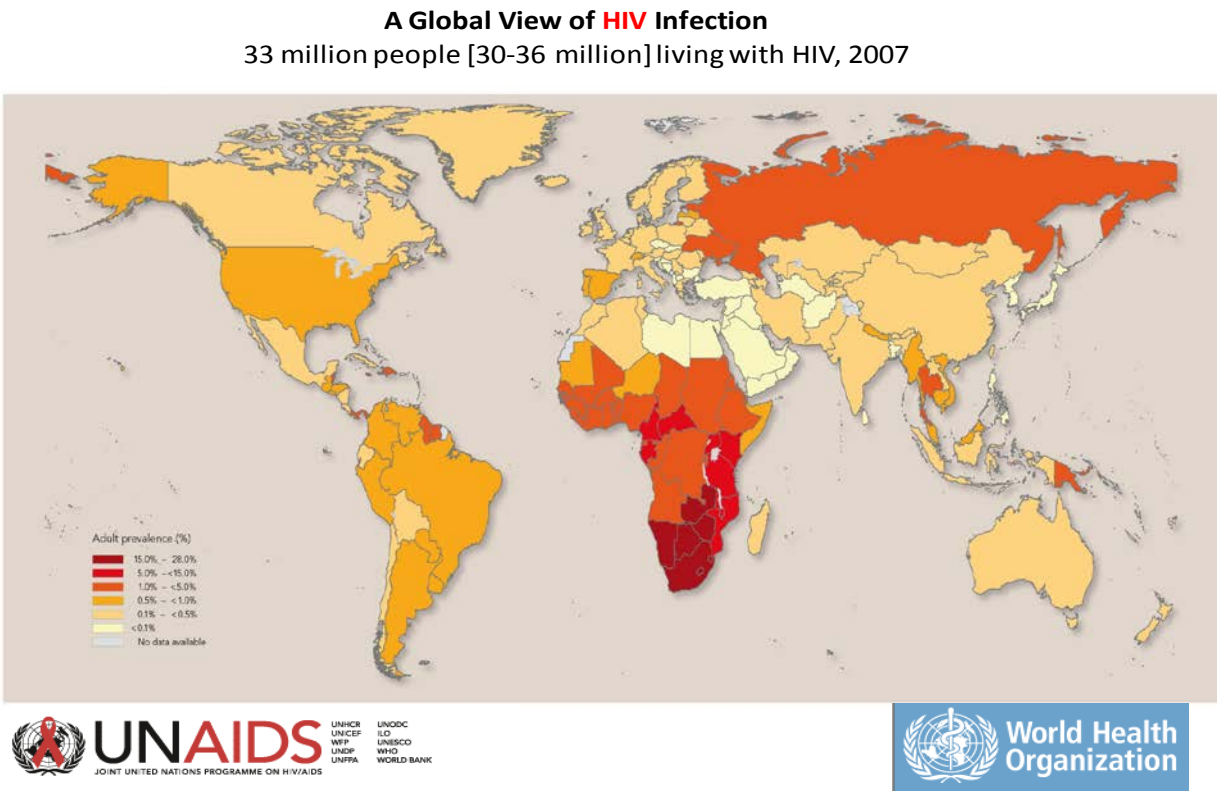

Figure 1: Global view of HIV infection (2007)

Thus far, the historical development of HIV/AIDS has been one marked by eventful experiences and growing understanding that the fight to win the HIV pandemic can only be won with a multifocal approach:

2.2 Historical Development of HIV/AIDS

In the 1930s, from the speculation that some form of simian immunodeficiency virus (SIV) being transferred to humans from chimpanzee meat, the first known case of AIDS (cased by HIV-1) was traced to a sample of blood plasma from a man who died in Leopoldville in the DRC in 1959.

In the 1960s, HIV-2, which was restricted to West Africa, is thought to have been transferred to people from Sooty Mangabey monkeys in Guinea-Bissau during the 1960s. A genetic analysis of HIV in 2003 suggests that it may have first arrived in the

United States in about 1968.

In the 1970s, the concept of AIDS was introduced but not clearly recognized until 1981 (Dane and Miller, 1992:30).

In the 1980s, the first recognized case of AIDS occurred in the USA and was linked to a promiscuous gay Canadian flight attendant who visited the USA (Times Magazine, 19th Oct 1978). However, by 1982, there was enough evidence of non-homosexual cases of HIV infection and thus rendered the name GRID as untenable diagnosis (Fee & Fox, 1988: 198). Thus, by September of the same year, CDC scientists first defined and used the name Acquired Immune Deficiency Syndrome (AIDS) to underpin that apart from gay men, there had been other infection cases (incl. drug injection users, people of Haitian origin and haemophiliacs – i.e. people infected through unscreened blood transfusion). Consequently, three modes of AIDS transmission were identified: sexual intercourse, mother to child and blood.

In 1983, Dr. Luc Montagnier, a virologist from the Pasteur Institute in France conducted research during which the lymphadenopathy-associated virus (LAV) was isolated and later became known as the Human Immunodeficiency Virus belonging to a group of viruses called retroviruses. Later Dr. Robert Gallo of the National Cancer Institute in Washington DC, USA, identified that HIV is the cause of AIDS in 1984. Heterosexually transmitted AIDS is then noticed in a group of African patients in Belgium. Doctors in Zambia and Zaire are aware of a new aggressive form of Kaposi's sarcoma, which had previously been endemic but non-fatal.

In 1984, cases of AIDS passed on through heterosexual intercourse began to appear, and AIDS epidemics were developing in Europe; one in gay men who have visited the US, another in people with links to Central Africa. Investigations began into the occurrence of AIDS in Rwanda, Zaire and other African nations. Western scientists confirm that AIDS was widespread in parts of Africa, with strong indications of heterosexual transmission. The first AIDS research project in Africa, ‘Project SIDA’ was launched in Kinshasha, DRC.

In 1985, the first International AIDS conference was held in Atlanta, USA. Following the previous year's discovery of the HIV virus, the first HIV test was licensed by the

US Food and Drug Administration (FDA). US blood banks were screened for the virus, while Western scientists debated whether "slim disease" in Uganda was a new syndrome or identical to AIDS. Evidence suggested that slims disease could not be distinguished from AIDS and ARC (AIDS related complex) by extreme weight loss and diarrhea. Thus slim disease may not have been a new syndrome but simply identical with AIDS as seen in Africa.

In 1987, AZT (Zidovudine), the first antiretroviral drug, became available to treat PLWHA after a successful clinical trial. The drug worked by blocking the action of HIV's enzyme reverse transcriptase, stopping the virus from replicating in cells. AZT slowed down the course of AIDS, delaying death.

In 1988, WHO declared the first World AIDS Day (1st December). This day was commemorated around the world and celebrated as progress made in the battle against the HIV/AIDS pandemic.

In the 1990s, the red ribbon became an international symbol of AIDS awareness in 1991. In 1992 In the US, AIDS became the leading cause of death amongst 24 to 44 year old men. The first combination drug therapies for HIV were approved and introduced, namely, DDC alongside AZT in 1993. CDC has revised the classification system for HIV infection to emphasize the clinical importance of the CD4+ T-lymphocyte count in the categorization of HIV-related clinical conditions. The AIDS surveillance case definition was expanded to three more clinical conditions: pulmonary tuberculosis, recurrent pneumonia, and invasive cervical cancer also in 1993.

In 1994, AZT was recommended in the USA to reduce the transmission of HIV from pregnant women to unborn fetuses. A study shows it cut the rate of maternal transmission to 8% - in women taking a placebo the rate was 25%. Over 12 years after the discovery of AIDS, the US government launches its first national media campaign explicitly promoting condoms[2].

In 1995, Saquinavir, a new type of protease inhibitor drug becomes available to treat

[2] http://www.cdc.gov/mmwr/preview/mmwrhtml/00018871

HIV. These drugs result in defective HIV forming, which cannot infect new cells. This new more powerful drug heralds the start of Highly Active Antiretroviral Therapy (HAART) - a combination therapy regimen using a "cocktail" of drugs. In March 1995, the VII International Conference for People Living with HIV and AIDS was held in Cape Town, South Africa - the first time that the annual conference was held in Africa. Research in Tanzania confirmed that treating people for sexually transmitted diseases such as gonorrhea reduced their risk of becoming infected with HIV

2.3 Emergence of Stigma as an obstacle in the fight against HIV/AIDS

Hitherto, there have been tremendous steps to fight HIV especially on plain medical and physical sphere. But soon, the balance in the psycho-sociological atmosphere among communities has emerged strongly as almost a decisive factor if the fight against HIV/AIDS was to be won. Initially, the concept of HIV/AIDS related Stigma seemed elusive and unfounded.

At the 2000 International AIDS conference in Durban, South Africa, Stigma was recognized as a major confounding problem of the HIV/AIDS pandemic (Holzemer, 2007: 541). This was followed by the 2006 national survey of the Kaiser family foundation on the impact of Stigma and Discrimination as experienced by the PLWHA. The highlights of the 18th International AIDS conference hosted in Vienna, Austria in 2010 hinted significantly on Stigma and Discrimination, not only for PLWHA, but also for risk groups (e.g. sex workers, drug users, MSM):

- The criminalization of men who have sex with men (MSM) and transgender people in Asia is holding back efforts to contain HIV/AIDS in the region.
- Of the 48 countries in the region, 19 of them – including Afghanistan, Bhutan, Kiribati and Malaysia – have outlawed sex between consenting male adults. These laws are used by vigilantes in ways that lead to abuse and rights violations. The police in these regions also target MSM and transgender people. Such targeting interrupts HIV prevention services and educational programs.
- Data showed that HIV-prevention services in the Asia-Pacific region reach only 9 to 20 percent of men who have sex with men, meaning that countries are falling short of their universal access targets. Unless prevention efforts receive nearly half of all new infections in Asia will be among men who have sex with men by 2020.

- The World Bank report noted the growing prevalence of HIV/AIDS among sex workers as well as other high risk groups in South Asia. Despite prevention and other efforts to reduce high-risk behaviours such as unprotected sex, buying and selling of sex, and injecting drug use, HIV vulnerability and risk remain high.
- Stigmatizing attitudes in the general population and discriminatory treatment by health providers and local officials, among others, intensify the marginalization of vulnerable groups at highest risk, driving them further from the reach of health services and desperately needed prevention, treatment, care, and support services. Daily harassment and abuse also cause health problems and affect mental health, thereby leading to depression, social isolation, and an array of adverse socioeconomic outcomes related to HIV.
- While injection drug use is recognized as a leading cause of HIV/AIDS transmission 25 countries in the Asia-Pacific region still impose the death penalty for offences related to the possession and abuse of drugs, creating a huge Stigma that means abusers often avoid treatment for fear of imprisonment. Drug users still have to go to jail before they can access harm reduction services.

Undeniably, HIV/AIDS is as much about social phenomena as it is about biological and medical concerns (UNAIDS, 2000: 6). Though a lot has been done to mitigate on the spread and impact of HIV (which should be seen as a confidence building measure), however being diagnosed with HIV today still can be as devastating as the illness itself. In most cases leading to job loss, school expulsion, violence, social ostracism, loss of property, and denial of health services and emotional support (ICRW, 2010: 1). This sense of rejection and loss on the part of PLWHA holds as true in the rich countries of the north as it does in the poorer and developing countries of the south (UNAIDS, 2006: 6)**.**

In 1987, Jonathan Mann identified three phases of HIV/AIDS epidemic: the epidemic of HIV, the epidemic of AIDS, and the epidemic of Stigma, discrimination and denial. He went on to note that the third phase is “as central to the global AIDS challenge as the disease itself” (Parker et al, 2002: 1).

2.4 What is Stigma?

Definitions: Erving Goffman (1963) defined Stigma as an attribute that is significantly discrediting possessed by a person with an "undesired difference" (UNAIDS, 2000: 9). For him, Stigma can be categorized into three types: (1) abomination of the body, (2) a blemish of individual character, and (3) tribal Stigmas of race, nation and religion. Put into context, HIV/AIDS related Stigma can be generally associated with the first and second types of Goffman's conceptual categories of Stigma. Cited in Busza (1999: 1), Gilmore and Somerville defined Stigma is an attribute used to set the affected persons or groups apart from the normalized social order, and this separation implies a devaluation.

Expanding on Goffman, Jones et al (1984) noted that people are stigmatized when they possess a "mark" (considered as a deviation from a prototype), seemingly discrediting the bearer of the mark. In other words, possessing a mark of deviance elicit an attributive process through which observers draw negative inferences about a stigmatized individual. The difficulty with this attributionally-based conceptualization of Stigma is that the stigmatized characteristic or "the mark" is not always linked to an underlying disposition that discredits the bearer. People may be stigmatized on the basis of obviously superficial characteristics without corresponding attributions about the stigmatized person's disposition (Derlega and Barbee, 1988:14).

According to Smart, the causes of HIV/AIDS related Stigma are multiple. It can be ignorance or insufficient knowledge as well as misbelief and fears about HIV/AIDS. It can be moral judgments about people and assumptions about their sexual behaviour. It can also be the association HIV/AIDS has with illicit sex and/or drugs, fear of death and disease, or links with religion and the belief that AIDS is a punishment from God.

2.5 Link between Stigma and Discrimination

Discrimination consists of actions or omissions that are derived from stigma and directed towards those individuals who are stigmatized (UNAIDS, 2005: 9). According to Bunting, discrimination is composed of, inter alia the actions or treatment based on the Stigma and directed towards the stigmatized (1996: 67). In relation to HIV/AIDS, discrimination may spring from social disapproval of the infection and its implied behaviours, or from fears due to lack of knowledge about how HIV/AIDS can or cannot be transmitted. But however is the case, the concepts of Stigma and

Discrimination are so closely linked that they are often referred to together and at other times used almost interchangeably. Accordingly, some authors choose to refer to discrimination as “enacted Stigma” (Busza, 1999: 2).

2.6 Manifestations of Stigma and Discrimination

Policy and Legal Contexts: S&D can take various forms and manifestations. First and foremost, HIV/AIDS-related S&D is commonly manifested in the form of laws, policies and administrative procedures, which at times are often justified as necessary to protect the general population (Kirp and Bayer, cited in Parker et al, 2002: 5). Key examples of this include things like; compulsory screening and testing for HIV, restriction of the right to anonymity, prohibition of PLWHA from certain occupation, even compulsory treatment of infected person etc (Gostin and Lazzarini, cited in Parker et al, 2002: 5).

Institutional Contexts: In academic institutions, children with HIV/AIDS or associated with HIV through infected family members have often been stigmatized and discriminated against by classmates or colleagues. Workplaces are also common grounds for S&D. Such practices as pre-employment screening, denial of employment or termination of employment of PLWHA, and mistreatment of individuals based on their HIV status underscores inherent stigmatization and discrimination (Parker et al, 2002: 6). In health care systems, there have been incidents of HIV testing without individual’s consent, breaches of confidentiality, and even denial of treatment and care (Andolan 1993; Tirelli et al. 1991; Carvalho et al. 1993; Panebianco et al. 1994; Ogola 1990; Masini and Mwampeta 1993, cited in Parker et al, 2002: 6).

Even within HIV/AIDS programs and in some religious institutions, PLWHA are not given same social accommodation and tolerance as others. HIV/AIDS related S&D has been reinforced by religious leaders and organizations, which has used their power to maintain the status quo rather than to challenge negative attitudes towards the marginalized as PLWHA (Parker et al, 2002: 6).

Community Contexts: For instance, in communities where cultural systems place great emphasis on individualism, HIV/AIDS may be perceived as the result of personal irresponsibility, and thus individuals are blamed for HIV status (Kegeles et

al. 1989, cited in Parker et al, 2002: 7). On the other hand, Panos and Warwick (cited in Parker et al) purported that in communities where cultural systems place greater emphasis on collectivism, HIV/AIDS may be perceived as bringing shame on the family and community (2002: 7). In a nut shell, no matter the society, PLWHA can hardly share equally social status and relationship as others.

Family Contexts: Instead of being the main source of care and support for PLWHA especially in most developing countries, negative family responses to infected individuals are often source of S&D in the home (2002:8).

Individual Contexts: According to Parker et al, the way in which HIV/AIDS related S&D manifest in individuals depends on family and social support and the degree to which people are able to be open about such issues as their sexuality as well as their serostatus (2002: 8). For Daniel and Parker (cited in Parker et al, 2002: 8), in contexts where HIV/AIDS is highly stigmatized, fear of HIV/AIDS related S&D may cause individuals to isolate themselves to the extent that they no longer feel part of community and thus are unable to gain easier access to services and support they need, a circumstance which sometime result in fatality.

2.7 Understanding S&D as Social Processes

According to Parker et al, social and political theory can help understand that S&D are not isolated phenomena or the expression of individual attitudes, but are social processes used to create some sort of social control and to produce and maintain social inequality (2002: 9). Just like most cultural meanings and practices embody interests used to enhance social distinction between individuals, groups and institutions, S&D is used to create difference and social hierarchy. Often used by dominant groups to produce, legitimize and perpetuate social inequality, these social processes exert great sense of hegemony on the stigmatized and some cases convince them to accepting existing hierarchies and allow social hierarchies to persist over generations (2002: 9).

However, to better understand S&D as a social process, we examine pre-existing conditions associated with S&D: sexuality, gender, race, and class (2002:1).

HIV/AIDS related S&D are closely related to sexual Stigma. This is because HIV is mainly sexually transmitted and the fact that the disease initially affected population

whose sexual identities are different from the “norm”. Thus, HIV/AIDS related S&D appropriated and reinforced the pre-existing sexual Stigma associated with sexually transmitted diseases, homosexuality, promiscuity, prostitution, and other forms of sexual “deviance” (Gagnon and Simon 1973; Plummer 1975; Weeks 1981, cited in Parker et al, 2002; 2)

Other pre-existing conditions that reinforce HIV/AIDS related Stigma are Race and ethnic S&D. The epidemic has at different times been characterized by racists as an African disease and at other times HIV/AIDS has been seen as the outcome of the West’s “immoral behaviour”. These pre-existing negative perceptions and assumptions has exacerbated the pervasion of HIV/AIDS related S&D especially among minority groups (Parker et al, 2002: 2).

Class inequality is part and parcel of almost every society. Besides, the rapid globalization and the growing polarization between the rich and poor has reinforced pre-existing social inequalities and stigmatization of the poor, homeless, landless and jobless. As a result, poverty increases vulnerability to HIV/AIDS, and being perceive as poor reinforces S&D especially for PLWHA (Parker et al, 2002: 2).

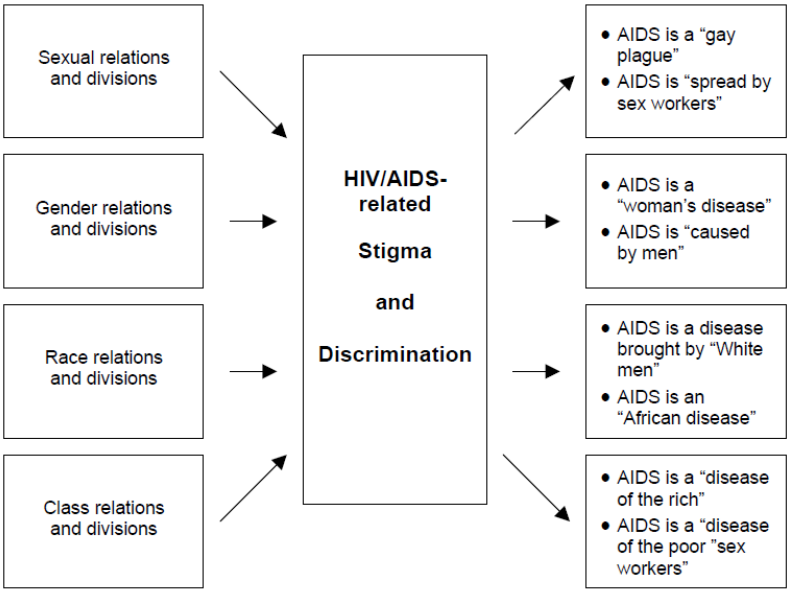

Figure 2: Link between HIV/AIDS and pre-existing sources of S&D (Parker et al, 2002: 3)

2.8 Stigma and Discrimination: Where Are We, Today?

Undoubtedly, a lot of work has been done to address HIV/AIDS related S&D. However, HIV/AIDS related S&D has remained among the most challenging obstacle in fight against HIV/AIDS. According to Edward Cameron of Constitutional Court of Justice in South Africa (2007), HIV/AIDS is probably the most stigmatized disease in history. He went on to say that if we do not appreciate the nature and impact of Stigma, none of our interventions can begin to be successful. HIV/AIDS related S&D compromises every aspects of intervention against the epidemic. It undermines prevention, treatment, care and support initiatives and strategic implementations (ICRW, 2010: 2).

