CHAPTER 5

HIV AND AIDS IN THE WORKPLACE

5.1   INTRODUCTION

It makes business sense for companies and the public sector to be involved in solutions for HIV and AIDS management. Companies acknowledge that AIDS puts their employees, their families and global communities at risk, thus dictating a radical and urgent attention to a safe and supportive workplace, where HIV positive employees are encouraged to contribute to the country's economy. Unless the HIV prevalence of the company is known, little can be done to implement strategies and preventative measures. This chapter looks at the HIV prevalence in South African companies, the efforts and strategies by SA business to mitigate the scourge of HIV and AIDS, as guided by employment equity legislation and corporate social responsibilities initiatives. This chapter also looks at successes and failures.

5.2   THE PREVALENCE OF HIV AND AIDS IN THE WORKPLACE

The impact of AIDS is still not fully understood in the workplace. The lack of understanding of the dynamics involved in the disease itself seems to portray a bleak picture of HIV and AIDS in the workplace. This is primarily because there is little published information in the South African work environment on the impact of AIDS from an employee perspective, rather than from an organisational perspective. What is known, is that HIV and AIDS will have an effect on jobs in terms of job load, stress level, job satisfaction and performance, relationship with co-workers and may ultimately influence the employees' decision either to leave or stay with employers (Hall, 2004, 110).

HIV and AIDS has become the single most concentrated threat to human rights in developing countries. It is a threat as it links the business, health and economy together and calls for a crucial role for business. In South Africa HIV and AIDS has increasingly become the dominant issue on the corporate citizen agenda. The economic impact is already been felt by most business sectors. In South Africa alone a current prevalence rate of 23% is estimated among people between the ages of 20 and 65 years, the most economically productive age bracket (UNAIDS, 2006:99). The prevalence for women is higher than that of men in the 15 to 24 age band, but higher for men at ages over 45 (Dorrington *et al.,* 2006).

The impact of HIV and AIDS on the company is through loss of productivity, increased costs and impacts on employee morale. (See **Appendix 10**). In a study by Guinness, Walker, Ndubani, Jama, and Kelly (2003) of seven companies in Southern Africa, it is reported that the cost of death due to HIV and AIDS was twice for that of white-collar financial firms than manufacturing and transport companies. However in a study done by SABCOHA in 2005 in South Africa, it was discovered that not only financial sectors were impacted significantly by HIV and AIDS, other sectors such as mining, transport, and manufacturing sectors had experienced the heaviest impact of the pandemic (*BER/SABCOHA…,* 2005).

A report in the AIDS Watch (2008) have projected that AIDS deaths of employees in the South African workforce will soon exceed all other causes of death put together. Another estimate by Major (2004:141) is that 43 199 public servants will have died of HIV and AIDS between 1985 and 2020 and about 126 000 would have retired as a result of ill health related to HIV and AIDS while still employed by government. According to Fakier (2004:89) by 2010 15% of highly skilled employees will have contracted HIV and AIDS. A recent survey of insurance policy applicants found that even though HIV was more prevalent among unschooled labourers, more people holding degrees were infected with HIV than those with only matric (Pienaar, 2004). In Zambia two thirds of the deaths are reported to be among managers (d'Adesky, 2003).

Anglo American, a global mining and natural resources company have been actively involved in the struggle against HIV since 1990, after their first HIV case in 1989. With the current prevalence of 22%, they have now broadened their efforts to include strategies to deal with HIV and AIDS among their suppliers and the communities where they do business (*Perspective…*, 2006:27).

Simon, Rosen, Whiteside, Vincent, and Thea (2000:22) argue that the decline in productivity and increasing costs due to HIV and AIDS will make it expensive for a company to perform. As a result, a company can reduce costs rather than raising its price by investing in mitigating the risks of HIV and AIDS among employees in order to remain competitive. The loss of skilled labour due to HIV and AIDS is likely to reduce the competitiveness of South African companies internationally. A 2003 Sanlam survey of benefit funds found group risk benefits increased as an expense on average by 15% to 20% (Hassim, 2004:29), compared to the 1999 Old Mutual survey of 15 companies which found that six of the companies surveyed were reducing death and disability benefits (Major, 2004:128).

Restructuring employee benefits is an example of how most companies are shifting the cost burden of HIV and AIDS onto the employees. The transfer from defined benefit to defined contribution pension funds has become a common way to avoid costs related to HIV and AIDS (Stevens, 2001:14). The United Nations regard HIV and AIDS not only as a health issue but an issue that cuts to the core of business practice (UNAIDS, 2000:2). Given all these realities, the focus of sustainability reporting on HIV and AIDS has been seen as an important aspect of business and what companies are doing (Fakier, 2004:90).

In the annual survey conducted by Global Health Initiative (GHI) of the World Economic Forum, 46% of the 10 993 business executives in 117 countries expressed concerns that the threat of HIV continues to reduce the workforce and has an impact on their operations. The concerns seem to have risen significantly by 10% compared to the previous year, which was 36% (*Perspective…*, 2006:37).

