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UNIVERSITY OF THE WITWATERSRAND
FACULTY OF HUMANITIES
WITS SCHOOL OF ARTS
DEPARTMENT OF TELEVISION

Topic: The Stigmatization of HIV-positive Women and the Role of Associations of People Living with HIV/AIDS (APWA).

By

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Research Report submitted to the Faculty of Humanities and Social Sciences, University of the Witwatersrand, Johannesburg, in partial fulfillment of the requirements for the award of the degree of Masters of Arts (M.A) in Dramatic Arts at the School of Arts.

Declaration

I declare that this Research Report is my own original intellectual work. It is being submitted for the award of the degree of Masters in Dramatic Arts (MA) at the University of the Witwatersrand, Johannesburg. To the best of my knowledge, it has not been submitted before for any degree or examination in any other university here in South Africa or anywhere else in the world.

Candidate: Namondo Magdaline Ikome Supervisor: Tawana Kupe (Prof)

Date…… Date: ……

Dedication

To my elder brother Dr. Francis Nguendi Ikome
To my parents
To all HIV infected and affected people in the world

Acknowledgements

This Research has been made successful through the assistance of many individuals who supported me intellectually, morally, spiritually and financially. I am indebted to them all. My first appreciation goes to my supervisor Prof. Tawana Kupe who came in to salvage this research from the doldrums of inactivity. His encouragement and zeal to work with me gave me the courage to forge ahead when I thought all was lost.

My appreciations also go to Miriam Mamatela, and Maropeng Maake staff at the Post-graduate office of the faculty of humanity who did all to help this research to proceed. I am also grateful to the graduate coordinator at the Wits school of Arts, Federico Freshi who intervened and facilitated my change of supervisor.

I want to also acknowledge the foundation work for this research laid by Prof. Joyti Mistry my first supervisor who saw me through my research proposal and Ulrika Kishna, Angie Mills and Tanja Sakota-Kokot, my lecturers at Wits Television. Many thanks go to the members of NAPWA-SA who facilitated this study. Special thanks go to Eugenia Kebine and Thanduxolo Doro.

I am very grateful to my elder brother, Dr. Francis Nguendi Ikome who kept his promise of helping me to study abroad. I am forever indebted to him for his relentless support through out my M.A studies at Wits University and my stay in South Africa. I am equally grateful to my brother Prof. Otto Mbambe Ikome for his guidance and input all the way from Canada through out this Research.

I also want to extend my appreciation to my other brothers and sisters who encouraged and prayed for me through out my academic sojourn in South Africa. Special thanks also go to

my friends who were with me morally and spiritual all through this journey. These include but not limited to Victorine and Emmanuel Anye, Mrs. Ruphina Eyole Monono, members of my house fellowship group of the Redeemed Christian Church of God, Roger Katende, Hope Luvuno and Themba Hlaisi. Finally I want to thank the lord all mighty for being steadfast and for guiding and protecting me through my studies.

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Abstract

Throughout history, many diseases have carried considerable stigma, including leprosy tuberculosis, cancer, mental illness and many STDs. Now HIV/AIDS is the topmost in the list of diseases that leads to devastating patient stigmatization. Despite international efforts to tackle HIV/AIDS, stigma and discrimination remain among the most poorly understood aspects of the epidemic. In the face of numerous intervention strategies, HIV/AIDS continues to spread and to pose a threat to the socio-economic transformation of South Africa.

The broad objective of this study was to investigate how the stigmatisation of HIV-Positive women is made manifest and look at how successful the National Association of people living with HIV/AIDS (NAPWA) in South Africa has been in achieving their objectives and goals of changing the perceptions people have about HIV/AIDS and creating awareness about the debilitating effect stigmatisation has in the society, especially when it viciously targets HIV-positive women.

A case study approach was used to examine the experiences of HIV/AIDS infected/affected women and NAPWA administrators. Methods used in the collection of data were self-administered questionnaires, participant observation and archival evidence in the form of documents. Through these methods, the study investigated ways in which the stigmatisation of HIV-positive women was made manifest, the role of NAPWA in fighting HIV/AIDS stigmatisation, how successful NAPWA has been in the fight against the stigmatisation of people infected and affected by HIV/AIDS in South Africa, challenges faced by NAPWA in the fight against HIV stigmatisation and discrimination, weaknesses of NAPWA and what impact all these have in the spread of HIV/AIDS.

The research results show that HIV-positive women suffer stigmatisation and that; organisations of people living with HIV/AIDS (e.g. NAPWA-SA) play a major role in eradicating the stigma attached to HIV/AIDS. It also suggests that APWAs in effect help to reduce the spread of the disease and prolong the life span of those infected by it.

All this not withstanding, the study also discovered that APWAs like NAPWA-SA need the support of government and stakeholders in South Africa to fully implement their strategies and programmes geared towards reducing stigma and the spread of HIV/AIDS.

CHAPTER ONE

1. Introduction

In 1987, the late Jonathan Mann, then director of the WHO Global Programme on AIDS, identified three HIV/AIDS epidemic-defined phases: the epidemic of HIV (detecting the virus), the epidemic of AIDS (developing the disease), and the epidemic of stigma, discrimination, and denial (coping with the condition in society). He noted that the third phase is "as central to the global AIDS challenge as the disease itself" (Mann 1987). Despite international efforts to tackle HIV/AIDS since then, stigma and discrimination (S&D) remain among the most poorly understood aspects of the epidemic. As recently as 2000, Peter Piot, Executive Director of UNAIDS, identified stigma as a "continuing challenge" that prevents concerted action at community, national, and global levels (Piot 2000).

To understand the ways in which HIV/AIDS-related stigmata appear and the contexts in which they occur, we first need to understand how they interact with pre-existing stigma and discrimination associated with sexuality, gender, race, and poverty. HIV/AIDS-related stigmata also interact with pre-existing fears about contagion and disease. Early AIDS metaphors—as curse, as death, as horror, as punishment, as guilt, as shame, as otherness—have exacerbated these fears, reinforcing and legitimizing stigmatization and discrimination. These perceptions, as I will show later, contribute substantially to the difficulty in containing the spread of the disease worldwide, in general, and in developing countries, in particular.

HIV/AIDS-related stigma is most closely related to sexual stigma. This is because HIV is mainly sexually transmitted and in most areas of the world, the epidemic is largely

associated with populations whose sexual orientation and proclivities deviate from the "norm." HIV/AIDS-related stigma has therefore appropriated and reinforced pre-existing sexual stigma associated with sexually transmitted diseases, homosexuality, promiscuity, prostitution, and sexual "deviance" (Gagnon and Simon 1973; Plummer 1975; Weeks 1981).

HIV/AIDS-related stigma is also linked to gender-related stigma. The impact of HIV/AIDS-related stigma on women reinforces pre-existing economic, educational, cultural, and social disadvantages and unequal access to information and services (Aggleton and Warwick 1999). In settings where heterosexual transmission is significant, the spread of HIV infection has been associated with female sexual behaviour that is not consistent with established gender norms.

1.1 Statement of Problem

The attributes of stigma currently associated with the scourge of HIV/AIDS contribute to and result in the powerlessness of many women with HIV/AIDS. Where women's risks are recognized, attitudes towards their infection are often judgmental and may involve a great deal of speculation and assumption about the behaviour that has led to the infection. Such stigma may lead to fear of disclosure and women may, as a result, delay or avoid speaking about their diagnosis, if they actually get one. Women living with HIV/AIDS in South Africa, for instance, have been the target of stigmatization from the time the first cases were diagnosed in the country. In South Africa, many communities "punish" people, especially women, (e.g., in 1998, Gugu Dlamini, an AIDS activist in Durban, came out as being HIV-positive on World AIDS Day. She was later beaten to death by her

neighbours)[1], for simply revealing their HIV status. An HIV diagnosis can cause family members, neighbours, and even medical providers to shun the HIV-infected person. This usually leads to the fear of disclosure and very often, HIV/AIDS victims come together in associations made up of people like them and sympathizers in a bid to fight this stigma. This has led to the birth of many organizations catering to the well being of people living with AIDS around South Africa. One of such organisations is NAPWA[2]- South Africa, the case study of this research.

The stigmatisation of women living with HIV/AIDS is certainly a major problem which may only be the tip of the iceberg with regards to the contributing factors in the spread of the disease. In this research, I use the NAPWA case study to investigate the conditions and circumstances surrounding this stigma, in order to document and empirically show how and why stigmatisation of HIV/AIDS sufferers contributes to the large-scale spread of the disease, especially in developing countries in Africa. I will also highlight the role of support organisations like NAPWA in reducing this stigma attached to the disease.

Part of my methodology includes a theme-specific definition of terms, as culled from existing literature and as contextually interpreted by this researcher. The following key concepts are highlighted to facilitate the understanding of their usage throughout this presentation.

Stigmatisation: Many definitions have been suggested for the word "stigma". It can be based on race, gender, class, religion, sexual orientation or disease. In this study, I look at stigmatisation based on gender and the HIV/AIDS disease. Stigmatisation is used here to

[1] "AIDS in South Africa" Culled from the AVERT.org website: http://www.avert.org/aidssouthafrica.htm

[2] National Association of People With Aids

refer to a social phenomenon in which labeling is used to isolate and identify individuals and/or groups as being abnormal and therefore undesirable. The modern term “stigma” comes from a Latin word describing a prick with a pointed instrument. A stigma is, literally, “a distinguished mark burned or cut into the flesh, as of a slave or criminal,” serving most typically as a “mark of disgrace or reproach” (Webster 183:1788).

HIV-Positive: According to a report from the US-Atlanta-based Centre for Disease Control (CDC), the Human Immunodeficiency Virus (HIV) is a retrovirus (a virus which uses the body's own cells to reproduce itself) that attacks the human body's immune system and causes the Acquired Immune Deficiency Syndrome (AIDS). By killing or damaging cells of the body's immune system, HIV progressively destroys the body's ability to fight infections and certain cancers. AIDS, the report continues, is the final stage of HIV infection and is usually characterised by a CD4 count of less than 200. ‘HIV-Positive’ in this study will mean having had a positive result in a blood test for HIV.

Women: According to the Oxford dictionary, the word ‘women’ means an adult human female. In this research ‘women’ will refer to adult female members of NAPWA who are infected or affected with HIV/AIDS.

Role: In this study ‘role’ refers to the part played by NAPWA in the fight against the stigmatisation of HIV/AIDS. The Oxford dictionary defines ‘role’ as an actor’s part in a play, film, etc., or a person or thing’s function in a particular situation. ‘Role’ can also refer to a set of responsibilities, activities and authorisations or the actions and activities assigned to or required or expected of a person or group. Thus this research will examine

the actions, activities and function of NAPWA-SA in the fight against HIV/AIDS and its attendant problems.

APWA: APWA in this research stands for Associations of people living with HIV/AIDS.

NAPWA-SA: This stands for the National association of people living with HIV/AIDS in South Africa. This association is used as a case study for this research and is made up of both people who are infected and affected by HIV/AIDS.

PWA: In this study, PWA stands for People living with HIV/AIDS.

1.2 Aim of Research

This research aims at examining the stigmatisation of HIV-positive women and the role of associations of people living with HIV/AIDS (APWA). It will focus on the HIV infected and affected women of the South African National Association of People living with HIV/AIDS (NAPWA), by looking at their lives as people infected or affected by HIV/AIDS and their lives as members of NAPWA. This research examines the lives of a group of women and addresses issues relating to their living conditions and circumstances created by stigmatization. I shall also look at NAPWA as an organisation, its activities and the role this plays when it comes to dealing with the stigma attached to HIV/AIDS. At the end of this research I hope to establish how the stigmatisation of HIV-positive women works and consider whether NAPWA is achieving its objectives and goals of changing the perceptions people have about HIV/AIDS-positive women and create awareness about the debilitating effect stigmatisation has in the society, especially when it viciously targets HIV-positive women.

Below are the salient themes examined in this study:

- The circumstances leading to HIV stigmatisation and how it is made manifest.
- What NAPWA is doing to educate members about coping with HIV/AIDS and stigma.
- What NAPWA is doing to sensitise communities about HIV/AIDS and the effect of stigmatisation.
- NAPWA's support for women living with HIV.
- The success of NAPWA in achieving its mission of fighting HIV-stigmatisation and discrimination of people infected and affected by HIV/AIDS in South Africa.
- Challenges involved in the fight against HIV stigmatisation and discrimination.
- How attitudes, beliefs and practise impact on NAPWA's ability to address the challenges of HIV/AIDS and stigmatisation.

It is expected that the information generated will contribute to:

- A better understanding of the manifestation of stigmatisation of HIV-positive women.
- A better understanding of the strengths, weaknesses and challenges of APWA'S in the fight against the stigmatisation of those infected and affected by HIV/AIDS.
- The formation of an informed practical framework that policy makers and practitioners in APWA can draw on to address the stigma attached to HIV/AIDS.

Through this research endeavour, I hope to significantly contribute to the quest for ways to change social attitudes, government policies and business practices, so that the HIV/AIDS scourge can be understood as another unfortunate pandemic that everyone must deal with until such time that we can find a cure or even eliminate it.

1.3 Background to the Problem

Every year, throughout the world, an increasing number of people are affected and infected by the HIV/AIDS pandemic either directly or through someone they know and/or care for. HIV/AIDS has affected millions of people worldwide. According to UNAIDS (2003:4) the global HIV/AIDS epidemic killed more than 3 million people, with an estimated 5 million acquiring the HIV virus, bringing to 40 million the number of people living with the virus around the world. Sub-Saharan Africa remains by far the region worst affected by the HIV/AIDS epidemic. In 2003, an estimated 26.6 million people in this region were living with HIV, including 3.2 million who became infected in 2002. AIDS killed approximately 2.3 million people in 2003 (UNAIDS 2003).

Women comprise an increasing proportion of people living with HIV/AIDS and of new infections worldwide. Over the last few years prevalence among women has accelerated from consisting of 41% of infected adults in 1997 to 50% in 2002. However, in Sub-Saharan Africa women represent almost 6 in 10, (57%) living with HIV/AIDS.[3] Sub Saharan Africa is the only region where more women than men are infected with the virus, and the share of women with HIV/AIDS is increasing. Among young people, the gender gap is even larger than among adults. 75% of all young people living with HIV are female, with the worst samples ranging from 20 infected girls to every 10 boys in one country, and 45 girls to every 10 boys in another country.[4]

More than one in five pregnant women are HIV infected in most countries in southern Africa, and in some countries, (in Gaborone, Botswana and Manzini, Swaziland) the

[3] UNAIDS 2004 report on the global AIDS epidemic

[4] UNAIDS 2004 report on the global AIDS epidemic

prevalence among pregnant women is up to 40 per cent. Within South Africa, in five out of the nine provinces, at least 25 per cent of pregnant women are HIV-positive.[5]

South Africa has become the AIDS epicentre of the continent. Current estimates are that one in five adults, or a total of about 5.3 million South Africans, are living with HIV or AIDS, with 1700 more being infected every day (Campbell 2003; UNAIDS 2003). The HIV/AIDS epidemic in South Africa represents one of the greatest threats and challenges to the socio-economic transformation of the country. According to the latest Love Life AIDS campaign literature (at the time that this study was conducted), from the year 2000, AIDS deaths are expected to rise sharply to an estimated 635,000 deaths per year in 2010. When compared to India, the world's second most populous country with one billion people, which has about 3.8 million people with HIV, the 5.3 million people with HIV /AIDS in South Africa, with a population of just 43 million, is a significant proportion of the population.

1.4 Context of Vulnerability

For reasons due to biology, women have always been more susceptible to contracting the HIV virus than men. Biological factors include: the higher viral concentration in semen compared to vaginal fluids, larger exposed surface and longer viral contact among women. However, these grounds alone cannot explain the sudden acceleration or the geographical concentration of the feminisation of the epidemic, which indicates that we must look beyond the immediate circumstance of biological vulnerability and to the broader socio-cultural context.

[5] As cited in the Commission of HIV/AIDS and Governance in Africa (CHGA) Nov. 2004. http://www.uneca.org/CHGA

The UNDP pre-Beijing Human Development report of 1995 states that, according to the Gender Development Index (GDI), no country was found to treat its women as well as it treats its men. Existing evidence from the last ten years on the general situation of women in Africa shows that little has changed[6] and that the data available on the HIV/AIDS pandemic highlight the fact that nowhere else are these observations more pertinent than when applied to the situation of women and girls within the framework of HIV/AIDS in Africa.[7] This confirms that the feminisation of the pandemic is rooted in the complex dynamics between HIV/AIDS and gender inequality.

Riding on the back of existing gender inequalities, HIV/AIDS aggravates the situation of women, translating existing differences in male and female statuses into even harsher conditions on the ground. The dynamics of gender and HIV/AIDS does this by creating multiple mechanisms that exacerbate the vulnerability of women both for contracting the virus, coping with the disease and caring for others affected by the pandemic. Many of these links do not only manifest themselves as mechanisms of vulnerability, but also become factors that fuel the spread of the epidemic.

With regard to coping with HIV and AIDS, women face more harm from stigma and discrimination than men, exacerbating the already unequal and poor access to testing, treatment and care. More so, as issues of women's sexuality are still culturally taboo, HIV-infected women experience higher rates of stigmatisation than HIV-infected men. HIV-

[6] Gender in Africa: the issues, the facts—an ECA pocket reference publication in collaboration with the World Bank

[7] Hilda Tadria, Regional Advisor, ACGD, "The Gender Dimensions of HIV/AIDS in Africa"

infected women also experience higher rates of rejection. The implication of this is further marginalisation of HIV-positive women, but also that women will be more reluctant to come forward for testing, as well as being more reluctant to come forward for HIV-related treatment and support, for fear of exposing their status.

Given that the struggles for gender equality begin in the family, it is also the primary site for greater stigmatisation, discrimination and violence against women. Research confirms that it is "not just the Sero-status that is key to altering women's lives, but equally (and at times, more) important, their spouse's/partner's response to the new crisis in the family".[8] As a result, many women hesitate to test for HIV and to disclose their HIV-positive status even to their husbands. Discrimination takes place in other areas as well, including in the workplace and in the community, making it more difficult for women to demand equal treatment and care. The ABC (*Abstain from sex until marriage, Be faithful to one partner, and if you can't, use a Condom)* message, which upholds faithfulness and is promoted in many HIV/AIDS campaigns is, in certain cases, found to intensify stigma as married women with HIV are unfoundedly accused of engaging in extramarital affairs.

However, the axis of any effective response is a prevention strategy that draws on the explicit and strong commitment of leaders at all levels, that is built on community mobilization, de-stigmatisation of the disease and that extends into every area of the country. The magnitude of the problem in South Africa, and the need for a collective response, was observed by former President Nelson Mandela in his address to the World

[8] Study commissioned in March 2004, by the Commission on HIV/AIDS and Governance in Africa, on "Gender Work and HIV /AIDS in Uganda''.

Economic Forum at Davos, Switzerland in February 1997: “The vision which fuelled our struggle for freedom, the deployment of energies and resources, the unity and commitment to common goals—all these are needed if we are to bring AIDS under control.” (AIDS Action Plan for South Africa, 2000).

This implies that government alone cannot succeed in fighting HIV/AIDS. The current President of South Africa, Thabo Mbeki, on launching the Partnership Against AIDS in October 1998, made an historic declaration on HIV/AIDS. He called on all South Africans to “join hands […] in partnership against AIDS […] to save our nation”, mentioning that government had taken the lead in a new focused initiative to address the multi-faceted nature of the epidemic. However, the government is further realising that it cannot succeed alone, and is therefore calling on all sectors of South African society to mobilise in order to meet this new threat and commit themselves to a unified response to address the multifaceted nature of the epidemic (AIDS Action Plan for South Africa 2000:1998). In an effort to combat the HIV/AIDS virus, the South African government has undertaken a national HIV/AIDS campaign, which has been running for several years. The government has also allocated more money to all provinces for HIV/AIDS prevention programmes.