Hence, there is need for continual research study to better understand S&D as in the theme of the research discourse: to understand through sociological analysis the nature, extent and comprehensiveness of Stigma in PLWHA.

2.9 Conclusion

The dialogue about and around HIV/AIDS-related Stigma has clarified that in as much as PLWHA have to deal with the symptomic diseases associated with HIV/AIDS and S&D, the latter is overridingly much worse than the disease itself. With several potential causes and manifesting in various forms, HIV/AIDS-related Stigma has negative effects on PLWHA and those also affected by HIV/AIDS. HIV/AIDS related S&D has social processes that puts into context pre-existing conditions that reinforces S&D for the infected and affected of HIV. In order to ensure adequate and successful interventions in the lives of PLWHA and AIDS, the issue of Stigma must be addressed pertinently, and comprehensive inherent support should be built into intervention programmes. Today, 30 years later HIV/AIDS-related S&D remains one of the leading barriers to effectively manage the HIV/AIDS pandemic globally.

CHAPTER THREE: RESEARCH METHODOLOGY AND DESIGN

3.1 Pilot Study

As in any empirical research, a pilot study was performed in order to identify and resolve potential gaps and shortfalls that may constitute problems in the research project.

The pilot study took place in Germiston, at NAPWA's headquarters whose members constituted largely the greater proportion of the participants. NAPWA stands for National Association of People Living with HIV/AIDS. Considering logistical difficulties and problems in finding willing participants, NAPWA was approached for assistance. The justification for approaching NAPWA was intended to highlight their role in helping finding potential participants contributing to the study and its findings while maintaining the fine line in observing ethical and confidentiality issues surrounding HIV/AIDS related studies.

Participants gathered in one of the offices, including the researcher, the study promoter, and a NAPWA Regional Coordinator. The purpose and intent of the research was explained to participants, who were requested to sign informed consent forms and had the research questionnaire explained to them in reasonable detail. The session took +/- 40 minutes including completing of the questionnaires by participants.

Following the pilot, it became apparent that the research questionnaire needs more clarification and adjustment; not only to be understood by the participants, but also aid interpretation of collected data especially in the quantitative analysis. They (the participants) informed the researcher that Stigma "in the beginning" [with diagnosis] was worse than when already living with the condition for a period of time. This factor motivated the researcher to include the time span of being HIV+ (this question was voluntary) in the biographical section of the questionnaire. Moreover, most of the participants were unemployed. Hence, all questions related to Stigma in the workplace were removed from the questionnaire. Participants did not understand as much the concepts of ***polygamy*** and ***monogamy***, therefore that question was also removed from the questionnaire.

Besides, it is beneficial to highlight that the targeted area of the pilot fall within the

designated areas of the actual research: West Rand (Evaton, Carletonville, and Randfontein), Ekurhuleni (Tembisa, Germiston), PWV-Area (Vanderbijlpark), and Vaal (Polokong, Khutsong, and Sonderwater), as illustrated in the figure below.

Research Venues

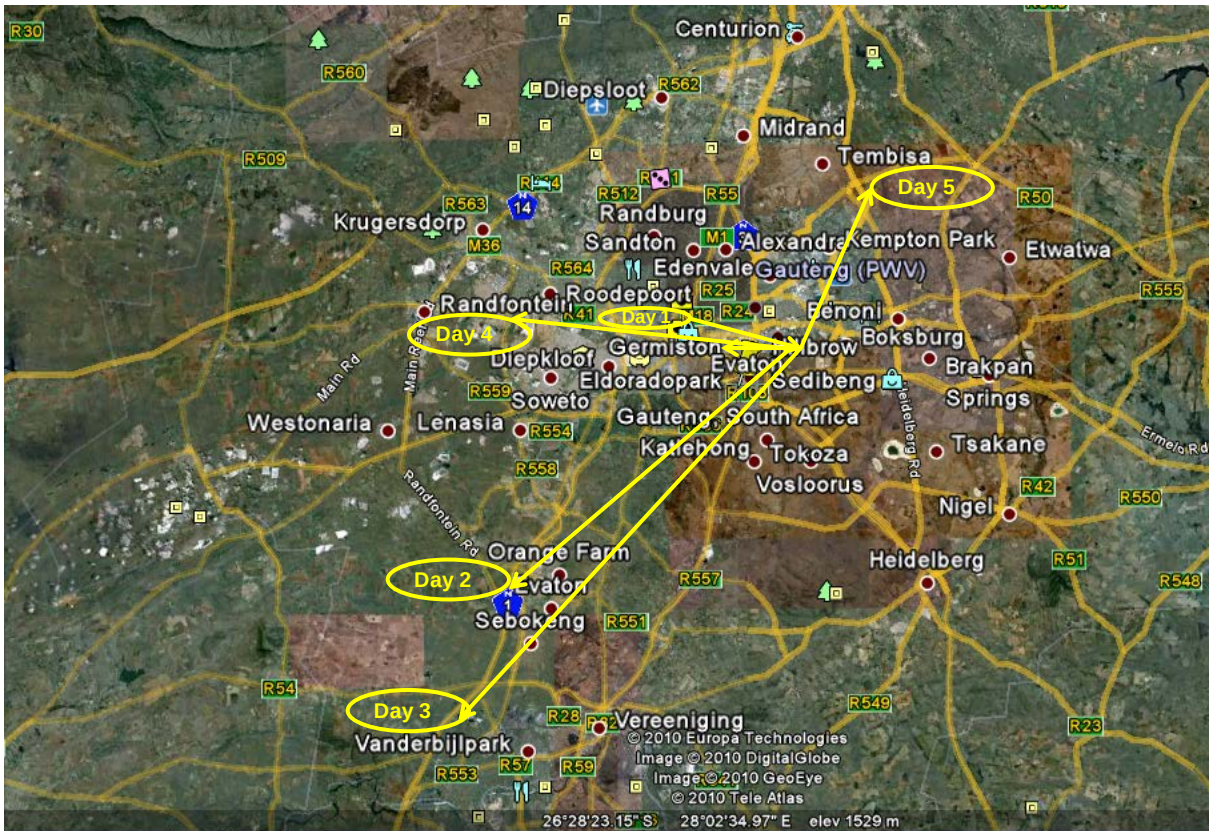

Figure 3: Data collection routes and venues

3.2 Sample & Recruitment of Research Participants

The sample was a non-probability sample, which NAPWA has identified and coordinated according to the researcher's requests. Therefore access was gained to interview participants in such remote areas that would never have been reached without NAPWA's assistance. Altogether 129 out of 150 participants completed questionnaires. The other outstanding 21 questionnaires were spoiled.

3.3 Chosen Research Design

This study was designed to be quantitative in nature. It is the first attempt to construct a predominantly quantitative measurement instrument including qualitative elements, found particularly in the demographical section of the questionnaire as well as a set of continuous scale questions. This type of scale would enable the

researcher to measure the extent, depth, and comprehensiveness of Stigma amongst PLWHA.

3.4 Data Collection Methods

The data was collected from the participants by means of a questionnaire extracted from a wide literature study, and refined by the pilot study. Due to participant literacy levels in general, emoticons (Smiley's) were inserted above each scale score to elucidate understanding of the scale, and facilitation of the questionnaire took place without compromising the scientific standards of excellence needed to be maintained in studies of this nature. The researcher, after completing the pilot study, and finalising and refining the research questionnaire, commenced with fieldwork on the sites as approved and provided by NAPWA.

The fieldwork was conducted during the period of October 2010. 8 fieldworkers from NAPWA co-ordinated and identified venues and, additionally, assisted with the selection of participants in Sedibeng, West Rand, and Ekurhuleni with the researcher, in consultation with the research promoter. To ensure compliance and data quality, fieldworkers were trained on informed consent procedures, maintaining of confidentiality, interviewing skills and completion of the study questionnaires. Fieldworkers were recruited from the community where the research was conducted to fit participants' demographic characteristics (e.g. race, ethnicity, language etc.). The Ekurhuleni fieldworker communicated and consulted proactively with the co-ordinators from closed and open support groups of PLWHA in the specific areas. The purpose of this was to advise the co-ordinators about the research study being conducted and encouraged them to facilitate participation. Communication strategies included communication through cellular phones with provincial secretaries, and interviews and completion of questionnaires were done on the specific days of the week when support groups meet. Fieldworkers were monitored on site by the researcher to ensure that they complied with all the ethical provisions of the study and checked that questionnaires are completed correctly.

The researcher could contact her promoter any time when encountering problems in the field to ensure that the study is carried out according to the agreed protocol. For example, certain people that were affected by HIV/AIDS, but not infected themselves, wanted to participate in the research study (for example care givers and family

members). When no venue was available, the co-ordinator organized participants (who willingly agreed) to an open field to continue with the empirical part of the research study. All the latter participants were living openly and positively with HIV. Some participants asked whether they can complete the questionnaire if they have not yet disclosed their HIV positive status, which was answered affirmatively. Daily progress reports on fieldwork were written and emailed to the promoter, and later taken up in the reporting of the research findings (please refer to Appendix F).

3.5 Analysis and Interpretation of Data

The data obtained from the questionnaire was subjected to analysis of the demographic traits of the sample, and Confirmatory Factor Analysis as well as Reliability Analysis of the two reliable measurement scales extracted from the research process was performed. Please refer to Chapter 3 for a detailed description of this process, as well as Appendix E in this ***dissertation of limited scope***. It is important to mention the scope of the dissertation at this stage of the research report, since many research findings can be drawn from the database resulting from the research. In line with advice obtained from the Head of Department of Sociology, as well as senior research experts in the Department, it was decided to contain the reported findings to the exposition of relatively high level demographic information, and the measurement of the sample on the two scales. This includes observation of central measures (the mean, mode, and median), and how these measures related to the distribution on the scales with regard to the scale midpoint, and the nature of the distribution on the scales.

3.6 Ethical considerations

This proposal was approved by the University of South Africa's Research Ethics Committee in October 2010, and adheres to the ethical standards of the Ethical Research Policy of UNISA.

3.6.1 Anonymity and Confidentiality

Interviews and completing of the questionnaires were held in designated venues, sometimes "sink plate" shacks provided by the provincial secretaries/ co-ordinators or fieldworkers from specific areas. Efforts were made to avoid interference from other members of the community. In addition, no names of individuals were recorded on

the questionnaires.

3.6.2 Access to Participants

Please refer to Appendix D.

3.6.3 Informed Consent

All youth and adults who agreed to participate were required to provide either written or verbal consent for participation in the research.

The research study, as already mentioned, adhered to the ethical research policy of UNISA. The following is a description of the process that was adhered to for obtaining informed consent:

- All adult participants (18 years and older) who agreed to participate were required to provide written consent. Where participants were illiterate a thumbprint was given on the consent form. Furthermore a witness also signed the consent form to certify that informed consent had been given by a participant.
- Field workers, provincial secretaries from NAPWA were trained in informed consent procedures.

3.7 Conclusion

This chapter was divided into two parts. The first part was the exposition of the research methodology and the second part will deal with the findings of the study. In the first part the research aim, the rationale for the study, the design, participants and the procedures of data collection were explained, as well as the ethical considerations that were observed during the study.

CHAPTER FOUR: RESEARCH RESULTS AND INTERPRETATIONS

4.1 Introduction

This chapter outlines the statistical findings of the study and include both quantitative, and to a lesser extent qualitative results and findings. Tables and graphs are presented to illustrate the results obtained. The findings in this chapter are reported in terms of the responses to the questionnaire.

4.2 Biographical Data of Participants

The questionnaire was compiled to accommodate certain biographical data of the participants (it was made clear during the process that this section is voluntary), such as age, gender, religion, employment, culture, marital status, and how long the participants have been HIV+. The results of this data collection are displayed below:

4.2.1 Age groups

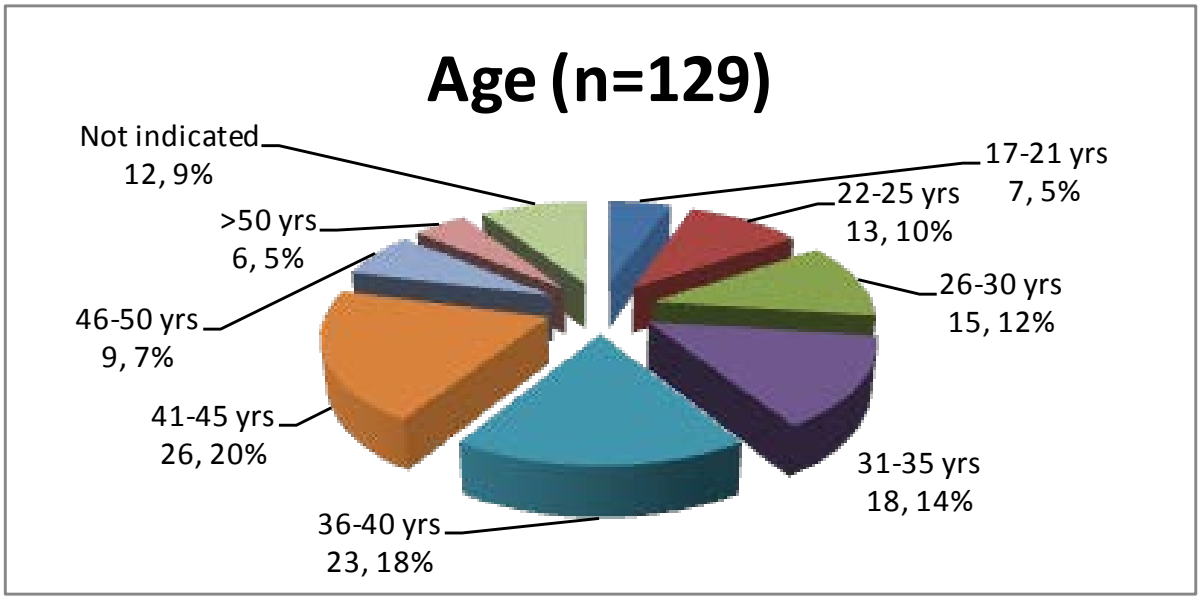

Figure 4: Age breakdown of participants

From the above graph, it is apparent that most participants fell in the age groups of 36-40 years, and 41-45 years (42%). The smallest number (6,5% of the sample) fell in the age group of 50 years and above. Though the UNAIDS survey (2008) (please refer to List of Sources) confirmed enlisted Africans between the age of 31 – 35yrs as one of the At-Risk groups, the large segment of people within this age bracket as suggested by the sample can be explained by the sporadic and randomised sampling

which in respecting confidentiality of individuals has not guaranteed the evenness of the sample, a fact which is highlighted as one of the limitations of the study.

4.2.2 Gender

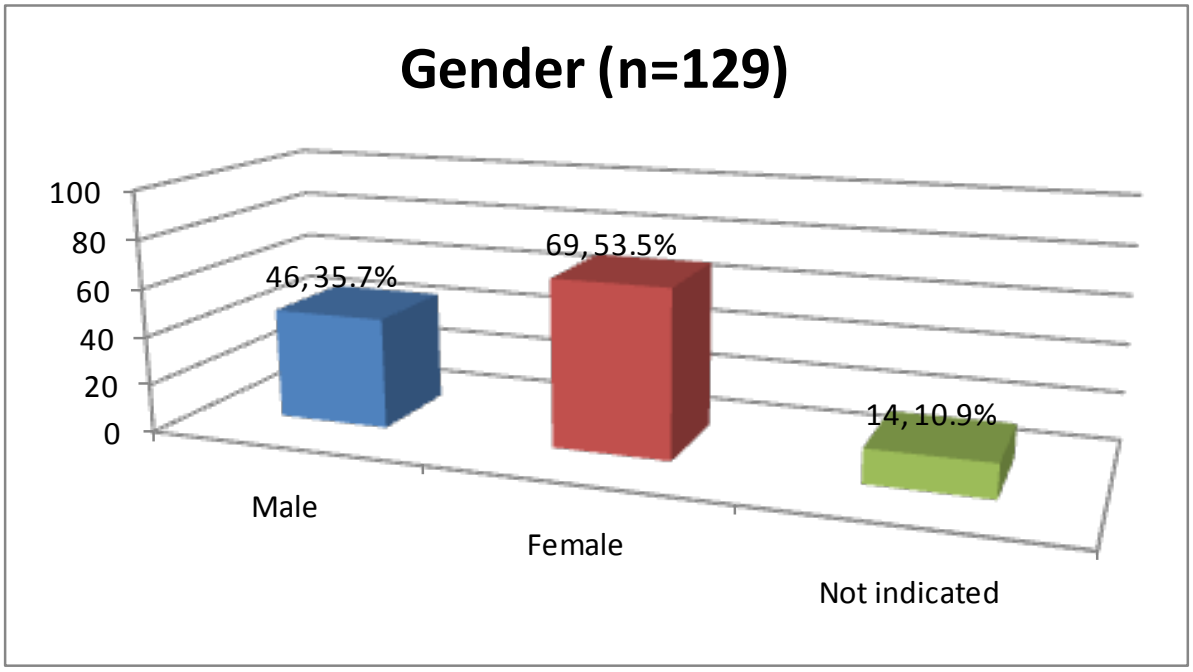

Figure 5: Gender Analysis

The graph indicates that the majority of participants were female. According to UNAIDS survey (2008), HIV prevalence remains disproportionately high for females overall in comparison to their male counterpart, a figure which has remain unchanged for some time now and evident in this study. Besides, the vulnerability of women to HIV as opposed to men has been estimated as high as two to one especially between the ages of 25 to 29 years.

4.2.3 Religion

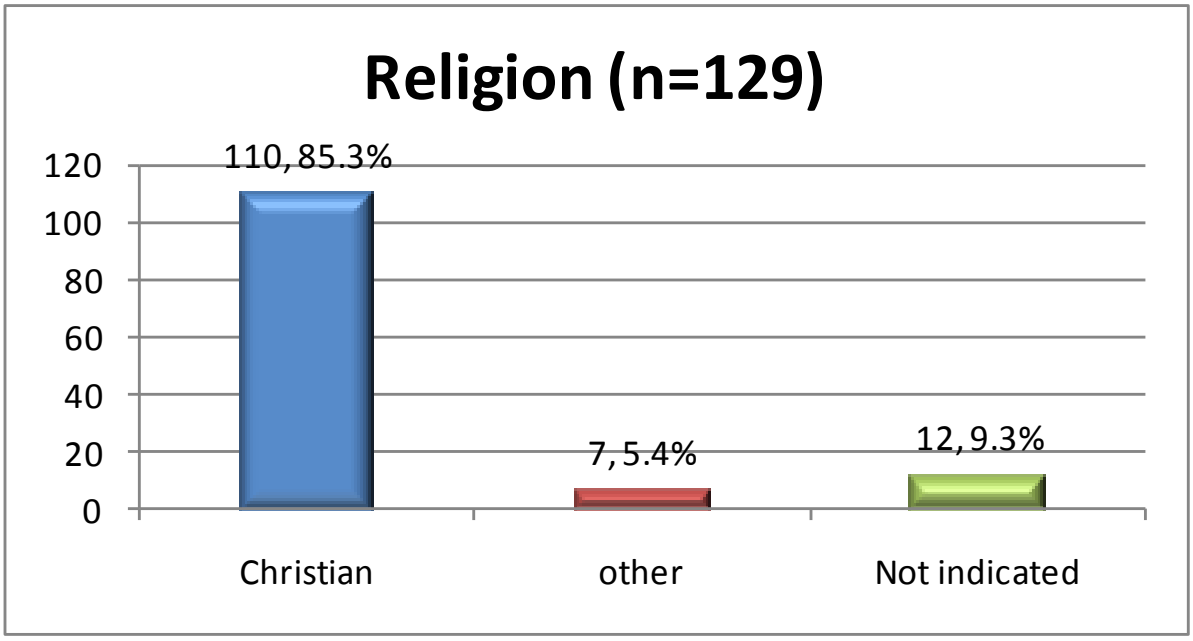

Figure 6: Religion Affiliation Analysis of the Participants

The graph indicates that a very high proportion of the sample were Christians. Though this decomposition tallies with the 2001 census (which saw the Christian population of South Africa at approximately 80%), the statistical significance of this data is apparent when an allusion is made of it to HIV related Stigma. Accordingly, the fact of HIV is treated as that of moral judgement. A religious leader in Zambia who discussed HIV-positive patients in a local clinic once said, “Those patients are promiscuous…careless with themselves. God is punishing them for disobedience…and that HIV is not traditional in nature, but an example of what God can do to those who disobey His commandments” (International Centre for Research for Women, 2006: 4).

