PEOPLE LIVING WITH HIVTHE EXPERIENCES OF EMPLOYEES LIVING WITH HIV REGARDING THE SWEDISH WORKPLACE HIV AND AIDS PROGRAMME

By

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ABSTRACT

Title: The experiences of employees living with HIV regarding the Swedish Workplace HIV and AIDS Programme

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To have an effective response to the AIDS pandemic, interventions need to address the root causes of risk and vulnerability to HIV, including socio-cultural norms relating to the sexual behavior of men and women, but also the issue of access to education, information on prevention and health services, as well as opportunities for descent work (ILO, 2011:iii). There is a realization that each part of everyday life is affected by the disease including the workplace. Therefore measures to sustain workplaces and prolong the productive work life of People living with HIV, must be taken to great levels in the workplace. The delay by the government and the private sector response in South Africa contributed to the impact of the disease in the loss of productivity.

There is a realization that through the availability of treatment, people living with HIV and AIDS can prolong their productive lives, however there is still an increased need for education, protection of rights and support from both workplaces and families. The aim of the study was to explore and describe the experiences of the Swedish company employees living with HIV and AIDS with regards to the Swedish Workplace HIV and AIDS Programme (SWHAP). A qualitative approach using a phenomenological design was the most appropriate for this study using in-depth interviews. The approach was used with the purpose of describing and understanding the complexity of the phenomenon from the participants' point of view, which in this study refers to employees who are HIV infected. To achieve the aims and objectives, one question was put forward to all participants: "What are the experiences of Swedish company employees living with HIV

and AIDS regarding the Swedish Workplace HIV and AIDS Programme?" Non-probability purposive sampling was used since it was the sampling method that gave the researcher the opportunity to use her judgment. The following selection criteria was used: employees of a Swedish company in South Africa, who have been diagnosed HIV-positive, who have participated in the Swedish HIV and AIDS Workplace Programme and of any race, culture, gender or age. English was the language of first choice, however where necessary Sepedi, Setswana, Xhosa, Zulu, which researcher is conversant in was used. Nine participants were interviewed using semi-structured one-to-one interviews. The interview schedule was used to provide the researcher with a set of predetermined questions which served as an instrument to engage the participants. Furthermore each interview was voice recorded with the permission of the participants to ensure that the researcher had an accurate reference point. Through the semi-structured interviews, the interviews were transcribed and the following themes were generated. Theme one: knowledge of the Swedish Workplace HIV and AIDS Programme; theme two: sense of security about procedures of SWHAP; theme three: support services from SWHAP; and theme four: emotional experiences.

Subsequently, conclusions that were made from the findings were:

All participants expressed their satisfaction with the support they received from the workplace structures such as management especially the clinic nurses. There was however the observation that most participants had not disclosed their HIV status to the other co-workers, which led to the conclusion that there may still be issues with stigma in their workplaces. The experiences felt by the participants were also attributed to lack of knowledge of the SWHAP as a funding organization, but can associate it with HIV knowledge transference in the workplace, which needs to be addressed by the application of the recommendations made.

Several recommendations were made to the respective workplaces and in particular the SWHAP, including that employees living with HIV need to be involved in every step of implementation of the programme in order to feel supported. Companies need to invest

in continuous training of health care professionals and social workers (if any), and peer educators on the new clinical management of people living with HIV, to enable them to be up to date with the developments. Peer educators need to be provided with continuous training in educating and supporting their peers and giving of information at their level in a confidential manner. Policies should be updated regularly to ensure compliance with the legislations regulating decent work for People living with HIV.

Keywords:

Employee

Experience

Workplace

Swedish

Support

Programme

Social work

HIV and AIDS

TABLE OF CONTENTS

CHAPTER ONE: GENERAL INTRODUCTION

CHAPTER TWO: HIV AND AIDS WORKPLACE PROGRAMMES WITH SPECIFIC EMPHASIS ON THE SWEDISH WORKPLACE HIV AND AIDS PROGRAMME AND PEOPLE LIVING WITH HIV

CHAPTER FOUR: CONCLUSIONS AND RECOMMENDATIONS

CHAPTER ONE
GENERAL INTRODUCTION

1.1   INTRODUCTION

The Human Immunodeficiency Virus (HIV) which causes AIDS was first identified in 1983. Since then, HIV has spread around the world, causing one of the most severe global epidemics of modern time. The initial response was led by the public and non-profit sectors, which have mobilized increasing human and financial resources to combat the disease, for which there is no cure yet. Increasingly, the private sector is becoming aware of the impact that HIV and AIDS is having on its workforce, production systems, markets and the local communities in which it operates (UNAIDS The Business response to HIV and AIDS, Impact, and lessons learned, 2000:8).

South Africa has been more affected by the HIV and AIDS epidemic than any country in the world. AIDS has stolen the lives of thousands of children, and has left many orphaned and vulnerable children in child-headed households. However, the epidemic has transformed the country, in some ways for the better, given the coordinated, integrated and cohesive response to mitigate the epidemic by the National Department of Health (The National Department of Health, 2012:1).

According to the International Labour Organization (2001), the HIV pandemic is one of the most significant challenges to health, development, and economic and social progress facing the world today. In countries such as Botswana and Swaziland that are affected the worst, the impact of HIV and AIDS has eroded decades of development gains, undermined economies, and destabilized societies. HIV is expected to be a leading cause of mortality and morbidity in many countries and populations. It is a known fact that the initial response of businesses to the HIV and AIDS pandemic was slow (Dickinson, 2004:627). However, over the past decade, the private and public sectors of South Africa have been more and more concerned with the impact of the HIV and AIDS epidemic on their workforce. For example in 2001 the Public Service Regulations was amended to

incorporate new Minimum Standards on HIV and AIDS, which, amongst others, included that health promotion programmes be introduced to deal with HIV and AIDS prevention, care, and acceptance of People living with HIV. The Minimum Standards also included that support for HIV and AIDS policies and programmes should be established through allocating responsibilities, human and financial resources, as well as structures and communication strategies, and that measures are put into place to monitor and evaluate HIV and AIDS policies and programmes (Ministry of Public Service & Administration, 2002:1).

Living with HIV in some instances has disadvantages such as loss of income, which may lead to poverty, terminal illness and eventually death. Over time country economies suffer because of the loss of production from sick employees and families suffer because of loss of income.

According to Longuet, Mecaskey and De Korte (2005:1), it is not always easy to run a profitable business operation in an environment where companies are faced with global competition and exposed to compounding factors that hinder growth and affect their bottom line. Whereas enabling factors, including transparency, well-educated employees, low interest rates and favorable trading conditions, are increasingly facilitating business development in some countries, disease and declining life-expectancy rates related to HIV and AIDS are continuing to have a negative impact on growth, and are threatening the viability of many organizations.

HIV is therefore seen as a business risk because it affects most people at their prime and productive years which leave employers with enormous financial burdens of recruitments, replacements, and retraining. Failure to implement effective workplace programmes leaves companies with a loss of productivity and bottom line. Because of the risk that HIV poses to the private sector as the main contributor towards the country's economy, companies were compelled to respond and put HIV and AIDS workplace programmes in place to mitigate the scourge.

HIV is not purely a health issue; it is also a problem that goes to the very core of business practice. Its effects are evident on two levels, the macroeconomic and the individual company levels, both of which require urgent responses if businesses are to remain competitive (UNAIDS The Business response to HIV and AIDS, Impact and lessons learned, 2000). The economic and human consequences of the spread of HIV and AIDS around the world are much more evident in countries where HIV has been the longest and where the epidemic is at its highest levels, for instance, South Africa. For many businesses, the impact of HIV and AIDS are already severely constraining their ability to be competitive, while for others the potential risks are significant in both higher and low HIV and AIDS prevalence regions (UNAIDS, 2000:13).

Employees are categorized as human resources of the company. Keeping the company human resource or employees healthy and functional is paramount and seen as a general company responsibility, like keeping other resources such as machinery, cars, buildings, and the like, maintained.

Generally speaking, many people living with or affected by HIV are discriminated against and stigmatized; both in the workplace and in their communities. It is, however, a constitutional right for people living with or affected by HIV to be treated with dignity and not be discriminated against. They also have the right to treatment, care and support services (South African Business Coalition (SABCOHA), 2006:21).

People living with HIV can face many forms of unfair discrimination in the work environment. The law protects employees and job applicants from unfair discrimination on the basis of HIV by eliminating unfair discrimination (on various grounds including HIV status) in any employment policy or practice. The law also encourages the promotion of equality on the basis of HIV in all employment policies and practices. Eliminating unfair discrimination on the basis on HIV in the workplace is a vital step towards reducing the impact of HIV on affected employees. Still, discrimination may be direct when a distinction, exclusion, or preference is made based on a direct reference to a person's

HIV status. For example, an employment policy that provides lower remuneration to employees living with HIV directly discriminates on the basis of HIV (SABCOHA, 2006:9).

In alleviation of some of the challenges faced by HIV-positive employees due to their HIV status, structured comprehensive workplace programmes always seem to provide solutions and tangible results. Workplace programmes contribute towards a global response to HIV and AIDS. HIV and AIDS affect every part of life in South Africa and threaten both the social and economic fabric of society and further cause a greater loss of productivity (Page, Louw & Pakkiri, 2006:104).

In line with the above, the International Council of Swedish Industry (NIR) and the Swedish Metalworker's Union, together with management and employee organisations in South Africa, launched a programme to support the fight against HIV and AIDS in Swedish related workplaces in 2005, namely the Swedish Workplace HIV and AIDS Programme (SWHAP) (Magnusson, 2005:6). These Swedish companies in SA are companies that are supported financially and technically to initiate, develop, and implement workplace HIV programmes.

These are comprehensive HIV and AIDS programmes which include prevention and awareness, voluntary counseling and testing, and employee support that includes clinical management of those who are HIV-positive. This is a workplace programme that provides opportunities for employees in various workplaces to get educated on HIV prevention, testing opportunities, and support for those who test HIV-positive.

The Swedish Workplace HIV and AIDS Programme is one such response which implements workplace programmes within Swedish linked companies. The researcher is interested in exploring the experiences of HIV-positive employees utilizing this programme in order to get a better understanding of how the workplace respond to their status and make recommendations for improvement on HIV workplace programming.

In this study, the researcher will describe how this research is investigating the experiences of employees living with HIV about the contribution of workplace programmes linked to the Swedish Workplace HIV and AIDS Programme (SWHAP).

1.2   DEFINITION OF KEY CONCEPTS

The following key terms for this study are subsequently defined:

HIV: Human Immunodeficiency Virus. A virus that progressively destroys white blood cells, called lymphocyte, and cause the AIDS disease (van Dyk, 2008:4). In this study, this will mean that in the work environment people who have contracted the virus and are not clinically and psychologically managed, get susceptible to infections such as TB, which inevitably affects their functioning. As a result, company productivity gets affected.

AIDS: is the abbreviation for Acquired Immune Deficiency Syndrome. It is caused by a virus (the human immunodeficiency virus or HIV) that enters the body from outside. Immunity is the body's natural ability to defend itself against infection and disease. A deficiency is a shortcoming – the weakening of the immune system so that it can no longer defend itself against passing infections. A syndrome is a medical term for a collection of specific signs and symptoms that occur together and that are characteristic of a particular condition. Although the word 'disease' is used when talking about AIDS, it is not a specific illness. It is really a collection of many different conditions that manifest in the body (or specific parts of the body) because the HI virus has so weakened the body's immune system that it can no longer fight the disease, causing agents that are constantly attacking it (van Dyk, 2008:4). In this study, this means that people who are infected with HIV and continue to work without clinical and psychological management will get to a stage (AIDS stage) where they will get ill as a result of opportunistic infections, and they will most likely die. This will result in financial loss to the company, because the individual will be absent from work for lengthy periods of time. The cost to the company when a person dies lies in the recruitment, placing and training of a new employee before the person can be productive.

Workplace: It is a working environment arena, which people on a very regular basis attend. Attitude formation and behavior change are regularly connected to working life and work culture. Consequently, the business world and labor unions have a golden opportunity to play a significant role in the endeavor to limit the repercussions of the devastating disease and to develop tools for combatting its effects (Magnusson, 2005:169).

Swedish Workplace HIV and AIDS Programme (SWHAP): A project launched by the International Council of Swedish Industry and the Swedish Metalworkers Union. The programme aims at strengthening the response to HIV and AIDS in the world of work by establishing and implementing prevention and care programmes in private and informal work (Magnusson, 2005:58).

The International Council of Swedish Industry (NIR) and the Swedish Metalworkers' Union (Metall), together with management and employee organizations in South Africa, Kenya and Zambia, launched a programme in 2005 to support the fight against HIV and AIDS in the workplace. The realization of its ambition was made owing to the grant from the Swedish International Development and Cooperation Agency, Sida. In these countries, the programme is focusing on some 25 workplaces that have a connection with Sweden in some way (Magnusson, 2005:6).

1.3   THEORETICAL FRAMEWORK

This study was underpinned by the general systems theory, which was the guiding framework aimed at explaining or making sense of the experiences of employees living with HIV regarding the Swedish workplace HIV/AIDS programmes. The general systems theory analyses and focuses on interactions within and across systems of family and friendship ties, neighborhood systems, organizational systems, social policy systems, and social structural systems (Healy, 2005:136). This further explains the general

systems theory at a simple level as elements which are in exchange, and which are limited.

The general systems framework gave an understanding of how individuals, who are employees living with HIV and AIDS, interact with organizational systems which in this study refers to the Swedish workplace HIV/AIDS programmes. The programmes comprise of knowledge and training, policies that protect confidentiality, and voluntary testing and organizational support structures after HIV diagnosis, amongst others.

These components constitute a "system" which functions or operates within a field or environment. Elements can be virtually anything you wish to label as such, the exchanges are any relationships that exist between elements, and the boundary is what you can see, hear, feel, or sense that separates the "system" from the background or environment. General systems theory emphasizes the role of these systems in contributing to individual and community well-being (Healy, 2005:136).

In this study, the researcher looked at the interaction and or experiences of employees of Swedish workplaces with their environment, and how the internal support in the form of workplace HIV and AIDS programmes, contributed to their wellbeing. This perspective, in essence, assisted the researcher to take to task the implementation of the Swedish Workplace HIV and AIDS Programme and explore how employees living with HIV experienced the programme.

1.4   CONTEXTUALIZATION OF THE TOPIC

"AIDS is uniquely destructive to economies, because it kills people in the prime of their lives." Kofi Annan (World Economic Forum, 2005) in (Longuet, et al. 2005:5).

Worldwide, HIV and AIDS is now the leading cause of premature death among people aged between 15 and 59 (Merson, 2006 in Longuet, et al. 2005:5). The International Labor Organization (ILO) has estimated that among the 38 million People living with HIV

worldwide, 36.5 million are of working age, and most of them live in Africa. The cumulative loss of labor force participants to HIV and AIDS globally reached 28 million in 2005. And without increased access to treatment, this figure could reach 48 million by 2010 and 74 million by 2015, 50 million of whom would be in Africa (ILO, 2004). By 2020, without successful intervention, 14 African countries will see workforce losses of 10 to 30% (Longuet, et al. 2005:5).

Magnusson (2005:5) also concur that every year, millions of human lives are lost because of HIV and AIDS. The already poor countries, and primarily those in southern Africa, are the most affected. HIV and AIDS is definitely a pandemic, but the possibilities of coping with the consequences of the virus are varied among individual countries.

The fact that the South African government failed to lead and coordinate a national response to AIDS is often used to rationalize South African business's slow response to the threat of the disease. Some observers have argued that the government's failure to respond to the crisis confronted companies with such a massive problem that their isolated actions would be ineffectual (Dickenson, 2009:54).

Dickenson (2009) further states that there has always been a constant shift of responsibility between government and the private sector when it comes to the HIV and AIDS response. Most workplaces had a late response to the disease which, as a result, placed a higher financial burden on individual companies and on infected individuals. In this study, the researcher will look at how corporate responses in the form of workplace programmes are improving what is already on high manifestation. The study will further explore whether these HIV workplace programmes manage to curb the spiraling effects of the disease on the lives of those who are infected and affected.

There are varied motives for businesses to respond to the HIV and AIDS pandemic. Amongst others, some of these motives may include, declining productivity, declining profits, and increased costs, such as recruitment costs, training costs of new employees and medical insurance (Daly, 2000:20).

However, it needs to be appreciated that people living with HIV have hopes, dreams, ambitions and plans for the future. Appropriate support for people living with HIV can restore all the hope and diminished dreams. This can be achieved through effective implementation of workplace HIV and AIDS programmes that give support to employees living with HIV, as well as their families.

1.5   RATIONALE AND PROBLEM STATEMENT

Although a number of studies have been documented on the impact of HIV on the workplace, not many of them have investigated the experiences of the recipients and or beneficiaries of such programmes, for example HIV-positive employees. There is also limited data on how HIV-positive employees experience the programmes that most workplaces are investing a lot of time and money in.

Apart from responding to the HIV and AIDS epidemic, HIV and AIDS workplace programmes aim at prolonging and sustaining the work-life of HIV-positive individuals by improving their quality of life. Productivity accelerates economic development, and this enhances the standard of living and quality of life of people. However, HIV is inclined to strike young adults, and therefore it reduces the life expectancy of the population as a whole, and increases the burden of the working age population who are required to care for the young and sick. In theory, the widespread use of strategic planning tools such as SWOT (strengths, weaknesses, opportunities and threats) analysis and scenario exercises that business use to understand the environment they operate in, would have identified HIV and AIDS as a potential threat at an early stage, had it begun to investigate this risk by measuring HIV prevalence in the workforce (Dickenson, 2009:53).

However, little research has been done on the contribution these programmes have on employees who are living with HIV and AIDS and the world of work.

The research question that will be addressed in this study will be:

What are the experiences of employees living with HIV regarding the Swedish Workplace HIV and AIDS Programme?

1.6   OVERVIEW OF RESEARCH METHODOLOGY

The aim of the study was to investigate the experiences of employees of the Swedish workplaces living with HIV and AIDS and the contribution of the Swedish Workplace HIV Workplace Programme. At the core of the HIV workplace programme was the employees who are diagnosed as HIV-positive and registered in the Employment Support Programme (ESP) to ensure that they are continuously monitored and receive both psychosocial and clinical support. Therefore, the research put specific emphasis on establishing whether these programmes had indeed made any contribution to people who are HIV infected.

Based on the title, the aim of this study was to explore and describe the experiences of Swedish workplace employees living with HIV and AIDS regarding the Swedish Workplace HIV and AIDS Programme (SWHAP).

The objectives of the study were:
• To conceptualize the field of HIV and AIDS in the workplace.
• To describe the Swedish HIV and AIDS Workplace Programme in SA.
• To explore the experiences of HIV-positive employees regarding participation in the Swedish HIV and AIDS Workplace Programme.
• To make recommendations for improvement of the Swedish HIV and AIDS Workplace Programme.

The researcher in this study employed the qualitative research approach. This approach assisted the researcher to answer the question: What are the experiences of people living with HIV about the Swedish Workplace HIV and AIDS Programme? The approach was further used for the purpose of describing and understanding the complexity of the

phenomenon from the participants' point of view, which in this study refers to employees who are HIV-positive (Fouché & Delport, 2011:64). There are several advantages that qualitative methods offer in social scientific research. Babbie and Mouton (2001:271) argue that qualitative research is naturalistic and the focus is the insiders' perspective of the social actors.

The type of research in this study was applied research. This study attempted to explain the experiences of people living with HIV and making sense out of their relationship with the world of business (workplace) through their attendance of the Swedish Workplace HIV/AIDS Programmes.

The study was exploratory in nature, in that it aimed to establish facts around the contribution made by the Swedish Workplace HIV/AIDS Programmes in the lives of People living with HIV. Babbie (2006:94) explains that exploratory studies are typically done for three purposes: to satisfy the researcher's curiosity and a desire for better understanding; to test the feasibility of understanding a more extensive study; and to develop methods to be employed in any subsequent study.

The researcher in this study used a collective case study design, to gain a better understanding of the HIV workplace programmes, how they facilitate the desired quality of life of employees who are HIV-positive and gave the researcher an extensive understanding of the lives of people living with HIV who are still part of the workplaces.

Strydom (2011:223) describes a population as the totality of persons, events, organization units, case records, or other sampling units with which the research problem is concerned. The study population in this study was HIV-positive employees employed in 24 Swedish companies in SA who have participated or are still participating in the Swedish HIV and AIDS Workplace Programme. Non-probability purposive sampling was chosen, as it is the sampling method that gives the researcher the opportunity to use her own judgment. Three Swedish companies were selected and included in this study. The following selection criteria were used to include nine employees:

- Of three Swedish companies in SA who granted permission for the research
- Who have been diagnosed HIV-positive.
- Who have utilised the services of the Employee Support Programme (ESP)
- Who have participated in the Swedish HIV Workplace Programme.
- Of any race, culture, gender or age.
- Who were willing to participate in the study voluntarily.
- Who are conversant in English, however, Sepedi, Setswana, Xhosa and Zulu, which researcher is conversant in, was also acceptable for participants who were not conversant in English. The interviews, which were conducted in African languages, were transcribed and translated into English.

Semi-structured interviews were used to collect data, using an interview schedule, which was voice recorded with their permission. The interviews were transcribed by researcher and the steps of data analysis of Cresswell were followed. Trustworthiness was ensured and all ethical considerations were adhered to.

1.7 LIMITATIONS OF STUDY

In full consideration of the sensitivity and confidential nature of the people living with HIV, the following limitations were experienced:

- Some participants agreed to participate in the study but were sensitive to being voice recorded.
- Participants were not always available since most companies operated on a shift basis.
- Some participants agreed to participate in the study, but later withdrew before they could be interviewed without disclosing a reason, which reduced the number of respondents and minimized data.

1.8 CONTENTS OF RESEARCH STUDY

Chapter 1: Introduction

This chapter introduced the study and its key concepts, the literature review, the theoretical foundation, the problem formulation and rationale, the research question, the aims and objectives, a brief overview of the research methodology, the limitations of the study, and the contents of the research study.

Chapter 2: Literature review

HIV and AIDS in the workplace will be discussed, including HIV programmes in the workplace, response to HIV, HIV workplace programmes – specifically the Swedish HIV and AIDS Workplace Programme – and workplace programmes and its contribution to people living with HIV.

Chapter 3: Research methodology and findings

This chapter will describe the research methodology, ethical considerations and the research findings.

Chapter 4: Summary, conclusions and recommendations

In this chapter the researcher draws conclusions based on research findings and makes recommendations for action and further research on the topic.

Chapter 2, which focuses on the literature review, follows.