However, generally, the South African government has been slow to react to the AIDS crisis, and it has become embroiled in a series of controversies resulting in disunity and conflict (Campbell 2003). These controversies have been described by Coombe (2000: 11) as: “detours, which have continued to divert the energies of activists, officials and politicians in needless controversy and futile confrontation.” Critics have argued that the

rapid spread of the HIV epidemic in South Africa has been compounded by poor government action to recognise and respond effectively to the source of the problem.

1.5 Contribution of the Study to the Advancement of Knowledge

Many associations of people living with HIV/AIDS (APWA) in South Africa have been created all over the country in line with local and national needs, but these associations are being overwhelmed by the growing number of people living with HIV/AIDS, the continuous denial, stigmatisation, and discrimination of people living with the disease, especially in rural impoverished areas (Barnett and Whiteside 2002; Marks, 2002).

APWA'S made of people infected and affected by HIV/AIDS themselves, can play a vital role in the formulation of appropriate strategies for addressing the problem of HIV/AIDS stigmatisation and discrimination and are a site for programme implementation and development.

A review of literature reveals that no studies from an HIV stigmatisation perspective have been conducted regarding the stigmatisation of HIV-positive women and the role of Associations of people living with HIV/AIDS in reducing this stigma. Thus, this study contributes to an understanding of how the stigmatisation of HIV-positive women is made manifest, the role of APWAs and provides an informed framework for the development and implementation of appropriate strategies for the fight against the stigmatisation of HIV-positive women.

1.6 Description of the Research Method and Scope of the Study

This study used qualitative research methods. The National Association of People living with HIV/AIDS in South Africa (NAPWA-SA), with headquarters in Germiston in the Gauteng province, was selected as a case study of APWAs in this research. This particular

APWA was chosen because it is the only nationally organised APWA in South Africa. More so, the fact that NAPWA is serving more than 5000 PWA a month nationally, representing the interests of 4.2 million people living with HIV/AIDS, and the fact that a majority of its members are women, made it a logical choice for this research. NAPWA-SA was also chosen over other APWA'S because my earlier documentary production for my Masters Course work practicals was done at NAPWA-SA; I am therefore familiar with the association, its Head Quarters and work environment. The research methodology is set out in detail in Chapter 3.

Selected HIV-positive women, Heads of administration, and HIV-affected women were handed self-administered questionnaires to provide relevant information regarding the manifestation of HIV stigma, activities carried out in the organisation, the problems experienced, existing strategies and infrastructure put at their disposal to address the challenges of stigmatisation and HIV/AIDS.

1.7 Organisation of the Remainder of the Study

This research report is divided into five chapters which correspond to the steps suggested in the research aims and objectives listed above.

Chapter two provides the literature review and theoretical framework on which the study is based. It reviews the findings of other researchers regarding stigmatisation and HIV/AIDS and women. It provides a focus for the study of key aspects related to women and HIV/AIDS as well as HIV/AIDS and stigmatisation.

These aspects include the social context of HIV/AIDS, theories of coping with stressful events, a range of responses to HIV/AIDS, for example denial, stigma, and finally, gender and HIV/AIDS.

Chapter three provides an account of the research methods. It describes the manner in which the sample was selected, and the way in which the self-administered questionnaires, some critical incidents and the case study were used to gather and interpret data.

Chapter four reports on the results culled from the case study.

Chapter five concludes the research report. It provides an analysis and discussion of the findings, including suggestions made by the participants of the study, as well as conclusions drawn by this researcher. This chapter also makes suggestions for future research.

CHAPTER TWO
Literature Review / Theoretical Framework

2.1 Introduction

This section reviews the incidental and *ad hoc* findings of other researchers regarding the concept of stigmatisation and the challenges of HIV/AIDS. This researcher will discuss stigmatisation in the context of HIV/AIDS, looking at it as an elusive social challenge. The theory of coping with stressful events in general and more specifically with chronic life-threatening illnesses such as HIV/AIDS will be examined. The literature of NAPWA-SA will also be looked at closely in this chapter. This chapter will also provide the theoretical background to the study. Other themes for discussion in this review will include HIV-positive women and HIV/AIDS.

2.2 HIV/AIDS and Stigma

While scholarly attention has been symbolically lavished on the PWAs Sero-positive body, the actual experiences of the HIV-positive person in the face of what Treicher in 1987 labelled the "epidemic of significant" has received less attention at least in academic literature. However, some exceptions have been made by Adam and Sears 1994; Adam and Sears 1996; Crossley 1997; Davies 1997; Carricaburu and Pierret 1995; Lang 1991 (cited in Green et al. 2000).

The amount of research focussing specifically on self-disclosure, as opposed to disclosure made by third parties, is growing but still not large enough. While a few scholars have investigated intentions to self-disclosure (e.g. Keyeles et al. 1988), or looked at the costs and benefits of disclosure (e.g. Holt et al. 1998) and some individual case studies of non-disclosure have been documented (e.g. Chiodo and Tolle 1992), much of the available

literature, limited as it is, takes the form of guidelines for HIV/AIDS counsellors (e.g. Green 1989a; Sherr 1991). The advice offered is generally impressionistic and suggestive, and although it may be useful to counsellors, it is not research-based. Much of that which is based on research is undertaken in regard to chronic disease or conditions other than AIDS (Green, G. & Sobo, E. 2000).

According to Green and Sobo, although there are publications that examine what it is like to be HIV-positive, it is only recently that such publications have come out of academic endeavours (e.g. Ariss and Dowsett 1997; Cajetan Luna 1997; Klitzman 1997). They suggest that academic publications often fail to contextualize the subjective, self-reported beliefs or experiences of the HIV-positive people and that they present and provide little in the way of objective analysis or quantitative verification or corroboration. They rather tend to take as self-evident the claims of discrimination, related social losses and a resulting shrinking of the social networks of PWAs.

Using NAPWA as a case study in this research is an important step towards getting first hand testimonies and experiences of HIV-positive women in order to contextualize these experiences and provide objective analysis of their situation. Moreover, Goffman reveals that, stigma is a social product generated by social interactions in which potentially stigmatising attributes are relevant to either party's expectations. The impact of stigma in everyday life is thus related to its inherently social nature; everyday, discrediting associations are made during the stigmatized individual's social interactions, whether imagined and anticipated or experienced for real (Goffman Erving 1963: 137). The social spoiling process associated with stigma may eclipse a person's social identity, so that she is treated as belonging to a stigmatized category (e.g. as a cripple, a drunk) rather than as an

individual, and devalued in the process (Zola 1993). With HIV/AIDS, people within this stigmatised category find refuge in associations made of people like them (e.g. NAPWA).

According to Herek, in certain historical settings, stigma has carried positive meaning; for example, “for Christians, stigmatic markings could signify special grace” (Herek 1990: 109). This not withstanding, modern social science focuses on stigma as a negative construct. According to an article by UNAIDS, stigma can also be defined as an attribute or quality which “significantly discredits” an individual in the eyes of others. More importantly, stigma is a process. Within a particular culture or setting, certain attributes are seized upon and defined by others as discreditable or unworthy” (UNAIDS, 2002). As stated in the “Siyam’kela” Research Study (2003) *Examining HIV/AIDS stigma in selected South African media*, stigma and stigmatisation are most easily understood as social processes, which play a key role in producing and reproducing relations of power and control in social systems. Stigma is therefore linked to social inequality. Stigma operates in relation to difference. By making social inequalities seem reasonable, it creates and reinforces social exclusion (The Policy Project, 2003).

Women in South Africa face social inequalities considered to be culturally right, paving the way for their exclusion in key issues like decision making, inheritance and economic power. This renders them powerless and makes them more susceptible to illnesses like HIV/AIDS. It is most often within support organisations like NAPWA that they can regain their voice and right to speak out. NAPWA thus endeavours to be a custodian of the interests and aspirations of PWA's and affected people. Generally they exist to protect PWAs from victimization, stigmatization, dehumanization and discrimination. The HIV/AIDS Charter, the Health Charter as well as the fundamental Human Rights as

enshrined in the South African constitution and basic democratic values are their guiding documents.[9]

Stigma may manifest itself externally or internally and may have different effects. External stigma (i.e. enacted) refers to actual experiences of discrimination (UNAIDS, 2000). This may include the experience of domination, oppression, the exercise of power or control, harassment, categorising, accusation, punishment, blame, exclusion, ridicule, or resentment. It may sometimes lead to violence against a person living with HIV/AIDS. Internal stigma (i.e. felt or imagined stigma) is the shame associated with HIV/AIDS and PWAs' fear of being discriminated against. Internal stigma is a powerful survival mechanism to protect oneself from enacted or external stigma and often results in the refusal or reluctance to disclose HIV status or the denial of HIV/AIDS and unwillingness to seek help (The Policy Project, 2003). In South Africa, HIV-positive women are most often blamed for contracting the disease. In some cases they are sent out of their homes by in-laws in the event of the death of their husbands. The fear of what might be done to them if their status is disclosed, leads to many not disclosing their status. It is within associations of people living with AIDS (like NAPWA), that many get the courage to tell family and friends.

In addition, academics describe stigma as a "master status". By that, they mean it eclipses all other aspects of stigmatized persons, their talents and abilities. In other words, you always see the stigma first and foremost (be it a mental or physical disability, drug addiction, a major "problem", such as being HIV-positive or having AIDS, being poor, being on welfare), and not the person (Statistics Canada, 2005).

[9] As stated in the NAPWA organizational charter. http://www.napwa.org.za/content/home.shtml

Other ways of conceptualising stigma can be seen in the writings of Jones, Farina, Markus, Miller, and Scott, who reserve the concept of stigma for outcomes of a discrediting process, where the target person is viewed as morally flawed and arouses revulsion (Jones. E.E., Farina, A., Markus, H, Miller, D. T & Scott, R.A. 1984). Birenbaum & Sagarin, also say when it comes to stigma, they are discussing the entire field of people who are perceived negatively, some for having violated rules, others just for being the sort of people they are or having traits that are highly valued (Birenbaum and Sagarin 1976). Katz also sees the concept of stigma as that of stigmatised individuals having attributes that do not accord with the prevailing standards of the normal and good. They are often denigrated and avoided—openly in case of known criminals and other transgressors, or covertly and even unconsciously when the disdained person is an innocent victim of misfortune (Katz, Irwin 1981:1).

Campbell (2003) looked at denial and stigma as psychological defences that protect people from what threatens to become an intolerable level of fear and anxiety by leading them to deny that they are at personal risk from overwhelmingly frightening problems. She observed that part of this process involved projecting fears of one's personal vulnerability onto stigmatised out-groups, and in the process dissociating oneself from a sense of personal risk from the feared problem. Stigma is itself an important part of the history of any epidemic. Barnett and Whiteside (2002) define stigma as "a social process; a feature of social relations reflecting the tension, conflict, silence, subterfuge and hypocrisy found in every society and culture." Aggleton and Parker (2002: 8) define stigma as "a quality that significantly discredits an individual in the eyes of others. It is a form of power over people and indicates disrespect for those people". Goffman (1963: 3) wrote, along the same lines,

that a person with a stigma is reduced in people's minds from a whole and usual person to a tainted, discounted one and that there was a distancing of the stigmatised person from the non-stigmatised, 'normal' people.

In a study conducted by Webb (1997) in South Africa, to determine attitudes towards 'people with AIDS' ('PWA'), trends of stigma, fear and ignorance predominated. In response to the question 'what should happen to people living with AIDS?' participants in the study answered that 'they should be killed,' or that 'they should be isolated'. Similar levels of stigmatisation were apparent in Natal communities, where over 70% of respondents wanted to see PWA either killed or isolated (Francis, 2001).

The response that PWA should be killed is extreme, but it has been a worldwide reaction to the epidemic. Webb (1997) cites an example in Britain in the mid-1980s where overt homophobia often culminated in hysterical press reports advocating the killing of PWA and isolation of homosexuals. In Zimbabwe, a member of parliament proclaimed that 'if a pregnant woman is found to have AIDS she should be killed so that AIDS ends with her'[10]. Similarly, in Ghana respondents in knowledge, attitude, practices and beliefs (KAPB) surveys often advocated 'injectables' to kill PWA (Webb, 1997).

In the context of HIV/AIDS, stigma is mostly simply defined as negative thought about a person or group based on a prejudiced position[11]. The 'undesirable differences' and 'spoiled identities' that HIV/AIDS-related stigma causes do not naturally exist, they are

[10] De Bruyn. *In advancing women's status*. Amsterdam, Royal Tropical Institute (KIT), 1995.

[11] To feel prejudice towards an individual or group is to hold an adverse opinion or belief without just ground or before acquiring sufficient knowledge (Blumenfield, 2000).

created by individuals and by communities (UNAIDS 2001). In other words, AIDS-related or AIDS stigma refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the individual groups, and communities with which they are associated. HIV/AIDS-related stigma builds upon, and reinforces, earlier prejudice, and it plays into and reinforces existing social inequalities—especially those of gender, sexuality and race.

Aggleton (2000) noted that, HIVAIDS-related stigma is perceived as 'a mark of shame' where the carrier of the virus is blamed, devalued and significantly discredited. Stigma also derives from HIV/AIDS' association with some of the most elemental parts of the human experience: sex, blood, disease and death. It is associated with behaviours that may be illegal or forbidden by religious or traditional teachings, such as pre- and extra-marital sex, sex work, homosexuality and injection during drug use (www.AIDSstigma.net, UNICEF, 2001).

When feelings of stigma prejudice and stereotypical beliefs move into the realm of behaviour, the result is discrimination (Francis, 2001). Discrimination (as described by Blumenfield, 2000, in Francis, 2001) refers to the negative treatment of an individual or group of people as it denies individuals or groups equal treatment. It occurs when a distinction is made about a person that results in their being treated unfairly and unjustly on the basis of their actual or presumed HIV status, or their belonging, or perceived belonging to a particular group. An example of this is when people living with AIDS are denied access to certain jobs such as teaching on the basis of prejudice and stigma.

HIV/AIDS-related stigma and discrimination is widespread. In Africa, as in other parts of the world, such stigma results in rejection, denial, and discrediting, and consequently leads

to discrimination, which inevitably leads to the violation of human rights—particularly those of women and children (UNAIDS, 2001). It is expressed around the world in a variety of ways, including:

• Ostracism, rejection, and avoidance of people with AIDS.

• Discrimination against PWA.

• Compulsory HIV testing without prior consent or protection of confidentiality.

• Violence against persons who are perceived to have AIDS or to be infected with HIV.

• Quarantine of persons with HIV (www.AIDSstigma.net).

Gilmore and Somerville (1994) explain that a common response when confronted with a frightening or intolerable situation is to attempt to flee or escape from it, or attempt to control it by inactivating or destroying it. By stigmatising the other we flee from the reality that we are collectively affected by HIV/AIDS. The fear generated by the stigma of HIV/AIDS ostracizes the individual, family and relatives. It divides communities whereas those same communities could help and care for each other. Stigma effectively silences many people for fear of the consequences to themselves within society, even more so where the stigma of HIV/AIDS builds on "already stereotyped and stigmatised communities" such as homosexuals and prostitutes (Gilmore and Somerville, 1994: 1349), what Pierret (2000: 1592) refers to as 'double stigma'. This exacerbates the difficulty of being open about the disease and hinders people from seeking medical help. This dilemma is clearly expressed by Campbell as follows:

> *Given the stigma and terror that surround the disease in the public imagination, people live in fear of rejection by their communities and formal health services, and fear for their children. Because of fear of rejection, people living with HIV/AIDS are often reluctant to seek out or access services, opting instead to live*

> *without support or treatment. Those who disclose their status often become victims of violence, either from partners or family members, or from communities where HIV is regarded with fear, denial and stigma. (*Campbell 2003: 5)

Sex workers in Summertown, a pseudonymous mining town near Johannesburg, said that if they were HIV-positive they would never tell anyone for fear of gossip and abuse, as well as fear of rejection, loss of clients and loss of love from regular partners. Campbell (2003) noted that it was sentiments such as these that made many people afraid to discover their HIV status, or when they did discover their status, to keep it a secret, even from close family members and neighbours. As a result, people chose not to disclose their HIV status, and deaths were generally attributed to other causes, such as drinking too much, or tuberculosis. Friends and relatives often collude in HIV/AIDS denial, as a gesture of support towards the affected individual or family. This collusion doesn't help efforts to discourage discrimination against HIV/AIDS victims and, worse still, it frustrates the implementation of comprehensive strategies for reducing infection rates and the epidemic spread of the disease.

Worldwide, the most common response to the epidemic has been the desire to see PWA isolated, both socially and geographically. In a study conducted by UNICEF (2001) on the extent of perceived and enacted HIV/AIDS-related stigma in Zambia, India, Ukraine and Burkina Faso, the desire for isolation of PWA was a common theme. In Zambia, people in the community frequently reported putting physical distance between themselves and people suspected of having HIV/AIDS. Not shaking hands, not sitting next to such people in buses, not sharing food and drinking utensils, were all signals of rejection. In India, where an individual was known to have HIV/AIDS, the community was said to slowly

reduce contact with the entire household. In some instances, in India, loud proclamations about the person having AIDS were made locally to isolate and reject people, and there were extreme examples of mass rejection (Francis, 2001). Govender (1992), quoted in Francis (2001: 4), cited an instance in India where on learning that a man was HIV-positive, the whole community joined together to buy him train tickets and forced the man and his family to leave for Mumbai.

In a South African study conducted with family planning clients in Johannesburg, 68.2% of respondents felt that AIDS patients should be isolated in hospital wards (Francis, 2001). Extreme forms of discrimination and stigma towards people known or suspected to be HIV-positive are also suspected or experienced in healthcare settings (UNICEF, 2001). Several reports reveal the extent to which people living with HIV/AIDS were discriminated against by the healthcare system. For example, PWA are reported to have been denied drugs, left in a hospital corridor, called names, subjected to degrading treatment and to have experienced breaches of confidentiality when medical staff were known to inform people attending the clinic about the HIV status of others. Stigmatisation in a healthcare setting is often evident in the negative attitudes of nurses, ward persons, doctors and technicians (UNICEF, 2001; Aggleton, 2001).

Furthermore, AIDS is an illness that is stigmatised owing to certain characteristics. Many people talk about AIDS as a 'divine punishment', 'the new leprosy' and 'the curse of modern times' (Pierret, 2000: 1593). A moralizing discourse about deviant behaviour and lifestyles places the blame on the infected. In Zambia, 'Shona' (Zambian language) words used to describe people living with HIV/AIDS are '*Zayero'* (prostitutes) and '*Mombwe'*

(for men having sex with many women). Politicians in Zambia have been reported as making stigmatising remarks such as "HIV/AIDS is only transmitted through reckless behaviour" (Pierret, 2000). As such, PWAs are depicted as being socially immoral. Churches in Zambia preached morality, condemned immoral behaviour and viewed HIV/AIDS as a punishment from God. Comments such as '…you are paid back for your misbehaviour, you deserve such suffering; you are paying the price of your disobedience to God', were common. In Uganda some churches imposed mandatory testing before marriage (UNICEF, 2001: 9-14; Goldin 1994).