4.2.4 Employment

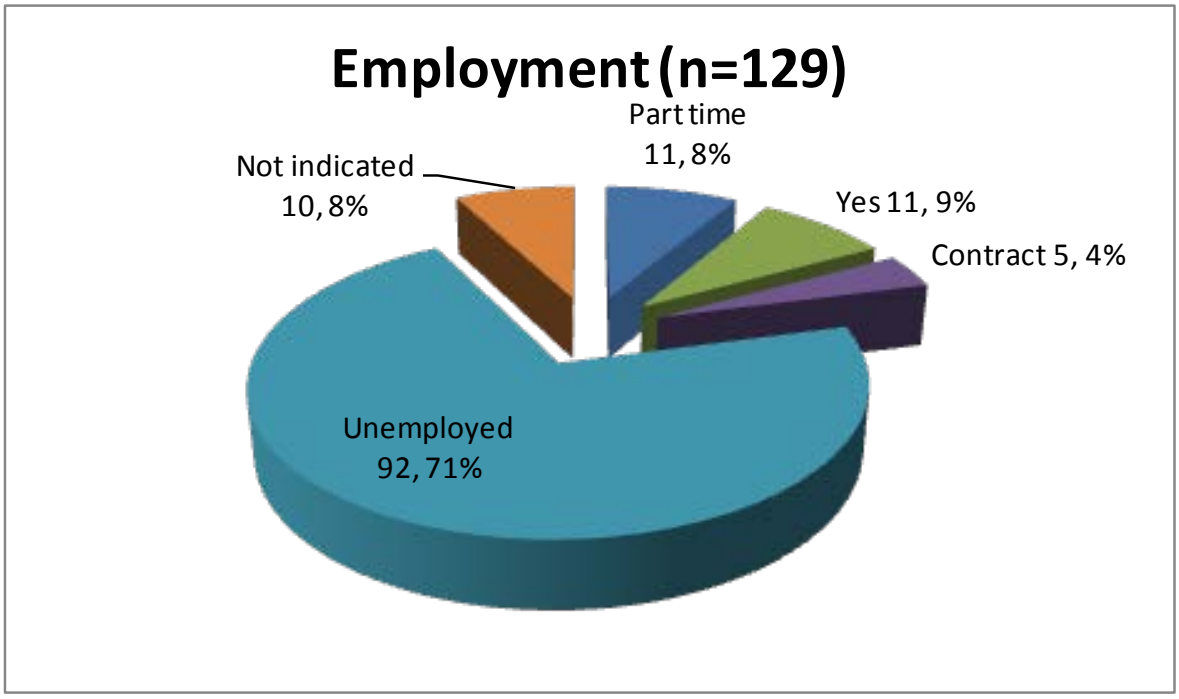

Figure 7: Employment status of the participants

As indicated during the pilot study already, a very high proportion (78%) of participants were not employed in the formal labour market and the informal sector, which can be an indication of Stigma, as well as the fact that literacy levels were such that it contributed to the fact that many participants just could not find employment because of their levels of illiteracy and the labour market that is relatively closed as a result of perpetuating economic recessions, both nationally and internationally.

4.2.5 Culture

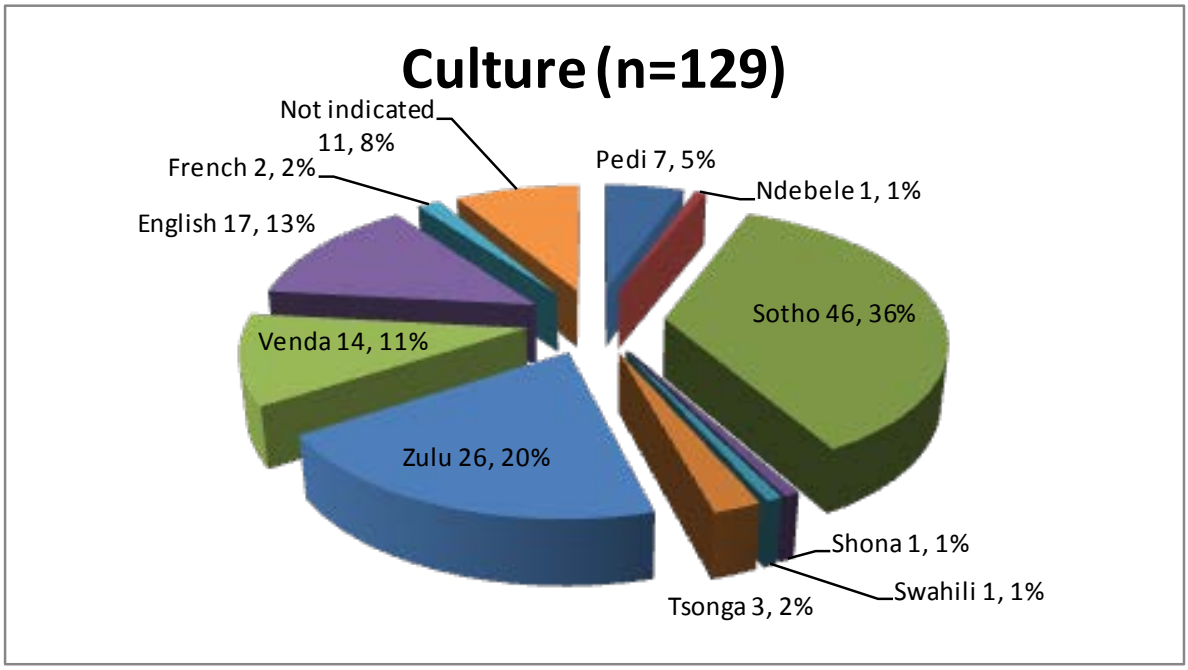

Figure 8: Culture

The highest proportion of participants was Sotho and Zulu. Swahili may be an indication that Zimbabweans were included in the sample, and French may be an indication of the possible presence of participants from the Democratic Republic of Congo and other French-speaking previous African colonies.

4.2.6 Marital Status

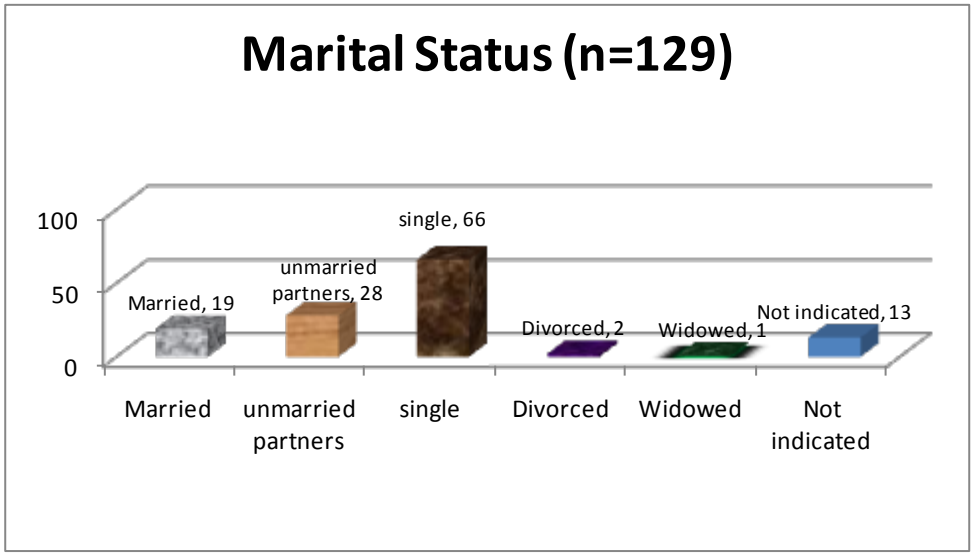

Figure 9: Marital Status of the participants

The marital status graph indicates that more than 50% of the sample were single, which again can be attributed to Stigma and some level of isolation experienced in behaviour towards them by, for example, significant others in their lives. Based still on the above cited UNAIDS survey (2008), HIV prevalence has been significantly high among singles and the unmarried, a fact which is verily underscored by the marital decomposition of the participants.

4.2.7 Period being HIV+

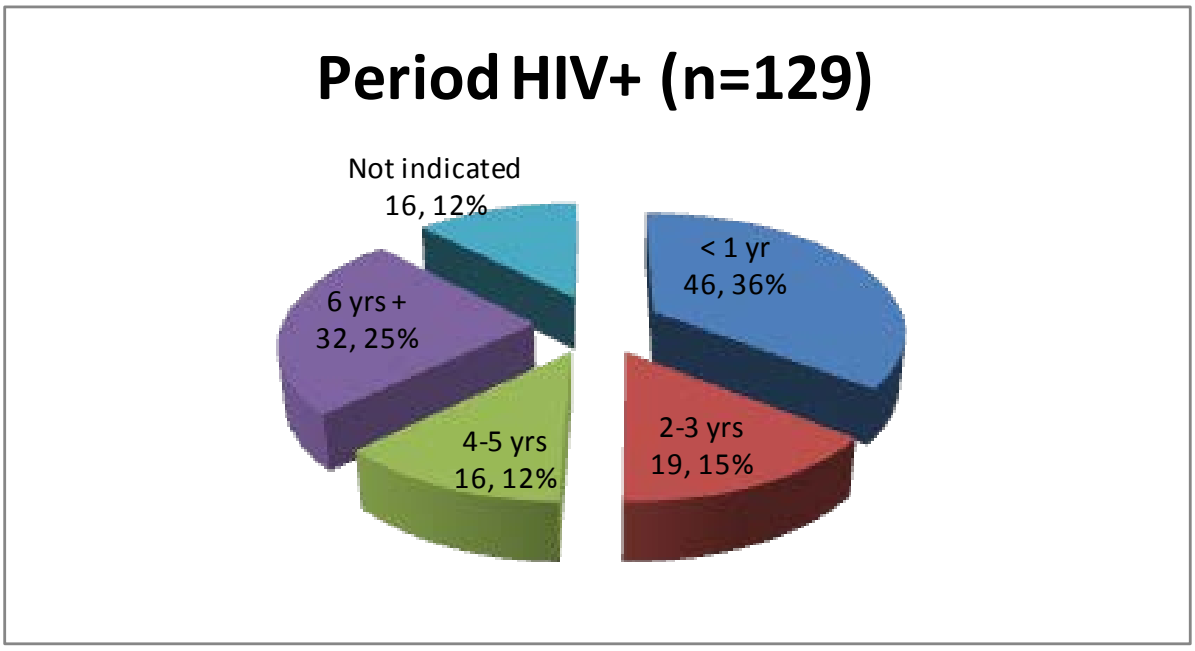

Figure 10: Length of time the participants have been HIV positive

In the sample, 41% of participants were HIV+ for less than one year, whereas 28% of participants were HIV+ for more than 6 years. It raises an important question about the reach of and success of HIV Prevention Programmes and the distribution of ARV's in general, and may also be an indication that levels of awareness of the condition are elevated, that more people are prepared to go for tests, and that awareness programmes are becoming more effective, taking into consideration the remoteness of some of the research sites.

4.2.8 Area

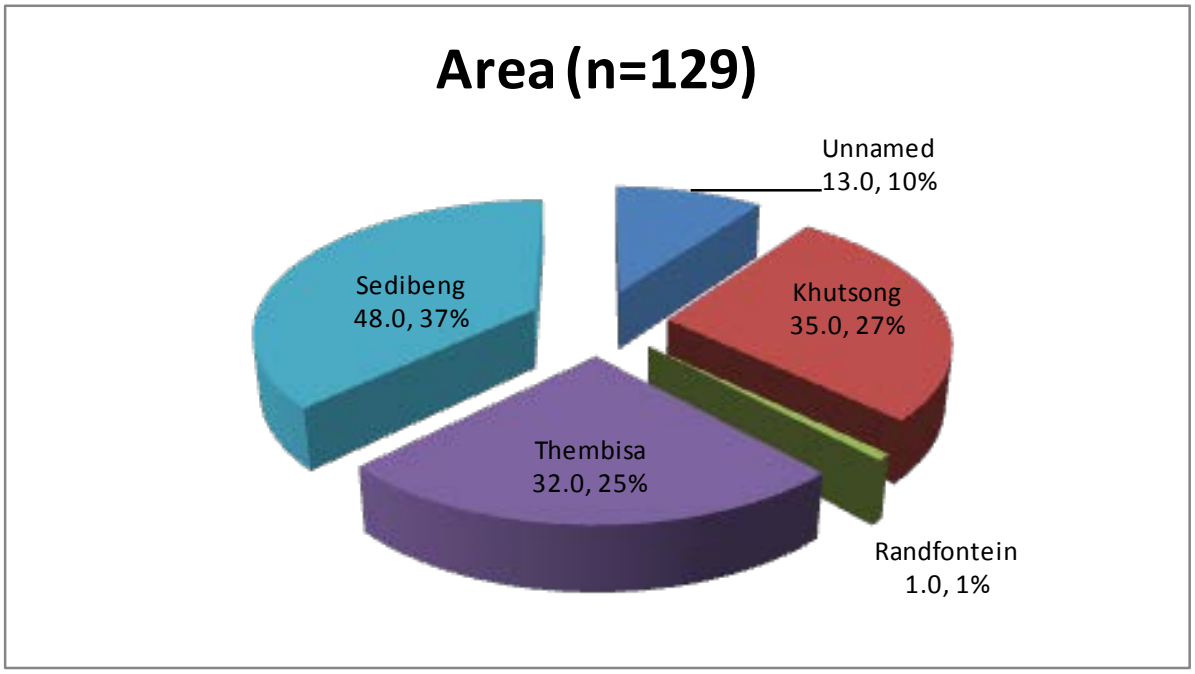

Figure 11: Areas from where the participants were chosen

The areas of Sedibeng, Khutsong, and Thembisa displayed the highest numbers of participants, respectively 39%, 29%, and 26%. This is attributed to the function of population density in the particular areas.

4.3 Research Results

Since this study is a ***dissertation of a limited scope***, descriptive statistics was performed, such as the number of participants falling into each category in the demographic questions (please refer to the questionnaire in Appendix B), and forms part of the small portion of qualitative research performed in the study. Furthermore, the computation of the frequency distribution (the count of responses given by participants on the individual scale items) was performed, and graphically displayed the count of the scores on the individual items (answers on the questions in the questionnaires) on the 5-point Likert-type scale used in the questionnaire. Henceforth questions will be referred to as ***items*** (please refer to Appendix B). Two unitary quantitative measurement scales measuring Stigma were extracted.

With the aid of the PASW Statistics 18 Programme (a programme similar to SPSS – the Statistical Package for the Social Sciences), the dataset was forthwith subjected to a Principal Component Analysis with a Kaiser's Normalisation specifying the

retaining of factors with Eigen values ("cut-off points") greater than or equal to one on all the scaled questionnaire items. Items with factor scores lower than 0.65 were eliminated, as well as factors with an Eigen value lower than one. The Confirmatory Factor Analysis procedure (CFA - a statistical technique used to verify the factor structure of a set of observed variables) allows the researcher to test the hypothesis that a relationship between observed variables and their underlying latent constructs. The research uses knowledge of the theory, empirical research, or both, to postulate the relationship pattern a priori and then tests the hypothesis statistically[3]. Items with loadings lower than between 0.60 and 0.65 were iteratively eliminated until scale items with loadings higher than 0.60 and 0.65 converged into components. After analysis of the respective (a "cluster" of items - please refer to Tables 1 and 2 below) as outputs of the Factor Analyses, two strong unitary components were extracted.

In order to determine the reliability of the resultant components, the items in the factors were subjected to a Reliability Analysis in order to determine Cronbach's Alpha, which measures the internal consistency of the factors extracted, later to be referred to as measurement scales.

The first component displayed the following scale items retained in the factor analysis extracted from the data set:

[3] http://www2.sas.com/proceedings/sugi31/200-31.pdf, (accessed on August 12, 2011)

Component Matrix[a]

Question/item	Component	
	1	2
verbal abuse2	.723	-.155
verbal abuse3	.646	-.467
Self-perception7	.589	.323
Healthcare9	745	041
Healthcare10	.655	.560
Healthcare11	.705	.361
Social isolation12	.775	-.092
Social isolation13	.719	-.045
Social isolation14	.719	-.357
Social isolation15	.743	-.300
Social isolation17	.703	.254
Social isolation18	.695	-.099
Emotions25	.702	.065

Extraction Method: Principal Component Analysis.

a. 2 components extracted.

Table No. 1: Component Matrix Behaviour

The items concentrated in the first component represent, upon analysis of the scale questions, a measurement scale measuring the experience of the ***behaviour*** towards the participants with ***diagnosis and thereafter***. It is suggested that this scale, containing 12 scale items be named the ***Stigma Diagnosis and Behaviour Assessment Scale***. The Cronbach's Alpha for this scale is 0.914, indicating that the scale is highly reliable. The second component was discarded due to weak loadings.

The second component displayed the following scale items representing respondent scores on the 5-point Likert-type measurement scale as displayed in the questionnaire (please refer to Appendix B) retained in the factor analysis extracted from the data set:

Component Matrix[a]

Question/item	Component
	1
Emotions20	.885
Emotions21	.829
Emotions22	.851
Emotions23	.775
Emotions24	.748

Extraction Method: Principal Component Analysis.

a. 1 component extracted.

Table No. 2: Component Matrix Emotion

The items concentrated in the second (above) component represent, upon analysis of the scale questions, resulted in a measurement scale measuring the ***Emotional Experience of Diagnosis and thereafter***. It is suggested that this scale, containing 5 scale items be named the ***Stigma Emotional Experience of Diagnosis and thereafter Assessment Scale***. The Cronbach's Alpha for this scale is 0.876, indicating that the scale too, is highly reliable.

4.4 Validity and Reliability

The pilot study served as a prime run to test the questionnaire developed out of the literature study. Only 15 participants could be recruited to partake in the pilot study. These participants, however, gave invaluable feedback in terms of the timeframe to be addressed in the questionnaire (with initial diagnosis) and which items needed to be reformulated and discarded. For example, it was clearly indicated to the researcher that polygamy as an intervening or contributory variable will not be relevant in this study. Accordingly, it did not have a noteworthy influence in the origination of Stigma related to HIV/AIDS. The questionnaire was therefore subjected to accommodate the inputs and opinions gathered from the pilot study. The literature study provided the researcher with thorough ***content*** validity, whereas the questionnaire revealed ample ***face*** validity, as proven by the overall scores on the scales and the spread with which the individual scale questions were answered (please refer to Appendix E).

Statistical validity (indicated by item loadings above 0.50) was achieved through comparison of the factor scores in the Component Matrix with the scores achieved as output in the Communalities, as illustrated in the tables extracted below:

Factor 1 - **Validity**

Component Matrix[a]

Question/item	Component	
	1	2
verbal abuse2	0.723	-0.155
verbal abuse3	0.646	-0.467
Self-perception7	0.589	0.323
Healthcare9	0.745	0.041
Healthcare10	0.655	0.56
Healthcare11	0.705	0.361
Social isolation12	0.775	-0.092
Social isolation13	0.719	-0.045
Social isolation14	0.719	-0.357
Social isolation15	0.743	-0.3
Social isolation17	0.703	0.254
Social isolation18	0.695	-0.099
Emotions25	0.702	0.065
Extraction Method: Principal Component Analysis.		

a. 2 components extracted.

Communalities *(indication of the variance of the scores – how far the variables lie from the central values)*

Question/item	Extraction
verbal abuse2	.546
verbal abuse3	.636
Self-perception7	.452
Healthcare9	.557
Healthcare10	.743
Healthcare11	.627
Social isolation12	.609
Social isolation13	.519
Social isolation14	.644
Social isolation15	.643
Social isolation17	.558
Social isolation18	.493
Emotions25	.497
Extraction Method: Principal Component Analysis.	

Table 3: Component Matrix and Communalities: Behaviour

The rule of thumb is that the cut-off point for items to be retained in Communality Matrices is that they should reflect a score of 0.5, as determined by the Statistical Package for the Social Sciences. Although certain item scores in the Behaviour communalities matrix are equal to the cut-off point of 0.5, (see va2, sp7, hc9, si13, si17, si18, and e25), the items were retained in the factor analyses and in the confirmatory factor analysis iterations. Only two item communalities in the factor Emotions were equal to 0.5 (si18, and e25). The researcher therefore retained these items in the scale. (Please see Table 1: Component Matrix above). It is anticipated that further research will confirm inclusion in the factors and therefore refine the factors.

Factor 2 - Validity

Component Matrix

Question/item	Component
	1
Emotions20	.885
Emotions21	.829
Emotions22	.851
Emotions23	.775
Emotions24	.748

Extraction Method: Principal Component Analysis.

a. 1 component extracted.

Communalities

Question/item	Extraction
Emotions20	.783
Emotions21	.688
Emotions22	.724
Emotions23	.601
Emotions24	. 600

Extraction Method: Principal Component Analysis.