CHAPTER TWO

HIV AND AIDS WORKPLACE PROGRAMMES WITH SPECIFIC EMPHASIS ON THE SWEDISH WORKPLACE HIV AND AIDS PROGRAMME AND PEOPLE LIVING WITH HIV

2.1   INTRODUCTION

The HIV crisis in Southern Africa is significant. It has been one of the biggest obstacles to redevelopment in South Africa, as the country has tried to bring about transformation with limited resources. An already inadequate public health-care system in South Africa has been faced with the task of improving its infrastructure while having to cope with the increasing demand of the HIV and AIDS epidemic. Broader political issues also compound the health crisis. The official response from the South African government has been nothing but controversial, with the government being accused of AIDS denialism and being seen to be resistant to providing anti-retroviral therapy in the treatment of HIV and AIDS (Rohleder, Swartz, Kalichman & Simbayi, 2009:3). As a result of limited resources, a multi-sectorial approach to the response to HIV and AIDS was needed in South Africa in order to intensify the response and to effectively eradicate and manage the scourge. Government, private sectors, and civil society need to show their visibility in dealing with HIV and AIDS.

AIDS has a profound impact on growth, income, and poverty in many countries. Economists estimate that the annual economic growth in half the countries of Sub-Saharan Africa will decrease radically as a direct result of AIDS. It can no longer be said that AIDS is only a health, social welfare or governmental issue. AIDS has become a challenge for every workplace, no matter the size and nature of the business (Van Dyk, 2012:464).

Any business that has a sustainability strategy realizes that HIV and AIDS is not only a social or health issue, but it is also an economic issue. This, in essence, has challenged

businesses to act and do something about the disappearing bottom line, their profits and the profitability of their businesses.

The workplace provides an ideal gateway to AIDS prevention and care. The workplace has its own culture that connects workers. Although staff members come from varying social backgrounds and cultures, speak different languages, and follow different traditions, employers and employees all share the same organizational culture in which they have the same visions, follow the same guidelines, and adhere to the same rules (Van Dyk, 2012:465).

It is a known fact that generally we spend between eight to twelve hours at the workplace per workday, which makes the workplace a second home for many. Thus, creates HIV and AIDS is not only an individual problem, but an organizational problem that challenges everyone in the organization to act and encourage the organization to strategize around it.

In order to understand the phenomenon of workplace HIV and AIDS programmes, especially how the beneficiaries of the services (people living with HIV in the workplace) experience these programmes, the focus of this chapter will be on:

- Conceptualizing and defining HIV,
- HIV and AIDS and the private sector's response to HIV,
- the Swedish HIV and AIDS Workplace Programme, HIV and AIDS in the workplace, the impact of HIV and AIDS in the workplace,
- HIV programmes in the workplace, and
- the impact of HIV on individuals in the workplace.

2.2   CONCEPTUALIZING AND DEFINING HIV

The outlining of the definition of HIV and AIDS and its context will give an understanding of the impact of HIV on the individual, his or her surrounding communities and

environments. Defining the concept will also highlight the HIV progression to AIDS in order to better understand how it impacts one's life at various levels.

2.2.1   HIV in context

The concept of HIV and AIDS is no longer new in Sub-Saharan Africa. There are periodic developments around the globe on the population of people living with HIV and AIDS, the number of new infections, and numbers of people on antiretrovirals (ARV) and other variables. These statistics help anyone who is interested in exploring the concept of HIV and AIDS to get an updated picture of the magnitude of the scourge.

The basic facts about HIV and AIDS in Sub-Sahara Africa are these: Sub-Saharan Africa has the most acute HIV and AIDS epidemic in the world. In 2013, an estimated 24.7 million people were living with HIV, accounting for 71% of the global total. In the same year, there were an estimated 1.5 million new HIV infections and 1.1 million AIDS-related deaths (UNAIDS, 2016:1). Since the beginning of the pandemic, 78 million people have contracted HIV and 35 million have died of AIDS-related causes (UNAIDS, 2016:1). As of December 2015, 17 million people living with HIV (46% of the total) had access to antiretroviral therapy. This propels the need for all people to know their HIV status to enable treatment and care programmes.

Over 70% of all deaths from AIDS occur in Sub-Saharan Africa. The pattern and course of HIV/AIDS in the sub-continent differ considerably from its incidence in other parts of the world. In Sub-Saharan Africa, it is spread chiefly through heterosexual transmission or from mother to child, whereas in other regions it is generally confined to high-risk groups – in particular, men who have sex with men, intravenous drug users, and sex workers (UNAIDS, 2008b:1). In Africa, the distribution of HIV and AIDS between men and women is broadly 50/50, whereas in Sub-Saharan Africa it is women who are disproportionately affected. Nearly 60% of Sub-Saharan African HIV and AIDS sufferers are women (Flint, 2011:4).

The disproportion of infection between men and women can also be attributed to the fact that women are predominantly the population of society who are highly likely to access health facilities and services, for example, to receive sexual reproductive health services and maternal health services. This gives women the opportunity to test for HIV, amongst other services. Men are always seen as the ones not accessing these services because of the time spent at the workplaces. These proportions of access to testing facilities motivate the initiation of workplace HIV programmes, because of the male domination and the time spent at the workplace by men.

Flint (2011:10) argues that former President Mbeki's 'dissident' views on HIV and AIDS, including his public questioning of the link between HIV and the efficacy of antiretroviral (ARV's) like AZT, achieved global notoriety. In 2000, he invited the prominent AIDS dissidents Peter Duesberg, David Rasnick and Harvey Bialy to serve on his AIDS Advisory Panel. Likewise, his Minister of Health, Dr Manto Tshabalala-Msimang (1999-2008) caused outrage by promoting beetroot, garlic and lemon juice as treatments for AIDS sufferers. While good policymaking may not have prevented the pandemic from spreading across South Africa, Mbeki and Tsabalala-Msimang's announcements undoubtedly intensified public uncertainty regarding HIV and AIDS and its spread. Furthermore, this led to the unpardonably slow rollout of ARVs (Nattrass, 2007 in Flint, 2011:10).

The majority of people agree that the structures and every aspect of South African society did not know how to respond to the pandemic of HIV and AIDS because of the uncertainty and denial of policy makers mentioned above. Most HIV and AIDS strategists still believe that the impact of the response to HIV could have reached far greater strides to date if it was not for the age of denialism by the South African government.

HIV and AIDS is, now more than ever, a disease that most adversely affects the poorest of those infected. It is increasingly a 'manageable condition' in developed countries, but a 'death sentence' in many poorer ones. International responses to HIV and AIDS in Africa highlight debates concerning unilateral versus multilateral approaches, with all post-

imperial baggage implied by this (Flint, 2011:18). Although it was a known fact in the past decades that HIV/AIDS mostly affects the poor, the initiation of the response to HIV/AIDS in the workplace tells us the opposite. The disease now also affects the working class because of the buying power that employment gives them.

Although HIV and AIDS appeared not to be impacting significantly, there is a significant HIV-positive population, of whom only a small portion may be symptomatic. Thus, the wave of morbidity, death and concurrent impact may still follow (Steven, 2001:18). HIV and AIDS is, in essence, seen as a slow progressing disease, which makes it difficult to see its impact on the morbidity and might even take longer for people to die. This factor could be seen as contributing to the slow response by various sectors.

2.2.2   Defining HIV and AIDS and the immune system

The knowledge, perceptions, and attitudes around this epidemic have had a significant influence on its understanding and how to deal with it. The sophistication around the understanding of what HIV/AIDS is, has made it a complex issue to deal with. Below are the definitions of HIV and AIDS.

2.2.2.1 HIV

Human immunodeficiency virus is a viral disorder that progressively destroys the white blood cells and causes acquired immunodeficiency syndrome (AIDS). Infection by the human immunodeficiency virus (HIV) eventually results in progressive deterioration of the body's immune system, allowing opportunistic infections, especially in adults (Berkow, Beers, Bogin & Fletcher, 1998:1275). For the purposes of this study, the researcher defines HIV as the virus that invades the human body and gradually destroys the body's immune system, which makes the body susceptible to a host of infections or diseases. The virus can be present in a person for several years before the person becomes sick.

2.2.2.2 AIDS

AIDS is an acronym for Acquired Immunodeficiency Syndrome. The disease is acquired, which means that it is not inherited, but caused by a virus (the human immunodeficiency

virus or HIV) that enters the body from outside. HIV destroys the body's ability to fight off infections and disease. **Immunodeficiency** thus refers to the inability (or deficiency) of the immune system to defend itself against infections. A **syndrome** is a medical term for a collection of specific signs and symptoms that occur together and that are characteristic of a particular condition (Van Dyk, 2011:5).

Evian (2008:119) described Acquired Immuno Deficiency Syndrome as an aggregate of signs, symptoms and illness resulting from a compromised immune system. The researcher defines AIDS as a stage where the virus has debilitated the body to the point where the immune system is compromised and cannot fight for itself against diseases that might lead to terminal illness and or death.

Because of the misunderstandings, myths, and misconceptions around HIV, its progression to AIDS and how people who are infected eventually die, most people were very scared of HIV and ignored education and testing opportunities.

UNAIDS (2008:8 in Van Dyk, 2011:5) describes AIDS as a fatal disease that can ultimately lead to death. Currently, antiretroviral drugs slow down the replication of the virus and can significantly enhance the quality of life, but they do not eliminate the infection.

It is the very definition by UNAIDS in 2008, that AIDS is a fatal disease, that created a public scare and prevented people from testing, while writers such as Van Dyk describe it in a more mild way by saying it is a collection of specific signs and symptoms which gives hope that it is manageable. With an understanding of the difference, people could better prevent and manage HIV and AIDS.

HIV and AIDS came a long way in Sub-Sahara Africa, and its history has had a great impact on how different structures of societies responded to it merely because of the misconceptions around it that were caused by the lack of understanding.

Van Dyk (2005:3) further explains that we say the disease is acquired because it is not a disease that is inherited. It is caused by a virus (the human immunodeficiency virus or HIV) that enters the body from outside. Immunity is the body's natural ability to defend itself against infection and disease. A deficiency is a shortcoming – the weakening of the immune system – so that it can no longer defend itself against passing infections. AIDS, for the purpose of this study, refers to the final stage of HIV infection that employees might be in, where his or her body cannot defend itself against infections. As a result, he or she becomes continuously ill and finally it affects their productivity.

2.2.2.3 AIDS and the immune system

The human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) are a major threat to the world of work as they are affecting the most productive segment of the labour force and reducing earnings. It is also imposing huge costs on enterprises in all sectors through declining productivity, loss of skills and experience (Steven, 2001:161).

With the understanding of HIV and AIDS, its complexities and how it destroys the human body, one can begin to understand how it affects the people who are in employment and depend on their health to earn a living wage. By understanding the progression of HIV to AIDS, it is critical for people to know their status to delay the progression from HIV to AIDS, especially for people who rely heavily on their health to earn a living and support their families.

Below is the diagramed illustration of how HIV progresses in the life of a working person and the cost to employers.

Time line	Progression of HIV/AIDS in the Workforce	Cost to Company
Years 0-7	Employees feel healthy and fully productive	No cost to company at this stage
Years 7-9	Illness begins for most employees, though some die, and others stay healthy	Sickness related costs are incurred (absenteeism, productivity, management time, medical care)
Years 9-10	Employee leaves workforce through death or retirement	End of service costs are incurred (benefit payments, funeral costs, management time)
Years 10+	Company hires replacement employee	Turnover costs are incurred (vacancy, recruitment and training)

Figure 2.1: Progression of HIV/AIDS and company costs in the absence of antiretroviral therapy (Longuet, et al. 2005:8)

2.3 AIDS AND THE PRIVATE SECTOR

Some people are tempted to say 'AIDS is a soft business issue best handled by the human resource function in the company'. However, the reality is that 'AIDS has a significant impact on bottom-line profits and needs to be part and parcel of line management's strategic thinking and decision making' (Whiteside & Sunter, 2000:99). Employers are increasing the size of their workforce to accommodate deaths during employment and because of widespread absenteeism. The role of businesses in societies

and in the economy of the country is known, however, not all business sectors know their role in improving the quality of life of its employees.

With people who are employed in the private sector's health impacting on the Gross Domestic Product (GDP) of the country, HIV cannot be a soft issue. It is an integral part of business sustainability.

The private sector has a crucial role to play in achieving economic growth in South Africa to raise the general standard of living. It is the primary source of employment, creates wealth, and supplies the population with food, clothing, housing, and most essential and non-essential goods and services (Whiteside & Sunter, 2000:98).

The researcher is of the opinion that in addition to the private sector having an important role to play in achieving economic growth in South Africa, it also has a crucial role in sustaining the livelihood of societies as their secondary responsibility. Furthermore, the workplaces need to consider that employees should not be counted as useful resources, but are human beings first.

Moreover, Whiteside and Sunter (2000:99) indicated that AIDS kills young and middle-aged adults during their most productive years. The authors also reported that the effects of HIV and AIDS on businesses are reduced productivity, increased costs, and loss of customers. These factors contribute to the depression of business and threaten the sustainability of business if not responded to by looking at the health of employees. Therefore, the impact of HIV in the short and long-term cannot be ignored and responsibilities cannot be shifted amongst each other. The private sector must own up and also take responsibility in intensifying its response to HIV and AIDS.

2.4 RESPONSE TO HIV AND AIDS

There was a realization in the business community that businesses cannot ignore nor deny the reality of the impact of HIV and AIDS on its profitability, prompting action to

respond to the HIV and AIDS scourge. Global movements were initiated to guide the private and public sector's response to HIV and AIDS in order to mitigate the disease, notwithstanding the fact that many countries, including South Africa, remained misinformed and in denial for a long time.

2.4.1 The international response

South Africa, as one of the citizens of the global community, was mandated to follow the lead of international legislations and regulations on HIV and AIDS as guiding frameworks to chaperon its response to the epidemic.

The international community was slow to respond to HIV and AIDS in Sub-Saharan Africa. For much of the 1980's and the 1990's, funding remained limited. However, the pressure to respond to the crisis led to the formation of three key donor programmes. These are: the World Bank's Multi-Country HIV and AIDS Programs for Africa (MAP), established in 2001; the Global Fund to fight AIDS, Tuberculosis and Malaria (henceforth 'Global Fund'), operational since 2002; and the USA's President's Emergency Plan for AIDS Relief (PEPFAR), authorized in 2003 (Flint, 2011:108).

Magnusson (2005:169) reported that everybody in the countries concerned, as well as the international community, must contribute their utmost to the cause of the fight against the HIV and AIDS pandemic. Furthermore, Magnusson (2005:169) stated that the disease affects each part of everyday life, including the workplace. Thus, to a great extent measures to battle the HIV and AIDS pandemic, its causes and implications, must be taken to the workplace.

In 2004 the Swedish government took a stance to respond to the HIV and AIDS pandemic in the Sub-Saharan Africa by introducing The Swedish Workplace HIV and AIDS Programme (SWHAP), which is fully described in Section 2.5 of this chapter.

2.4.2 HIV and the workplace in South Africa

International organizations like the United Nations, the International Labour Organization (ILO), the World Health Organization (WHO), the International Employers Organization, and regional bodies like the South African Development Community, have all issued statements with policy and programme guidelines to workplaces. These guidelines center on assessing and planning to contain the risk by ensuring non-discriminatory policies; awareness and prevention programmes; testing and counseling; care; support and treatment; outreach programmes into the community; vertical integration into the market and suppliers; development of partnerships and networks; monitoring and evaluating processes. There is also a body of international labour law that advocates fair labour practice and safe and healthy working environments (Steven, 2001:18).

The above legislations and guidelines assisted programme managers and implementers to respond to the need of HIV in the workplace. However, more often than not, most workplaces would decide to employ the activities according to the guidelines on an ad-hoc basis. This is due to some employers still viewing HIV as a government and social issue, as opposed to it being an economic threat. Yet, the reality is that workplaces are often guilty of not complying with the necessary legislations because of ignorance and resistance.

In South Africa, the response from employers has been varied. Employer organizations like Business South Africa are involved at a national level and view HIV and AIDS as a strategic business issue. However, at the individual employer level, HIV and AIDS is always seen as a strategic or economic issue and the responsibility is often left to human resource departments (Steven, 2001:18).

The response of the apartheid government to the crisis that was caused by AIDS was hopelessly inadequate and ignored the multitude of socio-economic and political factors that determine the way AIDS is spread. These include the migrant labour system, single-sex hostels, and the ensuing disruption of family life, endemic violence, inadequate and

inaccessible health care services, gender oppression and sexuality, and low literacy levels due to the grossly inadequate infrastructure (Steven, 2001:161).

Despite the redress of the apartheid systems, companies are still reluctant to embark on the journey and even when they respond, it becomes a compliance issue instead of a business sustainability issue.

Campbell and Williams (1990 in Dickenson, 2009:50) also emphasize that the earliest company response to HIV and AIDS was in the mining industry, which, in 1986 discovered 4% HIV prevalence rates among Malawian migrant workers. The Chamber of Mines' reaction was that 'no known carriers [of HIV] will be engaged [for instance. employed] [and] all recruits from high-risk areas will be tested at [the] source [of recruitment]' (Brink & Clausen 1987 in Dickenson, 2009:50). The union argued against pre-employment testing for HIV and eventually won an agreement with the Chamber of Mines to this effect. However, the Chamber rapidly scaled back the recruitment of Malawians. Such pre-employment testing (or profiling and avoidance of high prevalence groups) was designed to minimize companies' risk and did nothing constructive to respond to the epidemic.

Outside the mining industry, the first major company to deal with the disease was Eskom, the state-owned electricity corporation, which adopted an HIV and AIDS policy in 1988. Until 1993, Eskom conducted pre-employment testing for HIV (Department of Health, 2012; New Academy of Business in Dickenson, 2009:51). Eskom dropped pre-employment testing as counterproductive in 1993, but other South African companies continued to use this as a 'solution' to the threat of HIV and AIDS. Only in September 2000 did the Labour Court, responsible for interpreting Labor law, rule against the routine use of pre-employment HIV testing in the case of Hoffman 'A' v South African Airways (Aids Law Project 2000 in Dickenson, 2009:51).

In the late 1990's, large companies in South Africa launched comprehensive HIV/AIDS policies and guidelines for HIV/AIDS and STI in response to the epidemic. These included the Department of Health (1998), Ford Motor Company (1998), Illovo Sugar (1999), and

Daimler Chrysler (2000) (Global Business Council 2000; Randal 2002 in Dickenson, 2009:51).

In 2000 the tripartite National Economic Development and Labor Council negotiated a 'Code of Good Practice on Key Aspects of HIV and AIDS and Employment' (Department of Labour 2000, in Dickenson, 2009:51). This document focused on the rights of HIV-positive employees and provided a broad overview of what company HIV and AIDS policies should include. In 2003 the Department of Labour's HIV and AIDS Technical Assistance Guidelines offered detailed suggestions on workplace HIV and AIDS programmes (Dickenson, 2009:51). In 2004, SWHAP managed to launch comprehensive HIV and AIDS programmes in 19 Swedish companies in South Africa.

The response to the HIV and AIDS epidemic in the world of work is diverse. The ILO established a programme in 2001 and drafted a Code of Practice the same year to guide response to the epidemic as a workplace issue. Several countries have outlined enlightened legislation in the form of revised new laws that can play an important role in mitigating the impact of HIV and AIDS in the workplace and protecting the rights of people living with HIV/AIDS (Magnusson, 2005:57).

In affiliation with the national and international legislations, all HIV and AIDS policies and programmes in the SWHAP are therefore aligned to the ILO Code of Good Practice, the World of Work Guidelines, and other national guidelines, for example, the Occupational Health and Safety Amendment Act, No 181. of 1993.

South African mining companies have remained at the forefront of corporate efforts to check HIV and AIDS, because their workforce is the most vulnerable to the disease. This vulnerability stems from the extensive migrant labour system, in which male workers are separated from their families for extended periods of time, as well as the low socio-economic and educational status of most mine workers. The mining sector introduced large-scale antiretroviral drug provision for employees without health insurance. Arguing

that such an initiative was cost effective, Anglo American announced drug provision for all its employees on 6 August 2002 (Dickenson, 2009:51).

Demographic and social displacements due to HIV and AIDS have knock-on effects for economic growth rates, the severity of which depend on the prevalence of the epidemic. For example, the Bureau of Market Research of South Africa predicts that HIV and AIDS will significantly affect household expenditure. Families have to cope with losing their most economically productive members to the disease. Reduced income is accompanied by increased spending on health and end-of-life care, with corresponding reductions in household savings. People infected and affected by HIV and AIDS will increasingly rely on government health and other services, thereby substantially shifting the burden of expenditure onto government (Longuet, et al. 2005:6).

The predictions made above were not the end in itself, but a process that took different shapes with time. Up to a certain time in South Africa, it was true that families would have to cope with losing their most economically productive members to the disease. However, today we are witnessing an era of infected people living longer due to increased availability of treatment, support, and care, either from government and or workplaces.

The social and economic impact of the disease is intensified by the fact that AIDS kills primarily young and middle-aged adults during their peak productive and reproductive years. At the macro level, an effect of this nature on the workforce can impact the economies of entire countries. By reducing the labour supply and disposable incomes, AIDS affects markets, savings rates, investment and consumer spending. At the micro level, businesses will feel the impact of HIV and AIDS most clearly through their workforce, with direct consequences for a company's bottom line. These include increased expenditures on medical and health insurance costs, funeral costs, and death benefits, as well as recruitment and training needs due to lost personnel. In addition, firms experience decreased revenues as a result of higher absenteeism and staff turnover, reduced productivity, declining morale, and a shrinking consumer base (IFO, 2002:1).

Such a response needs to include three essential components. These are prevention of new infections, treatment and care of people living with HIV and AIDS, and mitigation of the current and future impacts of the epidemic.

Whiteside and Sunter (2000:98) is of the opinion that the manner in which AIDS has affected the private sector and the sector's role in responding to the epidemic, are two facts indicating that there will be a steady increase in illness and death, and much of it among the working age population. And there is little information on the impact AIDS has on businesses, at least not in the public domain. The researcher is of a different opinion than Whiteside and Sunter. Looking at the recent developments in HIV and AIDS care and treatment in South Africa, in which an estimated 3 million people live with HIV are on ART, there has been a significant decline in HIV-related deaths in South Africa. There are also a number of anecdotes on the impact of HIV on business. Magnusson (2005:59) states that the impact on enterprises results from both the direct and indirect effects of the epidemic. The firm incurs direct costs in applying its policies when individual employees are living with HIV and AIDS, but it is also subjected to indirect costs that aggravate when there is a high prevalence of HIV in their workforce.