In Burkina Faso, HIV stigma carries clear religious and sexual connotations. HIV is perceived as a disease of 'unfaithfulness', 'of refusing God', 'of sinners', 'curse from God', and of 'sexual wandering'. Religious and community leaders have been identified as perpetuating stigma by blaming and talking about retribution for immoral behaviour. Those infected were likened to Disciples of Satan, and PWAs were shunned in churches. In India one woman was told not to burn her husband on the funeral pyre but to electrocute him as the smoke would pollute the air (UNICEF, 2001). Pragge (1995), as quoted in Francis (2001) wrote about one family in Cape Town which could not find an undertaker to remove a body of a person who died of HIV/AIDS or a catholic church in which to hold a requiem mass. These stereotypes and stigmas, as noted by Francis (2001: 5), mark out PWA and become so ingrained that they are not seen as contestable. Those who are HIV negative or unaware of their HIV status, project themselves as representative of humanity, or the norm, by labelling people who are HIV-positive as 'sexually immoral', 'drug addicts' or as 'others'.

Campbell (2003) noted that this stigmatisation has driven the disease underground in many contexts, and serves as a major obstacle to HIV-prevention, given that HIV-positive people are far more likely to disclose their status and seek help and advice if they live in communities that are tolerant and supportive of people carrying the virus. People living with HIV/AIDS often prefer to hide the nature of their problem out of fear—fear of rejection, but also in many contexts fear for their personal safety.

In response to the fundamentalist approaches of some of the religions of the world, which characterise AIDS as divine punishment for transgressing religious and moral principles and values, Gilmore and Somerville cite the Episcopal Bishop of New York, who repudiated the notion that AIDS is a divine retribution: ‘‘*If God is really punishing people with sickness for their sins, don't you think the perpetrators of war, terrorism, and nuclear destruction would at least get herpes?*’’ (Gilmore and Somerville, 1994: 1350).

On the other hand, where HIV/AIDS results from deviant sexual behaviour and in defiance of social values, stigma may be an unconscious survival tactic that reinforces positive societal values. Individually, as well as socially, stigma can be a means of protection. With so overwhelming an epidemic, stigmatising HIV/AIDS may be an unconscious action to preserve a community from eradication in a relatively constructive manner.

2.3 Confronting Stigma

AIDS stigma is effectively universal, but its form varies from one country to another, and the specific groups targeted for AIDS stigma vary considerably. However, it should be noted that whatever its form, AIDS stigma, characterised by silence, fear, discrimination and denial, fuels the spread of HIV/AIDS. It undermines prevention, care and support; it also increases the impact of the epidemic on individuals, families, communities and

nations. These are some of the poignant reasons why 'stigma', as a social construct must be studied, understood and addressed both academically and socially.

This section makes recommendations for tackling stigma and discrimination, as suggested in a meeting convened in Dar es Salaam Tanzania, in June 2001—it was entitled "Stigma and HIV/AIDS in Africa: Setting the Operational Agenda". It was attended by 80 participants representing organisations of people living with HIV/AIDS, physicians, nurses, researchers, communications specialists, community workers, faith-based organisations and UN agencies from 15 countries, primarily from East and Southern Africa.[12] They specified different categories of instrumental people who included leaders at all levels— PWAs, human rights advocates, family, healthcare trend-setters and communications strategists— as having a clear responsibility to create a more open society free from stigma, silence or denial about the relentless epidemic.

2.3.1 Leadership

Leaders at all levels, not just those in government, but also religious and traditional leaders, were called upon to encourage supportive attitudes and responses to all those living with and affected by the epidemic. In particular, leaders were called upon to acknowledge that they were personally, as well as professionally, living with and affected by the epidemic as much as anyone else in society. The delegates felt that by discussing HIV/AIDS openly and sensitively and then taking action, leaders could make a difference.

[12] Details of the meeting can be found on HIV/AIDS: Advocacy for stigma and HIV/AIDS in Africa. The production is a product of UNAIDS, Health and Development Networks (HDN) and the Swedish International Development Agency (SIDA)

2.3.2 People Living with HIV/AIDS

The active involvement of persons living with or affected by HIV/AIDS is central to the fight against stigma. However, the responsibility is not theirs alone: all individuals and all sectors of society must accept the moral obligation to fight stigma and to promote openness, acceptance and solidarity.

2.3.3 Human Rights

Existing human rights instruments (notably international conventions, treaties, covenants and national legislation) confirm that discrimination against people living with HIV/AIDS, or those thought to be infected, is a violation of their human rights. These instruments also provide an array of formal mechanisms to monitor and enforce HIV/AIDS-related rights and rights of people living with HIV/AIDS, and to redress discrimination. Participants suggested that complementary strategies were required within homes and communities, healthcare settings, religious organizations and various communications media, both to prevent prejudicial thoughts being formed and to address or redress the situation when stigma leads to discriminatory action, negative consequences or denial of services.

2.3.4 Stigma and the Family

One participant pointed out that stigma within the family, or directed toward an affected family, was the most debilitating form of stigma and the hardest to address. By inhibiting open, honest communication, stigma made disclosure within the family difficult; yet without disclosure, prevention and care would be almost impossible. Families and communities are deeply intertwined in the African context. As such, they require support in preventing stigma, which would further enable their natural caring role. This would promote self-esteem for PWAs and their carers, and avoid vicious cycles of self-stigma.

The meeting prioritised the following key responses within families and communities which are relevant and could be applied by APWAs in addressing the problem of HIV/AIDS stigma in South Africa. It was suggested that:

- Life skills education and counselling should be promoted to help HIV-infected and affected people/learners cope with stigma.
- An essential 'package' of services, including voluntary counselling and testing (VCT) and follow up care be made available to all. This would enable individuals to learn their Sero-status and provide support for deciding whether to disclose their status to other family members.
- Awareness should be raised so that families and communities can access interventions, such as prevention of mother-to-child transmission, care and support services as they become available, or hold authorities accountable if not available.

2.3.5 Stigma in Health Settings

People working on the frontlines of HIV/AIDS care and prevention have both the responsibility and an opportunity to overcome stigma within their profession and workplaces. Their professional codes of ethics and conduct, social and professional authority, and their ability to act as educators and role models for their communities, all place them under an ethical obligation to be 'change agents' for reducing stigma.

Unfortunately, experience shows that healthcare institutions and individuals sometimes perpetuate stigma by stigmatising and discriminating against people, despite their professional codes. Furthermore, healthcare workers who are (or are presumed to be) HIV-positive may suffer discrimination from colleagues and from their communities.

2.3.6 Stigma and the Religious Sector

The religious sector (churches, mosques, religious schools, lay groups, religious NGOs, and ecumenical groups) has far-reaching influence throughout Africa and the rest of the world. Religious Institutions therefore have a responsibility to provide care, comfort, and spiritual support to individuals and communities who are HIV-infected or affected. In particular, religious leaders must play an active role in disseminating preventive messages and in leading the fight against stigma wherever it occurs.

The Dar es Salaam meeting suggested that the religious sector should:

- Ensure that religious leaders are 'AIDS competent' by including HIV/AIDS-related subjects, including counselling skills, in their pre- and in-service training.
- Integrate holistic care and support programmes in service and education activities, including life-skills for youth, home-based family care, support groups for infected and affected persons, and support for orphans.
- Identify religious language and doctrines that are stigmatising, and promote alternative language that is caring and non-judgemental.
- Promote humanitarian and spiritual values of compassion for marginalized and stigmatised groups.

2.3.7 Stigma and Communications

While mass media such as radio, TV, print, and the Internet can unintentionally promote stigma, they can serve as powerful tools to help reduce it. Given their potential to shape the attitudes, values and perceptions of large numbers of people, communicators have a responsibility to create clear messages about HIV/AIDS, to report accurately, and to do so in a sensitive and non-stigmatising manner.

With regard to communications, the Dar es Salaam meeting suggested that the mass media should:

- Build skills and capacity for journalists, editors, producers, AIDS activists, communicators and people working in the field of HIV/AIDS.
- Provide resources for sustained communication about HIV/AIDS that effectively reduces stigma.
- Develop media standards for reporting on HIV/AIDS in a non-judgemental and non-stigmatising manner.
- Hold communicators (both individuals and their organizations) accountable for upholding the above standards through broad-based monitoring mechanisms developed on a national/regional basis.

Promoting hope and acceptance is a key response to stigma at all levels of society. In contrast, doing nothing about stigma can only contribute to the growing death toll, as well as to distress and reduced quality of life. All those with influence and authority within society have a responsibility, individually and collectively, to act in order to reduce stigma about HIV/AIDS within their spheres of influence. Accountability — based on transparency, honesty and openness — is a key component in improving HIV/AIDS prevention, care and support efforts, and to helps bring this knowledge to more people on an on-going, sustainable basis.

Furthermore, while stigma and discrimination may never fully be eliminated, the recommendations suggested above would go a long way towards reducing them, and building the responsibility and accountability that is particularly needed among the rural population. Unfortunately, in South Africa, as indicated in chapter one, explicit and strong

commitment of leaders at all levels, especially those in government, is lacking. Leaders have become embroiled in needless controversy and futile confrontations, instead of taking action and discussing HIV/AIDS openly. Some religious leaders in South Africa have also been identified as perpetuating stigma, talking about HIV/AIDS as 'punishment from God' for immoral behaviour.

However, on a positive note with regard to PWA, in South Africa there are a number of people working under the banner of the National Association of People Living with HIV and AIDS (NAPWA). These people use their life stories as a powerful motivating force to make the general public aware of HIV/AIDS (Parker, Dalrymple & Durden 2000).

2.3 HIV-positive Women and Stigma

As more women in the developed world have become infected with HIV, there has been a growing body of literature on the specific problems they face (O'Sullivan and Thomson, 1992). Studies tend to focus on issues pertinent to women, such as the natural history of HIV in women, sexuality and reproduction, and different access to, and needs from, health services (Bury et al, 1992; Dorn et al, 1992; Doyal et al, 1994; Sherr, 1991). Women with HIV infection have been described as an "unrecognized population" (Smeltzer and Whipple, 1991) despite the unique concerns that HIV/AIDS presents to all women. Studies on stigma have demonstrated that women with HIV may be particularly stigmatised by society (Bunting, 1996, in Wojcicki and Malala, 2001); and women, in general, are stigmatised with regard to their sexuality and sexual behaviour.

In the case of HIV-positive women, stigma may be applied to actual infection or to behaviours believed to lead to infection. Because HIV/AIDS first affected groups of people who were already socially marginalised, the stigma attached to HIV/AIDS is often layered

upon pre-existing stigmas of sexual conduct and drug use (Herek & Glunt 1988). Stigma therefore plays into and reinforces existing social inequalities, being linked to power and domination in the community as a whole. The most marginalised and excluded groups in societies such as drug users, men who have sex with men, women and sex workers, not infrequently bear the brunt of stigmatization in relation to HIV/AIDS (Malcolm et al 1998 as cited in Green, Gill.1996).

Similarly, those infected with HIV are often seen as members of these predetermined groups (regardless of whether they are or not), thereby enabling denial of the individual that increases the general public's vulnerability to infection.

According to a qualitative data colleted by Green (1996), women's greater sense of shame and stigma is partly related to the "dirty image" of HIV, particularly its association with drug use and promiscuity and their home-based social role also makes them more visible and more vulnerable to stigma from local residents (Green, Gill. 1996).

The funding, research and public attention that have addressed women and HIV/AIDS have tended to focus on two groups: sex workers and pregnant women (Rosser, 1991). As Green Gill observes, in both cases, investigation is most often directed towards issues of transmission, rather than the impact of the disease on women. This emphasis on women as vectors of transmission is also evident in the research, health and policy issues regarding pregnant women and HIV/AIDS (Levine and Neveloff Dubler, 1990). Social judgments are attached, so that ''source of infection" implies guilt, culpability and moral blame.

Travers & Bennet also assert that, throughout the healthcare structures, women living with HIV/AIDS experience numerous barriers to exercising their power and control. Such practices as excluding women from drug trials, inequalities in the power relationship between doctor and client, the gender-defined roles that promote compliance and

passiveness among women, and the assumption of the male norm being the standard, all serve to restrict the choices available to women and, consequently, power over their health (Michele Travers and Lydia Bennett, 1996: 66).

Moreover, the lack of political, economic, legal, societal and personal power that typifies the position of women in so many cultures has resulted in negative consequences for women living with HIV/AIDS. Consequences of disempowerment include isolation, stigma, discrimination and neglect, because the powerless are rendered ineffective and voiceless. These consequences of disempowerment point to how the process of expressing and describing stigma is made possible in a place like NAPWA-SA.

Besides, once infected with the HIV virus, women are often socially ostracized and subjected to assault or abandonment by family members. Pregnant women who are HIV-positive may be subjected to forced sterilization or abortion. The fear of discrimination may discourage women from disclosing their status or seeking testing or treatment, thus exacerbating the impact of the disease.[13]

Continuing ignorance about the transmission of the HIV virus, the effects of AIDS itself and treatment regimes mean that women with HIV and AIDS are often unable to play social or economic roles in their communities. The impact of this can be exacerbated for those women who experience HIV and AIDS as primary care-givers, many of whom are limited in their efforts at social and economic participation by constructive regulations on land and property rights.[14]

[13] Culled from the Amnesty Internal website: http://www.amnestyusa.org/stopviolence/factsheets/hivaids.pdf

[14]The interconnections between Violence Against Women and HIV and AIDS; The Mothers Union: www.themothersunion.org

North and Rothenberg suggest that women's relative powerlessness in sexual relationships may make disclosure of sero-positivity to a partner particularly traumatic (North, R & Rothenberg, K. 1993). Hankins (1993) also identified lack of institutional support as a possible source of disadvantage for women, although in recent years there has been a burgeoning of organizations worldwide offering support specifically for women (Hankins, C. 1993).

He further argues that, women's role as mothers and homemakers may place women with HIV at a disadvantage. Whilst children may decrease a woman's sense of isolation, there is the extra burden of concern about eventual placement of children, disclosure of HIV status or AIDS diagnosis to them, obtaining childcare and possibly rejection by older children (Hankins, C. 1993).

A common response to diagnosis and the sense of isolation, which often accompanies it, is to make contact with HIV organizations and other people who have an HIV-positive diagnosis. Friendship may flourish owing to the shared experience of having the same disease and sometimes become extremely close and enriching. (Green, G.1996).

It would seem that a larger and more supportive social network is indeed a 'buffer' which supports Wortman's (1984) finding that good social support is important for coping psychologically with chronic illness, particularly are illness that is stigmatizing (Wortman, C.B. 1984).

2.4 Case Study: NAPWA-South Africa

Directly and indirectly, support groups like the Associations of People Living with HIV/AIDS (APWA), carry out the important functions of providing members with information that can help them cope with stigma and its effects. Researchers on stigma find

that the salience of the stigma itself is greatly reduced through some kinds of support groups. Psychologists and other social scientists researching stigma explain that the support group is a good place to share the stress of being stigmatized. As a member of an APWA group, a PWA also sees evidence of effective coping strategies and people coping successfully (Statistics Canada, 2005).

Thus, the stigma attached to HIV/AIDS has led many people infected and affected by HIV/AIDS to come together to form a common front in order to protect themselves from felt and imagined stigma. Organizations serving people living with the HIV disease face important questions regarding stigma. How can they provide for patients who live with the very real threat of being ostracized? How can they help individuals cope with stigma? What can they do to help prevent or eliminate HIV-related stigma? In an effort to address these questions, stigmatized groups continue their efforts to create a ‘‘stigma-free” social environment for themselves and their families.

The South African National Association of People Living with AIDS (NAPWA-SA) is a Non-Governmental Organisation (NGO) of People Living with HIV/AIDS. NAPWA-SA was created in 1994 as a volunteer-based organization. After 1994, it was transformed into a non-profit NGO. NAPWA-SA was created to deal with the issues of discrimination, care and support for PWAs. Through its National Office in Germiston in the Gauteng Province, it co-coordinates the needs and resources of PWAs nation-wide through the mobilisation of PWAs, partnership and collaboration with other stakeholders, advocacy and lobbying at all levels, gender programmes, organizational development and, care and support for PWAs.

Six of the local-area APWAs attempt to make people living with HIV and AIDS, especially women who form the majority of the membership in South Africa, more visible—a strategy

to empower PWAs to get more involved in the National AIDS Programme. With eight provincial offices, NAPWA's strategic importance is its ability to mobilize PWAs locally, provincially and nationally.

The objectives of NAPWA-SA include the representation, co-ordination and communication of the needs and resources of all PWAs in South Africa, ensuring that the human rights of all infected and affected people are recognized and upheld; the collection and dissemination of information relevant to all PWAs; supporting and developing support group structures and networks for all infected and affected people; promoting education that is sensitive and specific to the needs of all PWAs; providing guidance and support for all PWAs and affected people; exposing and preventing the exploitation of all PWAs; allowing freedom of expression to address the needs, demands and human rights of all PWAs in South Africa through advocacy and activism and, facilitating capacity building or empowerment of people living with HIV/AIDS.

NAPWA strives to ensure that it achieves its objectives through the following key programmes:

1. *Mobilization*: mobilize all people living with HIV/AIDS in order to build a national mass-based PWA movement to lobby and advocate for the care of members of people infected and affected by HIV/AIDS and to form a common front to fight against discrimination and stigmatisation.
2. *Advocacy and lobbying*: jointly advocate for the rights and needs of PWAs and to lobby for support, financing and recognition of PWAs.
3. *Partnerships and collaboration*: establish links and develop strategic partnership with key local and international organizations, institutions and governmental departments for mutual benefit so that their work will have a broad impact and will increase the possibility for positive change.

4. *Gender programme*: initiate and offer programmes and projects on gender issues in HIV/AIDS, relevant for women-members of NAPWA.
5. *Organizational development*: engage in relevant research and evaluation activities in the HIV/AIDS field as required by member's programmes and by other stakeholders in order to further the aims and objectives of the organization.
6. *Counselling and support*: To offer support and counselling services to all members of NAPWA and to facilitate, by means of referral, the accessibility of other services desired by its members.

Theoretically, NAPWA represents the interest of 4.2 million people living with HIV/AIDS. NAPWA is servicing more than 5 000 PWAs a month, nationally. Membership of NAPWA is mainly drawn from people living with HIV/AIDS. NAPWA has recently opened its membership to all affected people. People who provide care and support to PWAs also form part of the NAPWA family.[15]

According to the Treatment Action Group (TAG)[16], there are currently seven provincial coordinators. The main issues for NAPWA-SA currently are disclosure and visibility, community building and mobilization. Most of NAPWA's members are women. NAPWA South Africa has a budget of approximately $180,000.

2.5 Theoretical Framework

2.5.1 Conceptualising Stigma

According to Green & Sobo, the knowledge that AIDS carries a stigma is commonplace, at least among liberals and others who would defend people infected by it, but the term stigma is offered up, even in academic literature, as if it's meaning is understood by all in the same manner. That is, its meaning—and the meaning of the "AIDS = stigma"

[15] Culled from the *NAPWA Profile* document on their website; http://www.napwa.org.za/content/downloads/NAPWA%20Profile%20submitted%20to%20Johnic.doc
[16] Cited on the TAGline, a monthly online publication by the Treatment Action Group (TAG), a 501(c)(3) non-profit treatment advocacy organization in New York City

equation—is generally left unsaid (Green, G. & Sobo, E. 2000: 12). Thus to Green & Sobo, the meaning of stigma and the fact that AIDS always spells stigma, is usually left unsaid.