Table 4: *Component Matrix and Communalities: Emotion*

In terms of validity, the communalities exhibit scores of above 0.6 and are therefore all included in the factor. Again, one factor loading was retained in the factor (Emotions24), although it loaded 0.600

4.5 Interpretation of Research

4.5.1 Stigma Diagnosis and Behaviour Assessment Scale

The participants' distribution of scores on the scale below reflects and measures the diagnosis process and behaviour attributable to scores on the ***Stigma Diagnosis and Behaviour Assessment Scale***. The frequency distribution on the scale appears to be normal, taken into consideration the normal distribution curve imposed on the graph, with the mean (3.28) slightly above the scale midpoint (3.0). This type of distribution is an indication that the participants understood the questions in the questionnaire, and answered widely over the scale. The highest score is 25, appearing to be on the scale midpoint (3.00). The Median is 3.46, and the Mode is 3.77, situated very near the scale midpoint. Please refer to the table at the end of the paragraph, indicating the statistical output of the central values.

Below, the scores on the scales are discussed.

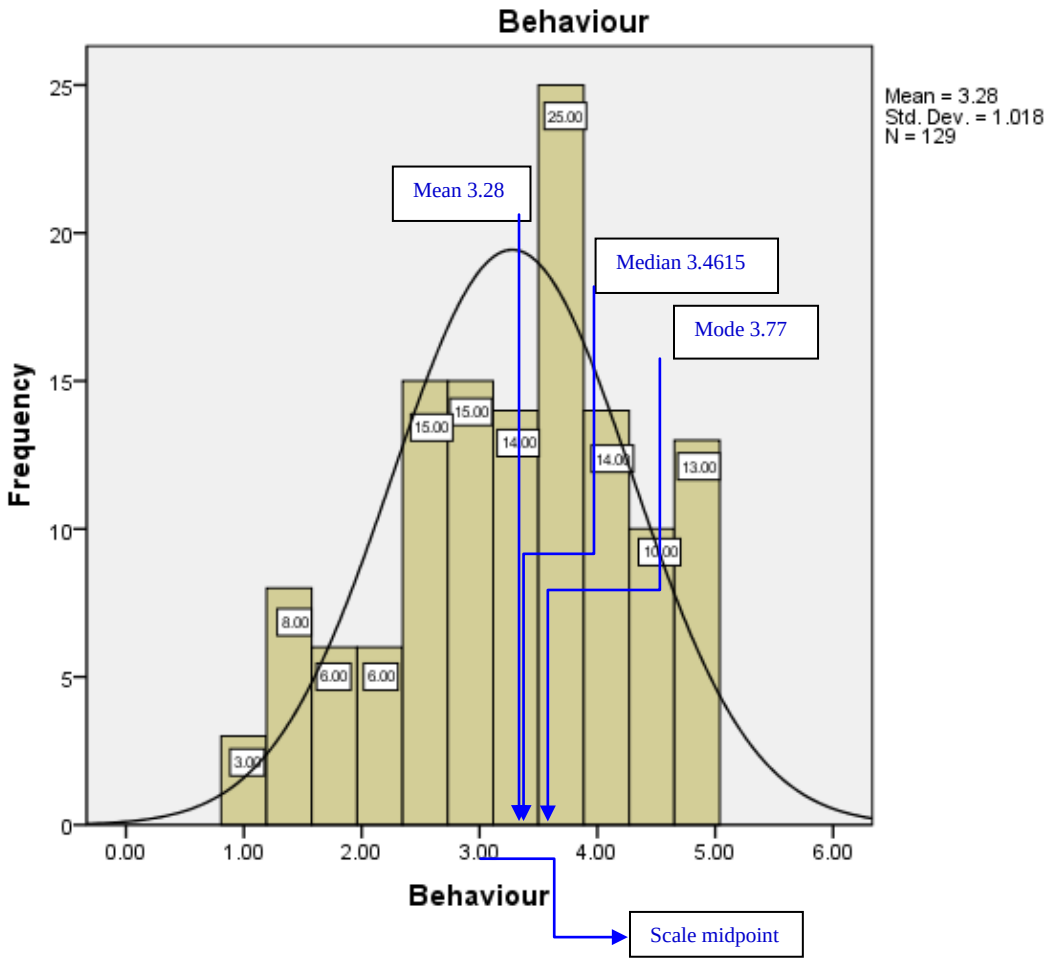

Figure 12: Stigma Diagnosis and Behaviour Assessment Scale

The participants' scores on the ***Stigma Diagnosis and Behaviour Assessment Scale*** indicate that this frequency table displays a normal distribution. At the time of diagnosis and thereafter, questions were asked about participants' HIV status, and gossiping was experienced widely. A few participants suffered physical injury (e.g. being assaulted) because of being HIV+. The participants generally felt that they were treated more or less the same than other patients at healthcare institutions, and rarely were refused care at these institutions. They were also not made to wait longer than other patients. Few participants experienced extreme rejection, while others did not experience rejection at all (at qualitative individual question analysis level, this question [re rejection] showed a bimodal curve). In general, participants experienced support, and some lost friends. One respondent stated that her family "totally rejected her". Participants were also quite certain that significant others will look after them when they become sicker. Participants were ambivalent about people purchasing food from an HIV+ vendor (bimodal distribution depicted at individual question level). Please refer to Appendix 5.

It is the view of the researcher, given the normal distribution above and the mode and the median being quite close to the midpoint of the scale, that behaviour related to Stigma with diagnosis and thereafter is slowly being integrated and culturally accepted into communities. It is, if that is the case, a positive result coming out of the research, since *it will contribute in addressing behaviour during implementations of programmes to reduce Stigma*. This is a possible recommendation arising from the research.

4.5.2 Stigma Emotional Experience of Diagnosis Assessment Scale

The participants' distribution of scores on the scale below reflects the scores on the ***Stigma Emotional Experience of Diagnosis Assessment Scale***. The frequency distribution on the scale appears to be positively skewed, with the mean (3.28) slightly above the scale midpoint (3.0). This type of distribution indicates that the items retained in the scale measured relatively negative emotions. The highest score is 25, appearing to be on the scale midpoint (3.00). The median is 2.20, and the mode 1.00. No multiple modes were reported. Please refer to the table at the end of the paragraph, indicating the statistical output of the central values.

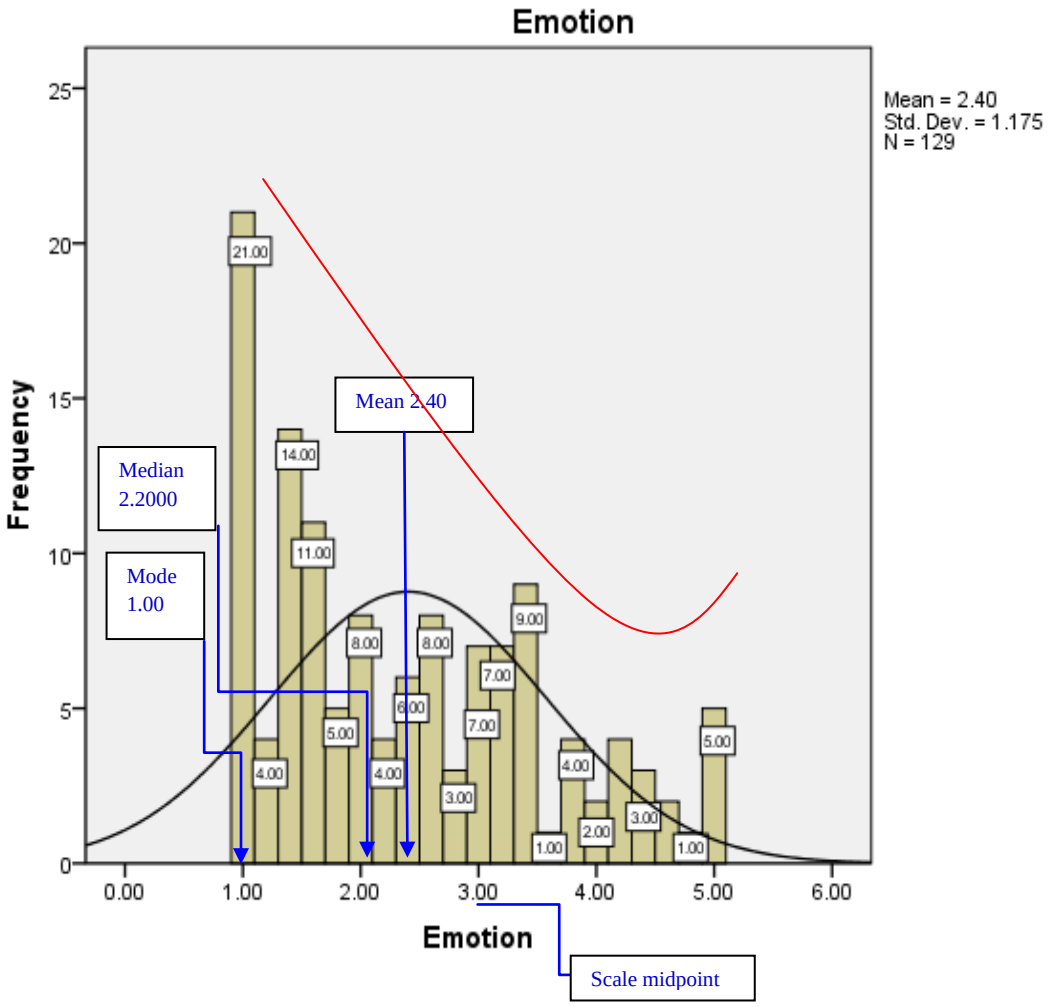

Figure 13: Emotional Experience of Diagnosis Assessment Scale.

The figure above indicates that all central values are left of the midpoint of the scale (3); which can be interpreted as a reversed "J" curve (The J-curve hypothesis of conformity rests upon the following conceptual basis. Instead of regarding conformity in the dichotomous "all-or-none" manner, the approach here suggested is one more consistent with general scientific procedure, namely, to measure degrees of conformity on a continuum[4]. This means that a "J" curve depicts a J with the commencement of the curve then progresses upwards to the right hand upper corner on the graph. A reversed "J" curve means the opposite of the course as depicted in a normal "J" takes as depicted in red in the graph above. The participants' score distributions indicate that (at both qualitative and quantitative levels), that they felt comparatively high levels of sadness, anger, fear, shame, and self-blame at the time of diagnosis after, and during disclosure of their HIV+ status. Stigma is thus

[4] http://www.brocku.ca/MeadProject/Allport/Allport_1939.html (Accessed on 2/02/2011)

experienced negatively ***internally*** at a significant level in this particular sample. This confirms research performed by Holzemer et al (***2009***: 79), who also found that care givers, such as nurses, are stigmatised because of the fact that they work with People Living With HIV/AIDS. Since these findings are recent, and the said research was performed in various African countries, it highlights the need for emotional support to HIV/AIDS sufferers AS WELL AS their caregivers. Therefore, recommendations regarding the role and stigmatisation of caregivers need to be considered extensively (refer Holzemer et al., 2009: 79). This finding also indicates that programmes introduced to reduce Stigma in PLWHA, need to include ***emotional support***, particularly during and directly after diagnosis. This will also be included as a recommendation.

4.6 Summary and Conclusion: Statistical Analysis and Observations

Behaviour as experienced with diagnosis and thereafter is interpreted as being behaviour that indicates relative integration of PLWHA in communities, therefore the relative normal distribution on that scale. Stigma reflecting in behaviour such as social isolation is therefore reducing and PLWHA are gradually being tolerated accepted in communities. Emotions experienced with diagnosis and thereafter, indicate that negative emotional Stigma is **still** experienced by PLWHA in this particular sample, and that this finding serves as a key focus point in programmes launched and implemented in communities where PLWHA are concentrated and cared for. Another area of focus, as pointed out as well by Holzemer et al (2009), is the experience of Stigma endured by caregivers and significant others of PLWHA.

CHAPTER FIVE: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

The goal of the study was, at first, to perform a preliminary mainly quantitative study to investigate Stigma in the sample that was acquired, and to a lesser extent an qualitative study into the nature and extent of Stigma as it manifests in people living with HIV and AIDS (PLWHA).

The main objectives of the study were:

- To determine the nature and extent of Stigma endured by PLWHA.
- To determine barrier/s Stigma can create in the implementation of intervention strategies to deal with the phenomenon.

This chapter provides insight into key aspects of the research as well as certain recommendations arising from the research findings as well as recommendations related to the research findings.

The key findings of the study will forthwith be aligned to the goal and objectives of this study. The **first** objective, to research the nature and extent of Stigma in PLWHA, has been achieved.

- The nature of Stigma was determined successfully in the context of this study, since the research findings indicated that, in this particular sample, it proved to contain a behavioural and an emotional aspect of Stigma as experienced by PLWHA.
- The extent of Stigma was confirmed as well. The research findings indicated that, in this particular sample, on a behavioural level, Stigma relating to PLWHA is gradually being accepted and acculturated into communities and that behaviour reflecting Stigma in particular, is stabilising into a normal behaviour pattern. The emotional aspect of Stigma was also confirmed in the study, especially noted in the psychological manifestation of sadness, anger, fear, shame, and self-blame experienced by the participants in the research.

The **second** objective, namely barriers that possibly may be experienced in programme implementations, the finding regarding the Stigma that caregivers experience, proves to be the main barrier resulting from this research. It is anticipated, however, that, should a larger sample could have been achieved, that more barriers would have been identified.

Below follows a summary of the key research findings of this study, both qualitatively and quantitatively.

5.2 Participant Biographical Data

Biographical variables	Categories									
Age	17-21yrs	22-25yrs	26-30yrs	31-35yrs	36-40yrs	41-45yrs	46-50yrs	>51		
	7 (6%)	13 (11%)	15 (13%)	18 (15%)	23 (20%)	26 (22%)	9 (8%)	6 (5%)		
Gender	Male	Female								
	46 (35.7%)	69 (53.5%)								
Religion	Christian	Muslim	Judaism	Buddhist	Other					
	110 (85.3%)	0	0	0	7 (5.4%)					
Culture	Pedi	Ndebele	Sotho	Shona	Swahili	Tsonga	Zulu	Venda	English	French
	7 (6%)	1 (1%)	46 (39%)	1 (1%)	1 (1%)	3 (2%)	26 (22%)	14 (12%)	17 (14%)	2 (2%)
Marital Status	Married	married Partn	Single	Divorced	Widowed					
	19(14.7%)	28 (21.7%)	66 (51.2%)	2 (1.6%)	1 (0.8%)					
Period HIV+	<1yr	2-3yrs	4-5yrs	6yrs+						
	46 (41%)	19 (17%)	16 (14%)	32 (28%)						
Area	Khutsong	Randfontein	Thembisa	Sedibeng	Unnamed					
	35 (27.1%)	1 (0.8%)	32 (24.8%)	48 (37.2%)	6 (4.7%)					

Table No. 5: Participants biographical data

5.3 Quantitative Research Findings

From the quantitative research data assembled, the main findings reflect the emergence of two highly reliable Stigma measurement scales. The first measurement scale is called the ***Stigma Diagnosis and Behaviour Assessment Scale*** (Reliability Cronbach's Alpha 0.914).

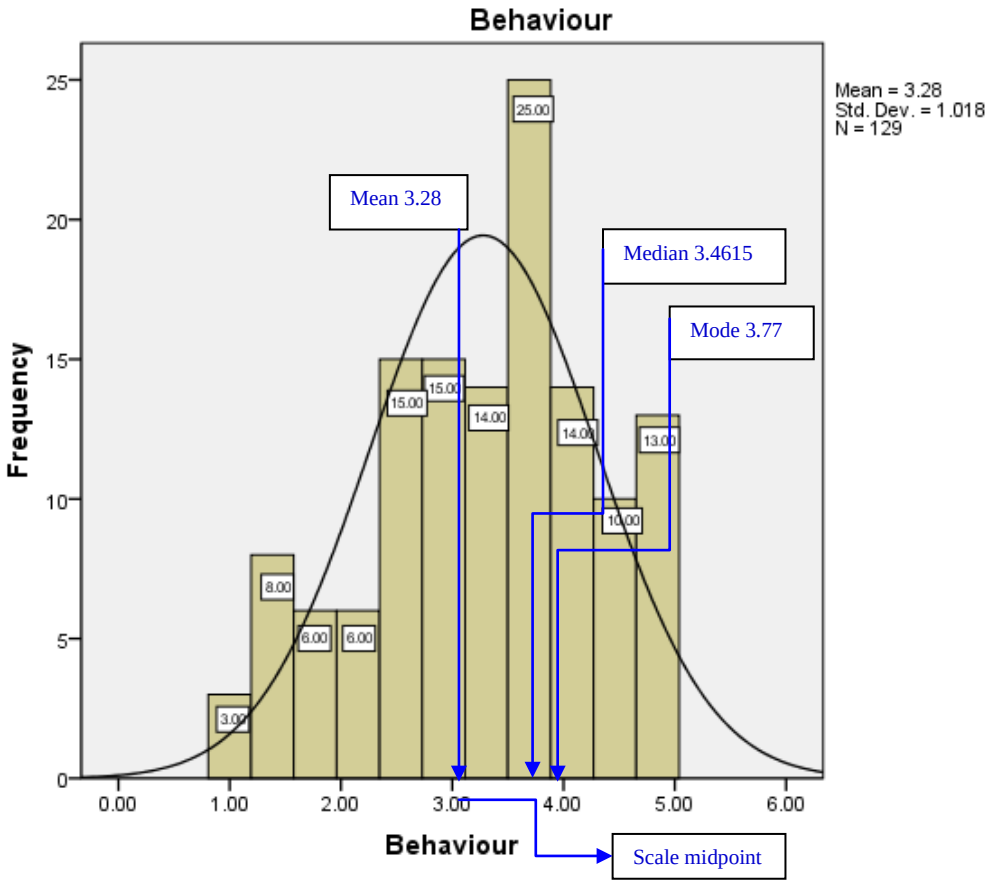

Figure 14: Stigma Diagnosis and Behaviour Assessment Scale

This scale demonstrates a normal distribution. The normal distribution of the scores on the items and the central values (the mode, median and mean) being quite close to the midpoint of the scale, indicate that behaviour related to Stigma with diagnosis and thereafter is slowly being integrated and culturally accepted into communities. This indicates a positive result coming out of the research, since *it will contribute, inter alia,in addressing behaviour during implementations of programmes to reduce Stigma*.

The second measurement scale is the ***Stigma Emotional Experience of Diagnosis Assessment Scale*** (Reliability Cronbach's Alpha 0.876).

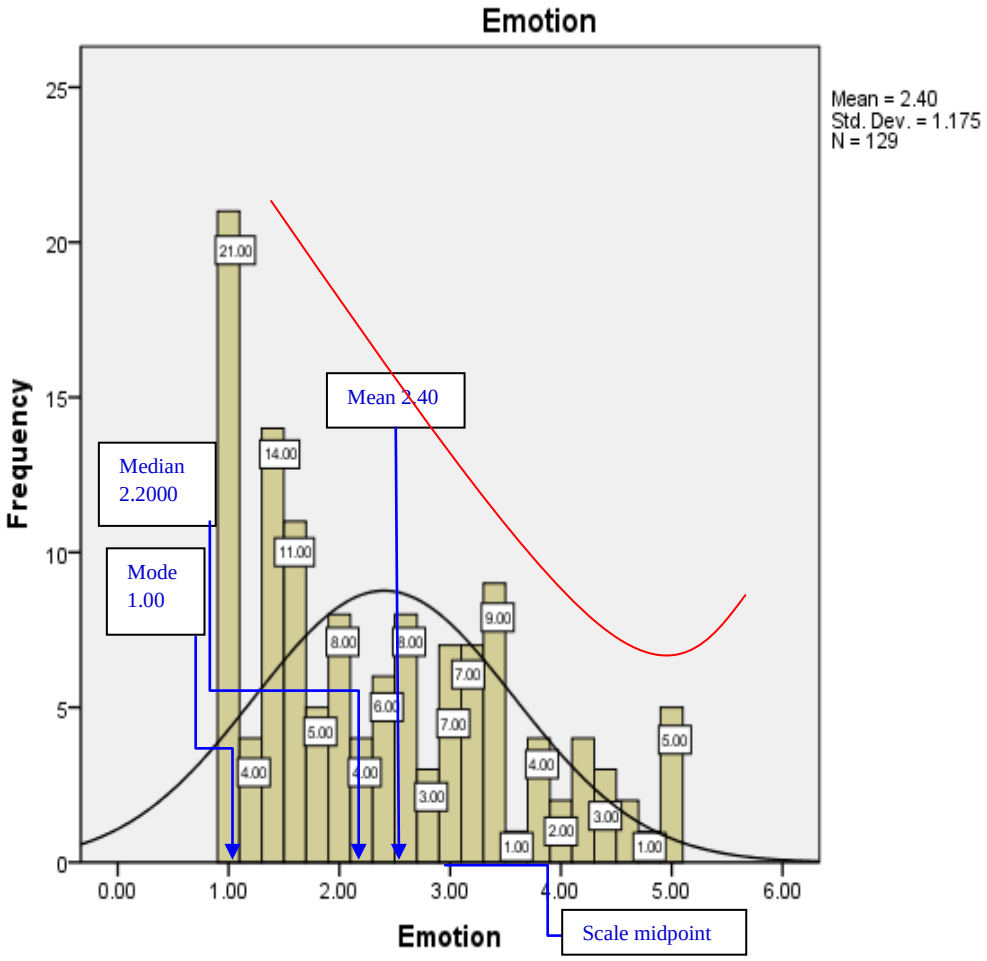

Figure 15: Stigma Emotional Experience of Diagnosis Assessment Scale

The figure above indicates that all central values (mean, median, and mode) are left of the midpoint of the scale (3); which can be interpreted as a reversed "J" curve. The participants' score distributions indicate that (at both qualitative and quantitative levels), they felt comparatively high levels of sadness, anger, fear, shame, and self-

blame at the time of diagnosis after, and during disclosure of their HIV+ status.