Therefore, an effective response should seek to address HIV and AIDS internally, among an institution's employees, and externally, among its surrounding communities. As employers, employers need to acknowledge that HIV and AIDS may have potentially significant implications for their staff and functioning, and take steps to mitigate the impact of HIV and AIDS on infected and affected employees. Externally, they should work to alleviate the impact of HIV and AIDS on the communities they serve. Most comprehensive HIV and AIDS programmes take cognizance of the fact that employees come from families and communities. Extending the response to families becomes the secondary objective of comprehensive programmes. In some workplaces, as a technique to increase the testing rates, family days are held where partners and spouses of employees are invited to participate in couples HIV testing opportunities and have so far yielded positive results.

The researcher is of the opinion that because of the ignorance surrounding the role of businesses in HIV and AIDS, most players in the private sector shift responsibility and hope HIV and AIDS is somebody else's problem; not realizing that somehow the epidemic will intrude on all our lives and ignorance will only make matters worse.

2.5   SWEDISH WORKPLACE HIV AND AIDS PROGRAMME

Regarding the private sector taking responsibility, Sweden, like other international players, responded to the call and put together a programme to help sustain and secure its business interests in the Sub-Saharan Africa.

The International Council of Swedish Industry (NIR) and the Swedish Metal Workers Union (IF Metal) jointly decided to initiate and implement a long-term strategy to contribute to the establishment of HIV and AIDS programmes at Swedish linked workplaces in South Africa, Zambia, and Kenya, countries that are severely affected by HIV and AIDS. The programme is called the Swedish Workplace HIV and AIDS Programme (SWHAP) and is co-funded by SIDA (Swedish International Development Cooperation Agency) (Magnusson, 2005:169).

IF Metal and NIR launched SWHAP in 2004 to address one of the most pressing health issues of our time, which has both severe and economic effects. This partnership has led to impressive, measurable results, improving the health of workers and their families, as well as the health of companies. We can all be very proud of this. It is also a partnership that runs through the entire programme, and is one of the greatest strengths SWHAP builds on; a long tradition of support to international solidarity, and it has shown that when the social partners, employers, and trade unions co-operate, together they create trust and credibility among workers. Stigma and discrimination can be effectively curtailed and there is greater sustainability of programmes when interests at all levels are represented. SWHAP is also an innovative approach to development where aid is channeled through the private sector for more effective and long-term results, where the strengths of

business in terms of logistics, systems and efficiencies, quite simply means that more can be achieved for less.

Contrary to some programmes at most workplaces, getting only management buy-in is not enough. Employees always get suspicious of HIV and AIDS programmes if it is a top-bottom approach, and if it is a bottom-up approach, management is sometimes reluctant to offer support. The observation in the SWHAP is that the involvement of trade unions helps to bridge the gap between employers and employees, because of the common agenda on the table which cuts across all levels of the company.

2.5.1   The general aims of the programme

The aims are:

- To assist employers and employees at Swedish-related workplaces to combat the HIV and AIDS pandemic.
- To make those workplaces the national spearheads of workplace related HIV and AIDS activities.
- To initiate a corporate engagement, globally.

2.5.2   Specific aims at project level

- To stimulate management and unions at the workplaces to work hand-in-hand to address the issue of HIV and AIDS.
- To support already existing HIV and AIDS programmes at the workplace with fresh resources.
- To stimulate the individual company to increase investments in HIV and AIDS activities in the workplace.
- To develop an effective network between workplaces.
- To disseminate information on HIV and AIDS (problems, setbacks, consequences of inaction) to external audiences (Magnusson, 2005:170).

SWHAP is an example of how workplace management and employees can work together to contribute to interventions that save lives and make business sense. The SWHAP

strategy to the companies has been to gain entry through management sensitization and setting up steering committees that are representatives of both workers and management for collaboration in programme implementation. The companies are supported to develop policies for HIV and AIDS as part of setting up structures and initiating sustainable elements of the programme, such as HIV prevention, peer education and testing, and treatment.

The SWHAP approach is directed by partnership with companies where funds from the Swedish government are used to promote the establishment of workplace HIV and AIDS programmes among Swedish-linked companies. This approach is seen as catalytic in a sense that it helps to promote ownership of HIV and AIDS programmes by the company, and also promotes sustainability, because the company includes the HIV programme in their strategic planning processes that includes budgeting. This is done through the cost-sharing model on a reducing scale. In addition, the partner companies following the model have been able to attain sustainable workplace programmes for an average three-year period and beyond.

2.6   HIV AND AIDS IN THE WORKPLACE

The workplace plays a crucial role in addressing HIV and AIDS and offers a valuable entry point to reach male and female workers in the setting where they spend much of their time. According to the International Labor Organization (in Magnusson, 2005:58), the workplace encompasses large and small, public and private, rural and urban workplace settings, the formal labour force and those who are informally productive, government authorities, the legal system and other institutions, such as academic bodies which shape the labour, employment and human resource environment.

With the advent of HIV and AIDS, it is no surprise that the South African programmes have had more to contend with than their international counterparts in the guise of a response to HIV and AIDS workplace programmes. It can be assumed that much of the attention and priority directed at Employee Assistance Programmes over the last few

years can be ascribed to its strategic links to HIV and AIDS as a workplace response (Steinman, 2009:18).

Another paradigm shift that occurred over the last few years is the movement towards a far more comprehensive and integrated model of workplace programmes. To a large extent, development in this regard has been in reaction to the traditional HIV and AIDS workplace programmes, which has often not been utilized optimally, given the stigma and discrimination associated with these programmes. The integrated, comprehensive health promotion model was aimed at all employees, not only vulnerable or high-risk employees. As such, this programme did not discriminate against anyone (Steinman, 2009:19).

The transition from pure HIV and AIDS programmes to HIV and AIDS and wellness programmes, has been welcomed and supported by the SWHAP and also observed to have increased the uptake of HIV testing due to reduced stigma. Apart from the stigma and discrimination that comes with the pure HIV and AIDS programmes, there was the realization that HIV by its nature cannot be dealt with in isolation. In its definition, it is a disease that by its nature is associated with other non-communicable diseases. The observation of the current trends in the HIV and AIDS programmes is that most workplaces see many spin-offs in having comprehensive Wellness and HIV and AIDS programmes compared to isolated HIV and AIDS programmes.

The question of whether or not employers should be involved in the fight against HIV and AIDS is a crucial one for the International Organization of Employers (IOE) members worldwide. Employers everywhere are asking themselves whether HIV and AIDS have a negative impact on business. Magnusson (2005:75) is in agreement that HIV and AIDS have an adverse effect on business. However, as much as the answer could be a conclusive yes, to date there is still some employers who think it is not their responsibility, but that of the government. It is recognized that the HIV and AIDS epidemic affects every workplace, with prolonged staff illness, absenteeism, and death impacting on productivity, employee benefits, occupational health and safety, production costs and workplace

morale (Magnusson, 2005:105). These are seen as indirect costs of not having an effective workplace programme.

Furthermore, Magnusson (2005:105) indicates that HIV/AIDS is still a disease surrounded by ignorance, prejudice, discrimination and stigma. In the workplace, unfair discrimination against people living with HIIV and AIDS has been perpetuated through practices such as pre-employment HIV testing, dismissals for being HIV-positive, and the denial of employee benefits. One of the most efficient ways of reducing and managing the impact of HIV and AIDS in the workplace, is through the implementation of an HIV and AIDS policy and programme. Addressing aspects of HIV and AIDS in the workplace will enable employers, trade unions, and government to actively contribute to prevent and control HIV and AIDS. In light of this, the Code has been developed as a guide for employers, trade unions and employees.

The role of the workplace in providing prevention and care, as well as the protection of rights, was recognized by the UN General Assembly in its 26th Special Session in 2001. The special session resolved in paragraph 49 of the Declaration of Commitment that the response to HIV and AIDS should be strengthened in the workplace by establishing and implementing prevention and care programmes (United Nations, 2012 in Magnusson, 2005:58).

HIV and AIDS pose a significant obstacle to the attainment of decent work and sustainable development. It has led to the loss of the livelihoods of millions of persons living with or affected by HIV and AIDS.
HIV and AIDS effects are concentrated among the most productive age group, and it imposes enormous costs on enterprises through falling productivity, increased labour costs and the loss of skills and experience. Also, fundamental rights at work are often violated on the basis of real or perceived HIV status, particularly through discrimination and stigmatization directed at workers living with and affected by HIV and AIDS (ILO Recommendation 200: No page).

This emphasizes the understanding of HIV and AIDS as not only a health issue but also a human rights issue. Employers need to realize that having HIV and AIDS programmes contribute towards decent work and responds to the protection of employee rights as it will be outlined in their policies. Also, implementers of HIV programmes need to understand the aspects of human rights violation, such as breach of confidentiality, access to treatment and care, discrimination, and so forth.

The development and implementation of workplace policies and programmes on HIV and AIDS facilitate access to prevention, treatment, care and support services for workers and their families and dependents, thereby also reaching out to the larger community. And yet, the important role of the world of work in addressing the pandemic has not been optimally utilized. If it is to make its full contribution to addressing the pandemic, it is essential for action in the world of work to form an integral part of HIV and AIDS policies, programmes and strategies (ILO Recommendation 200:No page).

In 2001, the ILO adopted the Code of Practice on HIV and AIDS (ILO Recommendation 200:No page) and the world of work, which has been widely accepted and used in many countries. In 2007, the Organization's constituents decided that the time has come to raise business' response to HIV and AIDS to a different level, through the development and adoption of an international labour standard. The resulting Recommendation No. 200 constitutes an unequivocal commitment by ILO's constituency of member States and representative of employers and worker, in close collaboration with organizations of people living with HIV and partner international organizations, in particular UNAIDS, to tap into the immense contribution that the world of work can make to ensuring universal access to prevention, treatment, care and support (ILO, Recommendation 200:No page). A key element for the success of workplace programmes is that the identification of needs and the formulation of programmes, as well as the actual implementation process at the workplace, should be the joint responsibility of management and employees.

2.7   IMPACT OF HIV IN THE WORKPLACE

There are varied impressions and assumptions from the employers that 'AIDS prevention and treatment programmes are very costly'. However, the reality is "The cost of doing nothing will shortly outweigh the cost of intervention" (Whiteside & Sunter, 2000:116).

Longuet, et al. (2005:12) quote one Kenyan company manager as saying, "If you lose someone you have trained for twenty years that is a great loss. Condoms and AIDS education cost peanuts".

The AIDS epidemic has not only had a profound effect on the personal lives of individual employees and employers, but it has also had an impact on their organizational and economic lives. There is probably not a single workplace in South Africa that has not been affected by AIDS (Van Dyk, 2012:464).

The effects of the epidemic on the workplace are further elaborated on as high morbidity (sick employees who have to take sick leave) and mortality (death) rates, increased absenteeism (employees take time off to care for sick family members or to attend funerals of friends, colleagues or family members who have died of AIDS), increased labour turnover (through death or early retirement), resulting in increased training costs, low staff morale with employees resenting taking on, or refusing to take on additional responsibilities for colleagues who are sick, a culture of stigma and fear of infection (Van Dyk, 2012:464). This further lowers staff morale as employees may be concerned about working with colleagues infected with HIV. There could also be loss of productivity due to high morbidity, absenteeism and mortality in the workplace, decrease in work performance when AIDS results in the death of an experienced skilled worker whose skills are challenging and expensive to replace, increased cost of employee benefits, such as health and medical aid, as well as increased insurance costs, higher production costs stemming from higher health-related expenses, lower quality of products and services, increased number of accidents due to fatigue and illness, and declining profits.

Figure 2.2 illustrates the compounding impact of the HIV infection on the workplace and the cost of not responding to HIV in the workplace.

2.8   WORKPLACE PROGRAMMES

According to Gatchel and Schultz (2012:365), workplace wellness programmes are a relative newcomer and there is tremendous variability in employer programmes and initiatives, intended to support employee health and wellness across workplace settings around the world. Many questions remain about the health benefits and cost-effectiveness of these formal and informal strategies to improve employee health, but most of the research so far has supported their effectiveness provided the programmes are sufficiently comprehensive, far-reaching, and targeted to the specific needs of individual workers and workplace settings.

However, the researcher is of the opinion that workplace programmes are not necessarily a newcomer considering that many large companies responded to HIV in the workplace as early as 1998, Eskom in South Africa, being an example. Programmes like the Swedish Workplace HIV and AIDS Programme, were initiated in 2004, which dates 12 years to date. There has been a perceived or real sluggish rate of response from small to medium size enterprises.

Dickenson (2009:50) even goes further to indicate that the earliest company response to HIV and AIDS was in the mining industry, which, in 1986 discovered 4% HIV prevalence rates among Malawian migrant workers.

Figure 2.2 below, illustrates the impact of Aids on the workplace.

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UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

AIDS IN THE WORKPLACE

| Increased absenteeism | Increased staff turnover | Loss of skills | Loss of tacit knowledge | Declining morale |

Insurance cover

Retirement Funds

Health and Safety

Medical assistance

Testing and

Funeral costs

Increasing demands for training and recruitments

Aids in the community. Declining markets, labour pool and suppliers

INCREASED COSTS

Declining re-investments

Declining reliability

DECLINING PRODUCTIVITY

DECLINING PROFITS

Figure 2.2:   The impact of Aids on the workplace (UNAIDS, 2000)

As can be seen in the above figure, HIV and AIDS threatens productivity, profitability and the welfare of employees and their families. Workplace HIV and AIDS policies and programmes can play a vital role in raising awareness around HIV, preventing HIV infection, and caring for people living with HIV. An HIV and AIDS workplace programme is an action-oriented plan that an organization can implement in order to prevent new HIV infections, provide care and support for employees who are infected or affected by HIV and AIDS, and manage the impact of the epidemic on the organization. Workplace

programmes promote that overall 80% of employees should know their status, 100% of employees who test HIV-positive must be registered for the care, support and treatment programme, 0% of AIDS-related deaths, and 0% of new infections. Workplace programmes would include a variety of programmes using different methodologies to prevent and control chronic, communicable and non-communicable diseases in the workplace. Such interventions can take the form of lunch-hour talks, voluntary testing programmes for HIV and AIDS, voluntary tuberculosis screening, hypertension and depression screening, to name a few (Steinman, 2009:16). Some of the methodologies used in most workplaces to create an ongoing communication on HIV and AIDS prevention and care are the Peer Educator Programmes. Peer educators are trained to ensure that there are continued HIV and AIDS messages in the workplace and that HIV programmes are sustained.

Business' responses to HIV and AIDS have shown that their actions and influence can extend into a number of broad areas, as illustrated in Figure 2.3 below:

1. Core Business Operations

2. Business Partners

3. Communities

4. Advocacy and Leadership
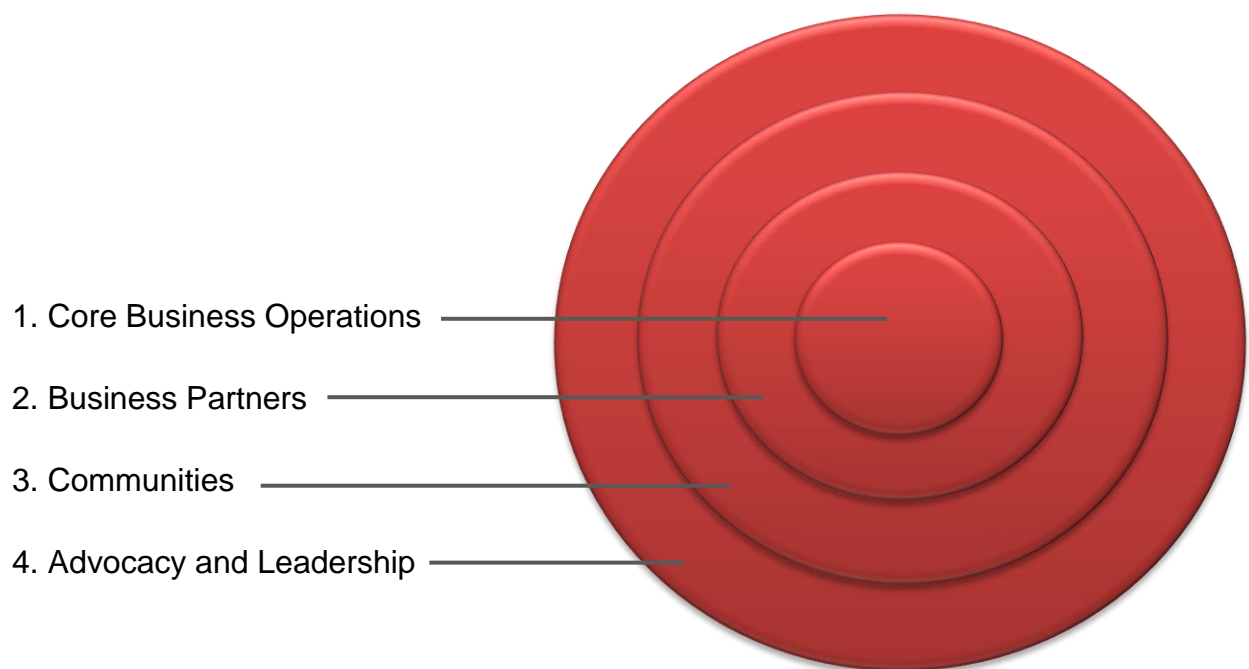
Figure 2.3:   UNAIDS, The Business response to HIV and AIDS, Impact and lessons learned (2000:19)

The above figure is a demonstration that HIV and AIDS workplace programmes' impact is not only evident on the employees, but can also contribute to the core of the business, improve business relations, impact communities, and help companies to show leadership in the business.

The majority of people living with HIV and AIDS in Sub-Saharan Africa are between the ages of young adulthood and early adulthood who are in the prime of their working lives. Thus, the workplace is an ideal arena to address the causes and implications of HIV and AIDS. HIV and AIDS challenges damage businesses through absenteeism, the decline in productivity, employee turnover, and the consequent added operational costs. Moreover, company costs for healthcare, funeral benefits, and pension fund commitments, rise as people take early retirement or die from illnesses.

For a successful programme to be implemented in the workplace, a number of activities need to be implemented and committed to. These can be seen as key elements of an HIV and AIDS programme.

2.8.1   Key elements of an HIV and AIDS workplace programme

For every successful programme, there are basic guidelines and procedures to be followed. Ones identified by the Western Cape government include:

- An impact assessment of HIV and AIDS on your organization.
- Implementation of HIV and AIDS awareness programmes.
- Voluntary HIV testing and counseling programmes should be made available.
- HIV and AIDS education and training should be made accessible.
- Condom distribution should be made available.
- Workers should be encouraged to receive treatment for STIs and TB.
- Create an open, accepting environment.
- Establish support programmes for employees affected by HIV and AIDS.
- Ensure the provision of antiretrovirals or referrals to relevant service providers.
- Offer counseling, and other forms of social support for infected employees.
- Create strategies to address direct and indirect costs of HIV and AIDS.

- Monitor, evaluate and review of the programme to evaluate its effectiveness.

These elements form the basis for a responsive HIV and AIDS programme. Most South African companies strive to achieve comprehensive programmes which are aimed at reaching the above-stated benchmarks. However, we still have a large proportion which only has some or none of these elements, or even render the activities on an ad hoc basis for varied reasons. The SWHAP offers and award criteria where it recognizes the companies that strive to attain all the benchmarks as an incentive for companies to do their best.

Longuet, et al. (2005:5) also agree that implementing a strategy that cares for people living with HIV and simultaneously minimizes risks of losing income, can be regarded as a business imperative. It is believed by many that a strong private sector is critical for creating wealth and long-term economic growth of the African continent. Meanwhile, it is not always easy to run a profitable business operation in an environment where companies are faced with global competition and exposed to compounding factors that hinder growth and directly or indirectly affect their bottom line. Whereas enabling factors, including transparency, well-educated employees, low interest rates and favorable trading conditions, are increasingly facilitating business development in some countries, disease and declining life-expectancy rates related to HIV and AIDS are continuing to have a negative impact on growth, and are threatening the viability of many organizations.

In this context, it can be agreed that it is important to understand how HIV and AIDS is affecting business, and what can be done to mitigate the impact on an organization. This emphasizes the importance of this study for the Swedish workplace companies.

It is further explained that the impact of HIV and AIDS manifest in its effects on the labour force and on working-age men and women in the private sector, the public sector, agriculture, the informal economy, and the populations of women and children in the most affected countries. The enterprise is now calculating the costs of the HIV epidemic, and many firms have concluded that the direct cost of inaction is far greater than the costs of

treatment. Foremost problems are absenteeism, loss of experience and technical skills due to the illness, and death of key workers, depleted savings and excess expenditure (Magnusson, 2005:56).

2.8.2 Policies of the workplace programme

A responsive HIV education plan includes several elements. First, the company must write a workplace policy on HIV. The policy will set standards for dealing with HIV across the company, provide support to employees who are infected with or affected by HIV, raise awareness and prevent infection among employees, help avoid a crisis when HIV becomes an issue in the company, and establish that the company will comply with legal responsibilities.

Magnusson (2005:100) indicate that there are policy principles. The same ethical principles that govern all health/medical conditions in the employment context apply equally to HIV and AIDS. However, the gravity and impact of the HIV and AIDS epidemic and the potential for discrimination create the need for a specific code on HIV and AIDS and employment. At the same time, given the increased risk of the spread of the disease under conditions of economic insecurity, non-discriminatory approaches enable economic and health management. The workplace policy components are further described in Magnusson (2005:101) as:

- **Education, awareness and prevention programmes**

Information, education, and prevention should be developed jointly by employers and employees and should be accessible to all in the workplace. Education on HIV and AIDS, where possible, should incorporate employee families.

- **Job access**

There should be no direct or indirect pre-employment test for HIV. Employees should be given the normal medical tests of current fitness for work, and the tests should not include HIV.

- **Workplace testing and confidentiality**

There should be no compulsory workplace testing for HIV. Voluntary testing for HIV on the request of the employee should be done by a suitably qualified person. Persons with HIV should have the right to confidentiality about their status.

- **Job status**

HIV should not be a factor in job status, promotion or transfer.

- **HIV testing and training**

In general, there should be no compulsory HIV testing for training. HIV testing for training should be governed by the principle of non-discrimination between individuals with HIV infection and those without.

- **Protection against victimization**

Persons infected by or believed to be affected by HIV and AIDS, should be protected from stigmatization and discrimination by workers, employers or clients.

The overall guiding principles of workplace policy development are embedded in the promotion of decent work for everyone, including people living with HIV and the protection of human rights.

In agreement with the development of policies, one can also emphasize that in a country where the human rights of people are protected by the constitution, policies need to be not only made, but also disseminated and interpreted to all employees to ensure the understanding of what the employer is committing to with regards to protecting the human rights of employees. Often we find cases where policies are made and employees are not even aware of the legal protection that these policies give them. Also, policies need to be revised periodically to ensure that they are in line with the ever changing national and international frameworks.