Many definitions have been suggested for the word "stigma". The modern term "stigma" comes from a Latin word describing a prick with a pointed instrument. A stigma is, literally, "a distinguished mark burned or cut into the flesh, as of a slave or criminal," serving most typically as a "mark of disgrace or reproach" (Webster 1983: 1788). Today, according to Goffman (1963), "the term stigma is used in something like the original sense, but is applied more to disgrace itself than to the bodily evidence of it" (pp. 1-2). Stigma, he adds, is equated with an "undesired differentness," of which there are three types: (a) physical deformities; (b) "blemishes of individual character" such as homosexuality and unemployment; (C) "tribal" stigmas of race, nationality and religion. The idea that stigma originates from one's failure to fulfil one's ascribed role stems largely from Erving Goffman's book (1963 edition), *Stigma: Notes on the management of spoiled identity*, which established the study of stigma as a valid academic pursuit. "By definition" he wrote, "we believe that the person with a stigma is not quite human" (Goffman Erving 1963. pp. 4-5). Goffman casts stigma as a socially constructed deviance label. Therefore, what is stigmatising in one place and time may not be so in another. In other words, stigma is a culturally relative construction. Moreover, stigma as Goffman describes it, is not an essential feature of an attribute (e.g. a physical deformity or a deviant act) but rather it emerges because of social reactions to such attributes.

Green & Sobo, also suggest that beside physical marks, non-physical characteristics too, such as spinsterhood, can serve as stigmata; in either case, an individual's failure to live up

to social and cultural ideals is highlighted, whether by a physical blemish or by a state of being—an identity or facet thereof (Green G. & Sobo, E. 2000).

Stigmatisation is a social phenomenon in which labelling is used to isolate and identify individuals and/or groups as being abnormal and therefore undesirable. It can be based on gender, race, class, religion, sexual orientation, disease, etc. In this project, I examine illness-based stigmatisation of HIV-positive women as an unfortunate social strategy for creating distance between the healthy and the 'incurable' ill. The fundamental questions I ask are whether or not this fear-based stigmatisation (*à la Camus*[17]) actually creates a safe shield between the ill and the healthy or if it instead contributes to the spread of the disease and the alienation of its victims. If so, what is the role of NAPWA in reducing the stigmatisation of HIV-positive women? What progress has NAPWA already made in this endeavour and how much more must it do to ensure compassion for, and understanding and fair treatment of, victims of the HIV/AIDS scourge?

2.5.2 HIV/AIDS as a Social Challenge

HIV/AIDS is much more than a medical condition — it has a social, economic and political impact from which no one is immune (Levi, 2002). HIV/AIDS has given rise to tremendous social challenges. More than any other disease, HIV/AIDS has the potential to disrupt many facets of our social fabric. For example, studies by Barnett and Whiteside (2002: 271-294), Coombe (2000) and others have shown that HIV/AIDS has an economic dimension in that it affects the most economically productive portion of our population, including adults of working age who often have young children and elderly parents, and it

[17] When death is associated with causes that are both scary and distasteful, society would tend to treat the dead with greater aloofness and less emotional attachment. (Camus, A. 1991)

often strikes more than one household or family member. It is a gender issue, because of the inequalities in relationships and age-old attitudes towards women.

Nettleton (1995) and Gilbert and Walker (2002) have established that social inequalities in terms of social class, socio-economic status, gender and race, put some individuals and groups in situations of increased vulnerability to disease, especially unforgiving afflictions like HIV/AIDS.

Individuals and organisations worldwide have mobilised to meet these challenges. There have been many innovations, some successes, many costly failures and many lessons learned along the way (Parker, Dalrymple and Durden, 2000). As the disease has advanced over time it has become possible to appreciate its complexity, and also to begin to understand what needs to be done to minimise its impact on societies, communities and individuals.

Throughout history, as observed by Parker et al (2000), communities have responded to environmental exigencies such as floods, earthquakes and famine by rapidly organising interventions, systems and practices to deal with these problems. Such responses are also occurring in relation to HIV/AIDS, but the gradual, insidious and complex nature of the epidemic has meant that responses have emerged slowly (Department of Health, 2000). In South Africa, communities have experienced the rise of youth groups that address peers on HIV/AIDS issues and prevention strategies, and care groups that provide support to families and individuals affected by HIV/AIDS — for example, the National Association of People Living with HIV/AIDS (NAPWA).

On the same note, based on the absence of a cure or vaccine, the effort to reduce the rate of HIV/AIDS infection should be directed to de-stigmatisation of HIV/AIDS, education and support of people who are already infected. The removal of the stigma attached to

HIV/AIDS and the support and care for infected people is vital for the success of prevention and control programmes (Karon et al., 1991; Levi, 2002). Most important of all is that the willingness to protect others may well depend on the support those infected receive themselves (WHO, 1992).

The overall purpose of supporting somebody who is ill, or may be experiencing the loss of a loved one or loss of a job, is to help him or her to cope. According to Meursing (1997), an HIV diagnosis is an event that heavily taxes coping resources of individuals and those they live with. Therefore, it is important to understand how people cope with such a serious life event and what is needed to improve coping.

2.5.3 The Coping Theory

Stressful events are, for some people, part of everyday life. According to Meursing Karla, the impact of stressful situations and experiences depends in large part on how the individual copes with them (Meursing, Karla 1997). Lazarus and Folkman, in Taylor (1986), define coping as the process through which a person manages demands, internal or external, that are appraised as taxing or exceeding the available resources.

Several researchers, such as Bandura (1995), Helman (1990) and Lewis (1966), have identified factors which influence coping style among individuals. Bandura (1995), for instance, states that the degree of control individuals feel they have over a stressor is central in the subsequent orientation towards taking action to master the problem itself, or towards reducing emotional strain. The extent to which individuals believe they can organise and execute the courses of action required to deal with events is what he calls ‘self-efficacy beliefs’. These beliefs are the outcome of the balance between situational demands posed by a stressor on the one hand, and a number of intra-personal and

contextual variables on the other hand. Relevant intra-personal variables influencing perceived self-efficacy are personal coping skills and biological resilience or vulnerability. Important contextual variables are the availability of social support and material resources for coping (Bandura, 1995).

One major influence on self-efficacy, as presented by Meursing (1997), is the availability of social support. Practical, material information and emotional support from friends and family increase the instrumental means to deal with a problem, and can act as a buffer against emotional strain, thereby increasing perceived self-efficacy. Even when a person initially judges a stressor to be beyond control, this judgement may well be revised once adequate social, material and emotional support become available. Thus, social support can stimulate active, problem-focused strategies, while lack of social support may result in the use of emotion-focused strategies. The relevance of this contrast to the present study is that APWA can provide social support to people living with HIV/AIDS by involving them and encouraging others to do so, listening to them, offering advice and providing knowledge through AIDS education. In terms of material support, APWA could start income-generating activities to help increase individual and family income. In terms of informational support, APWAs could act as venues for perusal of print materials such as leaflets, booklets, posters and stickers. With regard to emotional support, APWA may offer counselling.

More so, social models that provide an opportunity for vicarious learning may influence self-efficacy beliefs. Thus, a person's sense of self-efficacy can grow by seeing others similar to him/herself succeed by persevering. This factor is very relevant to this study since research has shown that exposure to people living with HIV/AIDS, both in media and

through personal contact, is informative and emotionally supportive. It engages people on a personal level and gives a face to the disease (Parker & Sobo. 2000). According to Bandura (1977), the example of successful social models may transmit knowledge, skills and strategies to achieve desired ends. Social persuasion employed by a trusted communicator (such as a counsellor) can also strengthen the belief that one has ‘what it takes’ to succeed, thus increasing motivation for sustained effort. Most importantly, self-efficacy is built upon performance experiences. Success and particularly success achieved in the face of adversity, increases self-efficacy beliefs.

CHAPTER THREE
Methodology

3.1 Introduction

This chapter sets out the research design, including the methods that were used to gather, organize and analyse information for this study. The chapter is arranged into three parts.

The first part describes the research design, the case study approach, the methods that were used to gather information, and triangulation techniques. The second part describes the research setting and sources of information. The third part explains how information was coded, organized and analyzed.

3.2 The Research Design

The fundamental question explored in this study is how the stigmatisation of HIV-positive women manifests itself and what role Associations of people living with HIV/AIDS play in reducing this socially created aberration. The information generated will contribute to the formation of an informed theoretical and practical framework that APWAs and governments can draw on to address the challenges of HIV/AIDS prevention and support in South Africa. There were several focus questions that guided the interpretation and analysis of information gathered from the respondents and documents. These were:

1. What is the role of NAPWA in the fight against the stigmatisation of HIV/AIDS-positive women?
2. How does the stigmatisation of HIV/AIDS-positive women manifest itself?
3. What impact does the stigmatisation of HIV/AIDS-positive women have on the spread of the disease?

4. How successful has NAPWA been in achieving its objectives and goals with regards to the stigmatisation of HIV-positive Women?

3.2.1 Case Study

'Case study' is used in research to mean the in-depth study of a problem or a situation, whether or not it has a direct implication for practice (Gailbraith, 1998). Case study design was used for the collection, analysis and reporting of data. It provided the logic that would link the initial study questions to the ultimate conclusions drawn from the study. According to Yin (1984: 23), "…case study methodology is an empirical enquiry that investigates a temporary phenomenon within its real life context; when the boundaries, phenomenon and context are not clearly evident; and in which multiple sources are used". This is in line with Merriam (1988), who defines a case study as an intensive description and analysis of a phenomenon or a social unit, such as individual, group, institution or community. In contrast to surveying a few variables across a large number of units, a case study tends to be concerned with investigating many if not all variables in a single unit by concentrating upon a single phenomenon or entity (the case). This approach seeks to uncover the interplay of significant factors that are characteristic of the phenomenon. In this study, the phenomenon under investigation is the stigmatisation of HIV-positive women and the role of Associations of people living with HIV/AIDS in addressing this problem, empirically show-cased through the study of the operational strategies, successes and limitations of the NAPWA-SA initiative.

A case study seeks holistic description and interpretation. According to Guba and Lincoln (1981), the content of a case study is determined chiefly by its purpose, which typically is to reveal the properties of the phenomenon under study. If conducted over a period of time,

the case may be longitudinal; thus changes over time become one of the variables of interest (Merriam, Sharan. 1988). This study, however, was concerned with describing a phenomenon, as it existed at the particular time of study. Case studies are particularly useful when there is little knowledge about a problem or an issue, as they may provide new insights into complex situations or organisations. A review of literature reveals that no studies have been done to examine the stigmatisation of HIV-positive women and the involvement of APWA in the delivery of prevention, care and support services and its effect on the curbing of the spread of HIV/AIDS, the reduction of stigmatisation and isolation of PWA as well as of others affected directly and indirectly by HIV/AIDS in South Africa.

The exploratory nature of the case study method helped me to explore hidden issues that were crucial for addressing the stigmatisation of HIV-positive women and the role APWA play in eradicating this stigma. The case study method was an effective tool to study both the context and complexities of the ways in which the stigmatisation of HIV-positive women is made manifest and the strategies taken by NAPWA to address this issue.

The case study design is useful for gathering rich and varied data, by making use of a variety of data collection techniques. These multiple methods of data collection, in turn, provide access to a wide range of facts, values, attitudes, ideas and opinions. It also allowed data to be cross-referenced, so that difficulties and tensions could be observed, noted and explored. The methods used in this study included a self-administered questionnaire, observation, document analysis, and critical incident review. These are described in more detail later in this chapter.

The process of conducting a case study consisted of several steps, as outlined by Merriam (1988). The first was the selection of the case to be analysed, done purposefully not randomly. In this study the National Association of people living with HIV/AIDS in South Africa (NAPWA-SA) was selected because it exhibited characteristics of interest to the researcher. The next step was to collect data using the range of data-collecting techniques mentioned above. As information from various sources was collected, I aggregated it; that is, abstracted generalities from particulars and looked for patterns characteristic of most of the data, then organized and classified them into manageable units.

According to Merriam (1988), case study data can be organized chronologically, categorically, or placed within a typology. In this study I used categories suggested through research questions and other issues raised in the review of the relevant literature. The final step in the process was the writing of case study narratives, which were a readable and descriptive picture of the ways in which the stigmatisation of HIV-positive women is made manifest and the role of NAPWA in the fight against stigmatisation.

However, as with other research strategies, case studies have their limitations, which counterbalance their strengths. According to Merriam (1988), some of the limitations of case studies are:

- Case studies can be expensive and time-consuming.
- Training in observation and interviewing techniques and/or documentary analysis is necessary.
- Case study narratives tend to be lengthy documents, which policy makers and others have little time to read;
- Writing the narrative to meet the needs of potential—though perhaps unknown readers—is not easy.
- Findings from case studies cannot be generalized in the same manner as findings from random samples; generalisability is related to what each user is trying to learn from the

study. Despite these limitations, the case study method is a particularly useful methodology for exploring an area or practice which was previously not well researched or conceptualized.

Finally, a case study, which has as its purpose the description and interpretation of a unit of interest, can result in abstractions and conceptualizations of a phenomenon that will guide subsequent studies (Merriam Sharan. 1988). Such was the purpose of this particular study, as it highlights the challenging problematic of stigmatisation and its effects in the stemming of the spread of HIV/AIDS.

3.2.2 Triangulation: An Analytical Tool

I adopted triangulation techniques and principles to assist with collection, analysis and interpretation of the data, and also to ensure as high a degree of validity as possible in the qualitative study. Following guidelines offered by Cohen and Manion (1989: 269-286), discussed more fully later in the study, I relied on triangulation between sources and methods. Triangulation structures employing multi-method approaches facilitate a fuller understanding of "the richness and complexity of human behaviour by studying it from more than one standpoint…" (Cohen and Manion 1989: 269).

Triangulation maximizes orthodox notions of validity through crosschecks provided by information from different perspectives, yet not at the cost of suppressing different and sometimes conflicting viewpoints (Cohen and Manion, 1989). This was congruent with the choice of the case study approach employed in this study. Multi-method approaches help to overcome understandable but dangerous researcher tendencies to rely on favoured research methods. They also reduce the chance that information gathered is essentially an artefact of a particular method.

3.3 Methods of Data Collection

In order to discover and understand the manifestation of the stigmatisation of HIV-positive women, and the role of NAPWA in fighting this stigma, this research was qualitative in order to asses the testimonies of the subjects and partly quantitative in order to scale the impact of the stigmatisation of HIV-positive women. This facilitated the in-depth examination of the phenomena, the use of subjective information, exploration of new areas of research and building of new theoretical frameworks.

Methods that were used in the collection of data were self-administered questionnaires, participant observation and archival evidence in the form of documents examined.

3.3.1 Self-Administered Questionnaires

Because of the sensitivity of the subject under investigation, I made use of anonymous structured self-administered questionnaires to collect data from HIV infected and affected women who are members of NAPWA and members of the NAPWA administration. The use of anonymous questionnaires was in a bid to protect the identity of the participants. According to Babbie (1998) a self-administered questionnaire is a method in which respondents are asked to complete the questionnaire unaided. Self-administered questionnaires were also used because of the sensitivity of the issue under study. For as Babbie (1998) states, respondents are sometimes reluctant to report controversial or deviant attitudes or behaviours in interviews but are willing to respond to an anonymous self-administered questionnaire. Questions sought to know the lives of participants as people living with HIV/AIDS, how family and friends treated them, how society treats them, how they overcome the challenges of stigmatisation, how they came to be NAPWA members, their hopes for the future. These interviews involved the following categories of participants:

1. **Sero-positive Women**

Here, the questionnaire targeted sero-positive women. This was in a bid to get answers about how they got infected, how they came to know their status; to whom they have disclosed it; how they look at life; the way people who know about their status treat them; how they exercise their rights as women in South Africa; challenges faced if any; their hope for the future; their reaction to the death of an AIDS colleague and what role NAPWA plays in their lives.

2. **Family/Friends**

Questions here targeted women who had family members and friends who are HIV-positive. This was in order to know how they treat their relatives or friends who are HIV/AIDS-positive. The interviews also sought to know what they think about the person who is infected. Do they blame the person? On the other hand, do they see him/her as a victim of circumstance? I also asked questions to know how their communities treat them knowing they have an HIV/AIDS-positive member in their family. How do they handle these challenges? Moreover, what do they think of NAPWA?

3. Staff/Administrators

The fact that NAPWA is the case study for this research warrants that those who head the association talk about the functioning of the association. Thus some questions targeted the staff and administrators of NAPWA in order to establish the role and function of NAPWA in the lives of HIV/AIDS-positive women. The questionnaires sought to find out how NAPWA manages the challenges involved in sustaining HIV/AIDS victims. What strategies they employed to fight against the stigmatisation of people infected and affected by HIV/AIDS (especially women). How they relate to the Government, NGO's and other

associations involved in the fight against HIV/AIDS in trying to find solutions to their problems.

All questions were in the English language and were both open-ended and close ended (with follow-up questions). This was in order to give room for the subjects to respond adequately. Participant's responded in English. Personal observation, structured and unstructured, of service delivery and internal organizational meetings were also used to collect data. I spent significant amounts of time with the subjects to follow-up their progress. I administered the questionnaires myself, thus cutting down on the cost of hiring and training research assistants. Moreover, the use of research assistants in a research in a sensitive area as HIV stigmatisation could lead to participant shying away, thereby reducing the number of participants. Questionnaire questions were also adapted to suit semi-literate or illiterate respondents.

3.3.2 Critical Incident Review

Some of the questions in the questionnaires allowed participants to present critical incidents which helped the researcher to gain insight into the way that the stigmatisation of HIV-infected and affected women is made manifest. According to Brookfield (1994), critical incidents are brief reports that describe events that are recalled vividly and easily because of their particular significance for the respondents. The researcher developed a series of questions that focused on critical moments or actions involving stigmatisation as judged by HIV- infected and affected women of NAPWA-SA.

These questions were deliberately framed to elicit description of specific events, rather than asking for general observations about ways in which HIV infected and affected female members of NAPWA are stigmatised. As such, they had an advantage of being non-threatening to respondents, yet still productive of revealing responses (Brookfield 1994).

3.3.3 Observation

As I interacted with the respondents, direct and non-participatory observation was taking place. Observation was useful in exploring topics that were difficult and uncomfortable for the respondents to discuss; for instance, attitudes towards each other, or interest shown in their work, and how they were coping with living with HIV/AIDS. Notes were made immediately after meetings. Cohen and Manion (1980: 105) note a fear that the observer's judgement will be affected by her close involvement in the group. I was careful not to become emotionally involved in matters at NAPWA-SA. The following aspects were observed:

- NAPWA's environment;
- The atmosphere at NAPWA;
- The appearance of NAPWA members (especially HIV-positive women);
- NAPWA facilities and equipment, as well as their condition;
- Services at the centre, and whether or not they were being used;
- The behaviours of the HIV infected and affected members of NAPWA (especially women);
- The activities organised for members to educate counsel and motivate members infected or affected by HIV/AIDS (especially those involving women);
- The relationships between those infected and those affected by HIV/AIDS;
- Links with the community and with service providers in the area.

The life styles and living conditions of those under study were observed through visits to their homes and invitations to lunch. Observations were written down and analyzed later.

3.3.4 Documentation

Documents also assisted in supplementing information from questionnaires and observation. Documents, such as the NAPWA Profile, organisational charts and annual reports helped to enrich the data obtained from questionnaires and observation.

3.4 The Setting of the Study

The research was undertaken at Germiston in the Gauteng province, South Africa, which is the location of the national headquarters of NAPWA-SA. The national headquarters of NAPWA was selected for this research because it was familiar to me. During my Masters regular course work, I had investigated, directed and produced a documentary on the lives of three NAPWA members based at Germiston. This documentary was titled 'HIV: the Beginning of a New Life'. The documentary followed the day-to-day activities of the three members including their lives as NAPWA members. The project took three months—that is, from conception to completion.