Stigma is thus experienced negatively ***internally*** at a significant level in this particular sample, confirming research by Holzemer et al (2009: 79), who, in addition, found that care givers (e.g. nurses partners, and family members) are also stigmatised because they work with People Living With HIV/AIDS. These findings are recent, and were performed in various African countries. The need for emotional support to HIV/AIDS sufferers as well as their caregivers is one of the key findings. Therefore, recommendations regarding the role and stigmatisation of caregivers need to be considered seriously (refer Holzemer et al., 2009: 79). This finding highlights that programmes introduced to reduce Stigma in PLWHA, need to include psychological and ***emotional support to caregivers.*** From the size of the sample (129 unspoiled questionnaires) and the number of questions (25), these findings indicate that participants **understood** the 5-point Likert-type scales fully and their responses were distributed over the whole of the scales, irrespective of the nature of the distributions.

5.4 Overarching Obstacles and Limitations of the study

As with all empirical research studies, obstacles and limitations always occur, as described below.

5.4.1 Logistical issues

The main obstacles and limitations occurred at ground level during the field work, with particular reference to distances travelled and the state of some of the research venues. Please refer to the image on page 22 to view the distances travelled in order to complete the field work. The field work lasted 5 days and included a distance of approximately 510 kilometres.

5.4.2 Study Sites

The reason why so many kilometres were travelled was that venues were quite some distance from one another. Another factor was the researcher‘s dependency on NAPWA for the identification of suitable sites. In spite of NAPWA making arrangements to meet with participants at certain sites, some of their coordinators experienced problems with suitable venues in the sense that there were time limitations on the use of the venues, and that some venues had to be reselected because participants failed to turn up. At one venue, participants refused to

participate in the research for reasons unknown, possibly fear of disclosing information about their HIV status and Stigma attached. At certain venues, participants did not understand English and the NAPWA coordinator had to translate the questionnaire question by question, which was time-consuming.

5.4.3 Infrastructure issues

Certain venues were extremely dilapidated and some were situated in sink shacks with no water, electricity and ventilation. The researcher was surprised to observe the level of service rendered by officials working in these circumstances with almost no resources available, for example lack of transport to these areas, some which were quite remote. No refreshments such as water and snacks were available for the participants. Participants had to leave their dwellings on foot very early to attend the research sessions. Weather conditions varied from extreme heat in the sink shacks to bouts of rain, wind, and dust.

5.4.4 Limitations and Obstacles

Certain participants had, at the time of the research, not disclosed their HIV+ status to anyone. The researcher assured the participants that they cannot be identified and that that particular group was “closed”. A limitation worth mentioning is that a significant number of caregivers and family members who were not HIV+, attended the sessions since they perceived themselves as affected by the HIV+ people they cared for.

Challenges in terms of dealing with a non probability sample includes that the researcher and NAPWA coordinator had to “take and work with what [we] got”.

The questionnaires were written in English which was translated into the participants’ language where necessary. This factor could have imposed a limitation on the study because the meaning of some of the original expressions could have been lost during translation, which is something that is very difficult to cater for in cross-cultural research. One cannot ignore the cultural and religious values and beliefs related to sex and HV/AIDS-related issues. This too, could have been a major obstacle.

5.4.5 Empirical research limitations

- It was extremely difficult to draw a “scientific” sample since NAPWA identified and coordinated the participants, venues, and times, and the researched had

to make do with what was encountered in terms of numbers of participants, who voluntarily participated in the research.

- The researcher relied on the accuracy of participants in completing the questionnaires. In addition the possibility that some of the participants might have provided desirable responses to please the researcher
- The representivity of the sample could be affected because of an inability to, within the limited time framework, other such organizations providing similar services as NAPWA member organizations within the Gauteng province could not be approached. This is, however, a factor that needs to be taken into consideration with follow-up research.
- A certain element of bias could not be avoided since the majority of participants in the research were Black Africans.

5.5 Strengths of the Study

- Two reliable and valid Stigma Scales were developed as a result of the study namely, the (1.) Stigma Diagnosis and Behaviour Assessment Scale, and (2.) Stigma Emotional Experience of Diagnosis Assessment Scale.
- New insights in the empirical research of HIV Stigma were gained. For instance, it is startling that regardless of the high level of HIV awareness and knowledge even in the most localities of Sub Sahara Africa, PLWHA are still coerced into using their own eating and bathing utensils as means to forestall contagion with the uninfected. Thus, the findings showed that, maybe contradictorily, but embedded in the reality of the research, behaviourally, Stigma is slowly being integrated and absorbed by communities. The emotional impact of Stigma remains high, is stressful and includes rejection by significant others and community members whilst blame, specifically self-blame, is experienced by PLWHA. This can serve as input to organisations in society occupying themselves with the condition, and those who develop policies, programmes, and interventions, to take this finding into consideration during implementation.

5.6 Recommendations

In this section, the goal and objectives of the research will be brought into alignment with the recommendations arising from the research and presented in tabular form below.

Goal and objectives	Recommendations
The main goal was to perform a preliminary quantitative and to a lesser extent, a qualitative study into the nature and extent of Stigma as it manifests in people living with HIV and AIDS (PLWHA). The main objectives of the study were: 1. To determine the nature, and extent, of Stigma endured by PLWHA in the Ekurhuleni, Sedibeng, and West Rand areas of Gauteng. 2. To determine barriers Stigma can create in the implementation of intervention strategies to deal with the phenomenon.	Irrespective of the fact that this is a dissertation of limited scope, it was deemed appropriate to formulate relatively comprehensive recommendations. **Government** 1. More preventive emphasis in national HIV/AIDS interventions and programmes. 2. National strategies need to be formulated to break down stigmatic barriers S&D create for PLWHA. 3. More effort should be excised to decrease myths and misconceptions about HIV/AIDS in order to fight HIV illiteracy and/or ignorance. 4. S&D should be made a pivotal issue in HIV/AIDS prevention and care programmes. 5. There should be reviews and reforms of laws, legislation, and regulations to foster a conducive climate for HIV infected and affected. 6. Mechanisms should be created to address and redress HIV/AIDS related S&D

	Institutions and Community 7. Sufficient knowledge about cultural and religious values and beliefs related to sex and HIV/AIDS should be disseminated. 8. Awareness should be created about the negative impact of HIV/AIDS related S&D and appropriate policies should be put in place to realise awareness. 9. There is need to mainstream a shared understanding that though all may not be infected, most are affected, and thus should work together to establish a more efficient and effective outcome of a shared understanding. **Family and Individual** 10. Significant others and carers should be involved in and supported at mainstream level and empowered in the care taking process by relevant policies and legislation. 11. The Diagnosis and Behaviour process needs to be taken into account with the implementation of interventions in order to broaden the addressing of the psychological dimension of Stigma prevention behaviour. 12. PLWHA (and their families) should be taught to understand that self-acceptance is vital to a balanced

	mind. 13. HIV/AIDS infection should not be seen as a death sentence, a punishment from God nor retributive justice of what PLWHA have done in the past. 14. Living with HIV/AIDS should be seen as a chronic medical condition which can be mirrored alongside other chronic conditions such as diabetes and cancer. 15. There is a need to mainstream the concept of positive living to enable PLWHA to think and act positively towards themselves and others, including their families. **Research** 16. There is a need for more research (such as at comprehensive and in-depth level) to gain a deeper and broader insight into HIV+ related Stigma in order to facilitate implementation of HIV/AIDS programmes, policies, practices, and other national and international prevention initiatives. 17. This study will be replicated at a broader, deeper, and more comprehensive level. 18. Research should be also be undertaken amongst caregivers, particularly, since they also experience Stigma, as well as the extent of the Stigma, and how

	these phenomena manifest and affect them in their own lives (this includes the infected as well as the affected). 19. Larger samples of research participants caring for PLWHA need to be researched. 20. More in-depth research need to be performed in **collaboration** with organisations active in this realm of HIV/AIDS and Health Research.

It is further recommended that more comprehensive and in-depth quantitative research be performed to gain a deeper and broader insight into HIV+ related Stigma in order to facilitate implementation of HIV/AIDS programmes, policy, practice, and other national and international prevention initiatives, and that this study be replicated.

Research should be undertaken amongst caregivers, particularly if they also experience Stigma and to what extent, and how these phenomena manifest and affect them in their own lives.

Larger samples of persons caring for PLWHA need to be researched, and more in-depth research need to be performed in collaboration with organisations active in this realm of Health Research.

5.7 Conclusion

The research and scientific rationale for the focus of this study was to measure and analyse the nature and extent of Stigma in people living with HIV/AIDS from a sociological viewpoint. A detailed review of literature on the history of HIV/AIDS from 1930-2010 (including themes such as Case Zero, HIV discovery, the gay connotation, Slim's Disease, the increase of HIV/AIDS in researchers' and ordinary people's consciousness, as well as the development of Stigma and negative perception of the condition in general) and trends in the field of HIV/AIDS were extracted and discussed. The researcher provided an analysis and reviews of the work of prominent authors in the field, including Erving Goffman, the pioneer in

conceptualising Stigma in the year 1963. Forthwith, an account of the research design (quantitative and qualitative), providing reasons for choices of measurement tools as well as an explanation of how the study was conducted, was given. The pilot study highlighted certain important issues about the questionnaire which was adapted accordingly. An explanation of how the research questions guided the study to elicit information on HIV/AIDS related Stigma from people living with HIV/AIDS was obtained. Lastly, conclusions and recommendations arising from the research findings were formulated.

Finally, apart from the quantitative analysis from this study, two Stigma measurement scales were developed: **A Stigma Diagnosis and Behavior Assessment Scale** and **A Stigma Emotional Experience of Diagnosis Assessment Scale**. While the former assessment scale measures behavioural responses of data collected from participants (detailing their statistical significance), the latter scale is used to analyse the emotional stigmatization of participants. Key findings and analytic commentary of outcomes are given with as precise as possible elucidation of how Stigma affects people living with HIV and AIDS, barriers Stigma creates in the implementation of intervention strategies, and recommendations on how to address Stigma in all its ramifications in our society today.

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LIST OF FIGURES

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APPENDICES

APPENDIX A INFORMED CONSENT

Participant Number:

Participant Information Sheet and Informed Consent Form

Title of Study: A SOCIOLOGICAL ANALYSIS OF THE NATURE OF, EXTENT AND COMPREHENSIVENESS OF STIGMA IN PEOPLE LIVING WITH HIV/AIDS IN CERTAIN AREAS OF GAUTENG REGION, NAMELY EKHURULENI, SEDIBENG AND WEST RAND.

Principal Investigator: Maylene Meyer

Supervisor: Dr. Denise Du Toit

Co-supervisor: Mr. Leon Roets

Institution: UNISA, Department of Sociology, Pretoria

INFORMATION LEAFLET AND INFORMED CONSENT

STUDY TITLE: A SOCIOLOGICAL ANALYSIS OF THE NATURE, EXTENT AND COMPREHENSIVENESS OF STIGMA IN PEOPLE LIVING WITH HIV/AIDS IN AREAS OF GAUTENG REGION (EKHURULENI, SEDIBENG AND WESTRAND

Investigator: Maylene Meyer

Supervisor: Dr. Denise du Toit

Co-supervisor: Mr. Leon Roets

Institution: UNISA, Sociology Department, Pretoria

DAY TIME AND AFTER HOURS TELEPHONE NUMBER(S): 0733821539

1. INTRODUCTION:

Hello, my name is Maylene Meyer, and I am enrolled as a MA student (Student number: 05997178) with the University of South Africa (UNISA) – Sociology Department. As part of the requirements for the Master's degree, I have to undertake research activities to complete a dissertation.

I would like to invite you to consider participating in my research study, entitled **"A Sociological analysis of the nature, extent and comprehensiveness of Stigma in People Living With HIV/AIDS (PLWHA) in Gauteng region namely Ekuhruleni, Sedibeng, West Rand"**

1. Before agreeing to participate, it is important that you read and understand the following explanation of the purpose of the study, the study procedures, benefits, and risks, and your right to withdraw from the study at any time.
2. This information leaflet is to help you to decide if you would like to give your permission to participate. You should fully understand what is involved before you decide to take part in this study.
3. If you have any questions, do not hesitate to ask me.
4. You should not agree to take part unless you are satisfied about all the procedures involved.
5. If you decide to take part in this study, you will be asked to give consent by signing the consent form.

2. PURPOSE OF THE STUDY:

The purpose of this study is to determine the depth, comprehensiveness, and prominence of Stigma endured by PLWHA, and the barrier it creates in the implementation of intervention strategies to deal with the phenomenon. Implications of the study further might show that, should high levels of Stigma occur when one is HIV/AIDS positive, it creates an intangible barrier that may influence the implementation of intervention programmes. Therefore, if Stigma is addressed timely and efficiently, intervention programmes may be more successfully implemented and value for money attained.

3. LENGTH OF THE STUDY AND NUMBER OF PARTICIPANTS:

- The study will be performed at Ekurhuleni, Sedibeng, Westrand, in Gauteng , South Africa.
- Approximately 200-350 members of NAPWA across the 4 sites will participate over a period of 1 month (October – November 2010).
- All the participants will be older than age 18.
- Participants will be given a questionnaire to complete and this may take approximately 20-45 minutes.

4. PROCEDURES:

- If you agree to participate in this study, you will not be identified.
- All responses to the questionnaire findings of the study will be anonymous and confidential.
- Your participation is voluntary. You have the right to withdraw at any point of the study, for any reason, without any prejudice, and no explanation is needed.

5. BENEFITS:

- There are no direct benefits in participating in the research study. However your answers to the questionnaire may contribute to help managers to efficiently address and improve HIV/AIDS related Stigma intervention programmes more successfully

6. FINANCIAL ARRANGEMENTS:

- Neither you nor your family will be expected to pay for any study procedures.

7. REIMBURSEMENT FOR STUDY PARTICIPATION:

- Neither you nor your family will be paid if you decide to participate in this study.

8. ETHICAL APPROVAL:

- This study protocol has been submitted to The University of South Africa (UNISA) the Sociology research Ethics Committee and written approval has been granted by that committee.

- If you want any information regarding your **rights as a research participant, or complaints regarding this research study**, you may contact Dr. Denise Du Toit (082 800 1815).

9. CONFIDENTIALITY:

- All information obtained during the course of this study, personal data and research data will be kept strictly confidential. Data that may be reported in scientific journals will not include any information that identifies you as a participant in this study.
- The information might be inspected by The University of South Africa's Sociology Research Ethics committee. Any information uncovered regarding your HIV status or state of health as a result of your participation in this study will be held in strict confidence. This information will not be disclosed to any third party in addition to the ones mentioned above without your written permission.

WRITTEN PARTICIPANT INFORMED CONSENT

I hereby confirm that I have been informed by the **interviewer,** Maylene Meyer, about the nature, conduct, benefits and risks of the study "A Sociological analysis of the extent and comprehensiveness of Stigma in people living with HIV/AIDS in Gauteng region namely Ekhuruleni, Sedibeng, and Westrand.

I have also received, read and understood the above written information (Participant Information Leaflet and Informed Consent) regarding the study.

- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the University of South Africa – Sociology department
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare permission to participate in this study.

PARTICIPANT:

Printed Name Signature / Mark or Thumbprint Date and Time

I**, Interviewer**, _Maylene Meyer herewith confirm that the above participant has been fully informed about the nature conduct and conduct and risks of the above study.

Interviewer/Fieldworker:

Maylene Meyer

Printed Name Signature Date and Time

VERBAL PARTICIPANT INFORMED CONSENT:

(Applicable only when participants cannot read or write)

- I, the undersigned, **interviewer**. Maylene Meyer. have read and explained fully to the participant, named.....……. the participant information leaflet.
- The account I have given has explained both the possible risks and benefits of the study. The participant understands these.
- The participant indicated that he/she understands that the participant will be free to withdraw from the study at any time for any reason and without jeopardising his/her subsequent treatment.

I hereby certify that, the participant has agreed to participate in this study.

PARTICIPANT:

Printed Name Mark or Thumbprint (if applicable) Date and Time

Interviewer/Fieldworker:

Maylene Meyer

Printed Name Signature Date and Time

APPENDIX B RESEARCH QUESTIONNAIRE

QUESTIONNAIRE: STIGMA RELATED TO HIV/AIDS

A Information about yourself

Please tick the category that fits you the best

1 **Age** (yrs) (17-21, 22-25, 26-30, 31-35, 36-40, 41-45, 4

2 **Gender** (male, female)

3 **Religion** (Christian, Muslim, Judaism, Bu

4 **Employment** (yes, no, part-time, contract, un

5 **Culture** (Nguni, Pedi, Ndebele, Sotho, Shona, Swahili, Tsonga, Zulu, Xhosa, Venda, Tswana, English, Afrikaans, French)

6 **Marital status** (married, unmarried partners, single

7 **How long have you been HIV+?** (<1yr, 2-3yrs, 4-5 yrs, 6yrs+) ***VOLUNTARY***

B Questions about HIV+-related stigma

Please answer the following questions to the best of your ability. The scale is as follows:

When you were diagnosed as HIV+, were you disappointed?