2.8.3   HIV and AIDS programmes

According to ILO (2015:95), workplaces are urged to:

- Take advantage of the conducive environments in which they are suited to scale up programmes that increase access to HIV services for female and male workers.

- Aim at eliminating discrimination and harassments.

- Address perceptions, prejudices, cultural beliefs and attitudes towards people living with HIV, among others, and adapt HIV workplace programmes to the needs of their constituents.

- Apply non-discriminatory employment practices covering recruitment, equal access to employment conditions and benefits, irrespective of HIV status.

- Use a number of policies, including those concerning human resources, employment equity, and others, to address the issues of stigma and discrimination.

- Emulate the effective practices of other workplaces that provide onsite psychologists to ensure that employees living with HIV receive appropriate counseling and support where necessary.

- Review and closely monitor HIV and AIDS workplace policies periodically to ensure they are well aligned with new epidemiological changes or changes in global/regional policies on human rights.

- Identify, train and equip peer educators from all levels within the organization to carry out effective education within the workplace to ensure the reduction of stigma and discrimination.

- Reward and encourage peer educators for the important roles they play.

There is also an emphasis that workplace programmes should take the form of workplace HIV and AIDS prevention, care and support programmes. Workplace prevention programmes should seek to inform employees about HIV and AIDS and promote behavioral changes that will reduce the spread of HIV, and provide services to reinforce behavior change. Additionally, the workplace programme should also seek to support those who have tested HIV-positive in the workplace through support programmes.

Dickenson (2009:57) suggests fo such programmes to include raising awareness about HIV and AIDS, creating a non-discriminatory environment, the prevention and treatment of sexually transmitted infections (STIs), voluntary counseling and testing (VCT), and the promotion and distribution of condoms. He further highlights that in order for programmes to stand the best chance of leading to behavioral change, HIV and AIDS awareness and

prevention programmes should provide basic knowledge which includes the information necessary to ensure that staff understand how the virus will affect them and their families, educate employees to develop skills for decision making, negotiation, and condom use. The programme should also develop an environment of acceptance and non-discrimination, promote positive living messages, provide incentives for HIV testing, offer information on available treatment, and deal with factors that increase the susceptibility of employees to HIV and AIDS, such as economic dependency and characteristics of the work environment that place staff at risk; working night shifts and travelling.

This forms the basis of an effective prevention programme, however, continued training for management and implementers on HIV and AIDS is also critical to the process. The success of every programme does not only depend on implementing the necessary benchmarks, but management education and buy-in is a very critical component. Most of all everyone in the company should understand why there is the need for such activities.

Prevention programmes must be linked to treatment, care and support programmes. These programmes should offer services to help employees cope with infection and should ideally provide support to employees and their families.
Both Dickenson and the ILO cross-country studies emphasize that treatment, care and support are an integral part of all prevention programmes. It is the responsibility of the employer after getting employees tested, to ensure that the employees who have tested HIV-positive are registered in a care and support programme. This can be linked to the in-house occupational health care clinics, internal or sessional social workers, Employee Assistance Programmes, or external outsourced service providers.

2.9   PEOPLE LIVING WITH HIV AND AIDS IN THE WORKPLACE

HIV/AIDS affects people from all facets of life, and the workplace is not unique. It goes without saying that due to the fact that HIV and AIDS affect men and women in their most productive years, the likelihood of having people living with HIV and AIDS in the workplace is high. With the acceptance of the reality of having PLWHIV (People Living with HIV) in

the workplace, workplace programmes are expected to look into factors such as workplace testing (laws and policies), meaningful involvement of PLWHIV, involving PLWHIV in the process, and reasonable accommodation for PLWHIV in the workplace.

Since there are multifaceted areas where HIV and AIDS affect the individual, the researcher will look at workplace testing, the impact on the individual, and workplace support.

2.9.1   Workplace HIV testing

HIV testing should not be included in any pre-employment policy or be used as grounds for refusing employment. HIV or AIDS do not, by themselves, justify termination of employment or demotion, transfer, or discrimination in employment. The mere fact that an employee is HIV-positive or has AIDS does not have to be disclosed to the employer. There is no warrant for requiring existing employees to undergo testing for HIV (Van Dyk, 2005:336).

With full understanding and acknowledgment of the legislation around pre-employment testing, workplaces can never be aware of their employees HIV statuses. However, through the availability of screening opportunities, the workplace can be aware of the HIV prevalence rate which can assist them to put measures in place to support those who are living with HIV.

According to Pratt (2003:82), many people remain completely asymptomatic and, unless tested for some other reason, they will be unaware that they are infected. However, they remain infected and infectious to others. Others may develop an unusual self-limited illness and then recover (acute seroconversion syndrome) during primary infection.

Employers must go to great lengths to establish an environment in which employees perceive the benefit of knowing their serostatus early. While supporting the idea of the importance of HIV and AIDS testing and support programmes, the researcher is of the opinion that once people are tested, there should not only be support programmes for

people living with HIV, but it should be ensured that those who have tested HIV-negative are supported and motivated to remain negative.

Although HIV testing was used in the past as a way of minimizing HIV prevalence in the workplace, especially in mines, with the developments in the protection of the rights of people living with HIV, it is now considered illegal.

Dickenson (2009:50) further indicates that pre-employment testing (or profiling and avoidance of high-prevalence groups) was designed to minimize companies' risk and did nothing constructive to respond to the epidemic.

2.9.2   Individual impact

Fan, Conner and Villarreal (2004:53) claim that many HIV-infected people do not associate the symptoms of the acute infection syndrome with HIV-infection. Most individuals then remain free of any clinical symptoms for viable lengths of time, typically many years.

This is more reason for everyone to get early detection of HIV while they do not show any symptoms of HIV-infection. Most people remain functional even after their diagnosis, especially if diagnosed early.

Fan, et al. (2004:53) further describe that those individuals who are HIV-infected, but who do not show any signs of the disease, are referred to as "asymptomatic". As time passes, many HIV-infected individuals begin to experience symptoms of HIV-infection.

Still, the impact of individuals' ill health and death depends on who the individuals are, their place in society, and the resources they, their households, communities and societies, have available. The reality for individuals is that, as with their chance of being infected, the impact of the disease will depend on their circumstances and the resources they can command (Barnett & Whiteside, 2002:183).

This can be seen as a true reflection of people living with HIV who have access to treatment, care and support, and those who are poor and do not have resources. People who are in employment and who have access to resources and support in their workplaces, stand a better chance of living longer with HIV and AIDS. Also, the strides that the South African government earned in availing free treatment for HIV and AIDS to all infected people who are ready to be on treatment, enables everyone in the country who are infected a better chance of living longer with the virus.

According to Van Dyk (2005:216), being HIV-positive affects people mentally, socially and emotionally. There are psychosocial experiences of a person living with HIV and AIDS which can be summarized as follows:

- **Fear:** HIV-positive people have many fears. They are particularly afraid of being isolated, stigmatized and rejected. They fear the uncertainty of the future, whether they will be in pain, and if they will die. Fear may be caused by not knowing enough about what is involved in being HIV-positive, and how the problems may be solved.

This may cause the infected person to isolate themselves and have a problem disclosing to others who may have given them support.

- **Loss:** HIV-positive people often feel that they have lost everything important and beautiful to them. They experience loss of control, loss of independence, loss of their ambitions, their physical attractiveness, sexual relationships, status in their community, and respect.

This immense sense of loss that is experienced might reflect the pivotal role that counseling plays on people living with HIV to restore all that is emotionally and mentally lost.

- **Guilt:** Guilt and self-reproach for having contracted HIV and for having also infected others, are frequently experienced by HIV-positive individuals. They often feel guilty about the behavior that may have caused the infection.

The introduction of HIV and AIDS has always been made in a way that people were judged for having contracted the virus because it was always associated with promiscuity.

- **Denial:** Most HIV-positive people go through a phase of denial. Denial is an important and protective defense mechanism because it temporarily reduces emotional stress.

HIV-positive people should be allowed to cling to their denial if they are not ready to accept their diagnosis, because denial often gives them a breathing space in which to rest and gather their strength.

However, during this period, people living with HIV need to be educated on responsible sexual behavior and the importance of counseling and medication, if needed.

- **Anger:** HIV-positive people are often very angry with themselves and others, and this anger is sometimes directed at those closest to them. They are angry because there is no cure for AIDS, and because of the uncertainty of the future.

Similarly to the guilt feelings, because of the perceptions that people in communities and societies have towards people who get infected, this can cause people living with HIV to live with anger.

- **Socio-economic issues:** Socio-economic and environmental problems such as loss of an occupation and income, discrimination, and social stigma may affect the infected person. Because many HIV-positive people also have financial problems, they often cannot afford to buy the antiretroviral therapy that might give them a longer lease on life.

The latter does not necessarily apply to the South African context which has a free antiretroviral therapy programme accessible to all people living with HIV. Also, for those who are in employment, the primary concern might not necessarily be a loss of income, but the support they might or might not get in the workplace.

With the acknowledgment of the fact that people living with HIV can be productive in the workplace, there is much-needed support from internal structures such as health care professionals, employee assistance practitioners, and/or social workers, management, and co-workers.

2.9.3   Support from health care professionals

Fan, et al. (2004:194) indicate that health care workers are another important target for educational efforts. The number of doctors who treat HIV-positive individuals and people with AIDS has grown, but it remains small compared to the need. Additional educational programmes are necessary to address concerns of doctors and other health care

workers. Some clinics or hospitals have made treating people living with HIV their specialty.

The majority of the corporates, especially multinational companies, recognized the need and made an investment in Occupational Health Care Clinics. These are the companies that give employees access to prevention and treatment of occupational diseases. These clinics are also used for primary health care services, including HIV prevention, treatment and care. All HIV-positive employees in that specific workplace get to be clinically managed by the clinic sister and psychosocially managed by the resident social worker.

The workplace can have either a resident or sessional social worker, or an Employee Assistance Practitioner. However, some workplaces cannot afford either. In recent years it has been observed that employers choose the services of an EAP rather than a social worker when it comes to HIV management.

Not all HIV employees support the services of in-house EAP and social work services in the workplace. Issues of stigma, discrimination, and fear of victimization, make employees uncomfortable to utilize them, or they just prefer to use external services even when confidentiality is being assured and adhered to. Therefore, above all, the PLWHV have a choice to be comfortable with whoever offers services; it may only be with the occupational health care nurse to manage them both clinically and psychologically.

2.9.4   Management support

Van Dyk (2005:340) further explains that employers have obligations and employees living with HIV have rights. Employees with HIV/ AIDS may not be unfairly discriminated against in the allocation of employee benefits. Employees with HIV and AIDS may not be dismissed solely on the basis of their HIV and AIDS status, and if an employee becomes too ill to perform his or her current duties, the employer is obliged to follow accepted guidelines regarding dismissal for incapacity before terminating an employee's services (as set out in the Labour Relations Amendment Act, No 12 of 2002). This is an indication that employers have a significant role to play in protecting the human rights and

employability of people living with HIV and AIDS, and that they also are obliged to act as a support structure.

The fact that a person has HIV will not by itself affect the employee or the workplace. Supervisors will not have to make accommodations or adjustments simply because one employee has a virus. HIV will not usually affect the performance of the employee. Still, it is possible in some cases that the emotional toll of the disease might interfere with the employee's ability to do their work. Some anecdotes indicate that because of a lack of acceptance of status, some HIV-positive employees remain in denial even after being diagnosed, which makes it difficult for them to be monitored. Some also prefer to be clinically monitored outside the workplace, to ensure that their status remains unknown. This can impact on the employees' performance due to the time they will need to be away from work periodically.

Parker (2000:86) elaborates that firms sometimes take 24 weeks to replace a deceased professional, depending on the skills required. Some multinationals in South Africa hire three workers for each skilled position "to ensure that replacements are on hand when trained workers die." He further identified the possible effects on operating profits of industries, workplaces and sectors. Specifically, AIDS-related illnesses and deaths of employees increase company expenditures and reduce revenues, expenditure on health care costs, funeral costs, and recruitment and training of replacement employees increase, revenues decrease as a result of absenteeism due to illness, and provision of care to persons with HIV and /AIDS, to name a few.

In this regard, the researcher is of the opinion that if workplace prevention, promotion, and care are effectively implemented, there might be no need to make adjustments to allow a person with HIV to perform essential functions of their job.

2.9.5 Support from family and significant others

As with any life-threatening illness, HIV affects the infected person and those surrounding them. A review by USAID (2002:59) reports that HIV is a predominantly sexually

transmitted disease, HIV and AIDS attacks the group that is sexually active, which usually involves 'prime-age adults at the peak of their income-earning years, who are often heads of families. The above report can be one of the factors that may influence how families receive the news of their loved one's HIV status and how to support them. Family members may have a fear of loss of income, which might lead to poverty if the infected member gets ill. However, naturally family members go through a series of emotions. Although it is not mandatory for an HIV-positive person, especially an employee, to disclose their status to others, it gives family members and colleagues the opportunity to support the person with HIV.

In the workspace context, other employees may feel sorry for the infected employee and try to accommodate his or her needs at all times or even treat them differently. Therefore, including family members in the support programme from the workplace is of equal importance to both the family and the employee living with HIV. Whiteside and Sunter (2000) demonstrate the importance of support and the levels of support for the person living with HIV in Figure 2.3. It also illustrates how the person is at the center of the socio-economic circle and how the impact of illness and death is being felt by families, the public health service, and some private sector firms (Whiteside & Sunter, 2000:84).

2.10   HIV AND DISCLOSURE

The concern for many people living with HIV is whether to disclose their status or not, and if they were to disclose, who will they disclose to. The decision whether or not to disclose being HIV-positive is difficult because disclosure (or non-disclosure) may have major life changing consequences. Counselors should help their clients/patients to carefully consider the benefits and the negative consequences that disclosure may have for them as individuals (Van Dyk, 2005:220).
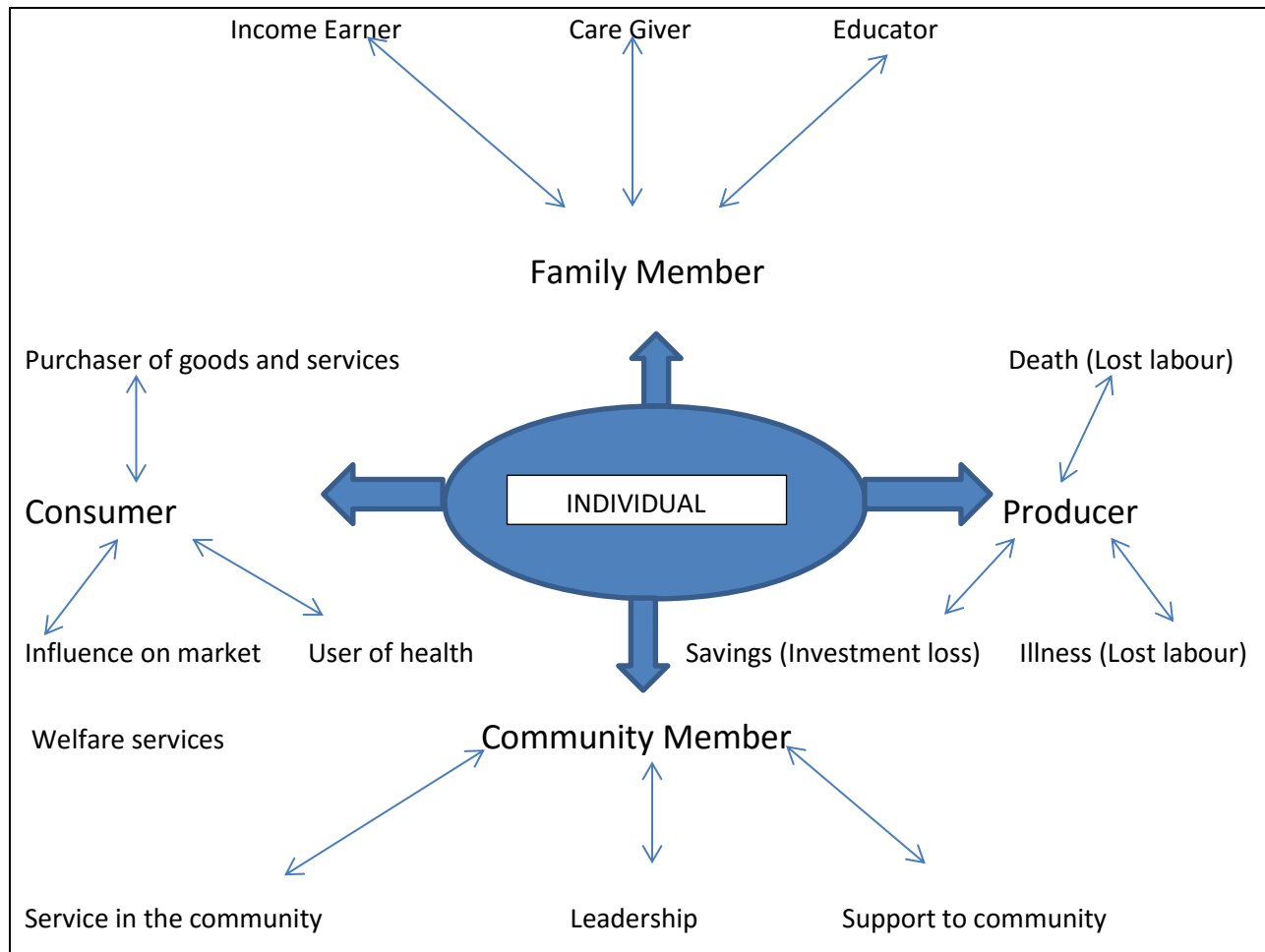
Figure 2.4: The individual as an economic and social actor (Whiteside & Sunter, 2000:84)

At this point, informed decision making is important for the client/patient. Thus, the client needs to be given information on the benefits and consequences of the decisions they are making.

It is indicated that because disclosure is a very personal and individual decision, all relevant, personal circumstances should be taken into account. Clients/patients should decide whether they want full disclosure (for instance publicly revealing their HIV status) or partial disclosure (for example telling only certain people, such as partner, spouse, relative or friend) (Van Dyk, 2005:220).

Greeff, Phethu, Makoae, Dlamini, Holzemer and Naidoo (2008:313) indicate that voluntary HIV status disclosure is described as managed and concealment disclosure. With voluntary disclosure, the people living with HIV and AIDS maintain control over the choice to disclose, to whom he/she should disclose and whether he/she should fully or partially disclose.

Living with a life-threatening condition is difficult enough without adding other emotional traumas like rejection, prejudice, stigma and being judged, which they already feel at that point. Therefore, disclosure can be accompanied by the following benefits:

- Disclosure can help people accept their HIV-positive status and reduce the stress of coping on their own.
- Disclosure can ease access to medical services, care and support, including access to antiretroviral therapy.
- Disclosure may help reduce the stigma, discrimination and denial that surrounds HIV and AIDS.
- Disclosure promotes responsibility. It may encourage the person's loved ones to plan for the future.

Disclosure can also be accompanied by negative consequences such as problems in relationships (for example with sexual partners, family, friends, community members, employer or colleagues), rejection, and the conviction that people are constantly judging one (Van Dyk, 2005:220).

With regard to health care workers, Viljoen (2005:68) postulates that health care workers are legally required to keep all personal information about a patient confidential. Particularly with the outbreak of HIV and AIDS, the Medical and Dental Board of the Health Professions Council of South Africa issued a set of guidelines on how to manage HIV and AIDS disclosure.

However, there are allegations that health care workers disclose HIV test results outside the professional framework of guidelines. When such an act happens, the doctor/nurse/patient relationship has been violated, and as such the individual health professional has breached an ethical code of conduct.

2.11   SUMMARY

The role of workplace programmes in diversifying the responses to the HIV and AIDS epidemic, including the impact on the world of work, is quite evident.

There is a clear demonstration that in responding to the epidemic, through commitment, resource allocation, legal frameworks such as policies and local and international partnerships, workplaces can foster effective responses and contribute towards the improved world of work. Businesses firstly need to invest in prevention programmes that will play a pivotal role in curbing the spread of HIV to prevent any further infections, give access to testing opportunities, condom distribution, and HIV education.

It is evident that HIV impacts on businesses, individuals, and families. However, through international aid and mainstreaming of HIV and AIDS programmes, workplaces have done their part in supporting people living with HIV in the workplace. Identified internal structures such as health care providers, employee assistance practitioners, managers and family members are also playing a pivotal role in ensuring the wellbeing of those infected.

The most emphasis is on the pivotal role that HIV and AIDS programmes play in the lives of people living with HIV; not only in the lives of people living with HIV but also in business sustainability for the benefit of the economy of the country.

The following chapter focuses on the research methodology and findings.

CHAPTER THREE
RESEARCH METHODOLOGY AND EMPIRICAL FINDINGS

3.1   INTRODUCTION

The literature review in Chapter 2 focused on the study of workplace programmes relevant to people living with HIV and AIDS. Literature clearly confirms the need for workplaces to support people living with HIV through workplace programmes. In addition, it reflects on how workplace programmes can contribute to productivity, sustainability, and a healthy workforce. To be able to conclude on the effectiveness of the Swedish Workplace HIV and AIDS Programme and its imprint on people living with HIV and AIDS, it is also important to understand the feelings and experiences that people living with HIV employed in the Swedish companies have about the programme.

The aim of this study was primarily to explore and describe the experiences of Swedish company employees living with HIV and AIDS with regards to the Swedish Workplace HIV and AIDS Programme (SWHAP). The objective that was addressed in this chapter was: To explore the experiences of HIV-positive employees regarding participation in the Swedish HIV and AIDS Workplace Programme.

3.2   RESEARCH APPROACH

The researcher in this study employed the qualitative research approach. This approach assisted the researcher to answer the question: What are the experiences of HIV-positive employees about the Swedish Workplace HIV and AIDS Programme? The approach was further used for the purpose of describing and understanding the complexity of the phenomenon from the participants' point of view, which in this study the researcher refers to as employees who are HIV infected (Fouché & Delport, 2011:64).

There are several advantages that qualitative methods offer in social scientific research. Babbie and Mouton (2001:271) argue that qualitative research is naturalistic and the focus is the insiders' perspective of the social actors.

The researcher got a better understanding of the Swedish Workplace HIV and AIDS Programmes and how they facilitate the desired quality of life of employees who are HIV-positive. The study also gave the researcher an extensive understanding of the lives of people living with HIV who are still part of the workplaces. As HIV is a sensitive topic, qualitative research was more suitable for personally obtaining information about employees living with HIV.

3.3   TYPE OF RESEARCH

In this study, the focus was to understand the experiences of people living with HIV and AIDS in the Swedish Workplace HIV and AIDS Programme. Applied research was employed since it places strong emphasis on application and solving problems in practice (Fouché & De Vos, 2011:95).