3.5 Demographics

3.5.1 Sampling Procedures

As stated earlier, this research focused on HIV-positive women. Other demographical issues like diversity (i.e. what differentiates the subjects), commonalities (i.e. what do the subjects have in common) with regards to age, and ethnic groups were examined. In order to facilitate this research, I selected women within the following age brackets:

1. Four HIV-positive women within the age group 20-40 years
2. Two women affected by HIV/AIDS
3. Two NAPWA administrators

All the above subjects were South Africans, women and members of NAPWA-SA.

3.5.2 Population of Study

Discrimination against women is a fact of life in all regions of the world, to varying degrees of course, and it is manifested in various ways. The human rights abuses that women deal with on a daily basis can become an almost insurmountable obstacle when dealing with HIV/AIDS. The reasons for selecting HIV-positive women in this study are:

1. The rate of HIV infection among women is a cause for concern and when combined with the stigma associated with the disease, the situation worsens, as has been reported in the South African context.
2. Women are the caretakers of the family and are responsible for actions, which elicit life (child bearing). Thus they need to be protected from discrimination and stigma in order for them to perform their roles as caretakers and caregivers.
3. Women also contribute to the growth and protection of the society. Stigmatising them because of their HIV status will lead to early death for many and make orphans of their children. Curbing the stigma targeted at HIV-positive women will be a big step towards prolonging life and reducing the rate of HIV infection.

3.5.3 Hypothesis

I test and document the hypothesis that HIV-positive women are stigmatised and this stigmatisation actually causes more harm on two fronts: the sick get sicker and die sooner because of abandonment; the disease spreads faster and further as more women avoid declaring their status. Considering that the South African Association of people living with HIV/AIDS (NAPWA) is a well-established AIDS organisation that caters to the needs of people infected and affected by the disease and the fact that women form the majority of its members, I have chosen to use them as my case study to gather reliable and qualitative data to test the preceding hypothesis. Through NAPWA, I look forward to accessing privileged

information which will enable me to show how HIV-positive women are stigmatised, and to establish that this stigmatisation of women living with HIV/AIDS has a devastating effect on the spread of the disease; incidentally, this provides a unique opportunity to assess the rate of success of NAPWA in combating stigma, and contributing to positive awareness about HIV/AIDS being everyone's concern not just those infected or affected by the disease. I have pledged to treat all collaborators with respect, decency and with the privacy that goes with this type of investigation[18].

3.5.4 Ethical Considerations

The University Postgraduate Committee approved the proposal on the merits of its deontological feasibility. The ethical clearance was also obtained from the Human Research Ethics Committee (Non-Medical); the clearance number was 60611.

Implicit in this study's research design and reporting has been the intention that ethical considerations be thoroughly integrated into every aspect of the study. The main points of concern, frequently categorised in discussions on qualitative research, are noted below and the ethical rationale employed is also stated:

No harm to the participants: The respondent's agreement was sought at the beginning of each interview firstly through the signing of a consent form and also the expressed willingness to proceed with answering the questionnaire with a tick of 'yes' after reading instructions at the beginning of each questionnaire.

Anonymity and confidentiality: I sought permission from the national director of NAPWA-SA and was given a signed authorisation form. I clearly stated the intent of the research—investigating the stigmatisation of HIV-positive women and the role of Associations of people living with HIV/AID (APWA) in redressing this situation. This was again reiterated

[18] I will apply the University's research ethics guidelines for carrying out research involving humans.

in the questionnaires administered to respondents. To ensure privacy, anonymity and confidentiality, real names of individuals were excluded in the study and the findings chapter avoided disclosing personal details that could be innocently reported, and misconstrued.

Voluntary participation: Participation was completely voluntary. A condition for participation was agreement that their views could be shared; an indication was made that participants were free not to respond to any question they were not comfortable with. Also the point was made that the questionnaires were not a form of examination, so there was no correct or wrong answer; this was communicated in writing to them. Thus, they were free to respond to the questions to the best of their ability.

***Informed consent*:** I explained to the respondents that participation was voluntary and that not participating in the study would not hold any negative consequence for them. I told them that they could withdraw from their agreement to participate in the study at any time. Written consent was obtained from the respondents. I also assured the respondents that there was no risk involved for them since their real names would not be used in the study. Ethical considerations, as an integrated whole, can therefore be located throughout the study; the aim was to conscientiously investigate and report based on theory and empirical findings, in an open but considerate format.

3.6. Data Processing, Analysis and Presentation

Analysis was interwoven with data collection from the beginning. This was important because problems associated with huge analysis at the end of the study were avoided, especially the difficulty of collecting additional information to fill in gaps and the inability to write interim reports. Secondly, early analysis allowed the researcher space to cycle back and forth between thinking about data and generating new strategies for collecting new,

often better, data, interpreted in the light of the themes which emerged as central to the study (Miles and Huberman, 1994). The research results were written up in the form of one case study, including the selected three sub categories, followed by a discussion of the main trends, which emerge within and across them.

This was essentially a qualitative study; therefore the major portion of the information was subject to processing techniques suited to qualitative data gathering. Processing and analysis were done manually.

3.6.1 First Steps

Qualitative data analysis methods, as suggested by Miles and Huberman (1994), during the early stages of research help organise data for later intensive analyses. My starting point was to convert field notes into 'write-ups.' This was done to produce intelligible products (data sets) that could be read and commented on by anyone.

A document summary form was prepared at the beginning, based on and similar to a data matrix, but with space for freehand notes and questions. *A contact summary sheet* was used to capture main concepts, themes, issues and questions from each questionnaire or observation. This was a single sheet with some focussing or summarising questions about a particular field contact, used to develop an overall summary of the main points.

3.6.2 Self-Memos

According to Saunders et al. (2000), self-memos allow the researcher to make records of the ideas that occur to him/her about any aspect of the research. The researcher wrote memos in the following instances:

- When writing up interview or observation notes, or producing a transcript of the event
- When categorising the data.

- When analysing data and when in the process of writing.

Ideas would occur to me in an observation session. In this case I would record the idea very briefly as a margin note and write it as a memo after the event. It was useful to carry a reporter's notebook to record the ideas, whenever and wherever they occurred. The memos were written in simple note form; however, as suggested by Miles and Huberman (1994), the memos were dated and cross-referenced to appropriate places in the researcher's written-up notes. Memos were filed together and were also updated as the research progressed, so that the researcher's bank of ideas continued to have currency and relevance (Glaser, 1978; Robson, 1993). Alongside the creation of self-memos, the researcher maintained a researcher's dairy to record ideas and the researcher's reflection on these ideas, as well as showing the researcher's intentions about the direction of the research (Saunders, 2000).

3.6.3 Conclusion

This research study was designed to investigate activities, knowledge and attitudes in a particular social context; therefore it was appropriate to use a case study approach.

This chapter has described the methods used to gather data for the cases and the rationale for selecting them. It gave an overview of procedures and the sample selected for the study, and considered how the data was analysed.

The next chapter (4) presents the findings *in toto* of this study. Chapter 5, the final chapter, discusses the research findings and draws conclusions in relation to the hypothesis and current and past research in the subject area.

CHAPTER FOUR
Research Findings

4.1 Introduction

The previous chapter presented the research design and the manner in which the research was conducted. It included a description of the participants in the sample and the limitations of the design. This chapter presents data gained from three categories of participants. That is, four women infected with HIV between the ages of 20 and 35, two women affected by HIVI/AIDS and two members of the NAPWA administration (i.e. the Project Director and the Project Manager).

In constructing the information from these eight participants, the researcher asked questions about the organizational structure of NAPWA, the role of NAPWA, strategies used in fighting stigmatisation, the effectiveness of the strategies, challenges and collaboration with the government. I also asked HIV/AIDS infected participants about their age, why they had an HIV test done, disclosure, reaction of family and friends, how long they have lived with HIV, whether they have witnessed stigmatisation, why they joined NAPWA, what they have gained, lessons learnt from being HIV-positive and what they think of the stigmatisation of HIV-positive women. Participants affected by HIV/AIDS were also asked about their reasons for joining NAPWA, how they reacted to the HIV-positive status of their friends and relatives, if they have experienced stigmatisation and what they have gained as NAPWA members.

The women infected with HIV category thus contains accounts of respondents' years of living with HIV, reasons for joining NAPWA, reasons for testing for HIV, incidents of

stigmatisation if any, treatment they received from the community and family, their opinion of HIV-positive people and their opinion on stigmatisation. Accounts also detail respondents' assessment of NAPWA, the number of years they have been members of NAPWA, what they have gained from NAPWA and lessons learnt from being HIV-positive.

The category of women affected with HIV contains accounts of participants' reactions to the fact that their relative or friend was HIV-positive, what they thought of them, if the community knows of their relations HIV-positive status, if yes, what is their behaviour towards them and how they respond to this behaviour and their opinion on NAPWA-SA.

The category of administrators of NAPWA gives the accounts of participants' testimonies of stigmatisation they hear from HIV-positive women, the strategies they engage in to de-stigmatise HIV-AIDS, the effectiveness of these strategies, achievements and challenges, how challenges are managed and their collaboration with the government of South Africa.

These categories will be presented in a specific order starting with HIV-positive women then HIV-affected women and lastly NAPWA administration, under the different headings of discussion.

Adams and Sears noted with concern that with an epidemic as big as HIV/AIDS, people's personal experiences are bound to be eclipsed by the statistics that record how many are infected and how many have already died (1998). Keeping statistical records is important to keep track of the epidemic, and prevalence of the disease. There is however an equal need to come to grips with the real, lived experience of HIV. People with HIV are discriminated upon and stigmatised because of their HIV-positive status. Those who experience this stigmatisation the most are women. In this research I worked with a handful

of women who were willing to give personalised, subjective accounts of their experiences of living with and affected by HIV. First of all I will give some background to NAPWA-SA.

4.2 Background to NAPWA-SA

4.2.1 Geographical Setting and Location

NAPWA-SA is located in Germiston South Africa's most important railroad hub. Housed in a two-story building, it has ample space to accommodate both the offices for the organisation and makeshift temporary living quarters for PWAs who have been sent out of their home because of their HIV-positive status. This makes it easier for the organisation to immediately accommodate PWAs temporarily while looking for permanent locations to house them. Situated at Knox and Simpson Street, the NAPWA head office from the outside, gives the impression of isolation. Visiting the NAPWA Head Office however, I observed that people living around that area avoided walking by the building. This gave the location a semblance of being avoided. I also observed that, the people who lived close to it most often watched those who enter and exit the building with keen interest and questions in their faces.

When I got inside the building, I realised that it was a different world from the one which is seen from outside. I noticed that inside the building the atmosphere was warm and friendly. Members were friendly towards each other, chatting together, sharing food, drinks and advice on which nutritive course to follow to boost their immune system. Observing them, I got the impression that they seem to have found a home and family amongst the members of NAPWA.

My observations also documented the fact that the appearance of PWAs at the Head Office goes contrary to the image of HIV-positive people looking gaunt and unhealthy that is

portrayed in the media. At NAPWA, the HIV-positive women I came across and worked with looked healthy and they dressed neatly and stylishly.

I also noticed that, the offices running the affairs of NAPWA situated at the Head Office were well equipped with modern computers, printers, fax machines, telephones, and photocopiers. They also had a media centre with video and still camera facilities. To cater to the needs of members who spend most of their time at the Head Office and those who visit to participate in rallies from different provinces and branches. The building, I also learnt, had a furnished kitchen.

There was also a wellness clinic with its own nurses and a doctor who were there to attend to the medical problems of NAPWA members. This, the project manager explained, was a measure to put a stop to the humiliation and discrimination PWAs went through in public hospital and health centres.

It also came to my attention that the Head Office also houses a craft centre where members are trained in weaving, embroidery, dying and a carpentry workshop to train on woodwork, such as how to make chairs, cupboards, and beds.

4.3 The Stigmatisation of HIV-positive Women

4.3.1 How is it made manifest?

I first went to the Head Office of NAPWA-SA in Germiston in July 2005. I went there to do reconnaissance for a documentary on people coping with HIV. At first, most of the members I met were not comfortable with me or open about their HIV status. When I got to explain that the documentary was purely for my schoolwork and that it will go a long way to educate people about HIV/AIDS and stigmatisation, they started slowly to talk to me about their situation. By the time I completed the production of the documentary, I had become close with most of them. So when I asked for volunteers to participate in my

research report project, many did not hesitate to accept to participate and answer the questions I asked. They accepted to participate, provided their real names were not revealed and that they filled a self-administered questionnaire. I divided the participants into the following categories:

4.3.2 Category 1: HIV-positive Women

In this category four HIV-positive women were interviewed in all. The women were between the ages of 20-40. This age range was chosen due to the fact that most of the women infected with HIV in NAPWA fall within this age group. In their response to the question of whether they have experienced stigmatisation, three of them answered yes and one disclosed that she has never experienced stigmatisation. This was interesting because I was not expecting to get someone who has never experienced stigmatisation. The other three who said they have experienced one kind of stigma or other had different ways in which they have been stigmatised. Below is an account of what the women had to say on incidents of stigmatisation. Pseudonyms are used to protect identities and particular descriptions that could be used to identify individuals are omitted.

4.3.2.1 Participant I: Pauline E.

Pauline is a twenty-nine year old South African woman from the North West province. In the questionnaire she disclosed that she has lived with HIV for nine years. She learnt of her status when she went to the hospital for an operation and the doctor took her blood and examined it for HIV without her consent. When her results were disclosed to her, the doctors informed her that she had six months to live and she was devastated. Here is what she said:

> *'After my operation when I came back for check-up, the doctor told me I had AIDS and I had six months to live […]. He told me just like that without counselling me. I was devastated'.*

Pauline's experience is not rare. Many PWAs have faced and continue to face this kind of treatment from the hands of health providers. It is always said that healthcare providers involved in the HIV/AIDS sector have both the responsibility and an opportunity to overcome stigma within their profession and workplaces. Their professional codes of ethics and conduct, social and professional authority, all place them under an ethical obligation to be 'change agents' for reducing stigma.

Unfortunately, experience shows that healthcare institutions and individuals sometimes perpetuate stigma by stigmatising and discriminating against people, despite their professional codes. Hospitals and healthcare providers have been known to be sources of stigmatisation for HIV/AIDS patients and make their lives at the hospital a living hell. Even members of the public who visit healthcare facilities are reportedly involuntarily tested for HIV without their consent or any form of counselling as provided by legislation guiding HIV diagnosis. Most people who go for HIV testing do not only face the problem of lack of counselling before the test but most often are given wrong diagnosis.

According to an Anthropological study on life in a hospice done by Nokuthula Lucinda for her PhD thesis, patients rights to healthcare, dignity, privacy and counselling before and after an HIV test are violated. The study reported cases where HIV patients are stigmatised by the nurses and other medical personnel. Here is what one of the case studies in that research had to say:

> *'At Bara they used to uncover me, talk about me as if I am not there, making a show—here's another victim. I lost my things; my cloths, etc. People would take my*

bed-letter and read. The nurses did not make up the bed I slept on...what the doctor said became the basis upon which I was judged. What right did they have to say this (that I am a victim of HIV/AIDS) about me?' [19]

Many people who are sick are afraid of taking an HIV test because of the stigma that goes with a positive diagnosis. For those who have been diagnosed they fear going to the hospital for treatment when they suffer from opportunistic infections. As Skhosana Nokuthula L. writes, most of the interviewees in her study expressed being terrified to be admitted at the Chris Hani Baragwaneth hospital in Soweto for fear of being subjected to abusive treatment (Skhosana Nokuthula L. 2001.p.45).

Also, in a survey conducted in 2002, among some 1,000 physicians, nurses and midwives in four Nigerian states returned disturbing findings. One in ten doctors and nurses admitted having refused to care for an HIV/AIDS patient or had denied HIV/AIDS patients admission to a hospital. Almost 40% thought a person's appearance betrayed his or her HIV-positive status, and 20% felt that people living with HIV/AIDS had behaved immorally and deserved their fate.[20]

Pauline explained that for her, being told straight forward that she had AIDS and will die in six months was like a death sentence. According to her, she moved around in a daze looking like a 'walking corpse' just counting the days until she died.

Pauline also disclosed that her community did not help matters. She recounted that in the community, some of those who knew her status treated her normally but most called her names and blamed her for getting the disease because she was promiscuous. They avoided her like a leper and refused to be touched by her.

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[19] Skhosana, Nokuthula Lucinda. (2001) *Women, HIV/AIDS and stigma: an anthropological study of life in a hospice.* Thesis (M.A.)—University of the Witwatersrand, 2001

[20] UNAIDS, HIV and AIDS-related stigmatization, discrimination and denial: forms, contexts and determinants, December 2004.

In school, Pauline experienced internal stigma. She disclosed that due to the fact that she looked thin and gaunt she had the feeling that everybody that saw her knew she was HIV-positive. According to her:

> '*Walking in school, I felt as if people were watching me and they knew and then I will be griped with fear and start gasping for breath like an asthmatic patient. It came to the point where I could not write my final exams*'.

Pauline also revealed that this fear made her to always isolate herself from the rest of the children in school. Internal stigma (i.e. felt or imagined stigma) is the shame associated with HIV/AIDS and PWAs' fear of being discriminated against. Internal stigma is a powerful survival mechanism to protect oneself from enacted or external stigma and often results in the refusal or reluctance to disclose HIV status or the denial of HIV/AIDS and unwillingness to seek help (The Policy Project, 2003).

According to Scovia Kasolo Nabagala, chairperson of the National Community of Women Living with HIV/AIDS in Uganda (NACWOLA), internal stigma begins with an individual not seeing the benefit of living and looking at him/herself as unfortunate and contemplating what other people are going to think about him/her. "*You are always conscious about your appearance and health status and always checking for signs that will alert others that you have HIV."* Scovia said. Pauline revealed that faced with this internal stigma, she decided to keep her diagnoses to herself. She felt lost in the world for a year and a half until she joined support groups to learn more about HIV/AIDS in order to take good care of her health and live longer. Pauline acknowledged that joining NAPWA brought new meaning to her life. With NAPWA she took control of her life and was free to disclose her status without fear of what people would say or think about her.

4.3.2.2 Participant II: Hope N.

Hope is a 27-year-old woman who has been living with HIV for seven years. She voluntarily got tested for HIV to set an example for other members of the youth group she was heading. Hope did not disclose her result for fear of discrimination and stigmatisation. According to Green Gill, a common response to diagnosis and the sense of isolation, which often accompanies it, is to make contact with HIV organizations and other people who have an HIV-positive diagnosis. Friendship may flourish owing to the shared experience of having the same disease and it may sometimes become extremely close and enriching (Green, Gill.1996: 53)

Thus, after three years of living secretly with HIV, Hope joined NAPWA to get information about living with HIV, deal with stigmatisation and to meet people with her condition. After joining NAPWA she disclosed her status to her family and was told to keep it secret. Her boy friend reacted by stopping sexual intercourse with her and started seeing other women.

> '*When I disclosed to my boy friend he stopped having sexual intercourse with me, but dated other women*' Hope disclosed.

Like Pauline, joining NAPWA gave Hope the courage to disclose her status. She also disclosed her status to some people in the community and:

> '*At first they were distancing themselves but it reached a point where they will not want to be seen standing near me or be in the same room as I...*'

Hope disclosed that the years she has spent as a NAPWA member have given her the courage to face discrimination and stigmatisation, head on. She also acknowledged that her membership with NAPWA has also given her hope for a better future with HIV.

4.3.2.3 Participant III: Esther M.

Esther is 34 years old. She has been living with HIV for 10 years and has been a member of NAPWA for these 10 years. Taking the HIV test for her was out of the concern she had for her health and to avoid affecting others unknowingly. According to her, she joined NAPWA the same year she got diagnosed with HIV in order to join other HIV infected people and in a bid to learn about the disease in order to educate people in the community about HIV/AIDS.