While there is still uncertainty about the exact extent of the HIV and AIDS epidemic in South Africa, it is estimated that HIV prevalence rates would peak at 13,1% among health workers (ING Barings, 2000). Kalyegira (2000: 2) indicates that one in five South African nurses are HIV positive. Furthermore, healthcare workers take care of patients with HIV-related illnesses and run the risk of becoming infected (Hall, 2004:111).

A study by Pela (2004) projects that up to 250 000 public servants may die of AIDS by 2012. Another study indicates that about 40% of educators died of AIDS-related causes nationwide in South Africa in 2000 to 2001 and these losses are heavily felt in rural areas (UNAIDS Fact Sheet, 2002).

HIV and AIDS is posing a scourge on the SA National Defence Force, with 22% of the 60 000 strong defence force being reported HIV positive. (The Star, 2002). The South African Police Services (SAPS, 2000) estimated that 35% of its officers between the ages of 25 and 29 years, and 45% of its officers between the ages of 30 and 34 years will be infected with HIV by 2015. The above statistics of various public services shows the impact of HIV and AIDS on the government sector, the largest single employer in the country.

In a survey of NGOs by O'Grady (2004:212), four of the nine surveyed NGOs had lost staff members due to AIDS. The staff loss was felt in the area of service delivery as the remaining staff had to increase their workload. Funeral attendance was indicated as a major issue affecting most NGOs, especially in African countries where traditionally the family needed several days to hold ceremonies. Most NGOs rely on community capacity through volunteerism to carry out their community projects, thus the impact of AIDS on their work is heavy as the availability of volunteers is dependant on their health status. Furthermore, community activities take precedence to any meetings, thus it was reported that scheduled meetings were often cancelled at the last minute due to a concurrent funeral that requires attendance of most community members.

The type of employment, occupation, nature and organisation of work, skills level and shortages of particular skills are factors that may determine the impact that HIV and AIDS will have on employees.

The HIV and AIDS challenge manifests itself in the impact of unscheduled sickness absenteeism that can only be inferred to be caused by the impact of HIV. According to the South African Constitution, employees are not compelled to disclose their status. As a result, it becomes difficult for the employer to manage sick leave caused by HIV and quantify the cost. On the other hand, those employees that may be comfortable to disclose their status still find the culture in the workplace lagging in encouraging disclosure. These employees are often feeling vulnerable and fear discrimination, victimisation and stigmatisation.

The high prevalence of HIV necessitates multi-sector and global initiatives in an attempt to deal with the pandemic. Such include the launch of the Global Health Initiative (GHI) of the World Economic Forum in June 2006. The World Economic Forum has called for companies and governments in Africa to join hands to form private-public partnerships to address the challenge of HIV and AIDS. Details of these efforts will be discussed further later in this chapter under business response on HIV and AIDS.

5.3   THE IMPACT OF HIV AND AIDS IN THE WORKPLACE

The impact of HIV and AIDS in the workplace ranges from big business with both skilled and unskilled workers to small, medium and micro enterprises (SMMEs). The challenges and impacts are not only a human resources issue but it is now being classified as a business risk, as it is beginning to affect the supply chain of the business. According to Bowler's (2004) presentation at the Symposium Proceedings University of the Witwatersrand 2004, the impact of HIV and AIDS will affect productivity, competitiveness profitability of service and other human resources impacts that will be felt in the rate of absenteeism, accident rates deaths, early retirement, disability retirements, industrial disputes and emigration (**Appendix 10)**. These impacts are already been felt by most businesses in South Africa.

In South Africa there has been increased costs related to increased employee benefits in the form of group life insurance, pension, funeral benefits and medical aids increases. It is only as recent as 2006 that the medical aids have moved away from limiting coverage for people infected with HIV. The coverage is now being classified as chronic, and the cost of coverage is unlimited just like other chronic health diseases (Discovery Health Newsletter, 2008). In addition Discovery Health is now classifying HIV test under the basic tests that are not charged from an employee's savings account but risk account; this however excludes certain plans such as the Core and Key plans.

Another aspect of the impact is evident in the competition among skilled workers, which tends to contribute to the escalating remuneration costs. Currently in South Africa there is increased wage differentiation and the assumption is that the contributing factors, in addition to employment equity factors, is the impact of HIV and AIDS. These aspects bring staff movement that leaves the business and employees to adjust to these changes. The changes often manifest in declining employee morale, loss of experience, loss of skills and loss of workplace cohesion and loss of management time.

One of the interesting aspects of the impact of HIV and AIDS, discussed by Bowler (2004), is the fact that the impact could be so adverse that in some businesses credit may need to be written off as customers die and sales volumes reduce. Stein (2001) adds that these impacts could contribute to reduction in savings and reduced disposable income as expenditure shifts to health and funeral-related expenses. With the increase of interest rates, high costs of petrol and food, South African consumers are already feeling the pressure of juggling the priorities of health, funeral-related costs, and basic needs.