Yes, a lot						No, not really
	1	2	3	4	5	

Interpretation of the scale:

1 You agree very strongly with the statement on the ***left***

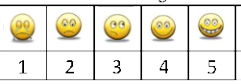
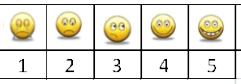
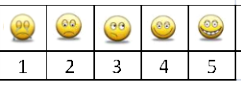
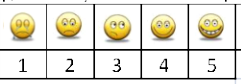
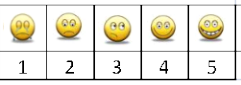
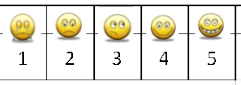
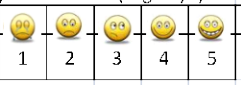
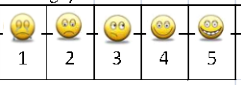
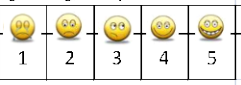
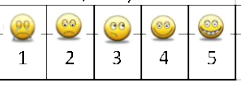
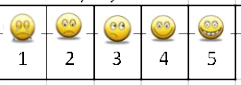
2 You agree strongly with the statement on the ***left***

3 You don't have particular feelings about the issue

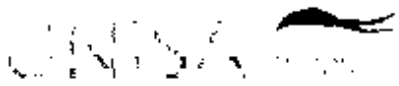
4 You feel quite strongly about the issue on the ***right***

5 You feel extremely strongly about the issue on the ***right***

VA1	When you were diagnosed, were you called names because you were HIV+?						
	Yes, a lot						No, not really
		1	2	3	4	5	
VA2	When you found out you were HIV+, did people ask you a lot of questions about your HIV+status?						
	Yes, all the time						No, not really
		1	2	3	4	5	
VA3	When you found out you were HIV+, did you notice people gossiping about you?						
	Yes, a lot						No, not really
		1	2	3	4	5	
SP4	When you found out you were HIV+, did you feel different from other (healthy) people?						
	Yes, very different						No, not really
		1	2	3	4	5	
SP5	When you were diagnosed as HIV+, did you feel that your life has changed?						
	Yes, I felt my life will end						No, I felt I will fight the disease
		1	2	3	4	5	
SP6	When you found out about being HIV+, did you feel "unclean"/dirty?						
	Yes, I wanted to bath all the time						No, I did not feel unclean/dirty at all
		1	2	3	4	5	
SP7	Have you ever been hurt physically (e.g. assaulted) because you are HIV+ when you were diagnosed?						
	Yes, a lot						No, not really
		1	2	3	4	5	
SP8	When you were diagnosed as HIV+, were you distressed by people's reactions on you HIV+ status?						
	Yes, I felt hurt						No, I felt strong enough to fight the disease
		1	2	3	4	5	
HC9	When you were diagnosed, and attended a clinic/hospital, did you feel that you received less care than other patients?						
	Yes, I had to wait a long time						No, not really
		1	2	3	4	5	

HC10	When you were diagnosed as HIV+, were you ever refused treatment?						
	Yes, the doctor did not want to see me						No, I received treatment
		1	2	3	4	5	
HC11	Did you have to wait longer for service because you were diagnosed HIV+ in the beginning?						
	Yes, I was told to wait						No, I saw health care workers according to schedule
		1	2	3	4	5	
SI12	When you were firstly diagnosed, did you feel that people avoided you socially, that you were sometimes rejected?						
	Yes, I felt alone						No, some people went on as if nothing was wrong
		1	2	3	4	5	
SI13	Since you were diagnosed, has social contact with other significant people in your life, became less?						
	Yes, it became much less						No, they support me a lot
		1	2	3	4	5	
SI14	Since being diagnosed, do you feel that people rejected you when it was discovered that you were HIV+?						
	Yes, I was rejected a lot						No, I wasn't rejected at all
		1	2	3	4	5	
SI15	In the beginning, just after diagnosis, did you lose friends due to yout HIV+ status?						
	Yes, I lost a lot of friends						No, I did not lose any friends
		1	2	3	4	5	
SI16	Since being diagnosed with HIV, have you suffered broken relation						
	Yes, I lost a lot of relationships						No, I did not lose any relationships
		1	2	3	4	5	
SI17	Do you think people close to you, (family, friends) will look after you if you become sicker?						
	No, they will not						Yes, they will
		1	2	3	4	5	
SI18	Do you think people will buy food from a HIV+ small food vendor?						
	No, they will not						Yes, they will
		1	2	3	4	5	
SI19	Do you think that an HIV+ pupil/student is a risk of infection to other pupils/students?						
	Yes, they are a huge risk						No, they are not a risk at all
		1	2	3	4	5	
E20	When you were diagnosed as HIV+, did you feel sad? (e.g. cry?)						
	Yes, I feld very sad						No, I didn't feel sad at all
		1	2	3	4	5	
E21	In the beginning, with diagnosis, were you angry?						
	Yes, I felt very angry						No, I didn't feel angry at all
		1	2	3	4	5	
E22	Since you were diagnosed HIV+ in the beginning, did you feel scare						
	Yes, I felt very scared						No, I didn't feel scared at all
		1	2	3	4	5	
E23	In the beginning, when you were diagnosed HIV+, did you feel ash						
	Yes, I felt very scared						No, I didn't feel scared at all
		1	2	3	4	5	
E24	Since you were diagnosed positive in the beginning, did you blame yourself?						
	Yes, I blamed myself a lot						No, I didn't blame myself at all
		1	2	3	4	5	
E25	In the beginning, since diagnosis, did you feel any rejection?						
	Yes, I felt a lot of rejection						No, I didn't feel any rejection
		1	2	3	4	5	
	THANK YOU FOR YOUR COOPERATION						

APPENDIX C UNISA ETHICAL CLEARANCE LETTER



Department of Sociology
College of Human Sciences
20 October 2010

Proposed title: A SOCIOLOGICAL ANALYSIS OF THE NATURE OF, EXTENT AND COMPREHENSIVENESS OF STIGMA IN PEOPLE LIVING WITH HIV/AIDS IN THE HILLBROW SUBURB OF JOHANNESBURG

Principal investigator: Maylene Meyer (05997178).

Reviewed and processed as: Class approval (see paragraph 10.7 of the UNISA Guidelines for Ethics Review)

Approval status recommended by reviewers: Approved

The Higher Degrees Committee of the Department of Sociology has reviewed the application for ethical review and considers the methodological, technical and ethical aspects of the request to be appropriate to the tasks proposed. Approval is hereby granted for the candidate to proceed with the study in strict accordance with the approved proposal and the ethics policy of the University of South Africa.

In addition, the candidate should heed the following guidelines:

- To only start this research study after obtaining informed consent from your research participants
- To carry out the research according to good research practice and in an ethical manner
- To maintain the confidentiality of all data collected from or about research participants, and maintain security procedures for the protection of privacy
- To work in close collaboration with your supervisor(s) and to record the way in which the ethical guidelines as suggested in your proposal has been implemented in your research
- To notify the Higher Degrees Committee of the Department of Sociology in writing immediately if any change to the study is proposed and await approval before proceeding with the proposed change
- To notify the Higher Degrees Committee of the Department of Sociology in writing immediately if any adverse event occurs.

Approvals are valid for ONE academic year after which a request for a continuation of the approval must be submitted to your supervisor(s)

Kind regards

D. Gelderblom (Prof)
Chair, Department of Sociology
Tel 012 429 6301

www.unisa.ac.za

Other ethical considerations

In order to make sure that the research was conducted according to the highest ethical standards, the following additional measures were used:

- The participation leaflet, informed consent and the questionnaire were explained to participants
- Participants were ensured that all their responses to the questionnaire findings will be anonymous and confidential.
- It was emphasized that participation in the research study was voluntary and they were not forced in any way to participate in the research.
- Participants had the right to withdrew at any point of the study for any reason, without prejudice, and no explanation was needed.

Lastly, due to workplace impediments which would have greatly facilitated the research, and requirements made at the very last moment regarding sites of research, the researcher approached NAPWA for assistance with obtaining participants for her research. Her manager recommended that she approach NAPWA, and with their assistance, the research was ultimately conducted in certain areas of the Gauteng Region namely Ekurhuleni, Sedibeng, and West Rand.

ETHICAL CLEARANCE

DEPARTMENT OF SOCIOLOGY

SUMMARY SHEET FOR THE ETHICAL CLEARANCE OF

POSTGRADUATE STUDENT PROPOSALS FOR THESES/DISSERTATIONS

CANDIDATURE DETAILS

A1 FULL NAME OF CANDIDATE

Maylene Elizabeth Meyer

A2 ACADEMIC AND PROFESSIONAL QUALIFICATIONS

Honours degree: Social Behaviour Change in HIV/AIDS

Registered Nurse:

Diploma in General Nursing

Diploma Community Health Nursing

Diploma Midwifery

A3 THESIS/DISSERTATION TITLE

A SOCIOLOGICAL ANALYSIS OF THE NATURE, EXTENT AND COMPREHENSIVENESS OF STIGMA IN PEOPLE LIVING WITH HIV/AIDS IN THE HILLBROW SUBURB OF JOHANNESBURG,

GAUTENG

A4 PERSONAL PARTICULARS

(a) student number:	
(b) current address:	6 Magnolia Flat, Alfred Van Zeeberg Street, Ext.6 Eldorado Park, 1811
(c) e-mail:	maydankers@yahoo.com
(d) telephone number(s)	073 382 1539

A5 PROMOTER(S)/SUPERVISOR/(S)

(a) Initials & surname:	Dr. DA Du Toit
(b) Contact details:	082 800 1815
(c) Department:	Sociology

B PROPOSAL SUMMARY SHEET

B1 ABSTRACT OF THE PROPOSAL

ABSTRACT

With Stigma and Discrimination identified as some of the leading factors impacting negatively and stalling the effective implementation of HIV/AIDS related interventions and programmes, this study intends to investigate the nature, extent and comprehensiveness of Stigma amongst people living with HIV and AIDS. It will attempt to determine the roots fuelling Stigma (with particular emphasis on Polygamy and migration). Thus, the research project will be guided by the following questions: (1) what is the extent, nature of, and comprehensiveness of HIV/AIDS related **Stigma** amongst the participants in the research sample? ; (2) Is polygamy a **contributory variable** to HIV/AIDS related Stigma in the research sample? ; And (3) what is the extent of the influence of **polygamy** on a formal and informal level in connection with HIV/AIDS related Stigma in the research sample?[5]

Using a qualitative and quantitative exploratory research methodology, the researcher will review existing writings and information on HIV/AIDS and Stigma. Above all, it will collect primary level data using a structured questionnaire and data

collection techniques from participants within the specifics of the data sample. The sample size will be in the vicinity of 200 - 350.

Data analysis, as indicated above, will be qualitative and quantitative. It will identify and show relationships between identified factors and variables as mentioned above. Besides, findings and conclusions will be drawn based on logical arguments that are substantiated by the writings of renowned authors, researchers, and theorists in the field.

The research will use the Harvard system of referencing and all referenced documents (incl. books, journals, articles, etc) will be listed in the bibliography section at the end of the document. Important documents will also be appended at the end of the write-up for direct reference, if need be.

B2 RESEARCH OBJECTIVES

Objectives of the study:

To determine the depth, comprehensiveness, extent and prominence of Stigma endured by PLW.
To determine the barrier Stigma is creating in the implementation of intervention strategies to deal with the phenomenon.
To determine if polygamy is contributing to HIV/AIDS related Stigma

B3 RESEARCH DESIGN

RESEARCH DESIGN AND METHODOLOGY

Type of study

This study will be a quantitative and qualitative exploratory study and will, besides content analysis, also involve hypothesis testing. The quantitative part of the study will entail a questionnaire with Likert-type continual questions that will measure the extent and depth of Stigma endured by the participants. ***Construct validity*** will be obtained by the questionnaire itself; since dimensions of Stigma that arose from the literature study will be utilized will form that basis of the questionnaire, as well as content obtained from the interviews. The type of data to be obtained in this study will therefore be numeric (questionnaire) and interactive, qualitative data obtained

from the open interviews with an interview guide that will be content-analyzed and integrated into the questionnaire.

Phases of the Study

The study will be conducted according to the phases below:

Exploratory phase: This will serve as sources for items to develop for the quantitative questionnaire. Using both qualitative and quantitative exploratory study, the research will review existing writings and information on HIV/AIDS and Stigma. It will collect primary level data using a well structured questionnaire and data collection techniques from participants within the specifics of the data sample.

Empirical phase: Administering of the questionnaire, and analysis of resulting data.

Analytical phase: Data analysis, as indicated above, will be qualitatively and quantitatively based. Data will be scrutinized and sanitized and, after thorough analysis by means of frequency distribution analysis, and various statistical analyses, such as factor analysis (should the literacy levels of participants allow interpretation of a continual scale, or cluster analysis, should that not be the case). Overall interpretations will be performed, and then in-depth analysis of the data will ensue. The results of the data analysis will be depicted graphically using frequency distribution charts, histograms, and demographic data will be presented using a variety of graphic outlays.

Results phase: – The results of the data analysis phase will be documented and interpreted in this phase, and should the results permit, certain recommendations will be made.

Units of analysis

The units of analysis will include People Living with HIV and AIDS (PLWHA) in Hillbrow, Johannesburg, Gauteng.

Reliability Analysis

In this study, the intention is to test the reliability of the questionnaire with the Reliability Analysis facility in SPSS, which produces a Cronbach Alpha index. Should the literacy levels of the participants not allow the usage of a continual scale, a categorical scale will be used, and cluster analysis will be performed on the scale questions, the reliability depicted by an alpha index.

POSSIBLE ADVANTAGES AND LIMITATIONS IMPACTING ON THE STUDY

Advantages

Sources known by the researcher from place of employment (mobile clinic, support groups, NGOs, and the City of Johannesburg Clinics)

The pilot study will provide insight into the situation, suggest the kinds of questions to ask and suggest the direction the research should take in terms of using a continual or categorical scale.

Limitation/s

Level of trust built up by the researcher with continuous contact with PLWHA, as well as time that might slow down the process should ethical clearance by certain of the research bodies might take longer than anticipated.

Cultural factors

Certain cultures are adverse to give negative replies out of respect for the researcher, which will be managed in order to prevent skewing and misinterpretation of questions and data.

Variables and Hypothesis Testing

Variables that will be utilized in the study will include demographical such as age, gender, faith (Stigma manifests regularly in certain church groups), amongst others. Hypothesis testing will be performed by utilizing certain demographic variables to determine how they measure on the scale/s. This output will produce information on the following null hypothesis:

The extent, nature of, and comprehensiveness of **Stigma** due to HIV/AIDS positivity amongst PLWHA is not negative.

DATA COLLECTION METHOD

The methods of data collection are both qualitative and quantitative. The quantitative dimension includes the structured questionnaire, while the qualitative dimension will address open structured interviews, performed voluntarily, confidentially, and anonymously. The questionnaires will be numbered and will include certain demographical variables as well. These variables will not divulge the identity of any respondent in any manner. The scale will be explained to the participants and the researcher will fill in the scores on each question in accordance by what the participants indicate..

SAMPLING

The sample for this research will include a minimum of 200 research participants, chosen from three sources, namely:

PLWHA that attend a mobile clinic that serves the Hillbrow area as a source of voluntary counseling and testing for HIV, taking bloods for CD4 counts and RPR, screening and syndromic treatment of sexually transmitted infection, TB screening etc, amongst other primary health care services.

PLWHA attending support groups run by the researcher's employer and other NGOs.

PLWHA attending the City of Johannesburg's HIV/AIDS clinic.

The process of documenting the scores on each question will be voluntary, confidential, and anonymous. The questions will be asked by the researcher in order to ensure that the participants understand the questions and give correct answers. Cultural factors will be considered and control questions will be built into the questionnaire. This will ensure that the data integrity at the data collection phase of the research is satisfactory and that sufficient control over the quantitative phase is exercised.

DATA ANALYSIS

Qualitative data: The qualitative dimension will consist of 20 preliminary structured voluntary, anonymous, and confidential interviews with open questions (based on the literature study), to be utilized as a type of pilot study. These participants will be chosen in a structured manner, choosing every 10^{th} respondent willing to be interviewed. During these interviews, the dimensions of the quantitative questionnaire will be tested in order to obtain ***content validity*** and ***face validity***. This data will then be utilized as input, in addition to the literature study, to assemble the quantitative questionnaire, which is intended to measure the depth, extent, and comprehensiveness of Stigma endured by PLWHA.

Quantitative data: Firstly, frequency distributions will be performed on all the variables. An item analysis (if relevant) will be performed in order to determine whether certain questions will have to be reflected to obtain the correct direction of the questions. A preliminary reliability analysis will be performed to assess overall reliability and internal consistency of the items (questions). Should the literacy levels of the participants allow it, factor analysis will be performed on two levels to determine the dimensions of Stigma as obtained in the statistical output of the analysis. The dimensions that will be produced by the second order factor analysis will then be analyzed in order to determine the items (questions) that crystallized from the factor analyses. A secondary reliability analysis will be performed to determine the reliability of the factors. The factors will be named as Stigma measurement scales, and compared to the dimensions that arose from the literature study. It is believed that this study will contribute to depth of analysis of Stigma attached to PLWHA. Only willing participants, chosen randomly, will be asked to provide data for the questionnaire. If participants' literacy levels don't allow for a continual scale, the scale will be changed to a categorical scale and a cluster analysis on one level will be performed.

The questions will exhibit a 5-point Likert-type scale and will take the issue of respondent literacy into consideration. Questions will be asked verbally and explained by the researcher when the questionnaires are completed (by the researcher) to ensure that participants understand the scale. This process will

involve hypothesis testing which will, amongst others, involve calculating the demographic variables' scores on the scales. More statistical analyses are in consideration, such as regression analysis, if respondent literacy levels allow it.

B4 HOW SHOULD THIS STUDY BE CHARACTERISED? (Please tick all appropriate boxes.)

	Yes	No
Personal. social and other relevant information collected directly from participants	√	
Participants to undergo physical examination [a]		√
Participants to undergo psychometric testing [b]		√
Identifiable information to be collected about people from available records (e.g. medical records, staff records, student records, etc.)		√
Other (Please specify)		

a. For medical or related procedures, please submit an application to a medical ethics committee.

Not applicable

b. Please add details on copyright issues related to standardized psychometric tests.

Not applicable

B5 WHAT IS THE AGE RANGE OF THE INTENDED PARTICIPANTS IN THIS STUDY?

From 18 years and up
If not applicable, please furnish a reason:

B5.1 If the proposed participants are 18 years and older, is the informed consent form for participants attached?

Yes✓	No	Not applicable

B.5.2 If the proposed participants are younger than 18 years, are consent and assent forms attached? (In order for minors -younger than 18 years of age- to participate in a research study, parental or guardian permission must be obtained. For minors a youth assent form is required.)

Yes	No	Not applicable✓

B 5.3 Do the intended research participants fall under the category "vulnerable participants" as described on page 1 and especially page 15, paragraph 3.10 of the Policy on Research Ethics of UNISA?

Yes	Please provide details and outline steps to protect such vulnerable groups:
No	Go to B 5.4

B5.4 Does the proposed study involve collaborative, multi-institutional or multi-country research? (Please see paragraph 6 of the Policy on Research Ethics of UNISA and make sure that the principal researcher complies with the stipulations of the policy)

Research in 1 country only	Please state country: South Africa_____
Research in more than 1 country	Please state countries:___Not applicable_____ _____ _____
Research to be conducted in 1 institution [c]	Details: NAPWA (People living with HIV and AIDS)_____
Research is multi-institutional [c]	Please give details: NAPWA's partner organizations as identified by the director, co-coordinator for Gauteng and researcher. Still to be identified._____ _____ _____

B5.5 Description of the process for obtaining informed consent (if applicable)

Participation information leaflet and consent forms will be printed. Participation leaflet and informed consent will be explained to participants All responses to the questionnaire findings will be anonymous and confidential. Participation of participants is voluntary and they will not be forced in any way to participate in the research. Participants have the right to withdraw at any point of the study for any reason, without prejudice, and no explanation is needed. Consent form to be signed off by participants If participants are unable to write, a thumbprint can be provided to sign the consent form.
Not applicable. Reason:

B6. DESCRIPTION OF THE RISKS POSED BY THE PROPOSED STUDY WHICH RESEARCH PARTICIPANTS MAY/WILL SUFFER AS WELL AS THE LEVEL OF RISK (IF APPLICABLE) (Please consider any discomfort, pain/physical or psychological problems/side-effects, persecution, stigmatisation or negative labelling.)

Foresee no eventualities as research will be conducted in their environment, offices and partner organizations participants' work.

B7. DESCRIPTION AND/OR AMOUNTS OF COMPENSATION INCLUDING REIMBURSEMENTS, GIFTS OR SERVICES TO BE PROVIDED TO PARTICIPANTS (IF APPLICABLE) (Will the participants incur financial costs by participating in this study? Will incentives be given to the participants for participation in this study?)

Not applicable

B8. DESCRIPTION FOR ARRANGEMENT FOR INDEMNITY (IF APPLICABLE)

Not applicable

B9. DESCRIPTION OF STEPS TO BE UNDERTAKEN IN CASE OF ADVERSE EVENTS OR WHEN INJURY OR HARM IS EXPERIENCED BY THE PARTICIPANTS ATTRIBUTABLE TO THEIR PARTICIPATION IN THE STUDY. (IF APPLICABLE)

Not applicable

C CANDIDATE'S STATEMENT AGREEING TO COMPLY WITH ETHICAL PRINCIPLES SET OUT IN UNISA POLICY ON RESEARCH ETHICS

I Maylene Elizabeth Meyer (Full names of student) declare that I have read the Ppolicy for Research Ethics of UNISA and that the contents of this form are a true and accurate reflection of the methodological and ethical implications of my proposed study. I shall carry out the study in strict accordance with the approved proposal and the ethics policy of UNISA. I shall maintain the confidentiality of all data collected from or about research participants, and maintain security procedures for the protection of privacy. I shall record the way in which the ethical guidelines as suggested in the proposal has been implemented in my research. I shall work in close collaboration with my promoter(s)/supervisor(s) and shall notify my promoter(s)/supervisor(s) in writing immediately if any change to the study is proposed. I undertake to notify the Higher Degrees Committee of the Department of Sociology in the College of Human Sciences in writing immediately if any adverse event occurs or when injury or harm is experienced by the participants attributable to their participation in the study. I have taken note of paragraph 5 of the Policy for Research Ethics in which integrity in research is detailed and have read and understood UNISA's Policy for Copyright Infringement and Plagiarism (see http://cm.unisa.ac.za/contents/departments/tuition_policies/docs/copyrightinfringement_and_plagiarism_policy_16nov05.pdf)

..... (Signature)

..... (Date)

This document was officially approved and signed by Professor Gretchen du Plessis, Department of Sociology, University of South Africa, on November 2, 2010.

APPENDIX D PERMISSION TO CONDUCT RESEARCH

The Director,
NAPWA, Johannesburg,
Gauteng Province

21st September 2010

Dear Sir,

Re: Approval for NAPWA members' participation in the research survey on sociological aspects of Stigma in PLWHA

Re our previous conversation, I hereby seek your approval for the participation and to use the responses from some members of your organization as contributory samples in my master's degree research.