For many women, being in a relationship puts them at risk of contracting HIV especially when they practise unprotected sex with their partners. Disclosing an HIV-positive diagnosis is a terrifying ordeal because of the fear of a negative reaction from the male partners. North and Rothenberg suggest that women's relative powerlessness in sexual relationships may make disclosure of sero-positivity to a partner particularly traumatic (North and Rothenberg Karen, 1993). *"He just accepted me though he was ashamed of me*" says Esther when asked how her partner reacted to her being HIV-positive.

More so, families are one of the sources of stigmatisation of HIV-positive people. They have difficulty accepting the fact that their family member has contracted the disease.

When asked how her family reacted to her being HIV-positive, Esther replied:

> '*Firstly, they were so scared and worried. They felt pity for me. When I joined NAPWA and they noticed that I have accepted my diagnosis and I was happy with my new life, they were able now to accept the fact that I am HIV-positive '*.

Unlike Hope, today Esther is very close to her family who give her support and love**.** She however disclosed that she does not live with her family not because she was sent away but because her job necessitated that she move from home to another town.

Also, HIV-positive women are stigmatised by members of their communities. People in a community may refuse to share objects, ostracize the person and family or beat and burn them to death like the case of Gugu Dlamini, an AIDS activist in Durban, who came out as being HIV-positive on World AIDS Day in 1998, and was later beaten to death by her neighbours)[21].

However, when a community has been educated and sensitized about HIV/AIDS and has come to terms with it, it becomes very supporting and accommodating of those who are afflicted by it. They interact with them, hug and touch them and even kiss them fondly with out any fear of contamination. Unlike Pauline and Hope, the community accepted Esther.

> '*They accepted me and ask for my assistance in matters concerning HIV/AIDS and when they have other problems and just need an ear to listen they come to me...especially girls*'.

According to Esther, as a woman living with HIV she is treated well in the community with no judgement or discrimination. Instead people respect her for her courage and bravery in accepting and living positively with HIV for 10 years. This goes to show that despite the widespread attachment of stigma to people infected or affected by HIV/AIDS, the experience of discrimination has not been constant or consistent across time or place.

4.3.2.4 Participant IV: Mary A.

Mary is thirty-one years old and has been living with HIV for six years. She became a member of NAPWA the same year she tested HIV-positive. During the interview Mary disclosed that she took the HIV test because she was very sick and the doctors had to find out what was wrong with her. When asked how she thinks she contracted the virus Mary responded "*I do not know how*".

[21] "AIDS in South Africa" Culled from the AVERT.org website: http://www.avert.org/aidssouthafrica.htm

Talking about family stigma, Scovia Nabagala of NACWOLA noted that it takes a lot of courage to open up to family members and have them understand and appreciate the dilemma you are in, as many of them may relate your situation to your past behaviour. Some of them may relate past deviation from expected behaviour in society to your current predicament. The situation is worse when it comes to your immediate and close family members, like your children whose understanding, depending on age, is limited to the obvious facts of life. These difficulties heighten the fear of opening up to one's family and impede the individual's ability to cope with HIV.

When asked about disclosing her status, Mary revealed that when she tested HIV-positive she told her mother who also told the other members of the family. The family reacted badly when they heard the news of her being HIV-positive. *"They were angry and ashamed of me, they blamed me for contracting the disease and they chased me out of the house,"* Mary recounts.

Stigma within the family, or directed toward an affected family, is the most debilitating form of stigma and the hardest to address. By inhibiting open, honest communication, stigma made disclosure within the family difficult; yet without disclosure, prevention and care would be almost impossible. Families and communities are deeply intertwined in the African context. As such, they require support in preventing stigma, which would further enable their natural caring role. This would promote self-esteem for PWAs and their care-givers, and avoid vicious cycles of self-perpetuated stigma.

For Mary, being isolated, abused and sent out of the house was very traumatising. After being sent out of their family house, like Esther, and Hope, Mary sought refuge in NAPWA. Asked why she joined NAPWA, Mary said "*to know more about people who are HIV-positive and to seek help*". Mary says as a NAPWA member she then began to open

up about her disease and started disclosing to some members of the community especially those who were ignorant about HIV/AIDS.

As a woman living with HIV, members in the community accused her of contracting the disease because she was promiscuous. A woman living with HIV may be doubly stigmatized—as a PWA and as a presumed sex worker. "*How otherwise could my niece become HIV-positive*?" asked the uncle.

Mary disclosed that members of her family were scared to touch, hug or help her for fear she would pass the virus to them. Some people in her community told the landlord to kick her family out of their rental accommodation. They stopped visiting her family and complained when she used communal facilities like the toilets and baths. Mary also recounts how many people in her community stopped exchanging food stuff with her, gossiped about her and openly talked and joked about her saying '*she won't live until Christmas'*.

Mary pointed out that, at this point she had no family or friend since they were all afraid to touch her or be associated with her. According to Mary, joining NAPWA was like finding a new family.

4.3.3 Category 2: HIV-affected women

In the first category of HIV-positive women I outlined four participants and presented their testimonies on how they have experienced stigmatisation in their lives as HIV-positive people. Under this category of HIV-affected women I will present the lived experience of two participants and show how they have experienced stigmatisation in their lives as people affected by HIV/AIDS.

The two participants, both between the ages of 30 to 40 years had a relation who was infected with HIV. Both of them disclosed that the community they lived in isolated their

family because they had people suffering from the disease living with them. Close friends and neighbours ceased to visit immediately they got information of the fact that their relative was sick with HIV. They revealed that it was difficult for them to go to community gatherings or shops because people will start pointing fingers at them and friends will hide themselves from them.

For Linda, a thirty year old woman who lost her aunt to HIV/AIDS related illnesses, when her aunt was diagnosed with HIV, she not only suffered discrimination from her neighbourhood but also in school. She recounted that her school mates got to know she had an HIV-positive aunt and they pointed fingers at her, mocked her, avoided her and also insinuated she too was HIV-positive.

> '*They treated me like a leper. I had no friends in school…going to school each day was an ordeal for me. I was treated like an outcast. So I had to abandon school.*'

Linda disclosed her school days experience. She explained that she was forced to abandon school because she felt victimised, threatened and isolated. Linda also disclosed that because of the reaction of the people in their neighbourhood her family isolated her aunt and locked her up in a room behind the house. They gave her separate eating utensils and beddings. This behaviour by her family according to Linda was very stigmatising for her because she loved her aunt very much. Linda took upon herself to take care of her aunt until she died a year after she was diagnosed with HIV. Linda revealed that she joined NAPWA after this to help educate other people about HIV/AIDS and the effects of stigmatisation.

4.3.4 Category 3: NAPWA Administration

In the previous category I discussed the stigmatisation experienced by two HIV/AIDS-affected people. In this category, I will discuss what NAPWA administrators say about the

testimonies of stigmatisation they get from some of their members. In this study, I interviewed two members of the board of administrators. That is, NAPWA's National Project Director and National Project Manager.

In the interview I conducted with them, they both acknowledged the fact that most of the members who come to join NAPWA are reported to have experienced stigmatisation and discrimination because of their HIV-positive status in one form or other. They both disclosed that most of the members especially women join NAPWA in order to overcome this stigma and to get support on how to fight this discrimination and live positively with HIV.

According to the Project Manager who handles most of the counselling sessions aimed at integrating new members, the testimonies of stigmatisation he hears are heartbreaking. He disclosed that some of the members who come to join NAPWA tell of situations whereby they have been sent out of their homes and NAPWA is the only resort for them. Some, he recounts, have been abandoned by their husbands or partners and are left to fend for themselves and the children. This is usually difficult especially when the women have no source of income. According to Nyblade and Field-Nguer (2000), the economic vulnerability of women exposes them to graver consequences when faced with the stigma and discrimination typically associated with being infected or affected by HIV/AIDS. When faced with the social ostracism and abandonment that often result, women frequently face tragic consequences because they lack the necessary economic resources to cope.

In South Africa, NAPWA has become the life-saver of many PWAs especially women because there they get consolation, accommodation and actually get to meet new friends who are going or have gone through the same predicament and are therefore eager and willing to talk HIV/AIDS, and then some! The Project Director also recounts situations

where communities and families have made life difficult for some of the women who are HIV-positive. They blamed the women for contracting HIV because they have been ‘sleeping around’ with other men. He disclosed that there was a case where the in-laws of a woman infected with HIV sent her out of her husband’s house after her husband died of HIV-related illnesses. They accused her of bringing the disease into their house and thus blamed her for the death of her husband. Left with nowhere to go and being unable to afford treatment for her ailment, she gave up hope of living until she was introduced to NAPWA. NAPWA has also received reports of some healthcare workers who still subject HIV patients to various forms of discrimination and injustices. The Project Manager revealed that there have been cases where members have been turned away from hospitals without being given any medical attention or treatment and they are told to go and die in their own homes.

According to the Project Manager, the worst kind of stigmatisation and discrimination so far reported is that experienced when dealing with institutions like banks and insurance companies, where PWA's are systematically denied access to the financial economy. He also mentioned the eviction of orphans whose parents have died of HIV and AIDS-related illnesses as another prevalent case of stigmatisation and discrimination reported to the association.

The Project Manager also disclosed that the latest case of stigmatisation they have heard from members is one in which the child of an HIV-infected couple was expelled from school because his parents are HIV-positive and two other cases where women reported losing their jobs when they disclosed their HIV-positive status.

The table below lists community-level contexts where HIV-related stigmatisation and discrimination has been experienced in South Africa, and examples of how this stigmatisation and discrimination has been manifested.

Contexts of Discrimination (adapted from Malcolm et al. 1998) Examples	**Examples**
Family/Immediate Community (e.g., village)	❖ Isolation of both the infected and affected due to fears of casual contact. ❖ Restrictions on participation in local communal events. ❖ Refusal to allow affected children in local schools. ❖ Lack of support for affected bereaved family members, including orphans.
Workplace	❖ Mandatory testing before hiring/refusal to employ. ❖ Involuntary periodic testing/dismissal on grounds of HIV status. ❖ Violations of confidentiality. ❖ Refusal to work with infected colleagues out of fear of contagion.
Health Services	❖ Refusal to treat. ❖ Violations of confidentiality. ❖ Provision of care in specific establishments (such as STI clinics) that further stigmatize the client. ❖ Behaviour with clients that clearly identifies their HIV status, instead of using universal precautions. ❖ Advice given or pressure applied for HIV+ person to undergo treatment that would not be emphasized for others (e.g., abortion, sterilization).
Media	❖ Demonization by public health campaigns of specified “transmitters” such as Sex workers, reinforcing division between “guilty” and “innocent” PWA. ❖ Depiction of HIV/AIDS as death, perpetuating fear and anxiety rather than normalization. ❖ Reinforcement of stereotypical gender roles that perpetuate women’s vulnerability to sexual coercion and HIV infection
Religion	❖ Denial of traditional rituals e.g. funeral practices; restricted access to marriage ❖ Restrictions on participation in religious activities

4.4 The Role of NAPWA-SA in Fighting Stigmatisation

In the above analysis through the testimonies of the various participants in this research, I have disclosed how the stigmatisation of HIV-positive women is made manifest. Under this section I shall now discuss the role NAPWA-SA plays in fighting the stigmatisation of people infected and affected by HIV/AIDS.

Support groups like the Associations of People Living with HIV/AIDS (APWA), carry out the important functions of providing members with information that can help them cope with stigma and its effects. Researchers on stigma find that the salience of the stigma itself is greatly reduced through some kinds of support groups (Statistics Canada, 2005). In South Africa, members of NAPWA also use their life stories as a powerful motivating force to make the general public aware of HIV/AIDS (Parker, Dalrymple, & Durden, 2000). This type of public disclosure can go a long way towards challenging attitudes, and encouraging acceptance of PWAs by the community. As well as being informative and emotional, disclosure engages people on a personal level and gives a face to the disease (Parker Dalrymple, & Durden. 2000).

4.4.1 What is NAPWA doing to educate members about coping with HIV/AIDS and stigma?

When I started this study, I was introduced to the Project Manager of NAPWA and advised to work with him. He gave a tour of the NAPWA establishment and talked me through other issues concerning the membership of NAPWA. He answered most of my questions concerning the management of NAPWA. When I asked the Project Manager what NAPWA was doing to educate members about coping with HIV/AIDS and stigma, he started by telling me that when NAPWA was transformed into a non-profit NGO in 1994, it dealt with the issues of discrimination, care and support for PWAs. He affirmed that,

through its National Office in Germiston, NAPWA co-coordinates the needs and resources of PWAs nation-wide through the mobilisation of PWAs, partnership and collaboration with other stakeholders, advocacy and lobbying at all levels, gender programmes, organizational development and, care and support for PWAs. He divulged that the organisation engages in the following programmes to help members to fight stigmatisation and to educate communities on issues concerning HIV/AIDS and the effect of stigmatisation:

4.4.1.1 Mobilization

According to the NAPWA profile document, the strongest point of the organisation is its strong ability to mobilize all people living with HIV/AIDS in South Africa. The Project Manager explained that the emphasis on mobilisation was based on the need and importance to build a national mass-based PWA movement to lobby and advocate for the care of members infected and affected by HIV/AIDS and to form a common front to fight against discrimination and stigmatisation.

He disclosed that sensitization and awareness campaigns were organised around the country to educate people about NAPWA and their role in fighting stigmatisation and discrimination of PWAs. It is critical for organisations like NAPWA-SA to provide a voice for the community of people living with HIV/AIDS. It was revealed that through the mobilisation programme, NAPWA-SA can boast of three hundred branches nationally with a membership of two hundred thousand of which close to 70% are women.

4.4.1.2 Advocacy and lobbying

NAPWA also uses advocacy to protect the rights of PWAs. According to the project manager, NAPWA members in the national and provincial bureaus are usually engaged in

demonstrations and campaigns to let their views be heard by the government. He revealed that some of the campaigns they engage in include, the 'food for all' campaign in which members usually converge for a month and go without food for most of the day in what they call a 'hunger strike' campaign to advocate for the need for PWAs to be well-fed before they can take ARV treatment for HIV. NAPWA also carries out campaigns during which they lobby for support, financing and recognition of PWAs.

4.4.1.3 Partnerships and collaboration

In order to facilitate the implementation of some of its programmes, NAPWA-SA establishes links and develops strategic partnerships with key local and international organizations, institutions and governmental departments for mutual benefit so that their work will have a broad impact and will increase the possibility for positive change. Here once again, the project manager revealed that NAPWA has a strong partnership with organisations that are linked to the communities like traditional leaders, traditional healers, teachers unions, church institutions, youth and women organisations, student organisations (both in secondary and tertiary institutions), AIDS service organisations, community development organisations and civic structures. They also have partnership with some government departments including public healthcare centres. Partnership with these structures the Project Manager explained, serves as mobilisation vehicles for project and programme implementation.

4.4.1.4 Counselling and support

Numerous studies suggest that good counselling assists people to make informed decisions, cope better with their health condition, lead more positive lives, and it prevents further transmission of HIV. Trained counsellors sometimes provide HIV/AIDS counselling

though nurses and caregivers are often in the ideal position to provide effective counselling, advice, and support.

Responding to a question on counselling and support, the NAPWA Project Manager explained that at NAPWA, counselling and support is provided to members by other members who have had training or experience in counselling and by those who have lived with HIV for a long time and are in a position to offer advice and support. He added that NAPWA also facilitates the accessibility of other counselling services desired by members by referring them to approved services.

The Project Manager explained that because NAPWA is made up of people who themselves are infected or affected by HIV/AIDS; they provide effective communication and counselling. This, he added entails, self-awareness of one's beliefs, values and assumptions, a respectful and non judgemental attitude, affective listening, including accurate reflection of issues or concerns. It also involved providing practical support, advice and information, discussing options for care, prevention and support, encouraging PWAs to make their own decisions and above all asking supportive questions that raise important issues in caring, non-judgemental ways.

More so, the Project Manager explained that counselling sessions and support programmes at NAPWA usually address feelings of shock, fear, loss, grief, guilt, depression, anxiety, denial, anger, suicidal activity or thinking, reduced self-esteem, and spiritual concerns. In addition, social issues such as loss of income, discrimination, social stigma, relationship changes, and changing requirements for sexual expression are also explored.

Through the above strategies, NAPWA enables PWA to develop their coping abilities and play a leading role in addressing the causes of stigma and discrimination, creating an enabling environment in which PWA can advocate for greater respect for their rights and achieve a reduction in institutionalized stigma and discrimination.

4.4.1.5 NAPWA's Support for Women Living with HIV/AIDS

A majority of the members of NAPWA-SA are women who are affected or infected by HIV/AIDS. The fact that a majority of NAPWA members are women goes to show that women are more susceptible to HIV and need support in order to survive and overcome the stigma associated with being HIV-positive. When I talked to the Project Manager about what NAPWA is doing to support female members, he explained that the organisation has projects and programmes, which deal specifically with issues concerning women and especially those infected or affected by HIV/AIDS. These programmes fall under the gender programmes section of the organisation.

I. Gender programmes

Under the gender programme, NAPWA-SA initiates and offers programmes and projects on gender issues on HIV/AIDS relevant for female-members of NAPWA. When asked to elaborate on NAPWA's gender programmes, the Project Manager explained that NAPWA implements clear gender activities focusing on the needs and plight of HIV/AIDS infected and affected women of the organisation. He revealed that because HIV infected and affected women are most often excluded in most activities in their communities once their HIV-positive status is known, NAPWA intends to ensure their active involvement in issues affecting them and society. He expressed the need for the inclusive participation of HIV-positive women in activities related to their wellbeing, their health and economic stability.

This he suggested will result in their independence and give them the power to fight discrimination and stigmatisation. The programmes and projects on gender according to the Project Manager also aim at raising awareness about the vulnerability of women to HIV, the impact of HIV on women, the impact of stigmatisation and also the need to increase the participation and involvement of women in community development initiatives.

More so, the Gender Programmes are also intended to emphasize the rights of marginalised women. According to the Project Manager, in most instances, policy programmes and legislation are drafted assuming all women are the same and have similar access to society's resources. As women are advantaged or disadvantaged in different ways, these programmes advocate equal access to social justice for women who are infected or affected by HIV/AIDS. The Director highlighted the fact that by focusing specifically on these groups of women, NAPWA hopes to broaden access to rights and available resources for all women affected or infected with HIV/AIDS in South African society.

The overall objectives of these gender-based programmes are:

- To highlight and address problems that women encounter in their day-to-day struggle as people infected or affected by HIV/AIDS.
- To conduct research on gender issues that affect women and to capacitate HIV-positive women on how to handle such issues and how to influence policies to accommodate them.
- To train HIV/AIDS infected and affected women on issues of HIV/AIDS, gender and reproductive health and facilitate the establishment of health and vegetable gardens to prolong the lives of HIV-positive people.

- To instil the culture of coping with HIV/AIDS and promote disclosure, strict respect of the prescribed ARV treatment plan and healthy living.

To achieve these objectives the project manager explained that the following strategies are employed by NAPWA-SA:

- Organisation of workshops and training in which women are informed of government policies regarding HIV/AIDS and stigmatisation.
- Establishment of a women's forum that meets at the local level to debate issues concerning HIV/AIDS and women, discrimination against women, battering and sexual abuse.
- Training workshops to educate women on project management, economic empowerment and capacity building.
- Provision of nutritious food, gardening lessons and equipment.

Currently on going NAPWA activities that focus on women are:

- Local economic development.
- Lobbying and advocacy.
- HIV/AIDS training workshops and establishment of health gardens.
- Facilitating HIV-positive women’s access to facilities and services.