In a survey done by Bowler (2004) in the Nelson Mandela Metropolitan Municipal Area, 64% of the workplace claimed HIV and AIDS related deaths ($N=14$, $N_1=22\ 265$). The study explored the impact of HIV and AIDS in the organisations in the area; 14 workplaces responded of which 13 workplaces were in manufacturing and one in the service sector. Significantly, in one workplace, Bowler's (2004) results indicated

anecdotal evidence through medical aid tracking of HIV positive employees that once ill, death followed quickly.

The impact of dying employees present a challenge to those left behind to continue with the work. As a result it can be clearly argued that the higher the prevalence, the higher the stress level on both employees and health workers. A study by Hall (2004: 113) of nurses in South Africa, revealed an alarming prevalence in 93% female patients and just over 6% in male patients. A total of 1 922 interviews were conducted among professional nurses, and nursing assistants. The study indicated that the impact on the prevalence is affecting half of the respondents in performing their duties and poses a challenge on their own wellness and their own safety. The results indicated that the perceived risk of infection is high compared to the actual infection of other infectious diseases, such as Hepatitis B.

What is generally known is that HIV and AIDS has and will continue to have an impact on the workplace in terms of work load, stress levels, job satisfaction and performance. This will become predominant as the workplaces continue to foster the work environment where openness is encouraged and those disclosing not stigmatised.

5.4   SOUTH AFRICAN BUSINESS RESPONSE TO HIV AND AIDS

The response of corporate South Africa to HIV and AIDS has been slow, partial, and erratic and somehow guarded (Dickson, 2004:37). A study by the South African Business Coalition on HIV and AIDS (SABCOHA) in 2003, which focused on large companies in South Africa, reported that only 60% of the 25 largest companies in South Africa had HIV and AIDS policies or programmes (Bendell, 2003:13). Numerous workshops and conferences have been held to assist employers and trade unions to develop policies and programmes in assessing and planning to contain the risk, ensuring non-discrimination and awareness. Where the impact of HIV and AIDS is the most profound, SABCOHA, in a 2005 study by BER, found that workplace programmes are becoming more mature and integrated into broader wellness programmes. The 2005 study by SABCOHA was expanded to include the transport sector and still found that the results from the 2005 survey did not differ from the 2004 survey.

There is significant pressure on the business sector from various stakeholders, including government, to act on the HIV and AIDS issue. These pressures and regulations are shaping and speeding up the corporate agendas in South Africa. The stakeholders are demanding that companies not only look at their financial performance but also take greater responsibility for the social and environmental impacts of the business (Save the Children, 2002:19). In South Africa the government has published an extensive Code of Good Practice on key aspects of HIV and AIDS and employment to guide workplace policies and programmes (Code of Good Practice, 2000). With regard to the risk of HIV and AIDS, according to the King II Report on Corporate Governance (Institute of Directors, 2002:1), companies are required to disclose the company's HIV and AIDS strategy plan and related policies to address and manage the risk and potential impact of the disease on the company.

Following the release of the King II Report, the Johannesburg Securities Exchange (JSE) announced its intention to implement a JSE Social Responsibility Investment Index (Johannesburg Security Exchange, 2002:2). The index facilitates investment in companies with good records of social responsibility in all aspects of business including HIV and AIDS, health and welfare. It further measures what companies are doing with regard to HIV and AIDS and measure the risks as determined by economic, environmental and social development (Fakier, 2004:90). For the first time in the Deloitte's survey of 'The Best Company To Work For 2005' in South Africa, current topical issues in the workplace such as feedback on HIV and AIDS, and work / life balance were addressed.

The South African Global Business Coalition on HIV and AIDS (SABCOHA) was established in 1997, specifically to increase the numbers of businesses that fight AIDS, making business valued partners in the fight against AIDS. SABCOHA provides technical advice and advocacy support for business organisations and helps to develop formal partnerships. One of the successful tools developed by SABCOHA has been manuals on HIV and AIDS policy development, training for managers and labour

leaders, employee education and global strategies for global business (SABCOHA, 2006).

Some of the HIV and AIDS responses for businesses include Corporate Social Responsibility Programmes (CSR) and internal HIV and AIDS programmes. The companies with CSR programmes are often viewed as glossy programmes and are resented by employees with no internal HIV and AIDS programmes. In a survey by (Dickson, 2004:51), it is stated that while the HIV and AIDS committee were not opposed in principle to the company providing high-profile donations to well-known but distant HIV and AIDS projects, they pointed out that there are more pressing priorities and often more desperate need on the company's doorstep. Where companies are managing the impact of HIV and AIDS on productivity and cost, it is through internal HIV and AIDS policies and through peer education. Within the context of HIV and AIDS in the workplace, peer educators can be seen as a third channel of communication.