As I have already explained to you, the theme of the research is "a sociological analysis of the nature of, extent, and comprehensiveness of stigma in people living with HIV/AIDS", and it (the research) will be supervised by Dr Denise Du Toit. Based on your approval, the schedule plan for the interviewing of the participants will be communicated to you accordingly.

Besides, on request, a copy of the research questionnaire can be sent for your perusal.

In anticipation to your response, thanks and God bless.

Regards,

Maylene Meyer

Approved by NAPWA
Nkululeko NXESI
NAPWA Secretary General

APPENDIX E STATISTICAL OUTPUTS AND ANALYSES

FACTOR ANALYSIS

```
GET
  FILE='F:\UNISA\Maylene statistics datafile\Datafile_stigma.sav'.
DATASET NAME DataSet1 WINDOW=FRONT.
FACTOR
  /VARIABLES va1 va2 va3 sp4 sp5 sp6 sp7 sp8 hc9 hc10 hc11 si12 si13 si14 si15
si17 si18 e25
  /MISSING LISTWISE
  /ANALYSIS va1 va2 va3 sp4 sp5 sp6 sp7 sp8 hc9 hc10 hc11 si12 si13 si14 si15
si17 si18 e25
  /PRINT EXTRACTION
  /CRITERIA MINEIGEN(1) ITERATE(25)
  /EXTRACTION PC
  /ROTATION VARIMAX
  /METHOD=CORRELATION.
```

Factor Analysis

Notes

Output Created		03-Nov-2010 19:04:57
Comments		
Input	Data	F:\UNISA\Maylene statistics datafile\Datafile_stigma.sav
	Active Dataset	DataSet1
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	129
Missing Value Handling	Definition of Missing	MISSING=EXCLUDE: User-defined missing values are treated as missing.
	Cases Used	LISTWISE: Statistics are based on cases with no missing values for any variable used.
Resources	Processor Time	00:00:00.031
	Elapsed Time	00:00:00.100
	Maximum Memory Required	35684 (34.848K) bytes

[DataSet1] F:\UNISA\Maylene statistics datafile\Datafile_stigma.sav

```
GET FILE='C:\Denise\Denise Data\UNISA\Maylene statistics datafile\Datafile_stigma.sav'.

DATASET NAME DataSet1 WINDOW=FRONT.
FACTOR
  /VARIABLES va1 va2 va3 sp4 sp5 sp6 sp7 sp8 hc9 hc10 hc11 si12 si13 si14 si15 si16 si17 si18 si19 e20 e21 e22 e23 e24 e25
  /MISSING LISTWISE
  /ANALYSIS va1 va2 va3 sp4 sp5 sp6 sp7 sp8 hc9 hc10 hc11 si12 si13 si14 si15 si16 si17 si18 si19 e20 e21 e22 e23 e24 e25
  /PRINT INITIAL EXTRACTION ROTATION
  /CRITERIA MINEIGEN(1) ITERATE(25)
  /EXTRACTION PC
  /CRITERIA ITERATE(25)
  /ROTATION VARIMAX
  /METHOD=CORRELATION.
```

Factor Analysis

Notes

Output Created		10-Nov-2010 08:34:40
Comments		
Input	Data	C:\Denise\Denise Data\UNISA\Maylene statistics datafile\Datafile_stigma.sav
	Active Dataset	DataSet1
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	129
Missing Value Handling	Definition of Missing	MISSING=EXCLUDE: User-defined missing values are treated as missing.
	Cases Used	LISTWISE: Statistics are based on cases with no missing values for any variable used.

Syntax		FACTOR /VARIABLES va1 va2 va3 sp4 sp5 sp6 sp7 sp8 hc9 hc10 hc11 si12 si13 si14 si15 si16 si17 si18 si19 e20 e21 e22 e23 e24 e25 /MISSING LISTWISE /ANALYSIS va1 va2 va3 sp4 sp5 sp6 sp7 sp8 hc9 hc10 hc11 si12 si13 si14 si15 si16 si17 si18 si19 e20 e21 e22 e23 e24 e25 /PRINT INITIAL EXTRACTION ROTATION /CRITERIA MINEIGEN(1) ITERATE(25) /EXTRACTION PC /CRITERIA ITERATE(25) /ROTATION VARIMAX /METHOD=CORRELATION.
Resources	Processor Time	00:00:00.062
	Elapsed Time	00:00:00.100
	Maximum Memory Required	74020 (72.285K) bytes

Component Matrix[a]

	Component				
	1	2	3	4	5
Verbal abuse1	.279	-.011	-.123	.244	.776
verbal abuse2	.716	-.128	-.038	-.229	-.218
verbal abuse3	.697	.122	.019	-.450	-.008
Self-perception4	.606	.121	-.412	-.307	.064
Self-perception5	.648	.017	-.367	-.295	-.046
Self-perception6	.472	.069	-.537	-.147	.279
Self-perception7	.567	-.242	-.239	.370	-.242
Selfperception8	.611	.046	-.389	.065	.013
Healthcare9	.716	-.162	.060	.046	-.229
Healthcare10	.545	-.571	-.081	.170	.091
Healthcare11	.624	-.416	.027	.084	.023
Social isolation12	.735	-.216	.092	-.144	.174
Social isolation13	.661	-.192	.253	.013	-.075
Social isolation14	.667	-.138	.320	-.085	.006
Social isolation15	.685	-.185	.283	-.071	-.147
Social isolation16	.237	.026	.571	-.190	.289
Social isolation17	.626	-.379	.148	.070	.213
Social isolation18	.697	-.015	.207	-.046	.123
Social isolation19	.461	-.113	.072	.602	-.004
Emotions20	.585	.633	.215	.068	-.053
Emotions21	.562	.584	.203	.046	-.059
Emotions22	.582	.593	.199	.064	.111
Emotions23	.546	.552	-.228	.214	.096
Emotions24	.447	.553	-.064	.251	-.191
Emotions25	.674	-.159	-.155	.079	-.297

Extraction Method: Principal Component Analysis.

a. 5 components extracted.

Communalities

	Initial	Extraction
Verbal abuse1	1.000	.754
verbal abuse2	1.000	.630
verbal abuse3	1.000	.703
Self-perception4	1.000	.650
Self-perception5	1.000	.644
Self-perception6	1.000	.615
Self-perception7	1.000	.632
Selfperception8	1.000	.531
Healthcare9	1.000	.598
Healthcare10	1.000	.667
Healthcare11	1.000	.571
Social isolation12	1.000	.646
Social isolation13	1.000	.544
Social isolation14	1.000	.573
Social isolation15	1.000	.610
Social isolation16	1.000	.502
Social isolation17	1.000	.607
Social isolation18	1.000	.546
Social isolation19	1.000	.593
Emotions20	1.000	.797
Emotions21	1.000	.704
Emotions22	1.000	.747
Emotions23	1.000	.711
Emotions24	1.000	.609
Emotions25	1.000	.598

Extraction Method: Principal Component Analysis.

Total Variance Explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	8.964	35.858	35.858	8.964	35.858	35.858	5.486	21.943	21.943
2	2.661	10.646	46.503	2.661	10.646	46.503	3.730	14.920	36.863
3	1.687	6.749	53.253	1.687	6.749	53.253	3.158	12.631	49.494
4	1.261	5.045	58.298	1.261	5.045	58.298	2.119	8.476	57.970
5	1.207	4.829	63.127	1.207	4.829	63.127	1.289	5.157	63.127
6	.970	3.881	67.008						
7	.894	3.577	70.585						
8	.741	2.964	73.550						
9	.691	2.762	76.312						
10	.614	2.457	78.768						
11	.601	2.406	81.174						
12	.559	2.237	83.411						
13	.512	2.048	85.459						
14	.462	1.849	87.308						
15	.444	1.775	89.083						
16	.422	1.689	90.773						
17	.391	1.566	92.338						
18	.338	1.350	93.688						
19	.313	1.250	94.939						

20	.291	1.163	96.102						
21	.258	1.034	97.135						
22	.243	.973	98.109						
23	.195	.780	98.888						
24	.162	.649	99.538						
25	.116	.462	100.000						

Extraction Method: Principal Component Analysis.

Component Matrix[a]

	Component				
	1	2	3	4	5
Verbal abuse1	.279	-.011	-.123	.244	.776
verbal abuse2	.716	-.128	-.038	-.229	-.218
verbal abuse3	.697	.122	.019	-.450	-.008
Self-perception4	.606	.121	-.412	-.307	.064
Self-perception5	.648	.017	-.367	-.295	-.046
Self-perception6	.472	.069	-.537	-.147	.279
Self-perception7	.567	-.242	-.239	.370	-.242
Selfperception8	.611	.046	-.389	.065	.013
Healthcare9	.716	-.162	.060	.046	-.229
Healthcare10	.545	-.571	-.081	.170	.091
Healthcare11	.624	-.416	.027	.084	.023
Social isolation12	.735	-.216	.092	-.144	.174
Social isolation13	.661	-.192	.253	.013	-.075
Social isolation14	.667	-.138	.320	-.085	.006
Social isolation15	.685	-.185	.283	-.071	-.147
Social isolation16	.237	.026	.571	-.190	.289
Social isolation17	.626	-.379	.148	.070	.213
Social isolation18	.697	-.015	.207	-.046	.123
Social isolation19	.461	-.113	.072	.602	-.004
Emotions20	.585	.633	.215	.068	-.053
Emotions21	.562	.584	.203	.046	-.059
Emotions22	.582	.593	.199	.064	.111
Emotions23	.546	.552	-.228	.214	.096
Emotions24	.447	.553	-.064	.251	-.191
Emotions25	.674	-.159	-.155	.079	-.297

Extraction Method: Principal Component Analysis.

a. 5 components extracted.

Component Matrix[a]

	Component			
	1	2	3	4
verbal abuse2	.742	.116	-.120	-.204
verbal abuse3	.683	.232	-.421	.078
Self-perception4	.595	.525	-.056	.182
Self-perception5	.658	.446	-.019	.145
Self-perception6	.466	.604	.141	.248
Self-perception7	.596	.029	.406	-.467
Selfperception8	.601	.357	.068	-.273
Healthcare9	.732	-.066	.068	-.293
Healthcare10	.635	-.231	.507	.245
Healthcare11	.684	-.204	.342	.159
Social isolation12	.766	-.118	-.115	.135
Social isolation13	.679	-.327	-.112	.199
Social isolation14	.678	-.300	-.375	-.116
Social isolation15	.707	-.283	-.319	-.157
Social isolation17	.673	-.277	.203	.288
Social isolation18	.681	-.172	-.145	.270
Emotions25	.703	-.014	.106	-.364

Extraction Method: Principal Component Analysis. a. 4 components extracted.

Communalities

	Extraction
verbal abuse2	.620
verbal abuse3	.705
Self-perception4	.665
Self-perception5	.653
Self-perception6	.663
Self-perception7	.739
Selfperception8	.567
Healthcare9	.630
Healthcare10	.774
Healthcare11	.651

Social isolation12	.632
Social isolation13	.621
Social isolation14	.703
Social isolation15	.706
Social isolation17	.654
Social isolation18	.587
Emotions25	.638

Extraction Method: Principal Component Analysis

Total Variance Explained

Component	Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %
1	7.562	44.480	44.480
2	1.531	9.007	53.487
3	1.104	6.497	59.984
4	1.011	5.947	65.930

Extraction Method: Principal Component Analysis.

```
FACTOR
  /VARIABLES va2 va3 sp4 sp5 sp7 sp8 hc9 hc10 hc11 si12 si13 si14 si15 si17 si18
e25
  /MISSING LISTWISE
  /ANALYSIS va2 va3 sp4 sp5 sp8 hc9 hc10 hc11 si12 si13 si14 si15 si17 si18 e25
  /PRINT EXTRACTION
  /CRITERIA MINEIGEN(1) ITERATE(25)
  /EXTRACTION PC
  /ROTATION VARIMAX
  /METHOD=CORRELATION.
```

Factor Analysis

Notes

Output Created		03-Nov-2010 19:06:27
Comments		
Input	Data	F:\UNISA\Maylene statistics datafile\Datafile_stigma.sav
	Active Dataset	DataSet1

		Filter	<none>
		Weight	<none>
		Split File	<none>
		N of Rows in Working Data File	129
Missing Handling	Value	Definition of Missing	MISSING=EXCLUDE: User-defined missing values are treated as missing.
		Cases Used	LISTWISE: Statistics are based on cases with no missing values for any variable used.
Syntax			
Resources		Processor Time	00:00:00.109
		Elapsed Time	00:00:00.100
		Maximum Memory Required	31864 (31.117K) bytes

[DataSet1] F:\UNISA\Maylene statistics datafile\Datafile_stigma.sav

Component Matrix[a]

	Component		
	1	2	3
verbal abuse2	.744	.240	-.027
verbal abuse3	.676	.301	-.389
Self-perception5	.641	.423	.012
Self-perception7	.592	.028	.494
Selfperception8	.591	.411	.185
Healthcare9	.739	.040	.147
Healthcare10	.640	-.326	.413
Healthcare11	.684	-.297	.258
Social isolation12	.771	-.076	-.143
Social isolation13	.687	-.332	-.201
Social isolation14	.687	-.212	-.384
Social isolation15	.718	-.174	-.309
Social isolation17	.678	-.345	.095
Social isolation18	.685	-.166	-.218

Emotions25	.709	.096	.207

Extraction Method: Principal Component Analysis.

a. 3 components extracted.

Communalities

	Extraction
verbal abuse2	.612
verbal abuse3	.699
Self-perception4	.615
Self-perception5	.590
Self-perception7	.596
Selfperception8	.553
Healthcare9	.569
Healthcare10	.686
Healthcare11	.623
Social isolation12	.621
Social isolation13	.623
Social isolation14	.665
Social isolation15	.642
Social isolation17	.587
Social isolation18	.545
Emotions25	.555

Extraction Method: Principal Component Analysis.

Total Variance Explained

Component	Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %
1	7.369	46.054	46.054
2	1.320	8.252	54.306
3	1.092	6.826	61.132

Extraction Method: Principal Component Analysis.

FACTOR

/VARIABLES va2 va3 sp5 sp7 sp8 hc9 hc10 hc11 si12 si13 si14 si15 si17 si18 e25
/MISSING LISTWISE
/ANALYSIS va2 va3 sp5 sp8 hc9 hc10 hc11 si12 si13 si14 si15 si17 si18 e25
/PRINT EXTRACTION
/CRITERIA MINEIGEN(1) ITERATE(25)
/EXTRACTION PC
/ROTATION NOROTATE
/METHOD=CORRELATION.

Factor Analysis

Notes

Output Created		03-Nov-2010 19:07:55
Comments		
Input	Data	F:\UNISA\Maylene statistics datafile\Datafile_stigma.sav
	Active Dataset	DataSet1
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	129
Missing Value Handling	Definition of Missing	MISSING=EXCLUDE: User-defined missing values are treated as missing.
	Cases Used	LISTWISE: Statistics are based on cases with no missing values for any variable used.
Syntax		FACTOR /VARIABLES va2 va3 sp5 sp7 sp8 hc9 hc10 hc11 si12 si13 si14 si15 si17 si18 e25 /MISSING LISTWISE /ANALYSIS va2 va3 sp5 sp7 sp8 hc9 hc10 hc11 si12 si13 si14 si15 si17 si18 e25 /PRINT EXTRACTION /CRITERIA MINEIGEN(1) ITERATE(25) /EXTRACTION PC /ROTATION VARIMAX /METHOD=CORRELATION.
Resources	Processor Time	00:00:00.109
	Elapsed Time	00:00:00.104

Notes

Output Created		03-Nov-2010 19:07:55
Comments		
Input	Data	F:\UNISA\Maylene statistics datafile\Datafile_stigma.sav
	Active Dataset	DataSet1
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	129
Missing Value Handling	Definition of Missing	MISSING=EXCLUDE: User-defined missing values are treated as missing.
	Cases Used	LISTWISE: Statistics are based on cases with no missing values for any variable used.
Syntax		FACTOR /VARIABLES va2 va3 sp5 sp7 sp8 hc9 hc10 hc11 si12 si13 si14 si15 si17 si18 e25 /MISSING LISTWISE /ANALYSIS va2 va3 sp5 sp7 sp8 hc9 hc10 hc11 si12 si13 si14 si15 si17 si18 e25 /PRINT EXTRACTION /CRITERIA MINEIGEN(1) ITERATE(25) /EXTRACTION PC /ROTATION VARIMAX /METHOD=CORRELATION.
Resources	Processor Time	00:00:00.109
	Elapsed Time	00:00:00.104
	Maximum Memory Required	28260 (27.598K) bytes

[DataSet1] F:\UNISA\Maylene statistics datafile\Datafile_stigma.sav

Component Matrix[a]

	Component		
	1	2	3
verbal abuse2	.735	.270	-.031

verbal abuse3	.666	.294	-.393
Self-perception5	.620	.314	.010
Self-perception7	.598	.191	.488
Selfperception8	.583	.499	.177
Healthcare9	.741	.130	.144
Healthcare10	.644	-.403	.421
Healthcare11	.694	-.296	.263
Social isolation12	.772	-.084	-.141
Social isolation13	.691	-.363	-.195
Social isolation14	.701	-.067	-.386
Social isolation15	.732	-.032	-.311
Social isolation17	.689	-.364	.101
Social isolation18	.688	-.204	-.214
Emotions25	.711	.215	.201

Extraction Method: Principal Component Analysis.

a. 3 components extracted.

Communalities

	Extraction
verbal abuse2	.615
verbal abuse3	.685
Self-perception5	.483
Self-perception7	.633
Selfperception8	.620
Healthcare9	.586
Healthcare10	.755
Healthcare11	.638
Social isolation12	.623
Social isolation13	.648
Social isolation14	.645

Social isolation15	.633
Social isolation17	.618
Social isolation18	.561
Emotions25	.592

Extraction Method: Principal Component Analysis.

Total Variance Explained

Component	Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %
dim 1	7.067	47.111	47.111
ensi 2	1.176	7.837	54.948
on0 3	1.092	7.281	62.228

Extraction Method: Principal Component Analysis.

```
FACTOR
  /VARIABLES va2 va3 hc9 hc10 hc11 si12 si13 si14 si15 si17 si18 e25
  /MISSING LISTWISE
  /ANALYSIS va2 va3 hc9 hc10 hc11 si12 si13 si14 si15 si17 si18 e25
  /PRINT EXTRACTION
  /CRITERIA MINEIGEN(1) ITERATE(25)
  /EXTRACTION PC
  /ROTATION VARIMAX
  /METHOD=CORRELATION.
```

Factor Analysis

Notes

Output Created		03-Nov-2010 19:09:01
Comments		
Input	Data	F:\UNISA\Maylene statistics datafile\Datafile_stigma.sav
	Active Dataset	DataSet1
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	129
Missing Value Handling	Definition of Missing	MISSING=EXCLUDE: User-defined missing values are treated as missing.
	Cases Used	LISTWISE: Statistics are based on cases with no missing values for any variable used.
Syntax		FACTOR /VARIABLES va2 va3 hc9 hc10 hc11 si12 si13 si14 si15 si17 si18 e25 /MISSING LISTWISE /ANALYSIS va2 va3 hc9 hc10 hc11 si12 si13 si14 si15 si17 si18 e25 /PRINT EXTRACTION /CRITERIA MINEIGEN(1) ITERATE(25) /EXTRACTION PC /ROTATION VARIMAX /METHOD=CORRELATION.
Resources	Processor Time	00:00:00.062
	Elapsed Time	00:00:00.060
	Maximum Memory Required	21700 (21.191K) bytes

[DataSet1] F:\UNISA\Maylene statistics datafile\Datafile_stigma.sav

Component Matrix[a]

	Component	
	1	2
verbal abuse2	.723	-.155
verbal abuse3	.646	-.467
Healthcare9	.745	.041
Healthcare10	.655	.560
Healthcare11	.705	.361
Social isolation12	.775	-.092
Social isolation13	.719	-.045
Social isolation14	.719	-.357
Social isolation15	.743	-.300
Social isolation17	.703	.254
Social isolation18	.695	-.099
Emotions25	.702	.065

Extraction Method: Principal Component Analysis.

a. 2 components extracted.

Communalities

	Extraction
verbal abuse2	.546
verbal abuse3	.636
Healthcare9	.557
Healthcare10	.743
Healthcare11	.627
Social isolation12	.609
Social isolation13	.519
Social isolation14	.644
Social isolation15	.643
Social isolation17	.558

Social isolation18	.493
Emotions25	.497

Extraction Method: Principal Component Analysis.