This study attempted to explain the social life of people living with HIV to try and make sense out of their relationship with the world of business (workplace). Babbie (2010:26) goes on to explain that in applied research, social scientists are committed to having what they learn make a difference, to seeing their knowledge of society put into action.

The study was exploratory in nature, in that it aimed at establishing the facts around the contribution made by the Workplace HIV programmes in the lives of people living with HIV and AIDS. Babbie (2006:94) explains that exploratory studies are most typically done for three purposes:

- To satisfy the researcher's curiosity and a desire for better understanding.
- To test the feasibility of understanding a more extensive study.
- To develop methods to be employed in any subsequent study.

The researcher, therefore, used the study to contribute to improved workplace programmes and general knowledge of the social aspects and general understanding of people living with HIV.

3.4   RESEARCH DESIGN

In this study, collective case studies research design was used. Which according to (Fouché, et al. 2011:322) is an instrumental case study extended to a number of cases. Cases are chosen so that comparison can be made between cases and concepts and in this way theories can also be extended and validated. Thus in the study a number of employees living with HIV were studied and concept of support from workplace programmes was validated.

The study further followed a descriptive case study research design, also known as an intrinsic case study, that strives to describe, analyze and interpret a particular phenomenon (Fouché & Schurink, 2011:320). The case study research design assisted the researcher to familiarize herself with the world of HIV-infected employees and understand their actions relating to workplace HIV programmes.

3.5   RESEARCH METHODS

The research method will be described in relation to the research setting, the study population and sampling, methods of data collection, data analysis, and trustworthiness.

3.5.1   Research setting

The research setting included three Swedish companies that employed people living with HIV. The researcher gained entry to participants by requesting permission to conduct the study through the CEO's of the companies.   The health service providers of the companies assisted the researcher to inform all HIV-positive employees about the research study using an information letter that included the aims and objectives, and methods of the study. These gave the participants time to think about whether they would

like to participate or not. Those who were interested in partaking were requested to provide their contact details to the clinic. The researcher then got the details from the clinic and contacted the potential participants to arrange an appointment for interviews.

3.5.2 Study population, sample and sampling method

A study population according to Strydom (2011:223), sets boundaries on the study units. It refers to individuals in the universe who possess specific characteristics. Babbie (2010:199) also defines a study population as that aggregation of elements from which the sample is actually selected. Strydom (2011:223) similarly describes a population as the totality of persons, events, organization units, case records, or other sampling units with which the research problem is concerned.

The study population in this study, according to the Employee Support Programme (ESP) reports, was 615 HIV-positive employees employed in 24 Swedish companies in SA who have participated or are still participating in the Swedish HIV and AIDS Workplace Programme. The researcher in this study was focusing on the experiences of HIV-infected employees employed in Swedish companies in SA, who have participated in the Swedish HIV Workplace Programme.

Strydom (2011:223) describes a sample to comprise of elements or a subset of the population considered for actual inclusion in the study, or it can be viewed as a subset of measurements drawn from the population in which we are interested. Non-probability purposive sampling was chosen, as it is the sampling method that gives the researcher the opportunity to use her own judgment.

Researcher could not include the whole study population of companies nor employees living with HIV in the study. Thus the Swedish companies were contacted and the first three who responded by granting permission for the study, were included in this study, namely Company A, B and C. The researcher compiled a list of names by carefully going through the ESP (Employee Support Programme) database of these three Swedish companies with their permission, until there were a sufficient number of potential

participants (Strydom, 2011:233). Many HIV-positive individuals choose to remain discrete about their status, therefore purposive sampling was the most appropriate method to be used, to only include participants who met the sampling criteria and who were willing to participate. The following selection criteria were used to include employees:

- Of three Swedish companies in SA who granted permission for the research
- Who have been diagnosed HIV-positive.
- Who have utilised the services of the Employee Support Programme (ESP)
- Who have participated in the Swedish HIV Workplace Programme.
- Of any race, culture, gender or age.
- Who were willing to participate in the study voluntarily.
- Who are conversant in English, however, Sepedi, Setswana, Xhosa and Zulu, which researcher is conversant in, was also acceptable for participants who were not conversant in English. The interviews, which were conducted in African languages, were transcribed and translated into English.

For the purpose of this study, in order to solicit enough valuable data, ten participants from three different Swedish companies, namely Company A, Company B, and Company C (i.e. 3 to 4 participants from each workplace) were asked via the ESP staff if they were interested in partaking in the study and provided their contact details. Out of the ten participants, three withdrew, without disclosing a reason and only seven consented and were interviewed. The data from the two participants from the pilot study pre-test was thus included in the main study data in the end, due to the richness of their data and the withdrawal of three participants from the main study, thus still totalling nine participants. The researcher collected data until saturation was reached.

3.5.3   Methods of data collection

In this study, semi-structured individual interviews were used as a data collection method. This type of interview is designed to describe the subjective, lived experiences of people and to comprehend the meanings that people attach to these experiences (Creswell,

2007:57). This assisted the researcher to gain in-depth knowledge from participants about their experiences of utilizing the workplace HIV programmes.

Delport, Fouché and Schurink (2011:352) describe semi-structured individual interviews as interviews that give the participants an opportunity to describe their own experiences, feelings and views on the phenomenon. In this study, participants of the Swedish Workplace HIV and AIDS Programme described their experiences of SWHAP. The interview schedule provided the researcher with a set of predetermined questions that were used as instruments to engage the participants and designate the narrative terrain. The letter of informed consent included permission to record the interviews, using a digital voice recorder.

The duration of the interviews was approximately 45 to 60 minutes. A quiet professional environment, where no interruptions occurred, was agreed upon by the researcher and participants (Greef in De Vos, Strydom, Fouche' & Delport, 2011:350). The researcher provided a setting that encouraged participation, involvement and interaction. Interviews were conducted at the respective company boardrooms, which served as a neutral and non-threatening environment. To get the most out of the participants, the researcher used the following facilitative communication skills: active listening, clarifying, reflecting, probing, exploring, paraphrasing, and summarizing.

The researcher is expected to have good listening skills to be able to obtain quality information during an interview. Listening skills enabled the researcher to have greater understanding and encourage the participants to continue talking when they were given the opportunity (Greef in De Vos, Strydom, Fouche' & Delport, 2011:345). The researcher showed interest in the participants by using responses such as "mmm" and nodding her head, which motivated the participants to describe more about the problem studied. By using these listening skills, the researcher was able to maintain continuous interaction with the participants and obtain clarity and meaning about the problem studied.

Clarification is a technique that was used to gain clarity of some statements from participants (De Vos, et al. 2011:345). The researcher asked questions in order to gain clarity about the research phenomenon (Greef in De Vos, Strydom, Fouche' & Delport, 2011:345). In this study, clarification helped to link the participants' understanding and their experiences about participating in the Swedish Workplace HIV and AIDS Programme.

Probing was used during the interviews with the purpose of deepening the responses of the participants to a question in order to increase the richness of the provided data. Probing persuaded the participants to give more information about the problem studied (Greef in De Vos, Strydom, Fouche' & Delport, 2011:345). The researcher asked a probing question after the response of the central question. It is aimed at gaining clarity and meaning about the phenomena studied.

Reflection was used as a process during which the researcher repeated the participants' ideas, thoughts and feelings to check whether these responses were well understood (Greef in De Vos, Strydom, Fouche' & Delport, 2011:345). The researcher repeated some key sentences from the participants' descriptions with the purpose of confirming with the participants whether it was what they had meant.

The researcher used reflective summary to summarize the participants' ideas, thoughts and feelings that were verbalized to see if they really understood what they were saying. The reflective summary has a structuring function and stimulates participants to give more information (Greef in De Vos, Strydom, Fouche' & Delport, 2011:345).

Data was collected until data saturation was reached. According to De Vos, et al. (2011:345), data saturation is a point in the study where the researcher begins to hear the same information repeatedly being reported and they no longer learn anything new. By the ninth interview, the researcher had already reached saturation point.

After the interviews, the researcher made full and accurate notes of what was going on. Field notes of the researcher's observations were also made after the interviews (Greef2011:359). These notes, together with the transcribed interviews, helped the researcher to remember and explore the process of the interview.

3.5.4   Data analysis

Schurink, Fouché and De Vos (2011:397) describe data analysis as the process of bringing order, structure and meaning to the mass of collected data. Data analysis refers to a process of taking raw data from the interviews and drawing various themes and patterns. The analysis of data was done by means of the qualitative analytical technique.

In this study, the researcher analyzed the information using Creswell's model of data analysis and interpretation as described by Schurink, et al. (2011:404-416).

3.5.4.1 Preparing and organizing data
* **Planning for recording of data**

During the process of the interviews, the researcher utilized a voice recorder for data collection. A notebook to record field notes after the interviews, was also used.

* **Data collection and preliminary analysis**

The two-fold approach: The first involves data analysis in the field during collection while the second involves data analysis away from the field following a period of data collection. The second part is known as 'the office approach', which may be conducted between visits to the field, prior to, as well as after, completion of data collection. According to Schurink, et al. (2011:405), generally the office approach focuses more on the pragmatics; the sorting, retrieving, indexing and handling of qualitative data. Data collection and data analysis occurred simultaneously in the field and out of the field.

* **Managing the data**

This is the first step in data analysis away from the site, which is also referred to as the intensive data analysis phase. At an early stage in the analysis phase, the researcher will organize the data into file folders, index cards, or computer files. This might seem like an impossible task; however, the following guidelines can be helpful: Start with an inventory

of what one has. Are the field notes complete? Are there any parts that were put off to be written later and need to be finished, even at this late date, before beginning analysis? Are there any glaring holes in the data that can still be filled by collecting additional data before the analysis begins? Are all data correctly labeled with a notation system that will make retrieval manageable (dates, places, interviewee identifying information?) Are interview scripts complete? (Schurink, et al. 2011:405). The researcher may choose any method that will enable her to find what she needs when she needs it. It is also important to make backup copies of all one's data. Field notes and interviews should be treated as valuable material (Schurink, et al. 2011:409). The researcher sorted through the data in preparation for the actual data analysis. The data was numbered starting with interview 1 (protecting the identity of participant) until the last one, and the field notes were added in the margin in preparation for the actual data analysis.

- **Reading and writing memos**

After the organization and conversion of data into transcriptions, the researcher continued with the analysis by getting a feel for the entire database. The researcher read the transcripts in their entirety, often several times to get immersed in the depth and details, trying to get a sense of the interview as a whole before breaking it into parts. Writing memos in the margins of field notes or transcripts or under paragraphs helped in this initial process of exploring the database. These memos are short phrases, ideas or key concepts that the researcher wrote to herself about the coding process called 'analytic memos' (Schurink, et al. 2011:409). In this study, the researcher started reading each interview to make sense of the data. The researcher made notes in the margins of the interview transcripts and commenced with generating codes.

3.5.4.2 Reducing the data

- **Generating categories and coding data**

At this stage, category formation represents the heart of the data analysis. This step in the process demands a heightened awareness of the data, focused attention to it and openness to the subtle, tacit undercurrents of social life. Identifying salient themes, recurring ideas or language and patterns of belief that link people and settings together, is the most intellectually challenging phase of data analysis. The process of category

generation involved noting regularities in the setting or people chosen for the study (Schurink, et al. 2011:410). The researcher coded the data and started writing out themes.

3.5.4.3 Testing the emergent understandings and searching for alternative explanations

This entails a search through the data during which one challenges the understanding, searches for negative instances of the patterns, and incorporates these into larger constructs, as necessary. According to Schurink, et al. (2011:416), there are also kinds of 'negative evidence' to consider such as: events that did not occur; events of which the population is unaware; events the population wants to hide; overlooked commonplace events; effects of a researcher's preconceived notions; unconscious non-reporting; conscious non-reporting; interpreting; and developing typologies.

The researcher went over the data and checked if there was anything that was missed during data analysis and considered if there were any unique themes.

3.5.4.4 Interpreting and developing typologies

Interpretation involves making sense of the data; the 'lessons learned'. Several forms exist such as, interpretation based on hunches, insights, and intuition. Developing typologies or systems for categorizing things or concepts is a very useful aid when making sense of qualitative materials. By developing typologies, one begins to make conceptual linkages between seemingly different phenomena (Schurink, et al. 2011:417), visualizing, representing and displaying the data. The data was organized to present a picture of what had been coded.

3.5.4.5 Presenting the data

This phase involves the creation of a visual image of the data. The researcher presented it in the form of a table indicating the themes and the sub-themes. Schurink, et al. (2011:419) state that some authors use metaphors to present data, and although metaphors can be an effective method to communicate ideas, it is warned that overused

metaphors are a sloppy unimaginative method of expression. However, for qualitative researchers, the process of writing is an integral part of understanding the 'story' of the data (Schurink, et al. 2011:419).

3.5.5   Trustworthiness

Trustworthiness was ensured by using Lincoln and Guba's model as described by De Vos, Strydom and Delport (2011:419) to ensure rigor in qualitative research. Rigor is defined as striving for excellence in research through the use of descriptive, scrupulous adherence to details and strict accuracy (Burns & Grove, 2009:720). In this research, the following constructs for trustworthiness were applied: credibility, transferability, dependability, and conformability.

- **Credibility:** Schurink, et al. (2011:419) refers to credibility as the alternative to internal validity in which the aim is to demonstrate that the inquiry was concluded in such a manner as to ensure that the subjects have been accurately identified and described. It refers to the ability of the researcher to carry out an investigation in such a way that the truth of the data and conclusions of the study are established. Credibility criteria included prolonged engagement, triangulation, peer evaluation, member checking, and authority of the researcher, as discussed in Table 3.1 bellow.
- **Transferability:** essentially refers to generalizability of data, that is, the extent to which the findings from data can be transferred to other settings or groups (De Vos, et al. 2011:420). Transferability criteria included a dense description of the results with direct quotations from participant's interviews and a complete description of the demographic data. In this research, an intense description of the results with direct quotations from participant interviews and substantiation with the literature were provided.
- **Dependability:** refers to whether the research process is logical, well-documented and audited (De Vos, et al. 2011:420). Dependability criteria include dense descriptions of the methodology, audit strategies, code-recode procedures, and peer evaluation to ensure reliability. The researcher kept records of all data so that an audit trail would be possible.
- **Conformability:** refers to the objectivity or neutrality of the data. The criteria for conformability include triangulation, reflexivity, and audit trail. The researcher tried to

ensure objectivity and at all times to avoid bias and subjectivity by removing herself from the research. The researcher kept memos, notes of observations, transcripts, audio recordings, and field notes to comply with the criteria mentioned above. Triangulation was ensured by using notes on observations, field notes and the recorded interviews with each participant, representative of different Swedish companies.

The application of the above is presented in Table 3.1.

Table 3.1: The application of strategies to enhance trustworthiness

CONSTRUCTS	STRATEGIES	APPLICABILITY
Credibility	Prolonged engagement	• Had to get consent from CEOs to get permission to conduct study • Engaged with participants through the health service providers • Had conversation with prospective participants about the study
	Triangulation	Multiple methods of data collection were used: semi-structured interviews and recordings, field notes and observations.
	Peer evaluation	The study was presented to the: • SWHAP board members

CONSTRUCTS	STRATEGIES	APPLICABILITY
		• Faculty of Humanities Ethics Committee SWHAP company Internal Ethics Committees Further discussions with colleagues such as nurses and other social workers. The process was aimed at sharing findings and personal views. Colleagues managed to review some of the work which helped to make an informed decision about whether the information was legitimate.
	Member checking	Informal member checking was done during interviews through clarifying and summarizing during the interview with the respondent. Formal member checking was done after interviews as part of debriefing

CONSTRUCTS	STRATEGIES	APPLICABILITY
		Discussion with participants after data was processed
	Authority of the researcher	The researcher has been trained on a Master's Level in Research Methodology. Supervisor has extensive qualitative research experience and has supervised many qualitative studies.
Transferability	Dense description of the results	In-depth descriptions of results were indicated with direct quotations from the interviews of participants. A dense description on the literature review about the significance of the study was given in Chapter 2. Results were substantiated with the literature.
	Nominated sample	Description of sampling methods used in the study was detailed.

CONSTRUCTS	STRATEGIES	APPLICABILITY
		Detailed description of the demographic information of the participants was provided.
Dependability	Dense description of research methods	Comprehensive description of data collection, data analysis and interpretation was provided.
	Code-recode procedure	Consensus discussions with an independent coder who has coded more than 10 PhDs' and more than 10 Masters was held.
	Audit trail	Documents as an audit trail of the transcribed semi-structured interviews, field notes and naïve sketches will be kept for 15 years, to enable other researchers to clearly follow the decision trail used by the investigator in the study as required by University of Pretoria as evidence until the research study has been published.

CONSTRUCTS	STRATEGIES	APPLICABILITY
	Peer evaluation	As discussed above.
	Triangulation	As discussed above.
Conformability	Peer evaluation	As discussed above.
	Triangulation	As discussed above.
	Audit trail.	As discussed above.

3.6   PILOT STUDY

Two participants were interviewed as a pilot test before the actual study could commence. The purpose of the pilot study was to investigate the feasibility of the planned research project and to refine the methodology of the research. The data that was obtained from the two participants in the pilot study was used in the primary study in the end, because three participants withdrew from the main study, thus leaving the researcher no option but to include the data from the two participants from the pilot test, totaling nine participants who participated in the study.

3.7   ETHICAL CONSIDERATIONS

The fact that human beings are the objects of study in the social sciences brings unique ethical problems to the fore which would never be relevant in the pure clinical laboratory setting of the natural sciences (Strydom, 2011:113). The researcher in this study took into consideration all applicable ethical issues as explained below.

3.7.1 Informed consent

Informed consent was obtained from the participants. The researcher developed a consent form which stipulated the overall purpose of the investigation and the main features of the design, as well as the possible risks and benefits of participating in the research (Kvale & Brinkmann, 2008:71). The fact that an audio recording of the interviews would be made, was stated in the letter of informed consent. Participants were given an opportunity to read through the letter and ask questions where clarity was needed. Participants were also informed that the data would be stored at the University of Pretoria for 15 years, as required.

The participants in the study were legally and physically competent to give consent, and they were made aware that they are free to withdraw their participation from the study at any given time.

3.7.2 Voluntary participation

Participants were aware that they participate in the research voluntarily and they are free to withdraw at any given point if they choose. The researcher at all times ensured that participants were aware of the fact that they can withdraw from the study without any consequences.

3.7.3 Deception of subjects

Deception refers to misleading participants, deliberately misinterpreting facts, and withholding information from participants (Strydom, 2011:118). Participants were not misled or deceived to participate in the study. Information regarding the study was not withheld and correct information about the study was given to the participants in the letter of informed consent.

3.7.4 Violation of privacy and confidentiality

The researcher in this study ensured that the participants' right to privacy and confidentiality were protected. The researcher gave verbal assurance of confidentiality and privacy by explaining at the beginning of the interviews that anything said in the

interview would be kept confidential. The interviews were conducted in a safe and non-threatening environment that ensured privacy and all data is kept in a secure location. Numbers were assigned to each participant to ensure the protection of their identity and enhance confidentiality.

3.7.5   Actions and competence of researcher

Through the process of the study, the researcher ensured absolute competence and adequacy in the course of the research. The entire study was conducted in an ethically correct manner (Strydom, 2011:123). Previously acquired counseling and interviewing skills through social work training enabled the researcher to conduct the research process in a competent and professional manner.   In addition, the researcher applied the theoretical knowledge acquired in the research module MWT 864 Research Methodology and a research report completed for her BSW degree to ensure competency in conducting the research study.

3.7.6   Harm to respondents

Knowing that participants could be harmed in a physical and/or emotional manner, the researcher ensured that there was no risk envisaged during the study. This was ensured by the researcher by thoroughly informing participants beforehand about any possible emotional harm and by referring them for counseling to another social worker, if needed, Mrs Naomi Nkabinde, with whom prior arrangements were made. This was, however, not necessary as there was no need.

3.7.7   Debriefing of participants

Being taken through a direct and reflective process, especially in the qualitative research, affects the persons involved and they may discover things about themselves that they did not know before (Strydom, 2011:122). Participants were given the opportunity to work in the aftermath of the experience of the study by means of a debriefing session with the researcher. This offered participants the opportunity to get their questions answered and misconceptions removed. Participants were taken through a direct reflective process, as

in qualitative research. This gave them the opportunity to discuss their feelings about the process immediately after the session.

The researcher also checked whether what she had heard in the interview was an accurate reflection, as a form of member checking.

3.7.8   Publication of findings

Making the research report available in simpler language is another way in which the project can be rounded off ethically so that subjects can know exactly what has happened to the information (Strydom, 2011:126). After the study has been completed, an article will be written with the supervisor as co-author and submitted for possible publication in a scientific journal. Findings will also be presented nationally and internationally at applicable conferences. Findings of the study will be introduced to the reading public in a mini-dissertation in the University of Pretoria Library.

3.7.9   Compensation

Since permission was sought from company management to get time off for participants to participate in the study, there was no form of compensation for participation in the study. Strydom indicates that in some instances people might want to participate in the study due to the compensation and therefore the aim of the study might be compromised (2011:121). However, this was not the case in this research as it was made clear that no compensation would be offered.

3.8   EMPIRICAL FINDINGS OF THE STUDY

As indicated earlier, this chapter presents analyses and interprets the empirical findings. Data were collected through in-depth individual interviews with nine (inclusive of the two participants from the pilot study) participants who are living with HIV and who have disclosed their HIV status in the Swedish workplaces. In this study, the researcher analyzed the data using text analysis according to Creswell's model with the aim of bringing order, structure and meaning to the mass of collected data. The data were

categorized into themes and sub-themes, interpreted, and verified with literature. The findings are presented in two sections as follows: **Section** 1: a biographical profile of the research participants; **Section 2: a** thematic analysis of the themes and sub-themes that emerged from the process of data analysis. Each theme and sub-theme will be discussed, verifying the findings with verbatim quotes from the interviews and substantiation with the literature.

3.8.1 Section 1: Biographical profile of participants

Participants in the research were profiled according to gender, age, marital status, race, language, highest qualification, company level of occupation and period of diagnosis.

3.8.1.1 Gender

In the study the majority of the participants were females. Eighty-eight percent (88%) of the participants were female, while 11% of participants were male. The high percentage of female participants is supported by the fact that the average percentage of VCT uptake in the Swedish Workplace HIV and AIDS Programme was recorded at 69% women and 31% men in SWHAP Annual Report (2016). The Guidelines for Integrating Gender focus on HIV and AIDS (2002:6) elaborates that gender-based inequalities contribute significantly to the vulnerability of young girls and women to HIV and AIDS. It further elaborates that because of their low status, women and girls are not in a strong position to negotiate safer sex. According to A Review (2002:13), the growth rate for the number of women with HIV has far outstripped the growth rate for men.