HIV and AIDS peer education is another method of disseminating HIV and AIDS information to employees. Since peer education programmes were started much earlier in many companies, the formalised version of these programmes began in 1997, and was modelled on a similar work-based programme run by the Zimbabwe AIDS Prevention Project in Harare (Bassett, 1998). The focus of the programme is to keep employees HIV negative and educate HIV positive employees on how to stay healthy. A study by Sloane (2004:269), evaluating HIV and AIDS peer education in South Africa, found the programmes to be ineffective and contributing little to improve Knowledge, Attitude, Behaviour and Practice (KABP) in the workplace.

Dickson (2004: 55) found that in large companies there has been significant mobilisation of peer education through stronger structures. Managers were involved and effectiveness, localisation and partnership with necessary resources were considered. In one of the medium-sized companies researched, management had not grasped the concept of peer education and had no plans to facilitate it. In the study by Stevens, Dickson and Mapolisa (2004:12), a case study of two companies in South Africa, it was

stated that the HIV and AIDS policy was clearly not a guiding document for employees. There was reference to training and peer education but nothing had happened two years later. These researchers did not find the policy document to be an operational policy that had the potential to inspire confidence in shareholders who would want to know that this endemic threat is being managed well.

Following the 2000 world summit on HIV and AIDS, the Global Reporting Initiative (GRI) was developed. The GRI HIV and AIDS framework is a process that involves multi-stakeholder collaboration (GRI, 2003:1). The main purpose of the GRI HIV and AIDS guideline document is to offer a framework for organisations to report on their HIV and AIDS policies and procedures, as well as performance regarding HIV and AIDS. It is too early to assess whether the GRI standardised format for reporting meets the needs of all stakeholders.

Dickinson (2004:71) identifies six aspects that drive companies to respond to HIV and AIDS. The drivers can be divided into two sections, which are *external* and *internal* driving forces. The external drivers are legal requirements and social pressures. The internal drivers are voluntary regulation, the business case, visibility and internal agents. He argues that the external drivers have been expanded within the corporate environment due to the weakness of the internal drivers. Legal requirements have helped companies to ensure compliance with the law. It is of interest to note that among those companies addressing HIV and AIDS in the workplace, they do so due to pressures such as high court rulings on HIV and AIDS-related cases, which are providing practical warning of no tolerance for discrimination and non-compliance. Such an example was employee who won a case after suing South African Airways (SAA) for discrimination based on his HIV and AIDS status when he did not get the position he had applied for because he tested HIV positive during the recruitment procedure. (AIDS Law Project, 2000:3 - The SAA case ('A' v SAA).

The pressure which is necessitated by the social crisis that HIV and AIDS poses to South Africa has been evident in the corporate social responses some of the companies

have made. The approach of companies until recently has been based on the visibility of those infected, and given the long incubation period of the virus; such approach according to Dickinson (2004:78) is reactive. Irrespective of the assurance by the company policies regarding non-discrimination, infected employees still find themselves in the vulnerable position and in fear of being directly targeted for downsizing processes. This response continues to make HIV and AIDS invisible.

Internal agents of HIV and AIDS in companies are often those with limited powers such as human resources junior staff. In cases where the champions have been leaders in the company, these cases relate to the person having been personally affected by the disease (Clark & Strachan, 2000:11). Trade unions in South Africa have been noticeably very active and vocal at national level with regard to policies and awareness. The Congress of South African Trade Unions (COSATU) has developed guidelines for shop stewards. The National Union of Mineworkers (NUM) and the South African Clothing and Textile Workers Union (SACTWU) have actively engaged employers on the issues of HIV and AIDS (Meeson, 2000; Bisserker, 2001; Petros, 2003).

According to an article by Lifeline, some organisations consider HIV and AIDS-related training to be too expensive, without considering the indirect costs of not educating themselves and their employees (*Management Today*…, 2004:46). Other companies in South Africa are recognising that the increasing poverty and inequality caused by the AIDS epidemic will undermine social, political and economic stability, ultimately leading to an environment that is not conducive for business. In South Africa while employees are beginning to fall ill from the HIV infection, companies are expected to assess their responsibility towards their employees, home based care and education interventions.

One of the most active areas in companies in dealing with HIV and AIDS has been that of employee benefits with specific reference to medical aids and pension fund benefits. However, the study by (Bowler, 2002: 25) in the Nelson Mandela Metropolitan Municipality, revealed that the major increase to employee benefit costs over the past four years were the costs of medical aids (83,3%) and pensions (66,6%) and can be attributed to HIV and AIDS. Of the attributed increases, 33% has been in life insurance

due to HIV and AIDS. Large companies such as Anglo American in South Africa have made the decision to respond to HIV and AIDS in a very comprehensive way, by the provision of anti-retroviral therapy to all its employees. According to a consultant at an HIV and AIDS Wits Symposium attended in 2004 at Wits University, this approach has put more pressure on other companies and it may not be relevant for all companies. The consultant assists companies in implementing sustainable development programmes (*HIV and AIDS Wits Symposium…*, 2004).