NAPWA also laid emphasis on the aspect of skills building among PWAs, with a focus on education, advocacy, media work, management, and reporting. This was done through various projects. It was disclosed that women head most of the projects in NAPWA. An example is the “Lesedi” project that involves the training of members on income

generation, such as cultivating vegetable gardens, weaving as well as running wellness programmes which highlight the use of ARVs and promote nutritive eating plans.

The Project Manager also made known the fact that women are trained to conduct public information campaigns and community forums aimed at promoting tolerance, compassion, understanding and the reduction of fear, stigma and discrimination. They are also encouraged to participate in public information campaigns and in HIV programmes and policy formulation.

4.4.2 What NAPWA is doing to sensitise communities about HIV/AIDS and the effects of stigmatisation.

Societal stigma refers to societal attitudes and norms that stigmatize people living with HIV. The individual often feels forced to do a 'self withdrawal' for fear of being judged, ostracized or shunned. An example is the societal attitude that 'AIDS is for prostitutes, for people who have nothing to offer.' In order to support PWAs to cope and live positively, it is important to understand and address these issues both at the personal and societal levels.

Noerine Kaleeba, Community Mobilisation Adviser, UNAIDS during the Dar-es-Salaam conference[22] on HIV stigma, described how communities move through stigma in four waves. She revealed that, in wave one, there is denial; in wave two, irrational fear, which results in rejection and stigmatization of people with HIV and their families; wave three brings a period of awareness arising from knowledge of transmission that allows reflection and moves people to the last wave, in which communities display tolerance and acceptance. According to her, communities do not move in a linear fashion from denial to acceptance or from one to the other. She noted that while people have had experiences where

[22]Culled from the Regional Consultation Report on the seminar on Stigma and HIV/AIDS in Africa: Setting the Operational Research Agenda that held in Dar-es-Salaam Tanzania from 4 - 6 June 2001

communities have moved toward greater tolerance and acceptance, they can revert to the wave of denial before coming back to tolerance. She also highlighted some of the factors that have helped move communities through the waves.

Wave 1 - Denial

In wave one, which is the wave of denial, Kaleeba disclosed that political commitment and the international red ribbon movement show that in their daily work communities are willing to stand in solidarity with people with HIV/AIDS.

Secondly, surveillance programmes, community level programmes, and the involvement of people with HIV/AIDS and affected families underscore the reality that HIV is a family disease.

Thirdly, people with HIV/AIDS need to have families, neighbours, and religious leaders to accompany them in this journey and lastly, the involvement of community gatekeepers is also crucial at this stage.

Wave 2 – Communities moving from denial to fear, rejection and stigma

During the second wave which involves communities moving from denial to fear, rejection and stigma, Kaleeba revealed that accurate and consistent information should be sensitively delivered, comprehensive care and support programmes formulated and implemented, and there should be the involvement of people living with HIV/AIDS. More so, there should be community discussion of norms and values (our people value the issue of care and support, so we need to get to the community) and guidelines on policies should be clear.

Wave 3 - Awareness

In the third wave which has to do with awareness, Kaleeba advised that the knowledge of the communities should be improved based on modes of transmission, awareness about the

available options for protection against HIV should be improved, fatalistic tendencies should be countered, people with HIV/AIDS should be involved and positive living should be promoted.

Wave 4 – Acceptance and tolerance

Under the fourth wave involving acceptance and tolerance, Kaleeba suggested that communities should be provided with support and solidarity, advocacy programmes and community-based care programmes. There should also be the involvement of people with HIV/AIDS and their families, involvement of community gatekeepers and community-based discussion of rights and responsibilities. Kaleeba believes that the evolution from one wave to another will help address stigma.

During the discussion on what NAPWA is doing to sensitize the community about HIV/AIDS and stigma, the Project Manager disclosed that they embark on door-to-door campaigns in order to gain access to significant amounts of people in the communities. These campaigns, he added, are geared towards de-stigmatising HIV/AIDS and in the process succeed in empowering communities about HIV/AIDS. Members of the community are also invited to attend and participate in the gender programmes organised by NAPWA in a bid to educate both men and women on issues of gender, human rights and HIV/AIDS.

As part of community building, the Manager divulged that NAPWA's sensitisation campaigns also aim at changing norms, increasing social support, and making community building as part of initial community-level interventions. Through this, NAPWA identify leaders, create new settings, and create opportunities for dialogue between the community and PWAs to address negative perceptions of HIV/AIDS.

NAPWA members also mobilize to disseminate accurate information about PWAs and dispel myths surrounding HIV/AIDS and PWAs, promote a compassionate community and individual response to PWA, and inform people about locally available voluntary counselling and testing (VCT) and support services.

The Project Manager revealed that NAPWA also organises basic HIV/AIDS information workshops to educate the community on the activities of NAPWA and its objectives. This, he emphasised, encourages members of the community who are infected or affected by HIV to seek support and for others to go and do the HIV test without fear of stigmatisation.

4.5 The success of NAPWA in the fight against the stigmatisation of people infected and affected by HIV/AIDS in South Africa. (The case of HIV/AIDS infected & affected women)

Since its creation in 1994, NAPWA has always strived to be an organisation that accepts, cares for, supports, empowers and defends the rights of people living with HIV/AIDS in South Africa. So far, they have come a long way from the 1990s when living with HIV/AIDS was like a death sentence. Today thanks to their incessant fight and campaign for the rights of PWAs, they have made PWAs more visible and given HIV/AIDS a human face. When I asked the Project Director how successful NAPWA has been in achieving its objectives of fighting HIV-stigmatisation and the discrimination of PWAs, he outlined a series of achievements NAPWA has had over the years.

According to him, NAPWA has launched more than 60 branches across the country, which goes to show that PWAs believe in NAPWA and know that NAPWA delivers on its promises of protection, care and support of PWAs. He also brought out the fact that during its inception, NAPWA was just an informal organisation with no formal membership system. This was due to the fact that the environment at that time was not conducive to

dealing with PWAs because of the discrimination and stigma that was associated with HIV/AIDS. The Project Manager disclosed that today, because of the lobbying, sensitization and advocacy carried out by NAPWA on behalf of PWAs, this system has been changed and many PWAs are openly joining NAPWA and registering with them officially.

Also, although it took time for the members of the communities to come to terms with the realities of HIV/AIDS, the Project Manager disclosed that today, NAPWA can boast of leading the disclosure and acceptance campaign in South Africa. This could be seen through the turn-out during sensitisation rallies and the increasing membership of those infected and affected by HIV/AIDS.

He also highlighted as an achievement the number of members who have succeeded in getting back their jobs or getting compensation for the loss of their jobs due to their HIV-positive status after the intervention of NAPWA. These interventions, he disclosed, are most often in the form of peaceful demonstrations, letters to government departments, agencies and to companies or organisations.

More so, the fact that PWAs can today stand up openly in gatherings and disclose their HIV-positive status, to the Project Manager is a great step from the days when PWAs were lynched for disclosing their HIV-positive status. PWAs are getting the respect they deserve as human beings and not judged because they are HIV-positive.

With regard to HIV-positive women, the Project Manager disclosed that NAPWA has witnessed an increase in the number of women who are disclosing their status, accepting it and living a positive life after counselling and support from the organisation. This

acceptance and willingness to disclose, he pointed out, shows that the levels of stigmatisation of PWAs are falling in most areas in South Africa.

There are also more HIV-infected and affected women involved in projects in the organisation. The Manager gave the example of projects like the LESEDI project and Eyesizwe Mines Asiphileni project, which are coordinated by women. Women can now be seen delivering lectures on HIV/AIDS and also giving personal testimonies about their lives as PWAs.

More so, in order to respond to the challenges that HIV-positive women face, NAPWA has succeeded in forming a men's movement that is a support group for men and is coordinated by officials from NAPWA. Through this group, the Project Manager revealed, NAPWA has been able to educate men on the vulnerability of women to HIV, the impact of HIV on women, the impact battering and maltreatment have on HIV-positive women.

4.5.1 Challenges involved in the fight against HIV stigmatisation and discrimination.

HIV/AIDS has always been a challenging disease and the stigma associated with it is not helping in the fight against the virus. As Hon. F.T Sumaye, the Tanzanian Prime Minister, said during the conference on 'stigma and HIV/AIDS in Africa : Setting the operational research Agenda' (2001) that was held in Dar-es-Salaam, I quote, "In Africa we are all living with HIV, whether infected or affected. We CAN reduce stigma—by promoting acceptance of people living with HIV/AIDS." This statement not withstanding, many people and organisations involved in the struggle for the acceptance PWAs and recognition of their rights, have most often faced stumbling blocks or challenges. NAPWA-SA has not been exempted from these challenges.

According to the Project Manager for NAPWA, the fight against the stigmatisation of PWAs has not been an easy one. He raised the following points as being some of the challenges NAPWA faces in their day-to-day struggle for the acceptance and recognition of their rights as human beings and citizens of South Africa:

4.5.1. I. Lack of funding

In the past NAPWA has received funding from the National Department of Health and the Interfund Christian Aid. The Project Manager disclosed that in the past few years funding from government has been reduced and it comes irregularly while the Interfund Christian Aid funding ended a long time ago. This creates financial constraints for NAPWA which delay the implementation of projects and programmes and also limit the scope of activities NAPWA can engage in.

4.5.1.2 Lack of resources

Here the manager elaborated that the organisation lacked enough resources like financial support, equipment with latest technology, and trained professionals in the HIV/AIDS field etc, to implement and sustain their programmes. This he disclosed often leads to projects being abandoned or delayed.

4.5.1.3 Lack of support from the media

The Manager pointed out that the media in South Africa concentrate on talking about the effect of getting infected by HIV and how to prevent infection. Little or nothing is said about how people living with the disease are coping and what APWAs are doing to help them in this coping process. They fail to pick up the verifiable fact that control and support of infected people helps in stemming the spread of the disease.

4.5.1.4 Lack of trained personnel

Dealing with issues concerning HIV/AIDS like any other, needs some know-how or training. The Project Manager disclosed that the administrative staff at NAPWA is mostly made up of people infected with HIV who have been discriminated against and who have not had the basic education or training. In this regard they lack the basic skills to run some of the projects carried out by NAPWA. This lack of training makes it a must for NAPWA to train its personnel which can be time consuming and expensive. All these he highlighted delay the implementation of some projects.

4.5.1.5 Other organisations using the NAPWA name illegally

He also disclosed that some organisations illegally use the name of NAPWA to operate in certain areas and to get funding and favours. Citing examples, the Project Manager alleged that the Treatment Action Campaign (TAC) in 1999 attempted to hijack the activities and functions of NAPWA to serve their agenda of uncritically promoting the use of toxic pharmaceutical drugs to the exclusion of side-effect-free, natural treatment approaches to AIDS. The Project Manager also went ahead to recall that when this failed they went ahead to stage a concerted campaign to destroy NAPWA by alleging misuse of donor funds. This he insinuated makes it difficult for NAPWA to get funding when they apply to some donors or sources of funding.

4.5.1.6 Attitudes, beliefs and practice

The Project Director and Manager both pointed out that despite calls by government and other organisations for the need to end the stigmatisation of those affected or infected with HIV/AIDS, they still get reports of discriminating practices against PWAs. These acts of discrimination, they disclosed, are committed by institutions like banks, hospitals,

insurance companies etc. These continued discriminatory practices according to them undermine the efforts of NAPWA to wipe out stigmatisation and impact on NAPWA's ability to address the challenges of HIV/AIDS.

4.5.1.7 Poverty of families affected by HIV/AIDS

Here the management of NAPWA disclosed that most families who have HIV/AIDS infected relatives lack the financial might to take care of them while they are sick and face a greater difficulty when they die because they cannot afford a burial. The burden then shifts to NAPWA and with the funding difficulties they face this can be a tall order for the organisation.

4.5.1.8 Members falling ill and dying

Many regard HIV/AIDS as a death sentence. One of the aims of NAPWA is to portray HIV not as a death sentence but as a disease that can be managed. The Project Manager pointed out that in order to manage HIV, infected persons have to adhere to the treatment, positive and healthy living. Neglecting these, he cautioned, usually leads to HIV related illnesses that if not well treated, can lead to early death. He disclosed that some members join NAPWA at the late stages of their illness and some do not follow the counselling advice they are given and these lead to their early death. The Manager pointed out that the aspect of members dying is usually scary for others and puts doubts and fear in the minds of others infected with HIV.

4.5.2 Networking and Partnership

The Project Manager explained that, NAPWA works with other organisations to ensure their campaigns and projects get the necessary support. He revealed that they had support

from the government of South Africa. He further went to explain that NAPWA had a partnership with organisations involved in the fight against HIV/AIDS (e.g. the Southern African Network of AIDS Service Organizations (SANASO), South African AIDS Consortium, Women and AIDS in Africa (SWAA), International Community for Women with HIV/AIDS (ICW), Network for People Living with HIV/AIDS in Africa (NAP+), Global Network of People Living with HIV/AIDS (GNP+), Medical Care Development International (MCDI) and Broadreach healthcare), the health service, community development organisations, women organisations and traditional healers.

The Medical Care Development International (MCDI) signed a two-year partnership with NAPWA-SA from 2003-2005 to implement the Reducing Stigma and Discrimination Project in Ndwedwe District, KwaZulu Natal, South Africa. This two-year project, according to the project manager, was intended to build NAPWA's capacity to utilize multiple approaches for community mobilization and to improve legal protection for PWA in Ndwedwe District. The project was based on the principles of a rights-based approach (e.g., universality, gender equality, accountability of duty-holders, participation) and principles of GIPA [23](Greater Involvement of People Living with HIV/AIDS) to effectively address internal and external stigma and discrimination.

4.6 What HIV Infected and Affected Women say about NAPWA

Six HIV infected and affected women participated in this research. Answering the question on what they have to say about NAPWA, most of them revealed that the various programmes that NAPWA carry out capacitate those infected and affected by HIV. They all revealed that joining NAPWA has enabled them to get psychological support. Some

[23] Greater Involvement of People Living with HIV/AIDS (GIPA)

acknowledged that joining NAPWA has helped them to regain their self-esteem and confidence, become courageous. They also attested to being able to acquire knowledge through educative seminars and training workshops on how to live positively with HIV/AIDS, personal development in HIV/AIDS activism whereby they have learned how to mobilise people, socialise with others without fear of discrimination, and the courage to disclose their status. Some also revealed that through NAPWA they now have basic training in project management weaving, knitting and garden management.

4.7 Weaknesses of NAPWA

Talking about the weakness of NAPWA, it appeared as if the organisation had no weaknesses of its own. This was because some of the participants either stated in their questionnaire that NAPWA had no weaknesses or did not bother to respond to that particular question. The Project Manager however highlighted as weakness the fact that some trained members who work for the organisation later leave for greener pastures adding to the already acute problem of shortage in trained personnel. He also projected as weakness, the inability of NAPWA to sustain some of its projects because of lack of resources and finance. He implied that these limitations make it impossible for NAPWA-SA to cover a wider scope. The shortcomings also make it an up hill task for the association to attain its objectives and goals.

CHAPTER FIVE
Discussion and Conclusion

5.1 Introduction

Theories of stigmatisation suggest that stigma is a social product generated by social interactions in which potentially stigmatising attributes are relevant to either party's expectations. Thus the impact of stigma in everyday life is related to its inherently social nature. Goffman (1963) suggests that everyday, discrediting associations are made during a stigmatized individual's social interactions, whether imagined and anticipated or experienced for real. Zola (1993) suggests that the social spoiling process associated with stigma may eclipse a person's social identity, so that she is treated as belonging to a stigmatized category rather than as an individual, and devalued in the process. People within this category usually find refuge in groupings or interactions with people in a similar situation.

In the case of HIV/AIDS, those affected or infected with the disease most often seek refuge and counsel in associations of people living with HIV/AIDS. Researchers on stigma find that the salience of the stigma itself is greatly reduced through some kinds of support groups. Support groups carry out the important functions of providing members with information that can help them cope with stigma and its effects. More so, psychologists and other social scientists researching stigma explain that the support group is a good place to share the stress of stigmatization.

This study is based on the assumption that, HIV-positive women suffer stigmatisation and that, organisations of people living with HIV/AIDS play a major role in eradicating stigma attached to HIV/AIDS. It also assumes that APWAs, in effect, reduce the spread of the

disease and prolong the life span of those infected by it. This is especially so since many HIV/AIDS infected people in South Africa are joining or are becoming members of APWAs and also because PWAs who become members are living longer with the virus as these APWAs have demonstratively helped improve the quality of their lives.

This was confirmed in this study by participants who assuringly indicated that some of them have lived with HIV for close to eight years and above. Besides, the study showed that members of NAPWA-SA can boast of a better quality of life given the fact that with training and jobs from NAPWA, they can now cater for themselves and afford good healthcare, food, accommodation and clothing.

In keeping with the coping theory, the researcher developed a qualitative design for the study. A series of recorded interviews were conducted with the Project Director and Project Manager at NAPWA. Also, self-administered questionnaires were handed to four HIV-positive women and two HIV/AIDS-affected women who are members of NAPWA. This fifth chapter discusses the findings of the research with a view to showing that HIV-positive women have experienced stigmatisation and that NAPWA plays a big role in addressing the challenges of the stigmatisation of PWAs, especially women. The geographical setting and infrastructure as well as the organisational and operational aspects of the NAPWA-SA Head Office, in Germiston, are discussed in the first part with specific reference to the way in which they impact on the organisation's ability to address HIV/AIDS stigmatisation.

This information is culled from the researcher's on-site observations and her reading of the NAPWA profile document. This is followed by the discussion based on the information gathered from what participants said on how the stigmatisation of HIV-positive women was made manifest, how these effected the participants' decision to join NAPWA and how

NAPWA carries out its function of protecting PWAs. Thereafter, the challenges faced by NAPWA in its quest to fight stigmatisation, as well as the successes, achievements and weaknesses are examined.

5.2 Geographical setting and location

The study identified the location of NAPWA-SA in Germiston, South Africa's most important railroad hub. The study established that because NAPWA-SA is housed in a two story building, this gives it ample space to accommodate both the offices for the organisation and make-shift temporary living quarters for PWAs who have been sent out of their homes because of their being HIV-positive. This, the study explains, makes it easier for the organisation to immediately accommodate PWAs temporarily while looking for permanent locations to house them.

Although the location of the NAPWA head office gives the impression of isolation, observations from the researcher revealed that the outward appearance differed from the one inside. The research found out that, inside the NAPWA-SA building the atmosphere was warm and welcoming. Members were friendly towards one another, chatting together, sharing food, drinks and advice on which nutritive course to follow to boost their immune systems. This goes to establish the fact that members of NAPWA have found comfort, love, care and shelter within the association—a far cry from the additional pain they had to endure from being stigmatised in their communities.

Oftentimes, most images of PWAs portray the human body as being in crisis and dramatically show PWAs as bed-ridden, fragmented, distorted and mutating. This study has however established that, outside public view, PWAs at NAPWA are healthy looking, neat and include stylishly dressed women. The researcher observed that the members of

NAPWA made it a point to dress neatly to work, engage in sporting activities, eat healthily and socialise normally.

With offices equipped with furniture and equipment from donors, the study exposed that NAPWA-SA is presently in a position to cater for the needs of most of the members and help them in achieving the recognition, love and treatment they deserve. The researcher however found out that these facilities will not be enough in the long run with the growing number of infected and affected people who join the organisation everyday.

This study also reveals that NAPWA members are saved from the discrimination and stigmatisation which is rampant in public hospitals and health centres due to the fact that NAPWA has a wellness clinic at their Head Office. This also goes further to confirm the fact that NAPWA-SA is doing all in its capacity to protect and take care of PWAs.