3.8.1.2 Age of participants

Age segregations

- 11,20% — 25-35
- 44,40% — 35-45
- 33,30% — 45-55
- 11,10% — 55-65
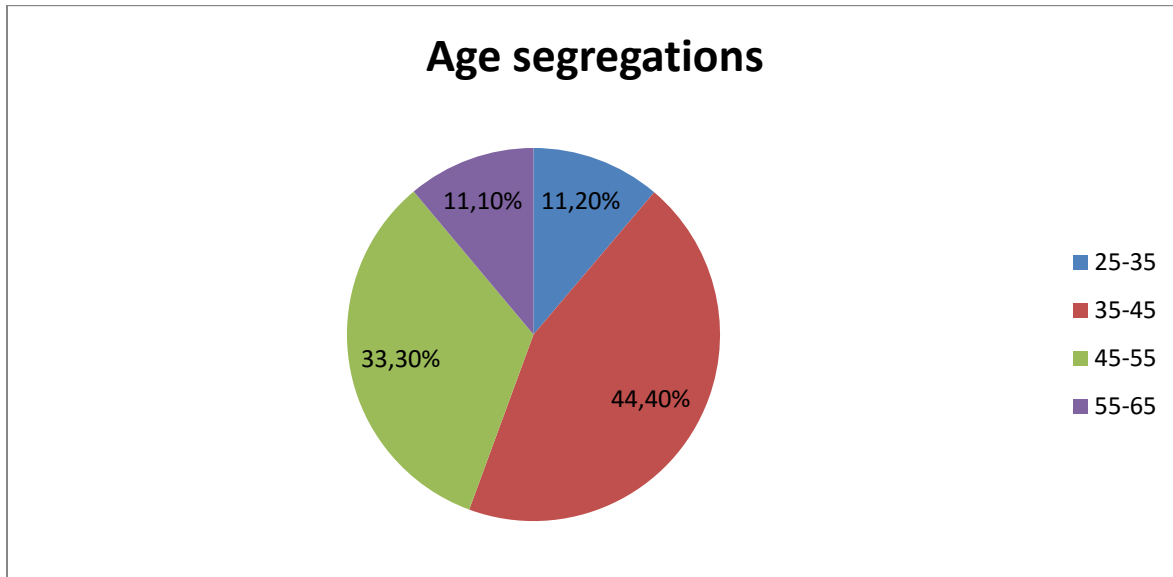
n = 9

**Figure 3.1: Age distribution of participants**

The majority of the participants were between the ages of 35-45 years and 45-55 years. According to A Review by USAID (2002:13), AIDS tends to strike young adults, and therefore it reduces the life expectancy of the population as a whole, and increases the burden of the working population. Other authors emphasize that since HIV and AIDS is predominantly a sexually transmitted disease, it causes illness and death among mature adults. The group at greatest risk is those between 15 and 50 years of age, often described as the 'sexually active'. These are the most productive people in any society (Barnett & Whiteside, 2002:3). The figure above seems to confirm the statements by various authors that HIV affects those in their active and productive years.

3.8.1.3 Marital status of participants

Figure 3.2 reflects the marital status of participants. The HIV and AIDS prevalence among single people were 55.5% compared with 33.3% for married people. There was also a very low percentage 11.2 of widowed participants. Studies have shown that there is a link between HIV and AIDS and marital status (Shisana, Zungu-Dirwayi, Toefy, Simbayi, Malik & Zuma, 2004:537). According to Shisana, et al. (2004:54), the relationship between

marital status and HIV and AIDS is complex. The risk depends on various demographic factors and sexual behavior practices. Increased prevention strategies that take socio-cultural context into account are needed for married people. Shisana, et al. (2004) further indicate that as early as the 1990s, researchers recognized that marriage could be a risk factor for acquiring HIV infection. Shisana, et al. (2004:537), argue that the risk of HIV in marriage is directly linked to non-use of condoms. Some studies have found that married people are less likely to use condoms as a preventive strategy for HIV. Looking at the data distribution from Figure 3.2, the risk of HIV infection did not differ significantly between married and unmarried participants.
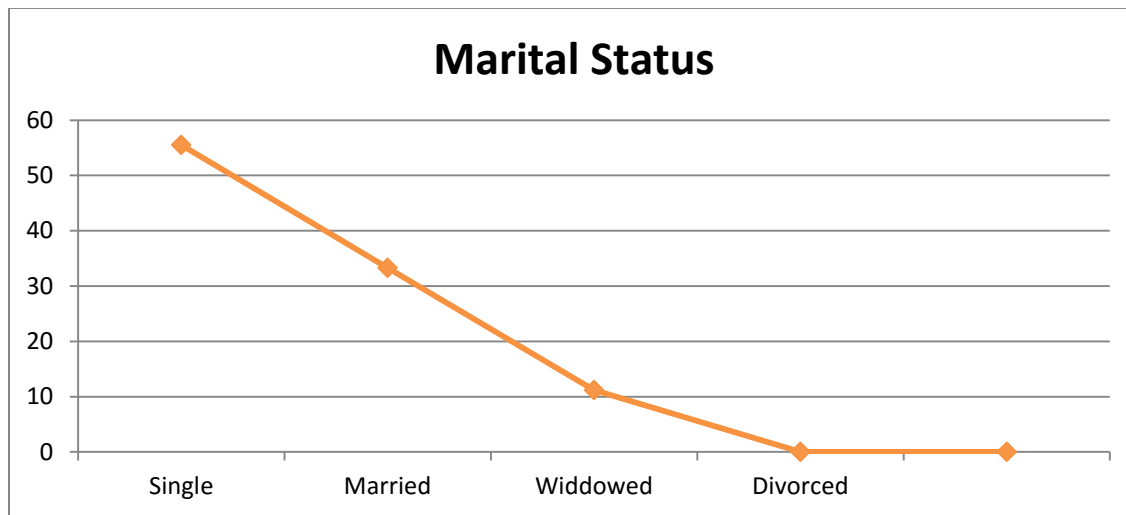
n=9

Figure 3.2: Marital status of participants

3.8.1.4 Race of participants

Most of the participants were African people. Fifty-five percent (55%) of participants were Coloured, while 44.5% were Blacks. With a view of the high percentage of Coloured participants in the study, one will note that two of the three companies that participated in the study had a greater number of Coloured employees than Africans. Dickenson (2009:7) however, explained that a national seroprevalence survey conducted by the Human Science Research Council (HRSC) indicated a vast difference in infection rates between the four racial categories used in South Africa: Africans, Coloureds, Indians, and

Whites. These four categories were inherited from apartheid and continue to be used in South Africa, both for official purposes, notably Employment Equity legislation, and, with some variation, in popular discourse. The findings of the study confirmed Dickenson's (2009:8) doubts that there is room to question the precise levels found in this survey that HIV prevalence is much higher among Africans than other racial groups because in this study there was greater prevalence among the Coloured population.

3.8.1.5 Language of participants
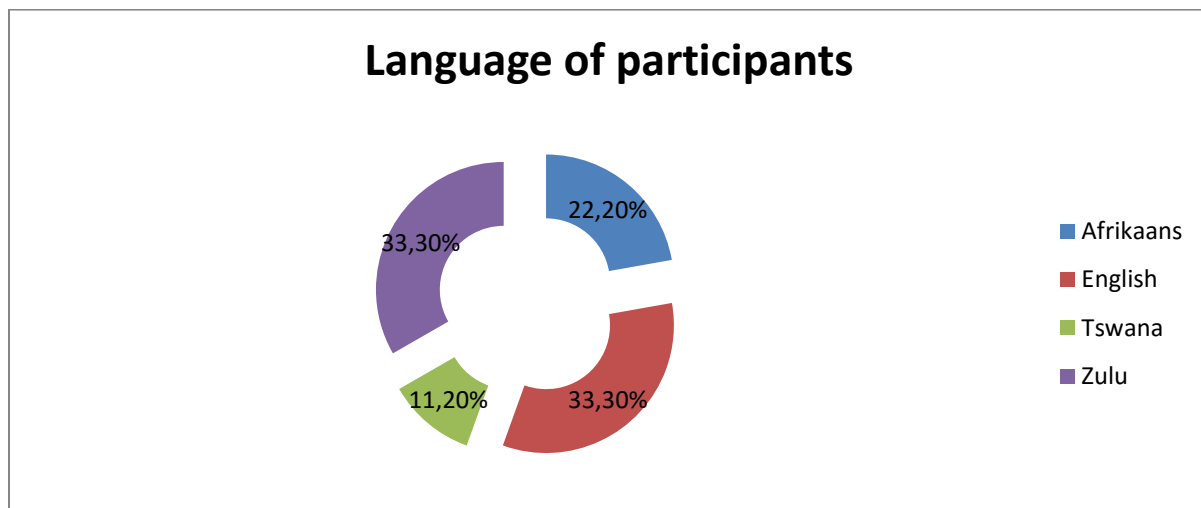
N=9

Figure 3.3: Language of participants

In this study, the language of choice was English as presented in Figure 3.3. The percentage of participants who were English speaking was 33.3% and another 33.3% was for Zulu-speaking participants. The remaining language percentages were 22.2% for Afrikaans and 11.2% for Setswana. The researcher accommodated four languages that were reflected by the sample. The preferred language of participants was primarily used.

3.8.1.6 Highest qualification of participants

Figure 3.4 below reflects the qualifications of the participants. The highest qualification of the participants was Grade 12 at 55%. The lowest qualification among the participants

was Grade 10 at 33.3%. A few of the participants reported having only finished Grade 11. This grouping gave an understanding that the participants were in a better position to read and write and had high levels of literacy. This can be related to their ability to read messages such as AIDS prevention pamphlets and prevention messages on the company notice boards.
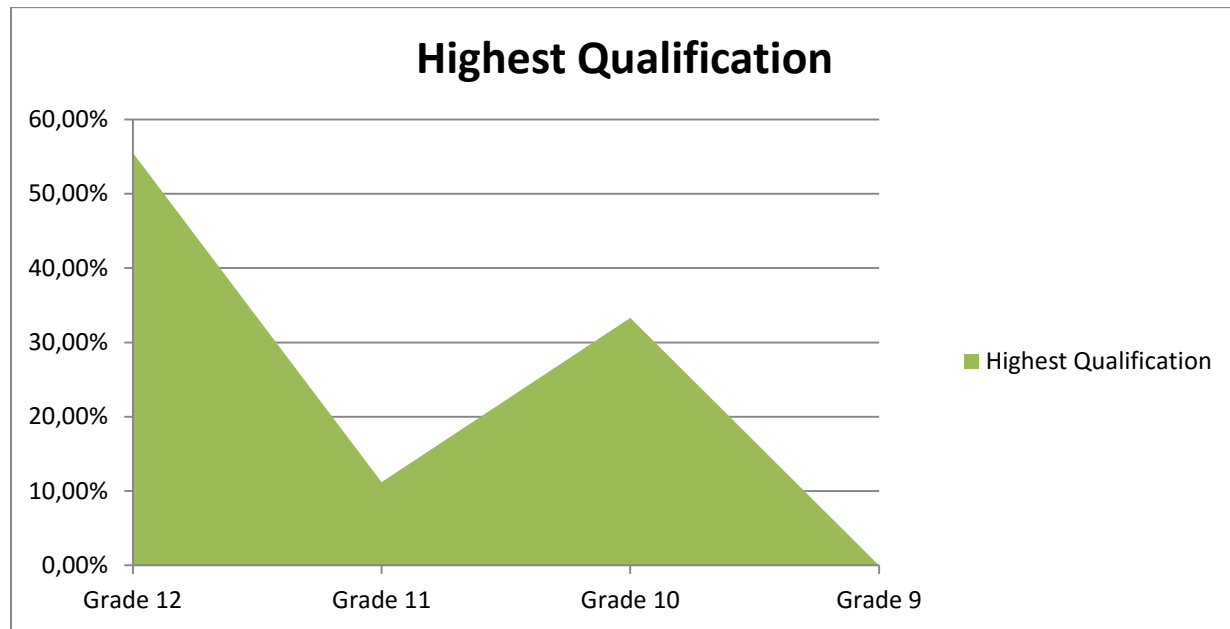
n = 9

Figure 3.4: Highest qualification of participants

3.8.1.7 Company occupational level

In this study, it was noted that 77.7% of participants were unskilled, while 22.2% were skilled. The study for Health Policy; School of Public health (2004:128), however, argues that while several studies, including the current one, report a higher prevalence of HIV amongst lower-skilled employees, we need to be clear that HIV is not just a virus reserved for so-called 'unskilled laborers'. By 2010 it was estimated that about 15% of highly skilled workers would be infected with HIV. The costs of HIV and AIDS may be most striking for skilled workers, where instant substitution is more difficult. This was the reflection among Swedish companies where the majority of employees were mostly unskilled labourers.

3.8.1.8 Period of diagnosis

Figure 3.5 reflects that the majority of participants in this study indicated living with HIV for more than five years and the other majority have been living with HIV for more than ten years. Page, et al. (2006:70) articulates that there are people with HIV and AIDS who live healthy and productive lives for many years, even without access to antiretroviral drugs. Some adults have been known to stay in good health for over two decades after being infected with HIV.

It is evident from the participants that people living with HIV are employable and can also contribute to the economy. Consider South Africa's well-known Justice of the Supreme Court of Appeal, Justice Edwin Cameron. He was infected in the early 1980s, received his results confirming that he was HIV-positive in 1986, but only started to take antiretrovirals in 1997. Thus, he continued to work effectively without antiretroviral treatment for almost 15 years (Page, et al. 2006:70) and has been living positively on ARV's for 19 years. This is what is evident with the participants in this study.
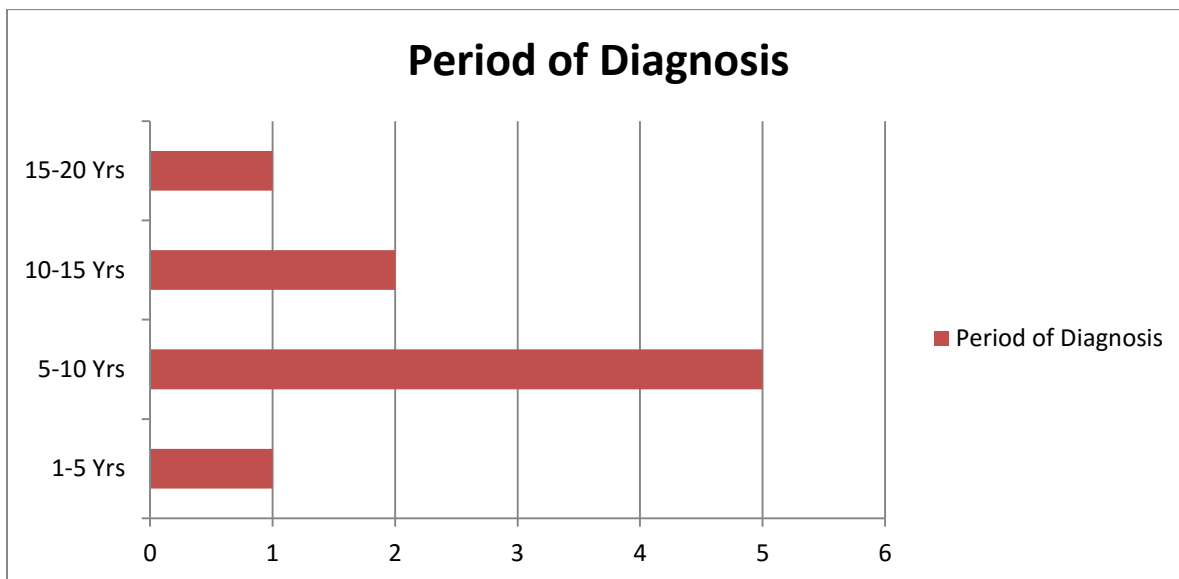
n = 9

Figure 3.5: Period of diagnosis of participants

3.8.2 Section 2: Qualitative thematic analysis

In this section, the qualitative data findings are discussed according to themes and sub-themes generated from the data.

Central theme: Participants felt safe and supported within the SWHAP by the company, sister/doctor, family, and significant others.

Table 3.2: Summary of the themes and sub-themes

NUMBER	THEME	SUB-THEME
1.	Knowledge of the Swedish Workplace HIV and AIDS Programme	1.1. Education/training on HIV 1.2. Motivates people to know their HIV status 1.3. Access to safe testing at the workplace
2.	Sense of security about procedures of SWHAP	2.1 Maintain confidentiality between professional and employee 2.2 Disclosure 2.3 Testing done in a safe environment
3.	Support services from SWHAP	3.1 Support from health care professionals 3.2 Family and significant others' support 3.3 Managerial/company support 3.4 Counseling support services
4.	Emotional experiences	

Each theme is discussed according to the following:

- Sub-theme;
  - o Quotations to verify the findings and substantiation with literature.
- Discussion on themes.

3.8.2.1 Theme 1: Knowledge of the Swedish Workplace HIV and AIDS Programme

The majority of the participants indicated that they know and are aware of the SWHAP. It was motivating to note that those who knew about SWHAP associated it with HIV and AIDS knowledge transference and the support that the programme gives to HIV-positive and all other employees. The three sub-themes that were identified were the following:

- Education and training on HIV
- Motivation for people to know their status
- Access to testing in the workplace.

The following quotes from participants confirm that participants had some level of knowledge of the SWHAP:

- "SWHAP ... is conducting on awareness in workplaces. What to be done and to prevent infection ... and its focusing on places. …"

- "SWHAP it is more like a Swedish company that participates in people that has HIV AIDS… It helps, it gives us knowledge and ..., yah it gives us more inside information on what's going on…"

- "SWHAP is the people that help the people that are HIV-positive…"

- "We were exposed here about SWHAP. That company is in a group with other companies. There is this group that was formed for HIV employees".

- "And on my personal life, she like the programme gave me that encouragement to say, I am not alone…"

Looking at the statements above, it can be noted that participants had varied knowledge about the SWHAP and its role in the workplace, but it was also encouraging to see that at the same time they have awareness and understanding of the SWHAP and its role in the Swedish workplaces.

Sub-theme 1.1: Education/training on HIV

Although a participant expressed being knowledgeable about the SWHAP, the majority emphasized being more educated on aspects of HIV and AIDS, since being on the

Swedish Workplace Programme. Most participants admitted having received some training on HIV from the workplace and or the SWHAP.

The following quotations reflected that participants received education and training:

- "Because of SWHAP I was very interested in it because, I learned a lot from them."

- "They taught us that don't let the disease take control of your life; you need to take control of the disease…"

- "The company has taught us, they gave us the knowledge that is what is HIV, how do you treat somebody with HIV"

- "When we have World Aids Day… different people from different places come over to do drama… For us to understand and to know about this".

- "The company has taught us, they gave us the knowledge on what is HIV, how do you treat HIV, somebody with HIV? They even give you events like World Aids Day on the First of December"

- "There are a lot of opportunities. There are a lot of things to encounter. There are lots of things to learn…"

Participants expressed that they have been exposed to HIV education and training through the programme. Page, et al. (2006:104) alludes to the fact that many people are aware of HIV and AIDS, but there appears to be a lack of basic knowledge about the disease. The participants' experience about the education received proved contrary to the literature formulation by Page, et al. that there appears to be a lack of basic HIV and AIDS knowledge. Participants articulated that they have been given opportunities to receive education and training on HIV and AIDS.

The various myths and misconceptions that people have about HIV and AIDS are further barriers to awareness and effective action. Organizations need to do more than inform employees about HIV and AIDS education and deal with underlying fears that may cause mistaken beliefs. HIV and AIDS education should not be a one-way transfer of information but should give workers a chance to discuss their fears and concerns. Furthermore, the authors recommend that HIV-positive people have a very important role to play in

educating, removing stigma, and highlighting the severity of AIDS to people around them (Page, et al. 2006:104).

This can be seen as a way of continuing education and also a good entry point for workplace peer education. Some literature also suggests that employee characteristics, such as difference in upbringing, value systems, knowledge about and experience with HIV, and willingness to learn new information, may have an impact on employee receptivity to training and acceptance of HIV information, and the attitude regarding the behavioral transmission of HIV (Walch, Lezama & Giddie, 2005:67). Because of the myths around HIV, it is of critical importance to ensure that everyone is educated and trained to have accurate information on HIV.

Sub-theme 1.2: Motivates people to know their HIV status

Most participants indicated that the workplace programme motivated them to know their status. This is a benefit to both the individual and the origination. According to Pratt (2003:82), many people remain completely asymptomatic and unless tested for some other reason, they will be unaware that they are infected. However, they remain infected and infectious to others. Others may develop an unusual self-limited illness and then recover (acute seroconversion syndrome) during primary infection. Steven (2001:178) confirms that Voluntary Counseling and Testing is the primary access point to HIV and AIDS clinical care and psychological support and provides an opportunity for education and motivation to modify behavior aimed at reducing the risk of HIV and AIDS transmission. It further explains that knowledge that leads to action, such as VCT participation, promotes risk reduction through increasing perception of risk, self-efficacy and personal skills (Steven, 2001:178).

The following quotes support this sub-theme:

- "Whether you tested positive or you tested negative you go home. The way I see it, it makes people want to or wish to…encourages people to test…"

- "That is why they encourage me SWHAP. With all the motivations and the things they give us…"

- "Then they encouraged us to get test everything…"

- "I got tested because of the information I got from work and I said to myself let me go get tested and find out what is happening?"

- "Yah, they let people with HIV and AIDS to and they come and talk to us"

These quotes confirm what the author explains about participants being motivated and encouraged to test voluntarily with the aim of reducing risk and modifying behavior, because once people know their status, they get to change their behavior. Steven (2001:178) further highlights that external factors affecting HIV and AIDS test participation, include perceived levels of stigma and support, confidentiality, and quality of services. The majority of participants confirmed that they received support and their status was kept confidential.

Sub-theme 1.3: Access to safe testing at the workplace

Most participants admitted to having tested at the workplace and that the procedures were safe and voluntary. Page, et al. (2006:108) also explains that testing or screening for HIV can have an adverse impact on the workplace because it can lower the morale of the staff. If employers force employees to be tested, it could also lead to fear and anxiety among the workers. It could create the impression that the employees are at risk of losing their jobs and will create panic.

Participants reflected the availability of free, voluntary, and safe testing at their workplaces:

- "It was a World Aids Day event, but they do it on a regular basis"

- "Yah, the first time they let all the people to test"

- "HIV testing being done in a safe environment"

- "Because another thing that made to get tested here is at work they make us to feel free about testing…"

- "Ok firstly it happened that when they first came for the HIV testing here at the workplace. I saw that they are doing it, they are using the right procedures…"

- "By saying anyone who wants to test like, you will get tested and will be confidential"

Barnett and Whiteside (2002:105) express that it is significant that HIV and AIDS interventions take place in a supportive environment. In 1998 the legislature passed the AIDS Prevention and Control (RA 8504). This prohibited mandatory testing for HIV and emphasized human rights, and it provided that individuals with HIV should have basic health and social services and that there should be accredited HIV testing centers.