A survey recently conducted by Markinor, across 130 small, medium and large Johannesburg Securities Exchange (JSE) listed companies in South Africa, reveals that only 45% of these companies have a fully documented HIV and AIDS policy and 59% of the companies are not aware of the HIV and AIDS prevalence within their workplace (*Succeed /Essential…*, 2004:5). Of the companies surveyed, 75% regard HIV and AIDS to be a long-term and not a current threat to the business, despite high statistical reports. The results reveal that 71% of the companies indicated that they have produced posters, 62% provided counselling for those infected, 61% distributed condoms, 53% had informal group discussions using HIV and AIDS literature, 46% hosted formal workshops by external experts, 45% supplied treatment for opportunistic infections and 44% provided treatment for STIs. It is noted in the study that 16% of these companies provided anti-retroviral medicine (ARVs) and 18% still intend to do so.

In South Africa there are few noticeable leading companies in addressing HIV and AIDS with the exception of sectors such as the mining sector, automotive manufacturers like Daimler-Chrysler and Ford, and Eskom. These sectors have been particularly transparent regarding HIV prevalence and have shown leadership and innovative approaches in developing strategies to manage the epidemic (Bowler, 2002:19). A number of surveys have indicated that the response of smaller companies lags behind (SABCOHA, 2004; Weiner & Mapolisa, 2003) these larger companies. A study of 80 small and medium enterprises (SMEs) with 20 to 200 employees in Gauteng in 2003, found that SMEs invest little in employee benefits and they did not view HIV and AIDS as a major impact on production costs (Connelly, 2004).

South Africa's big businesses have seen the impact of HIV and AIDS on small medium and micro enterprises (SMMEs) and their suppliers and for that reason they have extended their own HIV and AIDS programmes to these SMMEs. This strategy is an admission that by extending their programmes, it is an act of ensuring survival of the business as it is managing business risk. Illness and death of SMMEs' staff imposes costs along the supply chain of any business. Studies indicate that when large businesses worldwide use supply networks to address social issues, this yields more success in general and mitigates the continuous struggle of the SMMEs (Perspective, 2006:11).

Although media campaigns concerning AIDS have shown to have some impact on knowledge about the illness and the ways in which it is transmitted, they seem to have little impact on attitudes and behaviour. A study, measuring attitudes on AIDS, found that those who talk more frequently about HIV and AIDS and related issues will have more consistent attitudes than those who talk about it less frequently (Lalljee & Palmer-Canton (2001:87). However, it is important to note that the respondents may have been only those who have positive attitudes about AIDS; if the respondents had a mixture of those with positive and negative attitudes, the results may have been different. The results should be interpreted with caution.

More than 75% of the mines and financial services companies surveyed in the BER and SABCOHA study (2005), indicated that stigmatisation and discrimination has undermined the effectiveness of their HIV and AIDS programmes. Similarly, the study found out that stigmatisation and discrimination were of great concern to respondents in the wholesale, transport, manufacturing and building and construction sectors.

A study by Bowler (2004:27) evidently showed that in general companies in the Nelson Mandela Metropolitan Municipality had HIV programmes. The programmes were directed at prevention and care. Of these 92% ran awareness, education and training programmes and more than 80% claimed to monitor evaluate and review programmes.

Interestingly only 38% made female condoms available. Global Business Coalition on HIV/AIDS, Tuberculosis and Malaria (GBC) an international organization with representation in SA has recently unveiled a practical and focused tool for mobilising business response to the feminization of HIV and AIDS. The practical tool provides replicable good practices that are focusing on workplace programmes for women, advocacy efforts and philanthropy, involvement of communities and leveraging their products and services. In this plan businesses are encouraged to disclose information about their supply chains and clearly articulate what they are doing. The three diseases, namely; HIV and AIDS, tuberculosis and malaria are treated broadly and treated as part of a full holistic health and wellness programme.

The following key themes and good practices are emphasized:

- Multi-sectoral partnership and diverse collaboration including all levels of government.
- Business leadership and commitment for workplace and community engagement
- Systems of effective monitoring and evaluation
- Community involvement
- Creative media such as art and sport to deliver information and education

In addition to efforts by the various South African business the South African Public Department under the Public Service Ministry, has developed the draft of employee health and wellness strategy framework to address the challenges of psychological and health issues, including HIV and AIDS, mother to child HIV transmission. The draft document focuses on four pillars of importance, namely: HIV and AIDS management, health and productivity management, wellness management and occupational hygiene and safety management (DPSA document, 2007: 30). In the minister's foreword: "the framework encourages a multi-sectoral response to HIV infection and wide-ranging impact of AIDS and other diseases on the workforce, and recognises the importance of individual health, wellness and safety and its linkages to organisational wellness " Fraser Moleketsi.