Total Variance Explained

Component	Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %
dimension0 1	6.424	49.413	49.413
2	1.098	8.448	57.860

```
RELIABILITY
  /VARIABLES=va2 va3 hc9 hc10 hc11 si12 si13 si14 si15 si17 si18 e25
  /SCALE('ALL VARIABLES') ALL
  /MODEL=ALPHA.
```

Reliability

Notes

Output Created			03-Nov-2010 19:11:26
Comments			
Input		Data	F:\UNISA\Maylene statistics datafile\Datafile_stigma.sav
		Active Dataset	DataSet1
		Filter	<none>
		Weight	<none>
		Split File	<none>
		N of Rows in Working Data File	129
		Matrix Input	
Missing Handling	Value	Definition of Missing	User-defined missing values are treated as missing.
		Cases Used	Statistics are based on all cases with valid data for all variables in the procedure.

Syntax		RELIABILITY /VARIABLES=va2 va3 hc9 hc10 hc11 si12 si13 si14 si15 si17 si18 e25 /SCALE('ALL VARIABLES') ALL /MODEL=ALPHA.
Resources	Processor Time	00:00:00.016
	Elapsed Time	00:00:00.004

[DataSet1] F:\UNISA\Maylene statistics datafile\Datafile_stigma.sav

Scale: ALL VARIABLES

Case Processing Summary

		N	%
Cases	Valid	129	100.0
	Excluded[a]	0	.0
	Total	129	100.0

a. Listwise deletion based on all variables in the procedure.

Reliability Statistics

Cronbach's Alpha	N of Items
.914	13

```
FACTOR
  /VARIABLES e20 e21 e22 e23 e24
  /MISSING LISTWISE
  /ANALYSIS e20 e21 e22 e23 e24
  /PRINT EXTRACTION
  /CRITERIA MINEIGEN(1) ITERATE(25)
  /EXTRACTION PC
  /ROTATION VARIMAX
  /METHOD=CORRELATION.
```

Factor Analysis

Notes

Output Created		03-Nov-2010 19:13:13
Comments		
Input	Data	F:\UNISA\Maylene statistics datafile\Datafile_stigma.sav
	Active Dataset	DataSet1

	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	129
Missing Value Handling	Definition of Missing	MISSING=EXCLUDE: User-defined missing values are treated as missing.
	Cases Used	LISTWISE: Statistics are based on cases with no missing values for any variable used.
Syntax		FACTOR /VARIABLES e20 e21 e22 e23 e24 /MISSING LISTWISE /ANALYSIS e20 e21 e22 e23 e24 /PRINT EXTRACTION /CRITERIA MINEIGEN(1) ITERATE(25) /EXTRACTION PC /ROTATION VARIMAX /METHOD=CORRELATION.
Resources	Processor Time	00:00:00.062
	Elapsed Time	00:00:00.060
	Maximum Memory Required	4100 (4.004K) bytes

[DataSet1] F:\UNISA\Maylene statistics datafile\Datafile_stigma.sav

Component Matrix[a]

	Component
	1
Emotions20	.885
Emotions21	.829
Emotions22	.851
Emotions23	.775
Emotions24	.748

Extraction Method: Principal Component Analysis.

Component Matrix[a]

	Component
	1
Emotions20	.885
Emotions21	.829
Emotions22	.851
Emotions23	.775
Emotions24	.748

Extraction Method: Principal Component Analysis.

a. 1 component extracted.

Communalities

	Extraction
Emotions20	.783
Emotions21	.688
Emotions22	.724
Emotions23	.601
Emotions24	.560

Extraction Method: Principal Component Analysis.

Total Variance Explained

Component	Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %
dimension0 1	3.356	67.115	67.115

Extraction Method: Principal Component Analysis.

```
RELIABILITY
  /VARIABLES=e20 e21 e22 e23 e24
  /SCALE('ALL VARIABLES') ALL
  /MODEL=ALPHA.
```

Reliability

Notes

Output Created			03-Nov-2010 19:13:53
Comments			
Input		Data	F:\UNISA\Maylene statistics datafile\Datafile_stigma.sav
		Active Dataset	DataSet1
		Filter	<none>
		Weight	<none>
		Split File	<none>
		N of Rows in Working Data File	129
		Matrix Input	
Missing Handling	Value	Definition of Missing	User-defined missing values are treated as missing.
		Cases Used	Statistics are based on all cases with valid data for all variables in the procedure.
Syntax			RELIABILITY /VARIABLES=e20 e21 e22 e23 e24 /SCALE('ALL VARIABLES') ALL /MODEL=ALPHA.
Resources		Processor Time	00:00:00.000
		Elapsed Time	00:00:00.006

[DataSet1] F:\UNISA\Maylene statistics datafile\Datafile_stigma.sav

Scale: ALL VARIABLES

Case Processing Summary

		N	%
Cases	Valid	129	100.0
	Excluded[a]	0	.0
	Total	129	100.0

a. Listwise deletion based on all variables in the procedure.

Reliability Statistics

Cronbach's Alpha	N of Items
.876	5

Frequencies

Notes

Output Created			04-Nov-2010 11:35:06
Comments			
Input		Data	G:\Datafile_stigma.sav
		Active Dataset	DataSet2
		Filter	<none>
		Weight	<none>
		Split File	<none>
		N of Rows in Working Data File	129
Missing Handling	Value	Definition of Missing	User-defined missing values are treated as missing.
		Cases Used	Statistics are based on all cases with valid data.
Syntax			FREQUENCIES VARIABLES=va2 va3 hc9 hc10 hc11 si12 si13 si14 si15 si17 si18 e25 /STATISTICS=STDDEV MEAN MEDIAN MODE /HISTOGRAM NORMAL /ORDER=ANALYSIS.
Resources		Processor Time	00:00:05.444
		Elapsed Time	00:00:05.602

[DataSet2] G:\Datafile_stigma.sav

Statistics: Output of Central values

		Behaviour	Emotion
N	Valid	129	129
	Missing	0	0
Mean		3.2785	2.4047
Median		3.4615	2.2000
Mode		3.77	1.00
Std. Deviation		1.01847	1.17459

Verbal abuse1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	43	33.3	33.3	33.3
	2.00	16	12.4	12.4	45.7
	3.00	29	22.5	22.5	68.2
	4.00	22	17.1	17.1	85.3
	5.00	18	14.0	14.0	99.2
	41.00	1	.8	.8	100.0
	Total	129	100.0	100.0	

verbal abuse2

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	36	27.9	27.9	27.9
	2.00	24	18.6	18.6	46.5
	3.00	20	15.5	15.5	62.0
	4.00	22	17.1	17.1	79.1
	5.00	27	20.9	20.9	100.0
	Total	129	100.0	100.0	

verbal abuse3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	40	31.0	31.0	31.0
	2.00	28	21.7	21.7	52.7
	3.00	21	16.3	16.3	69.0
	4.00	23	17.8	17.8	86.8
	5.00	17	13.2	13.2	100.0
	Total	129	100.0	100.0	

Healthcare9

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	24	18.6	18.6	18.6
	2.00	14	10.9	10.9	29.5
	3.00	26	20.2	20.2	49.6
	4.00	25	19.4	19.4	69.0
	5.00	40	31.0	31.0	100.0
	Total	129	100.0	100.0	

Healthcare10

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	13	10.1	10.1	10.1
	2.00	21	16.3	16.3	26.4
	3.00	18	14.0	14.0	40.3
	4.00	21	16.3	16.3	56.6
	5.00	56	43.4	43.4	100.0
	Total	129	100.0	100.0	

Healthcare11

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	12	9.3	9.3	9.3
	2.00	23	17.8	17.8	27.1
	3.00	18	14.0	14.0	41.1
	4.00	35	27.1	27.1	68.2
	5.00	41	31.8	31.8	100.0
	Total	129	100.0	100.0	

Social isolation12

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	27	20.9	20.9	20.9
	2.00	16	12.4	12.4	33.3
	3.00	25	19.4	19.4	52.7
	4.00	22	17.1	17.1	69.8
	5.00	39	30.2	30.2	100.0
	Total	129	100.0	100.0	

Social isolation13

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	20	15.5	15.5	15.5
	2.00	17	13.2	13.2	28.7
	3.00	34	26.4	26.4	55.0
	4.00	20	15.5	15.5	70.5
	5.00	38	29.5	29.5	100.0
	Total	129	100.0	100.0	

Social isolation14

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	18	14.0	14.0	14.0
	2.00	24	18.6	18.6	32.6
	3.00	22	17.1	17.1	49.6
	4.00	28	21.7	21.7	71.3
	5.00	37	28.7	28.7	100.0
	Total	129	100.0	100.0	

Social isolation15

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	21	16.3	16.3	16.3
	2.00	23	17.8	17.8	34.1
	3.00	25	19.4	19.4	53.5
	4.00	20	15.5	15.5	69.0
	5.00	40	31.0	31.0	100.0
	Total	129	100.0	100.0	

Social isolation17

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	15	11.6	11.6	11.6
	2.00	10	7.8	7.8	19.4
	3.00	29	22.5	22.5	41.9
	4.00	20	15.5	15.5	57.4
	5.00	55	42.6	42.6	100.0
	Total	129	100.0	100.0	

Social isolation18

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	35	27.1	27.1	27.1
	2.00	13	10.1	10.1	37.2
	3.00	24	18.6	18.6	55.8
	4.00	26	20.2	20.2	76.0
	5.00	31	24.0	24.0	100.0
	Total	129	100.0	100.0	

Emotions20

		Frequency	Percent	Valid Percent	Cumulative Percent

Valid	1.00	57	44.2	44.2	44.2
	2.00	19	14.7	14.7	58.9
	3.00	22	17.1	17.1	76.0
	4.00	18	14.0	14.0	89.9
	5.00	13	10.1	10.1	100.0
	Total	129	100.0	100.0	

Emotions21

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	52	40.3	40.3	40.3
	2.00	25	19.4	19.4	59.7
	3.00	20	15.5	15.5	75.2
	4.00	13	10.1	10.1	85.3
	5.00	19	14.7	14.7	100.0
	Total	129	100.0	100.0	

Emotions22

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	52	40.3	40.3	40.3
	2.00	23	17.8	17.8	58.1
	3.00	21	16.3	16.3	74.4
	4.00	18	14.0	14.0	88.4
	5.00	15	11.6	11.6	100.0
	Total	129	100.0	100.0	

Emotions23

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	45	34.9	34.9	34.9
	2.00	22	17.1	17.1	51.9
	3.00	33	25.6	25.6	77.5
	4.00	10	7.8	7.8	85.3
	5.00	19	14.7	14.7	100.0
	Total	129	100.0	100.0	

Emotions24

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	49	38.0	38.0	38.0
	2.00	27	20.9	20.9	58.9
	3.00	23	17.8	17.8	76.7
	4.00	9	7.0	7.0	83.7
	5.00	21	16.3	16.3	100.0
	Total	129	100.0	100.0	

emotions25

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	21	16.3	16.3	16.3
	2.00	15	11.6	11.6	27.9
	3.00	31	24.0	24.0	51.9
	4.00	29	22.5	22.5	74.4
	5.00	33	25.6	25.6	100.0
	Total	129	100.0	100.0	

APPENDIX F FIELDWORK CORRESPONDENCE

From: Maylene Meyer
Sent: 20 October 2010 07:59 AM
To: Denise du Toit'
Subject: Feedback on Sedibeng - Evaton West 19 October 2010
Hallo Denise

Challenges:

Prov. Secretary of NAPWA did not organize the prospective participants.
Thozama liaised with Pastor Daniel Dube from the New Life Centre Mission (a partner organization of NAPWA) for the research participants (PLWHA)
Pastor Dube has an office made out of “sink plate”. He told me that I must not look at this office. He has a staff compliment of 100 employees and they all work in the community. His organization was hosting a HCT campaign in Palm Springs and asked us to join his team to organize participants for the research study, which we did. We will have to go back to Evaton on Thursday 21 October 2010 at 09h00. The coordinators of the New Life ministry has invited us to the open and closed support groups for PLWHA.

Despite all the challenges Thozama managed to arrange 20 participants that living positively and openly with HIV. We had no venue to accommodate the people, so we used my car and stood near an open field on a street corner in extension11 of Evaton West. I briefed them on the research study, and the inform consent, while Thozama interpreted in the participants vernacular language. Participants all agreed to participate in the research study and everybody completed the questionnaire.

The weather was very bad (wind, rain and sun) but we finished our goal.

Thank you for all your telephonic help, advice and support. It gave me strength to continue against all odds.

Kind regards,
Maylene

Juffrou word gou gesond. Navorsing is leeg sonder jou.

From: Maylene Meyer
Sent: 27 October 2010 11:03 PM
To: 'Denise du Toit'
Subject: Endulwini Section Thembisa update 27 Oct 2010

Date: Wednesday 27 October 2010

Venue: 753 Endulwini Section, Thembisa 1632

Project Manager: Ms Leanan Metswamere (Cell 073 091 8109, office 011 9201499)

Name of NGO: Simunye Support Group

Total participants: 13

Total participants completed and signed informed consent forms: 13

Total participants completed questionnaires: 12

Issues that came up:

- One volunteer strongly felt that she should also complete the questionnaire because she is affected by HIV and AIDS.
- One participant ticked off all the number ones. When I asked her why did she only ticked off the no. ones, she said: “I experience stigma a lot since I have disclosed my HIV+ status to my family and friends. I was rejected by them completely up to today”.
- Mr. Wellington Radebe accompanied us and used the opportunity to mobilize the support group to join a national march on the 5 Nov. 2010 in Pretoria. The march is organized by NAPWA. The purpose of the march is to prevent government from deregistration of social grants for PLWHA. He also asked them to recruit other people to join the march.

All members of the support group willingly participated in the research study.

From: Maylene Meyer
Sent: 27 October 2010 03:28 PM
To: ‘Denise du Toit'
Subject: Thembisa update: 27 Oct 2010

Date: Wednesday, October 27, 2010

Venue: Thembisa Main Clinic, Mcantse Section

Co-coordinators: Mr. Wellington Radebe (NAPWA HCT councilor) Cell 074 730 3394
Ms Thozama

Total participants: 20

Total informed consent forms completed and signed: 20

Total questionnaires completed: 20

Challenges that have emerged include:

The HCT coordinator expressed the following concerns around Stigma in the Thembisa community which he experiences

- PLWHA in the support group stigmatized themselves before other people stigmatized them. E.g. PLWHA is scare to be on ARV treatment
- When a PLWHA is visiting an ARV treatment clinic, people who she him/her spread rumors about the PLWHA before they have disclosed.
- In Thembisa people use 3 letter words to describe PLWHA. E.g. OMO, ENO, MTN, and other words like KAPSELA
- Families hide their family members that are ill with AIDS and are bedridden. When HB Carers want to give care and support, the family will say that the patient is gone, while he/she is at home.
- PLWHA is having his/ her own dish, cup, plate and bath within their families.
- Elderly people still believe that if you hug a PLWHA that it can be transmitted to them.
- PLWHA are dismissed from their companies (contract workers) because they have disclosed.
- PLWHA are chased from their homes ones they have disclosed their HIV positive status.
- Churches in Thembisa do not want to do candle light ceremony. They advised PLWHA not to take ARVs because it is westernised medicine
- Partners (men and women) do not want to disclose because they are scared that the wife or husband will run away

A 75 year old woman is HIV+ and lives openly and positively. She has completed the questionnaire with great joy and willingness

Overall the HCT councilor is a great inspiration to his support groups. All of them completed the questionnaires without hesitation

Groetnis,
Maylene

Dankie vir al die advies en leiding.

From: Maylene Meyer
Sent: 22 October 2010 03:11 PM
To: 'Denise du Toit'
Subject: Sedibeng: 21 October 2010
Update on Sedibeng:

Arrived at 08h00 at the gate of the cemetery in Evaton where Matibelo Mahasela and Elizabeth Liphaphang (NAPWA's field workers – Sedibeng) waited for me. Thozama could not go with me to Sedibeng, but mad arrangements with Elizabeth and Matibelo.

Arrived at 08h30 ***Evaton Plaza*** where the HCT campaigns continued organized by the New Life Church. Organizers of the campaign and others arrived in drips and drags. A new Pick and Pay store opened and had many food specials. They were now first checking the specials and went to buy groceries. Eventually a small shop

was unlocked at 10h50 where the support groups meet. It was very disorganized, but we pushed through. NAPWA field workers introduced me, then I explained the research study, the inform consent and the questionnaire. Then the NAPWA fieldworker had to interpret what I said in Sotho. One of the councilors displayed a cold war against the research and I was told that she instigated participants not to complete the questionnaires. From the approximately 30 participants on 3 signed the inform consent and completed the questionnaires. A very vibrant facilitator (Momekete Motsoeneng rescued the situation and told me that she will take us to her support group in Polokong in Van der Bijl Park .

Arrived at ***Polokong*** at 11h30. This was a closed support group, all on ARV's. Momekete first explained to them about the research, after getting their permission she called us and introduced me and the NAPWA field workers. I explained the research study, inform consent, questionnaire which was also interpreted into Sotho by the NAPWA's field workers. They were all willing to participate and completed the inform consent and questionnaires. I thanked them and we left to see another support group in "Sonder Water"

Arrived at "***Sonder Water"*** to 12h51. Pastor Ndlazi Petrus Manaba welcomed us. The venue was a "sinkplate shack" with no water and electricity. The support group members were all unemployed youth PLWHA. The room had no ventilation and it was extremely hot. Pastor introduced us to the group and we received a very warm welcome. I explained the research study, questionnaire and inform consent which was interpreted into Sotho by NAPWA field workers. The participants completed the inform consent and questionnaires. The co-coordinator thanked us and pastor prayed, then we left.

Issues that came up:

A young lady asked: "If I have not disclosed my HIV status, how do I complete the form?" I have reassured her and explain that she can still complete the questionnaire, if she wants to and she willing did.

A young man asked: "Why can't I complete the questionnaire. My brother is infected with HIV, therefore I am affected."

About 5 PLWHA, who does not belong to any support group made use of the opportunity to ask the facilitator if they can join her support group and she agreed.

NAPWA field workers also had the opportunity to touch base with their members in Polokong and Sonder Water. It is very difficult for them to visit these members because of distance, transport and finance.

NAPWA field workers asked for any donation of second hand clothes, food and blankets

Breakdown of participants that completed the inform consent and questionnaires:
Evaton Plaza: 3
Polokong: 26

Sonder Water: 27
Hlalasas: 21
Total: 77

From: Maylene Meyer
Sent: 27 October 2010 03:28 PM
To: 'Denise du Toit'
Subject: Thembisa update: 27 Oct 2010
Date: Wednesday, October 27, 2010

Venue: Thembisa Main Clinic, Mcantse Section

Co-coordinators: Mr. Wellington Radebe (NAPWA HCT councilor) Cell 074 730 3394
Ms Thozama

Total participants: 20

Total informed consent forms completed and signed: 20

Total questionnaires completed: 20

The HCT co-coordinator expressed the following concerns around Stigma in the Thembisa community which he experiences

- PLWHA in the support group stigmatized themselves before other people stigmatized them. E.g. PLWHA is scare to be on ARV treatment
- When a PLWHA is visiting an ARV treatment clinic, people who she him/her spread rumors about the PLWHA before they have disclosed.
- In Thembisa people use 3 letter words to describe PLWHA. E.g. OMO, ENO, MTN, and other words like KAPSELA
- Families hide their family members that are ill with AIDS and are bedridden. When HB Carers wants to give care and support, the family will say that the patient is gone, while he/she is at home.
- PLWHA is having his/ her own dish, cup, plate and bath within their families.
- Elderly people still believe that if you hug a PLWHA that it can be transmitted to them.
- PLWHA are dismissed from their companies (contract workers) because they have disclosed.
- PLWHA are chased from their homes ones they have disclosed their HIV positive status.
- Churches in Thembisa do not want to do a candle light ceremony. They advised PLWHA not to take ARVs because it is westernised medicine
- Partners (men and women) do not want to disclose because they are scared that the wife or husband will run away

A 75 year old woman is HIV+ and lives openly and positively. She has completed the questionnaire with great joy and willingness

Overall the HCT councilor is a great inspiration to his support groups. All of them completed the questionnaires without hesitation

Groetnis,
Maylene

Dankie vir al dies advies en leiding.

From: Maylene Meyer
Sent: 27 October 2010 02:13 PM
To: 'Denise du Toit'
Subject: West Rand update - Randfontein 26 Oct 2010
Date: Tuesday, 26 October 2010

Venue: Mohlakeng Recreation Centre, Randfontein

Co-ordinator Ms Nombulelo Sithole (NAPWA field worker – Randfontein)

Total participants: 7

Total completed informed consents forms: 7

Total completed questionnaires: 7

Challenges that have emerged include:

- Participants have left since they were waiting for us since 11h00. We have arrived at 14h00 due to events in Carltonville Khutsong.
- The field worker could not call them back. Participants is scared that if she talks to them in public people will know that they are HIV+
- Field worker says PLWHA in Randfontein will only talk to her behind closed doors or at her house.

We had to accept the situation. Thanked her and left at 15h00.

Kind regards,
Maylene