- **Discussion of theme 1**

Theme 1 gave a clear confirmation that participants were aware of the Swedish Workplace HIV and AIDS Programme and had participated and benefited from the services offered by the programme. The key finding from the theme was that the programme created availability of testing opportunities and education on HIV provided for by the workplace, which encouraged the employees to know their status. Also, testing was not only made available, but it was conducted in a safe environment and according to legislation and protocol. Participants' understanding of their company eco-map demonstrating their relationships with their environment or organizational systems was highlighted. Systems such HIV education, voluntary testing, and counseling and post testing support promoted the interest for employees to know their status and respond positively to the SWHAP

3.8.2.2 Theme 2: Sense of security about procedures of SWHAP

Despite the robust attempts by many institutions and organizations to demystify HIV initially portrayed as a deadly disease, HIV and AIDS remain a sensitive issue which is also regarded as a human rights issue. Protecting the human rights of individuals living with HIV and AIDS pays attention to aspects such as confidentiality, voluntary testing, and disclosure often at the forefront.

Sub-theme 2.1: Maintain confidentiality between professional and employee

The majority of participants emphasized that they did not have any problems regarding confidentiality after diagnosis or disclosure.

The following quotes from participants confirm that confidentiality is being upheld and taken seriously in all three Swedish workplaces.

- "By doing, by saying anyone who wants to test like, you will get tested and it will be confidential. When a person is done getting tested they will get counseling and after that the person will go home…"

- "…She takes confidentiality very seriously…she made it a point to me that she assured me that it was between us and I believe her and I know she is a very. A person you can confide in. you can confide in her everything…"

- "I never heard anyone talk about it ever…"

All employees, current or future, have the right to confidentiality with regards to their HIV and AIDS status. However, if an employee informs an employer of his/her HIV and AIDS status, the information by law, cannot be disclosed to any other person without that employee's written consent. If there is a breach of confidentiality in this respect, it can lead to disciplinary action and even dismissal (Page, et al. 2006:108). It is encouraging to note that most workplaces adhere to the legislation that helps to protect the confidentiality of people living with HIV and AIDS.

Sub-theme 2.2: Disclosure

The majority of participants indicated that they had disclosed their status to someone close to them like a family member, a friend, or colleague, including the clinic sister. Project Literacy (2001:43) enlightens that "when you feel ready to talk to someone that you feel comfortable with, and can trust, try talking to a person in your family or a friend that knows and understands HIV and who will not tell your secret to others." The quotes below from participants reiterate what the author articulates about the need to talk to someone that one trusts. According to Greeff, et al. (2008:313), voluntary HIV status disclosure is described as managed and concealment disclosure. With voluntary disclosure, the People Living with HIV and AIDS maintain control over the choice to

disclose, to whom he/she should disclose, and whether he/she should fully or partially disclose. Following are the quotations from participants about their disclosure experiences:

- "…I disclosed to my sister and I work with her here… and she is the only one that I told but I have never ever heard any news about me…"

- "I don't have much stress anymore. Like I used to look at them and think if I tell them they are going to stress out. But when I told my aunt she told me not to stress…"

- "Ever since I have been working here I don't want to lie. I am not even afraid to talk. If I see that you are sick… I talk you; hey you know it's like this, this and this. I talk about me…"

- "…the sisters for me to talk about this. I even told one of my family members…"

Participants expressed that they felt safe to disclose their status to people they were comfortable with, like the clinic sister and some of their family members. Project Literacy (2001:43) further advises that if a person feels comfortable enough with their status, they can choose to tell other people, people that they know and others that they might not know. This will encourage other people who are living with HIV to disclose their status. Page, et al. (2006:107) on the other hand believes that HIV-positive employees have to deal with stigma if their status is made known. There is a possibility that their colleagues will discriminate against them. People tend to treat those living with HIV as "others". However, it is reassuring to recognize that people living with HIV in the Swedish workplaces feel that they were never discriminated against because of their HIV-positive status.

Sub-theme 2.3: Testing done in a safe environment

All participants expressed that they were comfortable to test at their respective workplaces when testing was made available to them because they felt safe and it saved time. Similar findings were established in the multi-country study in Africa (ILO, 2015:44) where it was reported that workplaces used a variety of approaches to create an enabling environment for testing. These include developing and implementing workplace policies

and strong messages from senior management on zero discrimination. An enabling environment is characterized by management encouraging zero discrimination and stigmatization, maintenance of confidentiality and non-disclosure of HIV status. The following expressions were given by participants about them feeling safe to test at the workplace:

- "Ok firstly it happened that when they first came for the HIV testing here at the workplace. I saw that they are doing it, they are using the right procedures…"

- "…Because another thing that made to get tested here is at work they make us to feel free about testing…"

- **Discussion of theme 2**

Since HIV is still seen as a human rights issue, participants confirmed that their rights were protected throughout, from the testing period, to management and disclosure of their status. This is a clear indication that when the rights of people living with HIV and AIDS are protected, they are more likely to live a productive life. Theme 2 highlighted the importance of protection of confidentiality and giving the people living with HIV an opportunity to disclose their status to whoever they feel comfortable to self-disclose. Participants demonstrated their ability to navigate the various systems that affected their lives as a whole and how they respond to different services made available. At this point, the various sub-systems were interrelated and influenced one another. From participants getting tested, to the clinical management of the disease and disclosure, all were interlinked to how participant's confidentiality was protected.

3.8.2.3 Theme 3: Support services from SWHAP

The participants indicated after accessing testing services, they managed to get support from the SWHAP. Below is the sub-themes of the support from health care professionals, family and significant others, and management support.

Sub-theme 3.1: Support from health care professionals

All participants in the study indicated that they were supported by the clinic sister and in some cases the doctor as well. The majority reported that they only disclosed their status

to the clinic sister. They mostly expressed that the support from the sister helped them to cope with their mental and physical challenges. Most participants felt confident that their status is kept confidential by the sister. They also indicated that the sister supported them immensely with counseling, clinical management and medication when they were not feeling well.

The clinic sister's support was noted in the following quotes:

- "…Sister B gave it to us. She is the only one that supports this whole initiative and ..., I got it from her. She was very helpful…"

- "So the sister is there for me, they will give me support and they told me what to eat and what to do and ..., I must still, I live a positive life…"

- "…what I can say I feel free to talk to sister and comfortable more than anybody else…"

- "…The support that they have given me even the sister… she gave me support. She would advise you. She will talk about anybody else…"

- "…I said it made a big difference. The sister always monitors me…"

The aspect of support from health care practitioners in the workplace is confirmed by Page, et al. (2006:114); that the programme should manage and care for HIV-positive people and their families. This should be done through counseling and health care of infected employees.

This type of support expressed by participants can be viewed as a significant improvement from health care practices, as also pointed out by authors such as Fan, et al. (2004:180). These authors indicated that at the outset of the AIDS epidemic, numerous examples of discrimination were evident against those living with HIV and AIDS by health care workers and institutions. Some health care workers refused to treat those living with HIV. However, Fan, et al. (2004:180) highlights that currently, the situation has considerably improved from that at the outset of the AIDS epidemic. Part of the reason for this is the increase in our knowledge base of HIV and AIDS. In light of the above findings, it is very encouraging to note that in all three Swedish companies there are

health care professionals who not only played a supportive role to people living with HIV and AIDS but also adhered to their professional ethics of upholding confidentiality.

Sub-theme 3.2: Family and significant others' support

Support is a very critical component of HIV and AIDS management. Support may be given to people living with HIV in varied ways, including family support. Many participants in the interviews indicated that they received support from their family members after being diagnosed.

The quotes below reflect some of the participants' responses with regards to the family support they received.

- "…My mother has me and my sister and my sister is the only one I talk too… I explained to him saying my brother it's like this, like this and like this. And he said don't stress…"

- "…cause I got the good support from my family. We are a very close family… so I get a lot of support from them."

- "I don't have much stress anymore. Like I used to look at them and think if I tell them they are going to stress out. But when I told my aunt she told me not to   stress…"

The above quotes validated the participants' expressions of their support systems. Many reflected on the support they received from family members after they got diagnosed, which they perceived as being pivotal to their HIV journey. According to the WHO (2009:No Page), HIV infection affects all dimensions of a person's life; physical, psychological, social and spiritual. With adequate support, PLWHA are more likely to be able to respond adequately to the stress of being infected and are less liable to develop severe mental health problems. HIV infection can often result in stigma and fear for those living with the disease, as well as for those caring for them, and may affect the entire family. Infection frequently results in loss of socio-economic status, employment, income, housing, health care, and mobility. For both individuals and their partners and families, psychosocial support can assist people in making informed decisions, coping better with illness, and dealing more effectively with discrimination. It improves the quality of their

lives and prevents further transmission of HIV infection. It was therefore observed that the amount of support that the participants indicated they received and are still receiving from their family members contributed positively to them accepting their HIV-positive status and managing their lives effectively.

Sub-theme 3.3: Managerial/company support

Contrary to popular belief about the hostile relationship between employers and employees in the workplace, participants employed in the three Swedish workplaces expressed the following about the support they receive from management:

- "Yah, it helped me. It helped me a lot because, the company itself played a big role for me …the company made the services of the medical aid available so that we can be respected…"

- "…I believe that its support… it comes from the company… the company has taught us, they gave us that knowledge that what is HIV, how do you treat HIV, somebody with HIV? They even give you like a World Aids Day on the First of December…"

- "…It was wellness day…the company has supported us…"

- "The support that I got from my workplace is number one, the treatment because the sister tests us all the time and like she talks about it. We get the medication at work. We get everything at work. Which means they are very supportive"

- "The company has taught us, they gave us the knowledge that is what is HIV, how do you treat somebody with HIV"
- "But then, the company made the services of the medical aid available so that we can be respected."

The above expressions contradict conventional views of authors like Dickenson (2009:21), who points out that mistrust of management is widespread in South African workplaces. Page, et al. (2006:107) outlines the following as needed from management as a form of support to HIV-positive employees: Managers need to give assistance with access to health services outside the workplace. If these are not available in the workplace, time off from work should be allowed to attend clinics or counseling, transfer to lighter or less stressful duties where it is both necessary and possible, and when employees are no longer able to work, they should be offered early retirement with normal

medical benefits. Employees who retire due to ill health must be informed in advance of the benefits for which they may or may not be eligible (that is, medical aid, life insurance, and so on). The majority of participants confirmed that there is much-needed support from their employer or their managers.

Sub-theme 3.4: Counseling support services

By law, an HIV test should not be given without pre-test counseling, and the person should not be given his/her results without post-test counseling, even if the results of the test are negative (Page, et al. 2006:60). With the recent developments on HIV and AIDS, the WHO (HIV and AIDS Services, 2016:1) details that HIV testing services (HTS) include a full range of services that should be provided together with HIV testing. All HIV testing services should continue to be provided within the WHO's essential 5Cs: Consent, Confidentiality, Counselling, Correct test results, and Connection (linkage to prevention, care and treatment). This includes pre-test information, post-test counseling, linkage to appropriate HIV prevention, care and treatment services and other clinical and support services, quality HIV testing, accurate test results and diagnosis, and coordination with laboratory services to support quality assurance.

The majority of participants indicated that they got access to counseling both before and after testing. Some reported that the counseling is still continuing. The following affirming statements from participants confirmed the availability of counseling services in the workplace:

- "…they send you for counseling… that they can counsel you if you are in that position…"

- "…She was giving us therapy and ..., ok speaking for myself. She was giving me therapy, she was understanding, she is a good listener, she gave you more insight and she was making her available for questions when you want to ask and she is just an open person…"

- "…she encouraged me she said, she give me counseling and she said to me ..., Rochelle please just do the right thing because I've got 2 children of mine…"

- "…they send you for counseling… that I can counsel you if you are in that position…"

- "…I come for counseling and they talked to me and what not so I went to a place is there in Krugersdorp they give you counseling about all your issues and what not…"

- "When a person is done getting tested they will get counseling and after that the person will go home"

HIV counseling and testing have been available in South Africa since 1985 (Rohleder, et al. 2009:165). While counseling and testing have been shown to be an effective method of HIV prevention and is a critical point of entry for HIV treatment, care and support services among persons who are HIV-positive has been established as one important pillar of HIV management. It is encouraging to confirm that workplaces are following the proper procedures and protocols outlined by South African legislations in terms of counseling and testing of HIV-positive employees.

- **Discussion of theme 3**

The stigma surrounding HIV and AIDS makes life more difficult for people living with HIV and AIDS and their families. Loneliness, anxiety, stress, confusion, bitterness and depression can make people more vulnerable to illness if they do not get any kind of support. People living with HIV and AIDS need a lot of emotional, spiritual, psychological, social, physical, and clinical support. Theme 3 highlights the importance of support from health professionals, family, and colleagues. The majority of participants indicated that support was a very pivotal contributing factor in them living positively with the disease. To help participants to remain functioning as members of their families, society and workplaces for as long as possible, the effective use of internal and external support systems helped to improve their coping mechanisms. Systems such as their clinic nurses, local NGO'S, and members of their families such as their partners, spouses, children and siblings, became a strong support base for employees living with HIV.

3.8.2.4 Theme 4: Emotional experiences

Most participants expressed how they went through a series of emotions when they first got diagnosed. The following confirming statements from participants describe the intensity of the positive diagnosis on an individual. Rohleder et al. (2009:191), alludes that knowledge of one's status is a key turning point in a stream of actions as revealed by participants bellow:

- "I didn't want to talk about it, it made me angry"

- "At one point I was confused…"

- "Some people can't handle it and …They kill themselves".

Testing for HIV is very different from testing for any other disease or medical condition. The results of an HIV test can have enormous psychological and social implications for the person being tested (Page, et al. 2006:60). Fear brings about most of the actions and beliefs of people. Most people are not consciously aware of the fact that they feel this emotion. Fear is closely linked to denial, and both have similarities. Fear creates a view of the world where HIV and AIDS and everything surrounding it is seen with varying degrees of anxiety, unease, danger or stigma (Page, et al. 2006:106). Rohleder, et al. (2009:199) also confirm the feelings expressed by participants by pointing out that, the knowledge of status affects mood, relationships, social functioning, legal and human rights.

- **Discussion of theme 4**

Theme 4 confirmed the fact that testing HIV-positive is an emotional experience. Participants highlighted the fact that it is only normal to go through a series of different emotions after being diagnosed. This highlights the fact that an HIV-positive status is a life changing experience which can be emotionally draining. Participants acknowledged that the initial thought that AIDS always ends in death evoked irrational feelings. The internal company support systems, such as counseling and health care service providers, primarily geared towards offering psychological and social support to employees in the workplace living with HIV, assisted them to cope with the overwhelming emotions.

3.9   SUMMARY

The aim of this study was to understand the experiences of people living with HIV who are employed in Swedish workplaces and who are living with HIV and had been participating in the workplace support programme. The chapter focused on addressing the objective of exploring the experiences of HIV-positive employees regarding their participation in the Swedish Workplace HIV and AIDS Programme. From the qualitative data collected from participants, it was evident from theme 1 that participants were aware of the Swedish Workplace HIV and AIDS Programme and the role it plays in their workplaces. Participants indicated in theme 2 that they experienced being diagnosed with HIV through the workplace testing opportunities, gave them an opportunity to receive support from both the company clinics and management which helped them to cope with their diagnosis. From the data collected, it was highlighted in theme 3 that people living with HIV, if entirely supported in the workplaces, through workplace psychosocial support and employee assistance programmes, can be as productive and as efficient as any other employee in the workplace. It was further established in theme 4 that it is normal for people who have just been diagnosed to go through a series of emotions. This is what makes support a crucial component of workplace programmes.

The themes that were generated from the data were as follows:

- Theme 1: participant's knowledge of the Swedish Workplace HIV and AIDS Programme
- Theme 2: participant's sense of security about procedures of SWHAP
- Theme 3: participant's experiences on the support services from SWHAP
- Theme 4: participant's emotional experiences while participating in the SWHAP

The next chapter focuses on the conclusions and recommendations.

CHAPTER FOUR
CONCLUSIONS AND RECOMMENDATIONS

4.1 INTRODUCTION

The HIV epidemic has created an enormous strain on health care and the workplace. It is evident from previous research that it is challenging to run a profitable and sustainable business in an environment where companies are faced with compounding risk factors such as HIV and AIDS that hinder growth and directly or indirectly affect the company productivity. In this context, it was important to understand how HIV and AIDS is affecting businesses, what are the strategies that are in place in the workplace to support people who are living with HIV, and what can be done to mitigate the impact of HIV on organizations. Literature studies show that there is encouraging progress made in addressing HIV and AIDS both in the public and private sector and non-governmental organizations (NGOs). Yet, much remains to be done. In this study, the results indicated that workplace programmes create an opportunity for employees to gain more knowledge on HIV and AIDS, give access to testing in a safe environment, and offer support to those who have tested HIV-positive. HIV and AIDS workplace programmes play a crucial role in supporting people living with HIV.

This chapter will present the summary, where the achievement of the objectives and aim of the study will be discussed, and the key findings, conclusions and recommendations will be presented.

4.2 SUMMARY OF THE OBJECTIVES AND AIM OF THE STUDY

The objectives, aim of the study, and research question will be discussed in relation to how they were met through this study.

4.2.1 Objectives

The objectives of the study were:

- To conceptualize the field of HIV and AIDS in the workplace.
- To describe the Swedish Workplace Programme in SA.
- To explore the experiences of HIV-positive employees regarding their participation in the Swedish HIV and AIDS Workplace Programme.
- To make recommendations for improvement of the Swedish HIV and AIDS Workplace Programme.

The table below focuses on how the aim and objectives were achieved in the study.

Table 4.1: Achievement of aims and objectives

NO	OBJECTIVES OF THE STUDY	OBJECTIVES OF THE STUDY ACHIEVED
1.	To conceptualize the field of HIV and AIDS in the workplace.	This objective was achieved fully by conceptualizing HIV and AIDS in the workplace as discussed in Chapter 2. Section 2.4 highlights that there was a realization to the business community that the world of work cannot ignore nor deny the reality of the impact of HIV and AIDS on its profitability, which prompted action to respond to the HIV and AIDS scourge. Section 2.6 further highlights that the workplace plays a crucial role in addressing HIV and AIDS and offers a valuable entry point to reach female and male employees in the setting where they spend much of their time. In achieving this objective, it was realized how the general systems theory was applicable with regard to the effect on the individual in the workplace. Section 2.8

NO	OBJECTIVES OF THE STUDY	OBJECTIVES OF THE STUDY ACHIEVED
		shows that issues such as unfair discrimination against people living with HIIV and AIDS perpetuate counterproductive systems such as pre-employment HIV testing, dismissals for being HIV-positive, and the denial of employee benefits.
2.	To describe the Swedish Workplace Programme in SA.	This objective was fully achieved by the description in Chapter 2 of the Swedish Workplace Programme in the Sub-Sahara Africa, and particular focus on South Africa. It indicates in Section 2.3 that SWHAP is an example of how workplace management, and employees can work together to contribute to interventions that save lives and make business sense. The general systems theory gave an understanding of how individuals, who are employees living with HIV and AIDS, interact with organizational systems, which in this study refers to the Swedish Workplace HIV/AIDS Programmes. The SWHAP strategy for the companies has been to gain entry through management sensitization and setting up of steering committees that are representatives of both workers and management for collaboration in programme implementation. This objective was further achieved in Section 2.4 by showcasing how SWHAP is also an innovative approach to development. Here, aid is channeled through the private sector

NO	OBJECTIVES OF THE STUDY	OBJECTIVES OF THE STUDY ACHIEVED
		for more effective and long-term results, where the strengths of business in terms of logistics, systems and efficiencies mean quite simply that more can be achieved for less.
3.	To explore the experiences of HIV-positive employees regarding participation in the Swedish HIV and AIDS Workplace Programme.	This objective was achieved in Chapter 3 through the empirical research and is illustrated in the discussion of the qualitative empirical findings on the experiences of people living with HIV and AIDS regarding the Swedish Workplace Programme. In Section 3.5.3 it is highlighted that qualitative data was collected in this study through semi-structured individual interviews used as a data collection method. This type of interview was designed to describe the subjective, lived experiences of people and to comprehend the meanings that people attach to these experiences (Creswell, 2007:57). This assisted the researcher to gain in-depth knowledge from participants about their experiences of utilizing the workplace HIV programmes. This objective contributed to the realization about how the employees living with HIV interacted with their internal systems within their environment which were their respective workplaces and how the internal support in the form of workplace HIV and AIDS programmes, contributed to their wellbeing.

NO	OBJECTIVES OF THE STUDY	OBJECTIVES OF THE STUDY ACHIEVED
		The themes that were generated from the data in this regard were as follows: • Theme 1: Knowledge of the Swedish Workplace HIV and AIDS programme • Theme 2: Security about procedures of SWHAP • Theme 3: Support services from SWHAP • Theme 4: Emotional experiences while participating in this workplace programme The themes helped to achieve this objective by realizing that the goal of the establishment of workplace programmes should be to try and keep healthy infected and affected employees working. With treatment programmes being affordable, disease management is a strategic option for companies.
4.	To make recommendations for improvement of the Swedish HIV and AIDS Workplace Programme.	This objective was achieved by the recommendations in this chapter (Chapter 4). These recommendations focus on aspects to help contribute to the improvement of the Swedish HIV and AIDS Workplace Programme. There were some conclusions, such as that the majority of participants knew about SWHAP but did not know its role in their workplaces. This indicated how disengaged the individuals and the organizational systems were. Section 4.3.1.1 recorded a key finding that reported that there were participants who

NO	OBJECTIVES OF THE STUDY	OBJECTIVES OF THE STUDY ACHIEVED
		were either not aware of the SWHAP or did not know the difference between the SWHAP and their company service provider.

These objectives contributed to meeting the aim of the study, which was as follows.

4.2.2 Aim

The aim of the study was to explore and describe the experiences of Swedish company employees living with HIV and AIDS with regards to the Swedish Workplace HIV and AIDS Programme (SWHAP).

4.2.3 Research question

Based on the above, the following research question was addressed and met by means of the study with the themes, as generated by the study answering the question.

"What are the experiences of Swedish company employees living with HIV and AIDS regarding the Swedish Workplace HIV and AIDS Programme?"

4.3 KEY FINDINGS AND CONCLUSIONS

The following conclusions were made based on the empirical findings of the study which explored the experiences of people living with HIV in the Swedish companies.