5.5   SUMMARY

The high prevalence of HIV and AIDS raises concerns among business leaders. Although there is much debate on whether the prevalence statistics available is the true picture of the real challenge, a number of surveys indicate latent crisis in the world of work. Companies are put under pressure from various sources to respond to the HIV and AIDS pandemic. For this reason the above literature indicates that many companies are taking responsibilities to mitigate the challenges of HIV and AIDS. It is however very difficult to gauge the efficacy of their response due to the potential competition that has been created by pressure and the publicity. Despite the value that can be derived from HIV and AIDS reporting, there are differing opinions about the value of the GRI framework as a reporting tool. Standards developed by GRI and SABS have a potential to give guidelines to proper reporting and monitoring, to currently minimise the inconsistency and incomplete reporting on these programmes.

CHAPTER 6

DIFFICULTIES EXPERIENCED BY HIV AND AIDS INFECTED AND AFFECTED WOMEN IN THE WORKPLACE

6.1   INTRODUCTION

Research has examined the particular stressors faced by women and the economic, social, and psychological costs of being female in the labour market and in the workplace. However, there is little information on the impact of HIV and AIDS on working women. There is an abundance of literature on the economic impacts of HIV on business which has spurned action globally (Reed, 2004:231), however there is little in terms of evaluation and empowerment programmes for working infected and affected women. This chapter provides an overview on the demands and stressors faced by women, with a focus on the HIV infected and affected women in today's workforce.

6.2 THE EFFECT OF HIV AND AIDS ON SOUTH AFRICAN WOMEN

There is still a tendency amongst researchers on HIV and AIDS to focus on the general impact of HIV and AIDS on the general population despite the reportedly high impact on women. With increasing number of women in to the world of work, this could be making a great impact on their roles as working women and caregivers. South African women are reportedly to be significantly affected by HIV. The explosive growth is noticeable in the extremely rapid increase in HIV prevalence among women attending antenatal clinics from 26,5% in 2002 to 29,1% in 2007, as discussed previously in Chapter Three. It is important to note that the statistics from antenatal studies only measure those women that are not a member of a medical aid or cannot afford private clinics. Those women who are attending private clinics are not counted in these statistics. It can be inferred that majority of women attending private hospitals are working women or women who are economically active or in a position to afford private hospitals. According to Majors (2004:136), in 1985 women accounted for 36% of the total workforce in the public sector. There was a noticeable rise to 41% by 1991

(Standing, Sender, & Weeks, 2002:158). In 2000, new female entrants in the public sector brought the total number of working women to about 55% (Public Service Commission (PSC), 2000:23) and this has been stable until 2004 (PSC, 2004).

According to Statistics South Africa, 53% of the employed labour force is married (Mutedi, 2003). A Human Science Research Council (HSRC) study conducted in 2002 by the Nelson Mandela Foundation showed that women aged 20 to 24 years had twice the HIV prevalence rate compared to young men in the same age group (NMF/HSRC, 2003:9). An estimated 3% of South African households in 2002 were found by the NMF/HSRC study to be child-headed, and the assumption is that most of these children are girls. Another study showed that in Zambia and Zimbabwe, for every 15 to 19 year old HIV infected boy, five or six girls in the same age group are infected (UNICEF, UNAIDS, WHO, 2002:17).

The South African Medical Research Council (MRC) indicated that death among women in South Africa, aged 20 to 49, rose by 168% between 1998 and 2003 (Reuter, 2004). A survey of HIV infected girls in Kwa-Zulu Natal Province showed that 10% of them reported their first sexual experience as forced rape (UNICEF, UNAIDS, WHO, 2004). With the risk of HIV and AIDS, women are the most vulnerable gender, especially in South Africa. According to Rape Crisis reports, South Africa has the highest *per capita* rate of reported rape in the world, indicating 115,6 for every 100 000 members of the population as of 1988 (Rape Crisis, 2003).

In a study of the development of high risk sexual behaviour by college students in 1996, it was found that during a three months time frame, about 49% (42 out of 86) of men and 64% (66 out of 103) of women have engaged in unprotected vaginal intercourse. Only 1 person reported using a condom (Scandell, Klinkenberg, Hawkes, & Sprinns, 2003:121). The study suggests that more women are engaging in high risk sexual behaviour than men. Jones (1996:23) indicates that HIV prevalence is growing the fastest among women. In a heterosexual relationship, it is easier for HIV to be transmitted from a man

to a woman than from a woman to a man, making women more vulnerable than men as discussed previously in a chapter discussing gender and HIV and AIDS.