Furthermore, the Head Office also houses a craft centre where members are trained in weaving, embroidery, dying and a carpentry workshop to train on woodwork like making chairs, cupboards, and beds. Training in these fields empowers NAPWA members and gives them a livelihood. This implies that NAPWA is playing an important constructive role in the lives of its members, especially HIV-positive women.

5.3 How HIV/AIDS stigmatisation is made manifest

Theorists like Goffman (1963), Herek (1990), and Meursing (1997) suggest that stigma may manifest itself externally or internally and may have different effects on the victim. Findings from the study revealed that some of the participants witnessed the manifestations of external stigma. Of the four HIV-positive women interviewed, three disclosed that they had witnessed stigmatisation in the form of rejection, isolation, abuse and accusation. Aggleton and Warwick (1999) suggest that the impact of HIV/AIDS-related stigma on

women reinforces pre-existing economic, educational, cultural, social disadvantages and unequal access to information and services. This study highlighted testimonies on HIV-positive women who were not viable economically due to the fact that they had been abandoned by their husbands because of their status. The study established that this poor economic situation pushed them to seek support from NAPWA. This researcher suggests that the fear of being abandoned and left without economic support influences many women not to seek diagnosis for their ailments and when they do, they refuse to disclose the results.

The study also revealed that most of the HIV-positive women had been stigmatised and this was made manifest in different ways. All but one of the women interviewed acknowledged the fact that they have been stigmatised because of their HIV-positive status by family members, friends or members of the community they lived in. Stigma and stigmatisation are most easily understood as social processes, which play a key role in producing and reproducing relations of power and control in social systems. Stigma is therefore linked to social inequality and operates in relation to difference. By making social inequalities seem reasonable, it creates and reinforces social exclusion (The Policy Project, 2003). From the testimonies of the women who participated in this research, one can infer that this exclusion usually gives the victim the impression of not belonging or not being wanted. They are thus quick to seek help where they will be accepted and APWAs usually come handy in HIV/AIDS cases.

The study recognized that most of the infected and affected women who participated in the research joined NAPWA because of the discriminatory treatment they received from friends and family members. Two of them disclosed that they joined NAPWA to learn

more about living with HIV/AIDS and to help others not to allow themselves to become victims of stigmatisation.

Within a particular culture or setting, certain attributes are seized upon and defined by others as discreditable or unworthy. Irwin (1981) perceives the concept of stigma as that of targeted individuals having attributes that do not accord with the prevailing standards of the so-called 'normal' and 'good'. They are often denigrated and avoided covertly and unconsciously even when the disdained person is an innocent victim of misfortune. Interviews with the PWAs showed that communities are still in denial and largely ignorant of matters pertaining to the pandemic, and are inclined to uphold cultural taboos surrounding the topics of sex and death. They thus tend to blame PWAs for contracting the disease because they were promiscuous and sinful.

Gilmore and Somerville (1994) explain that a common response when confronted with a frightening or intolerable situation is to attempt to flee or escape from it, or attempt to control it by deactivating or destroying it. In the study, participants affected by HIV/AIDS established that by stigmatising the 'other', people flee from the reality that they are collectively affected by HIV/AIDS (Gilmore, N., & Somerville, M. 1994). The fear generated by the stigma of HIV/AIDS not only ostracizes the individual, family and relatives, it also divides communities whereas members of these same communities could help and care for each other.

From the testimonies of participants in this research, one can safely confirm that HIV-positive women at NAPWA-SA had been stigmatised because of their HIV-positive status. The study has thus established that most of the women joined NAPWA-SA in order to combat stigma, seek support and acceptance from others suffering from the same condition and learn about living with the disease.

5.4 The Role of NAPWA-SA in Fighting Stigmatisation

Coping theory stipulates that the impact of stressful situations and experiences depends in large part on how the individual copes with them (Meursing, 1997). Lazarus and Folkman, in Taylor (1986), define 'coping' as the process through which a person manages internal or external demands that are appraised as taxing or exceeding the available resources. Coping theorists like Bandura (1995), Helman (1990) and Lewis (1966), have identified factors which influence coping style among individuals. This depends largely on self-efficacy or the extent to which individuals believe they can organise and execute the courses of action required to deal with events. And as Bandura puts it, how to deal with these events largely depends on important contextual variables, including the availability of social support and material resources for coping (Bandura, 1995).

Meursing (1997) confirms that one major influence on self-efficacy is the availability of social support. Practical, material information and emotional support from friends and family increase the instrumental means to deal with a problem, and can act as a buffer against emotional strain, thereby increasing perceived self-efficacy. In this study, it is shown that NAPWA has been the pillar for stigmatised HIV/AIDS infected and affected women—hence confirming the 'social support' premise advanced by Meursing (1997).

Through interviews with the Project Manager and Director of NAPWA, the researcher discovered that NAPWA is doing a lot of things to protect PWAs especially those who are members of the association. The study established that NAPWA engages in counselling and support, partnerships and collaboration, advocacy and lobbying, as well as mobilization. Through these activities, NAPWA is able to sustain PWAs, help them maintain good health, fight for their rights, educate them about coping with HIV/AIDS, stigma and mobilise other PWAs around South Africa. The study also shows that NAPWA

is active in the sensitisation of communities about HIV/AIDS and the effect of stigmatisation on the spread of the disease and the survival and mortality of patients. According to Campbell (2003:123), an important requirement for translating knowledge into behaviour change is a feeling of personal vulnerability to HIV infection. This study has disclosed that NAPWA's sensitisation campaigns have gone a long way to reduce and change the attitude of 'othering' and lack of a feeling of personal vulnerability to HIV infection that most communities exhibited in previous years. The sensitisation of communities, the research further explains, is also geared towards creating informed public awareness and encouraging acceptance of PWAs which will eventually help eradicate the stigma attached to the disease.

5.5 Challenges Faced by NAPWA-SA

This study identified several challenges faced by NAPWA in fighting HIV/AIDS and stigma. Major challenges identified were, lack of funding, unchanged attitudes, beliefs and practice, poverty of families affected by HIV/AIDS, lack of resources, members falling ill and dying, untrained personnel, other organisations using the NAPWA name illegally and lack of support from the media. These challenges, the study exposed, directly impact on the ability of NAPWA to plan and implement effective HIV/AIDS prevention and support programmes.

The study has however also established the fact that although NAPWA faces a number of challenges in the execution and implementation of its policies and objectives, it has made great strides in its fight against the stigmatisation of PWAs. This is evident through the number of new branches that have been created over the years throughout South Africa, the increase in official membership of the association, the willingness of PWAs to openly talk

about their HIV-positive status, their involvement in major policy-making meetings, and the active role HIV-positive women play in fostering the goals of the organisation.

The fact that NAPWA has achieved so much and HIV-positive women are playing an active and decisive role in the implementation of the agenda of NAPWA goes to show the important role this association plays in fighting HIV/AIDS stigma and in prolonging many lives by simply-being open, helpful and accommodating. Helping PWAs to break down their sense of isolation, develop a safe social space for themselves, and then learn from each other, gain strength, and identify priorities as a group, can begin the process of normalizing their presence within any given community.

Conclusion

Communities according to Parker, Dalrymple & Durden (2000), have responded to environmental exigencies such as floods, earthquakes and famine by rapidly organising interventions, systems and practices to deal with these problems. Such responses are also occurring in relation to HIV/AIDS, but the gradual, insidious and complex nature of the epidemic has meant that responses have emerged slowly (Parker, W., Dalrymple, L., & Durden E. 2000).

However, around the world, wherever HIV spreads, people living with HIV often quickly establish networks of self-help, support, and empowerment. Associations and networks of people living with HIV/AIDS have emerged in almost every country around the world as powerful mechanisms for strengthening community responses to the HIV/AIDS pandemic. These associations and networks recognize the challenge of living with HIV/AIDS as the daily reality of ordinary men and women from all walks of life and every sphere of society in all parts of the world. This study has shown that NAPWA-SA is one such association that has been able to create a safe place for PWAs in South Africa.

The impact of HIV/AIDS on women is particularly acute. In many developing countries, like South Africa, women are often economically, culturally and socially disadvantaged and lack equal access to treatment, financial support and education. In a number of societies, women are mistakenly perceived as the main transmitters of sexually transmitted diseases (STDs). Together with traditional beliefs about sex, blood and the transmission of other diseases, these beliefs provide a basis for the further stigmatisation of women within the context of the incurable and deadly HIV/AIDS.

Certainly, NAPWA-SA faces challenges in its day-to-day function as an association that caters for people who are considered by many as outcasts, offenders of traditional and societal norms and sinners in the eyes of God. This not withstanding, NAPWA-SA's achievements in its role as care-giver and sanctuary for PWAs (especially women) proves that networking and sharing experiences, can serve not only as a powerful therapy for individuals, families and communities, but also as a catalyst for promoting effective and appropriate national responses to HIV/AIDS and stigmatization.

To this end, it will be in tune with findings from this study to suggest that NAPWA-SA has been at the forefront of prevention, care, acceptance, support and leadership strengthening efforts at the community, national and international levels. As Malcolm et al state, "The increased visibility of people with the disease in the community can result in greater community acceptance and support" (1998: 364).

Looking back at the findings of the study, one can venture to say that NAPWA-SA has made it possible for PWAs (especially women) to become active members throughout the South African society. This possibility provided by NAPWA, as shown in the research, has led to HIV/AIDS infected and affected women learning to live with the stigma against them and consequently, this has encouraged more people to publicly identify themselves as HIV-positive. Definitely, this will go a long way to reduce the spread of the disease as people will be able to see the need to protect themselves against HIV/AIDS.

Today, HIV/AIDS threatens the welfare and wellbeing of people throughout the world. At the end of the year 2005, 40.3 million people were living with HIV or AIDS and during the year 3.1 million died from AIDS-related illnesses. HIV-related stigma and discrimination remains an enormous barrier to effectively fight against the HIV and AIDS epidemic. Combating the stigma and discrimination against people who are affected by HIV/AIDS is

as important as developing the medical cures, while governments and researchers work towards preventing and controlling this global epidemic. The stigma attached to HIV/AIDS can cyclically expand from one generation to the next, thus placing an endless and needless emotional burden on those left behind.

This study has revealed that organizations of people living with HIV can be a key driving force in the AIDS response, and with appropriate support, individuals living with HIV can play a central role in their own country, region, or locality in the direction and delivery of AIDS programmes. Their participation as seen in the study, gives a personal power and immediacy to AIDS efforts—the kind of motivation that drives and inspires others into action. Tackling stigma and discrimination is fundamental to creating the kind of environment where people living with HIV can flourish and contribute in a meaningful way.

Governments, society, companies and stake holders need to recognise the role that APWAs like NAPWA-SA are playing in the fight against the HIV/AIDS epidemic and stigmatisation; in fact they should give them the needed assistance and support to help them continue carrying out and implementing their projects.

In hind sight, we have learned from history that epidemics and pandemics are fuelled by ignorance, fear, discrimination and ultimately painful and psychologically paralysing stigmatisation by peers, family and community alike. The South African NAPWA experience points to the redeeming good in all of us as caring and forgiving human beings. There is after all, some hope, distant as it may appear, for victims and society at large to envisage some form of reprieve from even the most devastating of illnesses like HIV/AIDS. It takes a simple initiative to act and the will-power to tolerate others who may fleetingly look different due to falling prey to a natural scourge. HIV/AIDS stigmatisation

is an equally ‘deadly’ ‘scourge’ when left unchecked. This study points to why fewer die and many more survive in developed countries (where this issue is more tactfully addressed) than is the case in developing countries like South Africa.

This study has shown that APWAs like NAPWA-SA are able to contribute to the fight against HIV/AIDS by helping to fight stigmatisation. It also revealed that NAPWA has not been able to fully perform or achieve its objectives due to the numerous challenges it faces. Taking this into consideration, there is a need for further research in the area of exploratory and investigative studies that support the development of policies and programs that will recognise, promote and support Associations of People living with HIV/AIDS. Such a framework also implies new approaches to programme development and intervention that engage societies, communities, and those who experience stigma and discrimination. Creating a climate in which stigmatisation and discrimination of PWAs are no longer tolerated, therefore requires a dramatic and sustained change of mentality, requiring a variety of on-the-ground interventions—in particular, social and community mobilization and APWAs empowerment to fight stigmatisation—and structural interventions, especially laws and policies that recognise APWAs as instruments in the fight against the spread of HIV/AIDS and the stigma that is attached to it.

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Appendix A: Informed Consent Form

For the Research on: The Stigmatisation of HIV-positive Women and the Role of Associations of people living with HIV/AIDS (APWA).

Date of Interview:----------
Start Time:----------
End Time:----------
Respondent Code:----------

1-To be read to all before beginning interview:

I, Magdaline Namondo Ikome am a student from the Wits School of Arts Department of Television University of the Witwatersrand Johannesburg. I am conducting a research for my Masters Research Report on the Stigmatization of HIV-Positive Women and the Role of Associations of People living With HIV/AIDS (Case Study: NAPWA- SA).This study is purely for academic purpose. This is not a test or an examination and my questions do not have 'right' or 'wrong' answers. Please answer the questions to the best of your ability. Your participation in this study will go a long way to help in the fight against the stigmatization and discrimination of people living with HIV/AIDS, especially women. There is no financial compensation for participating in this study since I am a student and this study is neither funded nor sponsored. Information obtained in this study will be kept in strict confidentiality. You are free to abstain from answering questions you are not comfortable with.

2- CONSENT

I ---------- consent to participate in the research initiative conducted by Magdaline Namondo Ikome, student from the Television Department of the University of the Witwatersrand. As a participant I understand freely my legal rights in participating in such a research project .I am part of this project voluntarily and without duress.

---------- **----------**

Signature of Participant **Signature of M.N. Ikome**

Appendix B: Letter of Authorization from NAPWA-SA

NATIONAL ASSOCIATION OF PEOPLE LIVING WITH HIV/AIDS



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Fax: +27(011) 255 6415

nkululeko.nxesi.@napwa.org.za
WWW.napwa.org.za

Organise, Mobilise and Empower P.W.A.'S

Registration No. 014 –453 - NPO

LETTER OF AUTHORISATION

This is to attest that Ikome Namondo Magdaline, a student from the Department of Television of the University Of Witwatersrand, has been given authorization to carry out a research study on the stigmatization of HIV-positive women and the role association of people living with HIV and AIDS at the National Association of People Living with HIV and AIDS (NAPWA-South Africa) in the fight against HIV and AIDS.

She will be given all necessary assistance to facilitate her research.

Date ……..

Signature ……
Nkululeko Nxesi
DIRECTOR NAPWA SOUTH AFRICA

Appendix C: Questionnaire for the Study

1. Interview number……
Interview Group: HIV/AIDS POSITIVE WOMEN

TO BE READ BEFORE FILLING QUESTIONNAIRE:
Hello, my name is Namondo Ikome a student from the Wits School of Arts Department of Television University of the Witwatersrand Johannesburg. I am conducting a research for my Masters research Report on the Stigmatization of HIV-Positive Women and the Role of Associations of People living With HIV/AIDS (e.g. NAPWA- SA).This study is purely for academic purpose. Your participation in this study will go a long way to help in the fight against the discrimination of people living with HIV/AIDS especially women. There is no financial compensation for participating in this study. Information obtained in this study will be kept in strict confidentiality. You are free not to answer any question you do not feel comfortable with and you can stop answering the questions at any time. It will take approximately 30 minutes to fill this questionnaire.

Would you like to continue? (Tick one) ☐ Yes
☐ No

1-How old are you?

2- How long have you been a NAPWA member?

3- Why did you join NAPWA?

4- What are the strengths of NAPWA?

5-What are the weaknesses of NAPWA?

6- What have you gained from being a NAPWA member?

7-What would you like to be added or adjusted in the management of NAPWA?

8a-Would you advise a friend or relative to join NAPWA?

8b- If yes why?

8c-if No Why not?

9-Have you had an HIV test?

10-Why did you have an HIV test done?

11-How long have you been living with HIV?

12-How did you contract the disease?

12a-Are you married or in a relationship?

12b-If yes, how did your partner react to your HIV positive status?

13-How did your family react to your HIV status?

14-Do people in your community know about your status?

15-How do people who know about your status treat you?

16-How do people who know your HIV status react when you touch them physically?

17-How do people in your community treat you as a woman living with HIV?

18-What lesson have you learnt from being HIV positive?

19-Do other people who are not HIV positive share objects with you?

20-How close are you with your family and friends?

21-Are you employed?

21b- If not, why?

22-Do you live with your family?

22b-If not, why?

23-What do you think of those who are HIV positive?

24-How are you treated as a woman living with HIV?

25a -When you tested for HIV did you disclose your status?

25b - If yes, to whom?

25c-Why?

25d - and if no, why not?

26a-Have you experienced stigmatization?

26b- If yes how?

26c- What do you think of the stigmatization of HIV-positive women?

27-How often do you attend counseling sessions organized by NAPWA?

28-Where and when do you attend these counseling sessions?

29-Of what help has these counseling sessions been to you?

2. Interview number……..
Interview Group: QUESTIONS FOR HIV/AIDS AFFECTED FAMILY /FRIENDS

TO BE READ BEFORE FILLING THE QUESTIONAIRE:

Hello, my name is Namondo Ikome a student from the Wits School of Arts Department of Television University of the Witwatersrand Johannesburg. I am conducting a research for my Masters research Report on the Stigmatization of HIV-Positive Women and the Role of Associations of People living With HIV/AIDS (e.g. NAPWA- SA).This study is purely for academic purpose. Your participation in this study will go a long way to help in the fight against the discrimination of people living with HIV/AIDS especially women. There is no financial compensation for participating in this study. Information obtained in this study will be kept in strict confidentiality. You are free not to answer any question you do not feel comfortable with and you can stop answering the questions at any time. It will take approximately 30 minutes to fill this questionnaire.

Would you like to continue? (Tick one) ☐ Yes
☐ No

1-How did you react when you're child, relative / friend told you they were HIV positive?

2-What do you think of your relative/friend being HIV-Positive?

3a-Does your community know your relative/friend is HIV-positive?

3b- If yes how do they behave towards you?

4-How do you respond to their behavior?

5-What do you think of NAPWA?

3. Interview number……
Interview Group… QUESTIONS FOR NAPWA STAFF/ ADMINISTRATORS

TO BE READ BEFORE FILLING THE QUESTIONAIRE:
Hello, my name is Namondo Ikome a student from the Wits School of Arts Department of Television University of the Witwatersrand Johannesburg. I am conducting a research for my Masters Research Report on the Stigmatization of HIV-Positive Women and the Role of Associations of People living With HIV/AIDS (e.g. NAPWA- SA).This study is purely for academic purpose. Your participation in this study will go a long way to help in the fight against the discrimination of people living with HIV/AIDS especially women. There is no financial compensation for participating in this study. Information obtained in this study will be kept in strict confidentiality. You are free not to answer any question you do not feel comfortable with and you can stop answering the questions at any time. It will take approximately 30 minutes to fill this questionnaire.

Would you like to continue? ☐ (Tick one) Yes
☐ No

1a-Do you have any female HIV-infected members in your organization who have or are facing stigmatization because of their HIV Status?

1b-If yes, what are some of the testimonies you hear of the stigmatization of HIV-Positive women of your organization?

2-What strategies do you engage in to fight the stigmatization targeted at NAPWA members especially women?

3-How effective are these strategies?

4-What are your achievements so far when it comes to fighting the stigmatization of women?

5-What are the short comings?

6-What are some of the day to day challenges you face as an organization of people Living with HIV/AIDS?

7-How do you manage these challenges?

8-How well do you collaborate with the government and other organization?

Thanks for participating in this Research. If you have any further questions about this Research; feel free to contact me at 073 775 8682.