4.3.1 Theme 1: Knowledge of the Swedish Workplace HIV and AIDS Programme

The theme focused on establishing whether participants knew SWHAP and how much knowledge of SWHAP they have.

4.3.1.1 Key findings

The majority of the participants indicated that they know and are aware of the SWHAP and those who knew about SWHAP associated it with HIV and AIDS knowledge

transference and the support that the programme gives to HIV-positive and all other employees.

4.3.1.2 Conclusions

In this study, participants affirmed their knowledge of the Swedish Workplace HIV and AIDS Programme and the role it plays in the workplace. However, there were other participants who were either not aware of the SWHAP or did not know the difference between the SWHAP and their company service provider. The latter articulated that they know more about the contracted service provider rendering HIV and AIDS services than SWHAP. The participants who had knowledge of SWHAP indicated that they acquired knowledge on HIV and HIV testing services in the workplace through the SWHAP. In addition, the participants emphasized that the SWHAP, motivated them to test for HIV in order to know their status.

4.3.1.3 Recommendations

- Swedish Workplace HIV and AIDS Programme should be more visible to the employees in the workplace.
- Swedish Workplace HIV and AIDS Programme should engage employees on the role and objectives of the programme in the workplace.
- It is recommended that the Swedish Workplace HIV and AIDS Programme embark on the following to fulfill the above two aspects:
  - Awareness raising and education for behavior change. HIV education is accessible on many platforms for people to access. However, there are still new infections despite all the work done by government, civil society and the private sector and NGOs.
  - Workplace HIV and AIDS programmes can reinforce employees' knowledge about HIV transmission and its prevention.
  - Companies in partnership with government or service providers should hold annual awareness days, for example during World Aids Day, about the programme to create internal and external visibility.

- Give more information on HIV and AIDS to encourage HIV voluntary testing by setting testing targets and monitoring them.
- Encourage development and distribution of information and education branding material/pamphlets.

4.3.2 Theme 2: Security about procedures of the Swedish Workplace HIV and AIDS Programme

This theme focused on the protection of human rights of individuals living with HIV and AIDS, paying attention to aspects such as confidentiality, voluntary testing, disclosure, stigma and discrimination. This linked to the internal legal systems which ensured that the individual's overall well-being in the world of work and world of HIV are protected, since HIV is perceived to be a human rights issue.

4.3.2.1 Key findings

The majority of participants emphasized that they did not have any problems regarding confidentiality after diagnosis or disclosure. Confidentiality is being upheld and taken seriously in all three Swedish workplaces. It was encouraging to note that most workplaces adhered to the legislation that helps to protect the confidentiality of people living with HIV and AIDS.

4.3.2.2 Conclusions

One of the inherent principles of the Swedish Workplace HIV and AIDS Programme is to ensure that employees have access to testing in a safe and confidential environment. This was affirmed by participants who highlighted the safety procedures endorsed by the workplace programme when they are offered HIV testing. None of the participants felt threatened by workplace policies and procedures. Participants emphasized that the programme upheld the principles of confidentiality and made it easier for them to self-disclose to their significant others.

4.3.2.3 Recommendations regarding security of procedures and policies

HIV workplace policies are designed according to national legislations and frameworks, and these are regularly amended. It is recommended that company workplaces:

- Align and update their policies regularly. Regular updating of policies and creating awareness around them will promote a safe environment and encourage all employees to have the confidence to use the programmes maximally without fear of being victimized.

As a result of explicit policies, it is believed:

- this will assist in the eradication of stigma attached to HIV, and
- monitoring and getting feedback from employees living with HIV and organizations such as SWHAP will make adjustments to improve the programme to become a best practice workplace programme.

4.3.3   Theme 3: Support services from SWHAP

This theme focused on the support from health care professionals, family, significant others and management. This is linked with the psychosocial underpinning of the helping or holistic caring attitude of the human professions such as nursing and social work. The theme is further related to the three system levels. One referred to the impact of family support on the individual; two referred to care providers who provided medical and psychosocial support; and lastly policies that are interlinked to all support activities. All these systems were found to be contributing towards the individual's complete wellbeing.

4.3.3.1 Key findings

All participants in the study indicated that they were supported by the clinic sister and in some cases the doctor as well. The majority reported that they only disclosed their status to the clinic sister. They mostly expressed that the support from the sister helped them to cope with their mental and physical challenges. Most participants further said that they are confident that their status is kept confidential by the sister. This is linked with the

general systems' underpinning where the helping or holistic caring approach of the human professions, such as nursing and social, work are seen as support systems for their clients. Nurses are placed in the continuum of the caring professions as they get in close contact with their patients in a caring and supportive manner.

4.3.3.2 Conclusions

While counseling and testing have been shown to be an effective method of HIV prevention and is a critical point of entry for HIV treatment, care and support services among persons who are HIV-positive have been established as one important pillar of HIV management.

4.3.3.3 Recommendations

Management should demonstrate commitment and leadership by dedicating resources towards the implementation of programmes. They should show commitment by building public-private partnerships with external stakeholders to improve employee access to health services and compliment the workplace programmes externally. There should be advocacy for larger company contribution towards the medical aid to ensure that antiretroviral (ARV) treatment is freely available for people living with HIV.

Finally a 'one size fits all' approach to making programmes efficient cannot be used and the following can be used to improve the effectiveness of programmes:

- Management should be more involved in the programme, not only buying in, but ensuring that the HIV programme is mainstreamed in every aspect of the company. This can be ensured by including HIV and AIDS programme management in the key performance areas of the top, senior and middle managers.
- Programmes are not to be run by one person, for example, occupational health nurses or human resource managers, but should be decentralized to committees and peer educators.

HIV testing in the workplace needs to be done on an annual basis; however, workplaces find it difficult to motivate employees to test every year to ensure that there are no new infections and/or seroconversion. Workplace committees need to find innovative strategies to keep programmes alive and employees motivated to test annually, especially after baselines have been established. An innovation such as family wellness days where couple testing is promoted, usually motivate employees to get tested.

4.3.4 Theme 4: Emotional experiences

Theme 4 confirmed the fact that testing HIV-positive is an emotional experience. This is linked with the psychosocial approach that outlines that when a person learns of a positive HIV test, they face a host of psychological and social stresses. HIV-related stigma is associated with psychological distress and can interfere with coping, adjustment, and management of HIV. Efficient management of HIV requires timely testing for HIV infection so that persons who are infected can learn of their serostatus and gain access to treatment, care and support, thereby benefiting from available treatment options.

4.3.4.1 Key findings

Most participants indicated that after accessing testing services they managed to get support from the SWHAP. Participants also highlighted the fact that it is only normal to go through a series of different emotions after being diagnosed. This confirms the fact that an HIV-positive status is a life changing experience which can be emotionally draining.

4.3.4.2 Conclusions

Notwithstanding the progression that has been achieved in the effective management of HIV and AIDS, HIV is still perceived as a life-threatening disease. The majority of participants indicated that even if they know and understand that HIV can be treated and managed, when one is diagnosed with the HIV, it evokes sad emotions. The participants expressed that when they got diagnosed, they went through a series of emotions such as fear, anger, and confusion. This again supports the need for interventions that puts emphasis on emotional support for people who have just been diagnosed with HIV.

4.3.4.3 Recommendations

Support systems should be made an imperative in workplace programmes. Workplace programmes should be developed around the needs of employees living with HIV. The following need to be taken cognizance of:

- The employees living with HIV need to be involved in every step of implementation of the programmes in order to feel supported. Ensuring support for employees living with HIV indicates that treatment is free and easily accessible in the workplace and this will minimize absenteeism and increase productivity in the workplace.
- Based on the constant developments in the HIV field, it is important for companies to invest in continuous training of health care professionals, social workers (if any), and peer educators on new clinical management of people living with HIV to be up to date with the developments. Empirical findings have indicated that people living with HIV in the workplace are highly dependent on the support they receive from the health care professionals; therefore, the continuous training will play an important role in assisting the practitioners to give support with confidence.
- Regarding the emotional experiences, workplace programmes should provide support for employees living with HIV even outside the work environment, through information about external support groups for employees living with HIV that can help with psychological and psychosocial issues. Creating support groups within the work environment will encourage sharing of experiences and coping strategies amongst employees living with HIV in order to support each other.
- It was evident in the empirical findings that family plays an integral part in supporting people living with HIV, especially after diagnosis. Workplace programmes need to integrate families into the programmes to ensure that holistic support is available for them if necessary. This can also help in breaking the cycle of infection and reinfection by ensuring that partners and spouses of employees also have access to HIV education, knowing their status, and those who are positive to get supported through the workplace programme.
- Workplace programmes need to put more emphasis on peer educator programmes to strengthen the support to employees living with HIV.

- Peer educators need to be provided with continuous training in educating and supporting their peers and giving information at their level in a confidential manner.

4.4 CONCLUSIVE REMARK

Throughout the study, it has been demonstrated that HIV and AIDS programmes are playing a crucial role in contributing towards mitigating the impact of HIV and AIDS in workplaces by offering an array of support initiatives.

Support systems, such as health care professionals, are very critical in offering counseling to keep employees living with HIV healthy and productive throughout their work life. There is a need for every workplace to have an HIV policy and programme that includes education, peer educators, treatment, care and support, in order to ensure that employees affected by AIDS are supported. The company should also recognize the seriousness of HIV and AIDS, care for their employees, respect the rights of employees, observe confidentiality at all times, mitigate for employees not to be discriminated against in any way, and be committed to doing everything in their power to eliminate the risk of AIDS-related deaths. Finally, it is crucial for companies to make serious considerations and mainstream HIV and AIDS programmes.

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ANNEXURE A: SWHAP APPROVAL LETTER

Swedish Workplace HIV/AIDS Programme

To: University Ethics Panel
University of Pretoria
South Africa

Stockholm, 5th March 2015

Re: Permission to conduct research related to the Swedish Workplace HIV and AIDS Programme (SWHAP)

Dear Madam/Sir

This is to herby confirm that I have assessed and approved a request for Ms. Mary Motaung to conduct research for her Masters thesis within three companies which have cooperated with, or benefitted from, the programme in South Africa.

With respect to the nature of the research, permission is given on condition that:

- Ms Motaung conducts all research and report-writing in her own free-time,
- Ms Motaung receives additional written permission from each participating company,
- it is clearly understood and stated in communication with the companies and in the final thesis that SWHAP does not in any way or form sponsor or support the research and neither do the expressions of the student necessarily reflect those of SWHAP or its financiers,
- the names of companies used will be kept anonymous and will not be mentioned in the study,
- all information will be used anonymously and confidentiality will be adhered to in this process,
- informants will only be included in the study if they give their formal consent that they are willing to participate voluntarily in sharing their experiences about the utilization of HIV workplace programmes,
- as Ms Motaung is a consultant currently working for SWHAP, she is bound by our intellectual property rights, which state that:
  - o The Consultancy will, when performing its mission, be granted access to confidential and sensitive information about the participants in the SWHAP programme. The Consultancy undertakes to, during the term of this agreement and thereafter without any limitation in time, maintain in strict confidentiality all information and documentation about, or related to, the individual participants (companies and/or persons) in the SWHAP programme (including both their names and how they have performed) which the Consultancy receives when performing its mission. The

IFMETALL   NIR   Näringslivets Internationella Råd
International Council of Swedish Industry

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Fax: +46 8 665 90 29
E-mail: info@swhap.org
Website: www.swhap.org

foregoing shall also apply to any information which may serve to identify a participant in the SWHAP programme.

o   For the avoidance of doubt, the foregoing shall not prevent the Consultancy or the individual persons performing the work from using information from the mission which have been made anonymous for academic non-commercial purposes. Information shall only be deemed anonymous if it is impossible to identify the participant to which the information relates.

We hope that the thesis and its conclusions will be shared with SWHAP and will be of interest to and benefit for the programme.

Yours faithfully

John Viner
Programme Manager
The Swedish Workplace HIV/AIDS Programme (SWHAP)
International Council of Swedish Industry (NIR)/
Swedish Industrial and Metalworkers' Union (IF Metall)

ANNEXURE B: COMPANY APPROVAL LETTERS

LEONARD DINGLER

A Member of the Philip Morris South Africa Group of Companies

1st September 2015

To University Ethics Panel

RE: PERMISION TO CONDUCT RESEARCH WITHIN SWHAP

Leonard Dingler (Pty) Ltd has acknowledged, assessed and approved a request for student Ms. Mary Motaung to conduct her research for her Master's thesis in relation to a Swedish workplace HIV/AIDS (SWHAP) programme implemented by Leonard Dingler at the company premises. With respect of the nature of the research, permission is given on condition that participants will only be included in the study if they give their informed consent that they are willing to participate voluntarily in sharing their experiences about the utilization of HIV workplace programmes. The information acquired will be used anonymously, and confidentiality will be adhered to throughout this process and neither the consenting employee nor the Company shall be identifiable from the final report.

We hope and trust that depending on the outcome of the study, feedback will be given to the company on how recommendations from this study could be implemented to further contribute to an effective and efficient workplace HIV programme.

Best regards

J. Fraser Rowland
Director Operations Southern and Eastern Africa

Leonard Dingler (Pty) Ltd, Cnr Siding Avenue & Christopher Street, Boksburg East, 1459. Tel: + 27 11 841 9000 Fax: + 27 11 841 9031
Company Reg. No. 1998/018017/07/07   Vat Reg. No 4700183710

DIRECTORS: C J Dilley (British), M R O Sjoeblom (Swedish) and C Z Limbert

Autoliv
Southern Africa

Wednesday, April 15, 2015

To University Ethics Panel

RE: PERMISION TO CONDUCT RESEARCH WITHIN SWHAP

Autoliv has acknowledged, assessed and approved a request for student Ms. Mary Motaung to conduct her research for her Master's thesis at Autoliv as one of the Swedish Companies. With respect of the nature of the research, permission is given on condition that participants will only be included in the study if they give their informed consent that they are willing to participate voluntarily in sharing their experiences about the utilization of HIV workplace programs, information will be used anonymously and confidentiality will be adhered to in this process.

We hope and trust that depending on the outcome of the study, feedback will be given to the company on how recommendations from this study could for instance contribute to effective and efficient workplace HIV programs.

Best regards.

David Kretschmer
Managing Director

Autoliv Southern Africa (Pty) Ltd
Registration No: 1955/003642/07

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P O Box 3058
Kenmare
1745

Phone: +27 11 279 2600

Physical address:
19 Fransen Street
Chamdor, Krugersdorp
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Directors : D J Kretschmer (Managing), F Kohrs*
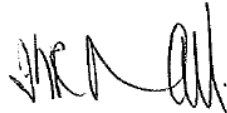*German

To University Ethics Panel

RE: PERMISION TO CONDUCT RESEARCH WITHIN SWHAP

Assabloy has acknowledged, assessed and approved a request for student Ms Mary Motaung to conduct her research for her Masters thesis at Assabloy as one of the Swedish Companies. With respect of the nature of the research, permission is given on condition that participants will only be included in the study if they give their informed consent that they are willing to participate voluntarily in sharing their experiences about the utilization of HIV workplace programmes, information will be used anonymously and confidentiality will be adhered to in this process.

We hope and trust that depending on the outcome of the study, feedback will be given to the company on how recommendations from this study could for instance contribute to effective and efficient workplace HIV programmes.

Best regards.

....

ASSA ABLOY (SA) (Pty) Ltd
Occupational Health Clinic
176 Progress Road
Technikon Roodepoort 1724
PO Box 146 Roodepoort 1725
Tel: 011 761 5042/ Fax: 086 710 2146

ANNEXURE C: INFORMED CONSENT FORM

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Social Work & Criminology

SECTION A: RESEARCH INFORMATION

RESEARCHER:

Mary Motaung
SWHAP (Swedish Workplace HIV/AIDS Programme
4871 Summerfields Estate
Samrand
Centurion
0152
0842080421

TITLE OF THE STUDY

The experiences of employees living with HIV and AIDS regarding the Swedish Workplace HIV and AIDS Programme (SWHAP)

INTRODUCTION

Ms M Motaung is currently busy with the Masters Degree MSW (Health Care) at the University of Pretoria. One of the requirements for the completion of this degree is to conduct research on a relevant topic in the field of study and present the findings in a mini-dissertation.

PURPOSE

The researcher has chosen to explore the experiences of People Living with HIV and AIDS in the Swedish Workplace HIV Programme. This in essence to explore the contribution the workplace programmes have on the quality of life of beneficiaries, especially employees who are living with HIV.

PROCEDURES

The study will consist of interviews that will be approximately 45 to 60 minutes in duration and will be conducted at your respective company boardroom which will serve as a neutral and non-threatening environment. The researcher will approach the Swedish company clinics and ask the service provider to inform employees who have participated or still are participating in the Swedish HIV Workplace Programme about the research. Those who are interested in partaking will be requested to provide their contact details to the clinic. Researcher will then get the details from the clinic and contact the potential participants to arrange an appointment with respective candidates. Participants will only be included in the study if they

give their informed consent that they are willing to participate voluntarily in sharing their experiences about the utilization of HIV workplace programmes. This includes permission for the researcher to get relevant information from their client files, as well as to record the interview and later transcribe it. Confidentiality will be adhered to in this process. It is required that the data from this research be stored for archival and research purposes at the University of Pretoria for 15 years, after which it will be destroyed.

RISKS

If you should experience any emotional harm or discomfort as a result of the interview, you may withdraw from the study at any time. I (The researcher) will refer you to the company internal social worker in case of any needed counseling.

BENEFITS

You will not personally benefit from participation in the study. However, depending on the outcome of the study, feedback will be given to the companies on how recommendations from this study could for instance contribute to effective and efficient workplace HIV programmes. The findings of this study will be helpful in order to understand how the beneficiaries of the programme are experiencing it.

RIGHTS OF PARTICIPANTS

You have a right to participate voluntarily out of your own accord and may choose to withdraw from the study at any time and without any negative consequences. You will receive debriefing from the researcher after engaging in the interview and will be referred to the company social worker for counseling should any difficulties arise resulting from the interview. You will also have the right to access the research document once the study is completed.

CONFIDENTIALITY

The researcher will assure confidentiality and privacy as anything said in the interview will be kept confidential. The interviews will be conducted in a safe and non-threatening environment that will ensure privacy. The interview will be voice recorded with your permission and all data will be stored at the University of Pretoria for 15 years for research and archival purposes. Numbers will be assigned to each participant to ensure confidentiality and to protect your identity.

RIGHT OF ACCESS TO THE RESEARCHER

You will have access to the researcher for the duration of the study and for three months after completion of the study. Should you contact the researcher after this time, it will be considered as the beginning of a new client, the researcher will use her social work capacity to allow the necessary access or you will be referred.

Please sign the consent form on the next page.

Kind regards,

 Ms M Motaung   Researcher

SECTION B: RESEARCH LETTER OF INFORMED CONSENT

By signing this form I am giving permission to participate in the research and acknowledge that I understand what it entails.

I, _____(Full name and surname of participant) hereby confirm that I have been informed by the researcher, Mary Motaung about the nature, conduct, procedure, benefits and risks of the research study. I am aware of what is required of me as participant. I have read the purpose of the study and understand how the research process will be followed. I have asked relevant questions that I may have had.

I agree to take part in the study and understand that my personal details will be kept confidential. I agree to partake in a personal interview with the researcher, for her to tape record the interview and for her to access information needed from my personnel file.

I further understand that if I choose to withdraw from participating in the study at any time, I will not suffer any negative consequences.

PARTICIPANT:

Name and Surname:_____

Signature:_____

Date:_____

RESEARCHER:

Name and Surname:_____

Signature:_____

Date:_____

ANNEXURE D: EDITORIAL LETTER

Between The Lines
Leatitia Romero
Professional Copy-Editor, Translator and Proofreader
(BA Hons)

Cell: 083 236 4536
leatitiaromero@gmail.com

9 November 2016

To whom it may concern:

I hereby confirm that I have edited the thesis of Mary Mabebe Kau, entitled: "THE EXPERIENCES OF EMPLOYEES LIVING WITH HIV REGARDING THE SWEDISH WORKPLACE HIV AND AIDS PROGRAMME". Any amendments introduced by the author or supervisor hereafter, is not covered by this confirmation. The author ultimately decided whether to accept or decline any recommendations made by the editor, and it remains the author's responsibility at all times to confirm the accuracy and originality of the completed work.

Leatitia Romero

(Electronically sent – no signature)

ANNEXURE E: SEMI-STRUCTURED INTERVIEW SCHEDULE

PLANNED INTERVIEW SCHEDULE

Title of the study: The experiences of Swedish company employees living with HIV and AIDS regarding the Swedish Workplace HIV and AIDS Programme (SWHAP)

Course: MSW (HEALTH CARE)

M.M. Motaung: 22300483

1. When did you start to work with the present company?

2. Do you know anything about SWHAP? Motivate
3. When/ how did you learn or get to know about SWHAP?
4. When were you diagnosed with HIV?

5. Did you test as part of the Swedish Workplace Programme initiative at your company? If not where did you get tested?

6. When were you diagnosed with HIV?

7. Tell me about the experience of hearing you were HIV-positive

8. Tell me about any confidentiality issues you might have had after you got diagnosed?

9. Tell me about the support you were offered after testing HIV-positive at your workplace?

10. Tell me about who supported you?

11. Tell me how were you supported?

12. Tell me how the support made a difference in your work and family life living with HIV?

13. Have you disclosed your status to anyone and to whom?

14. Tell me how you went about disclosing your status and how the person reacted.

15. Have you experienced any form of stigma – internal?

16. Have you experienced any form of stigma – external

17. What recommendations would you make to SWHAP?

ANNEXURE F: LETTER OF ETHICAL CLEARANCE

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

02-Jul-2015

Dear Ms Mabebe Motaung,

Project: The experiences of employees living with HIV regarding the Swedish Workplace HIV and AIDS Programme.

Researcher: Mabebe Motaung

Supervisor (incl. other investigators): Motaung, Mabebe MM—Carbonatto, Charlene CL—

Department: Social Work and Criminology

Reference number/s: GW20150326HS

Thank you for the your response to the Committee's previous correspondence.

I am pleased to inform you that the above application was **approved by the Faculty of Humanities Research Ethics Committee** at an *ad hoc* meeting held on **02-Jul-2015**. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof Karen Harris
Acting Chair: Postgraduate Committee and Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail:Karen.harris@up.ac.za

Kindly note that your original signed approval certificate will be sent to your supervisor via the Head of Department. Please liaise with your supervisor.

Research Ethics Committee Members: Prof KL Harris (Acting Chair); Dr L Blokland; Dr JEH Grobler; Prof B Holmeyr; Ms H Rupp ; Dr G Fanebance Warrens; Dr C Puttergill, Prof GM Spies; Dr Y Spies; Prof K gtard