In a pilot study by Bowler (2002:22), HIV prevalence per 1000 employees by gender, race and age for a sample of 20 HIV positive employees, showed that the prevalence is higher in female than males. Furthermore, it was higher in Africans than Coloureds and higher in the 25 to 34 year age group. The study was done in the Nelson Mandela Metropolitan Municipal area in the Eastern Cape in 2002. There was also an indication of only 20 HIV positive employees out of 1000 attending a wellness programme. A study in a rural area in the South African province of KwaZulu-Natal showed that of 13% of women, whose husbands worked away from home, two-thirds were infected with HIV (Morar, Ramjee, & Karim, 1998:23).

New approaches in HIV and AIDS programmes to lessen the vulnerability of women, includes efforts to keep couples together. A Norwegian relief agency working in Malawi hired and trained the wives of their drivers who frequently travel away from home to work as their 'distribution' assistants (James & Mullins, 2003:3). This effort is aimed at reducing the opportunities for highly mobile staff members to use their relaxation time for practicing risky behaviours. In addition, the programme generates a source of income for the family and is a programme that may be suitable for South African women.

HIV positive women experience many problems, including the absence of savings and other assets that cushion the impact of illness and death. These costs relate to the costs of drugs when available to treat opportunistic infections, transport costs to health centres, reduced household productivity through illness and diversion of labour to caring roles, loss of employment through illness and job discrimination, funeral and related costs. On the other hand, for a working woman, a compassionate undertaking for an affected family member can serve as a burden that can limit her economic opportunities (UNAIDS, 2006:90).

There is enormous strain on the capacity of women to cope with the psychosocial and economic consequences of illness, to such an extent that many families experience great distress and often disintegrate as social and economic units. When AIDS has eliminated the breadwinner who was the husband, the wife is often further exposed to poverty which then increases her chances of contracting HIV. This could be true in the cases of young women who will often be forced to engage in commercial sexual transactions, sometimes as casual sex workers, but often on an occasional basis as survival strategies for themselves and their dependants. The effects of this behaviour on HIV infection in women are only too evident and partly account for the much higher infections rates in young women who are increasingly unable to sustain themselves by other work in either the formal or informal sectors.

In a South African study in 1996, it was surprisingly reported that young girls think of short-term survival rather then long-term well-being. Short-term survival strategies often included exchanging sex for schooling, a job, money, or a roof over one's head. It is important to develop strategies that will protect young girls from the risks of HIV or premature death (Poku, 2001:198). The position of women in the current HIV and AIDS pandemic in South Africa is made precarious by the severe forms of stigmatisation that people who acknowledge their status currently have to face. The story of Laetitia (not her real name) as narrated by McGeary (2001: 48-50), symbolises that to acknowledge AIDS is to be branded as monstrous. Apparently, Laetitia was fired by her employer after falling sick in 1996. Following losing her job, her children were ashamed and frightened upon her disclosure, and her mother raged about the loss of money instead of Laetitia's health. The neighbour avoided her, young boys threatened to burn her house and seeking assistance from the police was not helpful. The story of Laetitia evidently shows the struggle of many working women who have families who do not understand the difficulties of women and employers who are in denial of the AIDS pandemic.

6.3 THE DIFFICULTIES EXPERIENCED BY HIV AND AIDS FEMALE CAREGIVERS

Caregivers are people who provide care for people with HIV and AIDS. Caregivers, who are mostly women by virtue of their caring role provide individual attention to bedridden

patients at their homes: feeding, washing and dressing them, reading to them, passing on health advice and offering companionship to help lessen their isolation (Irin PlusNews, 2008:1). Some are volunteers, while others receive a government stipend and others are family members of the infected. Caregivers in the content of family members, health providers and educators are discussed here.

There are several stressors experienced by caregivers such as care giving tasks, feelings of fear, and loss associated with each infection. In addition, there is social stigmatisation, loss of social support, feelings of rejection, and financial concerns. Dealing with uncertainty that surrounds HIV infection and AIDS is a stressor common to family caregivers (Brown & Powell-Cope, 1991; McGinn, 1996).

A study conducted by Gordon-Garofalo (2004:14) revealed that the most psychological stressors associated with HIV and AIDS were fear of contagion, stigmatisation, revelation of lifestyle, sense of helplessness, and grief. The most common stressors identified among family members were conflicts surrounding care and support provision. Gordon-Garofalo (2004:25) concluded that illness severity, suddenness of onset, and change in patient functioning were stressors as well. The impact on caregivers is determined by the severity of the illness. Therefore, the stressors could be grouped into two categories: the *primary stressors,* which are associated with care and household management and *secondary stressors*, which result from strains from primary stressors, i.e. financial, occupational, social, and emotional consequences.

Due to the stigma surrounding AIDS, spouses and partners are often reported to be anxious about discussing their needs with family and friends and thus becoming socially isolated. Gordon-Garofalo (2004:14) adds that uninfected partners also often feel resentment towards infected partners. Stigma attaches itself strongly to women because of the negative assumptions made about sexual behaviour risks, even when a woman has not engaged in any (UNAIDS, 2006:90). For infected women with a small baby, the fact that they are advised not to breastfeed their babies, puts a burden and causes them to carry the stigma around HIV and AIDS. In India, 90% of HIV positive women, who

were infected by their husbands, found themselves being subjected to more discrimination and stigmatisation than their husbands (ILO, 2003).

Individuals, not regarded as belonging to a high risk group, may also need assistance in coping with the epidemic. The care of patients with HIV-related disorders places stress on providers of care. Factors contributing to this stress include fear of contagion, prejudice against high-risks groups, unfamiliarity with AIDS, and the high prevalence of this disorder in some geographical areas, which limits training (Bowler, 2004).

Psychiatric intervention among caregivers includes education and offer opportunities to express their rational and irrational fears and despairs regarding the care of patients with HIV-related illnesses. The unwarranted fear in many caregivers of acquiring AIDS is determined in part by the ignorance, displacement, and the newness and uncertainty surrounding the AIDS pandemic.

The role of primary caregiver has a significant impact on women and their participation in the labour force. Perkins (2000:61) indicates that approximately 2,2 million people provide unpaid care to frail elders at home. Of those, 72% are women of 45 years or older, with an average age of 57. It is estimated that more women will quit their work for care-giving roles than those who continue to work, 20% will reduce working hours or take unpaid leave (Perkins, 2000). It has been well talked about in the South African media that the scourge of AIDS has affected the education sector. The challenges with the number of learners dropping out of school to support families who have been orphaned because of AIDS (most of them girls), threatens to erase the gains in education in the last ten years (Whitelaw, 2000). Educators teach learners that may frequently be absent from school to take care of ill family members.

Caregivers are likely to be overwhelmed by the high mortality rate and decrease in life expectancy. In countries such as Zambia and Zimbabwe, NGO staff members have taken several orphans and vulnerable children into their homes after their parents have died of AIDS (O'Grady, 2004:210). The task to care for dying children presents an

emotional, familial, societal, economic, and spiritual impact to the caregivers. Inside families, caregivers may be largely concerned about contracting HIV through casual contact, and outside the family, they might fear the gossip that can greatly affect the whole family and their social standing.

6.4 THE STIGMATISATION OF HIV INFECTED AND AFFECTED WOMEN

Theories on stigmatisation, such as sociological ones, highlight the reality that stigmatisation is the highest concern, because it is both the cause and effect of secrecy and denial, which can be seen as the catalyst for HIV transmission. According to (Rankin, Lindgren, Rankin & Ng'Oma, 2005: 4) the fear of stigmatisation limits the efficacy of HIV testing programmes across sub-Saharan Africa. The HSRC (2005:19) defines an HIV and AIDS stigma as an enduring attribute of an individual infected with HIV that is negatively valued by society. Alonzo and Renolds (1995: 304) on the other hand provide a more complex reading suggesting that a stigma is not merely an attribute, but represents a language of relationship as labelling one person as deviant - reaffirms the normalcy of the person doing the labelling.

6.4.1 Stigma

One of the theories on stigma is sociological theory. In sociological theory stigma is described as an attribute, behaviour or reputation, which is undermining an individual or group in a certain way (Ritzer, 2006: 16). The theory links stigma with stereotype and whether the person or group is accepted or rejected. The sociological theory implies that the society may establish the means to categorize and label the identified person or group and give them a social identity. In expanding sociological theory, (Falk, 2001:1) identifies two types of theories. Namely, existential stigma and achieved stigma. Existential stigma, implies a condition which the target of stigma either did not cause or over which the person has little control. He then defines achieved stigma as that which is earned because of behaviour or attitude and the person is blamed as having contributed to the cause that led to being labelled. Example of this behaviour is seen primarily in the social stigma that focuses on disease-associated with stigma. Such diseases are HIV

and AIDS, epilepsy, mental illness and disabilities. In studies involving these diseases, both positive and negative effects of social stigma have been discovered. In the work by the HSRC (2005:19) on theories of disease stigma, the definition of stigma is proposed as "an ideology that claims that people with a specific disease are different from normal society, more than simply through their infection with a disease agent." There is a differing experience amongst people living with HIV and AIDS, some have reported that their stand on HIV disclosure have yielded positive results, whilst others have differed. The treatment of dehumanisation, often influences the decision of infected women to disclose or not to disclose their HIV status. Cases where there are designated hospitals or sections for access of HIV treatment can further reinforce the fear of stigma amongst HIV infected women. Despite increasing access to prevention of mother to child transmission initiatives, including anti-retroviral drugs, the perceived disincentives of HIV testing, particularly for women, largely outweigh the potential gains from available treatments in some countries, such as South Africa and Zambia (UNAIDS, 2007:241).

The study on the impact of HIV-related stigma by (Reece, Tanner, Karpiak and Coffey, 2007:73) revealed that the threat of social stigma prevented people living with HIV from revealing their status to others. Participants in their study with high HIV concerns proved to be 3.3 times more likely to be non-adherent to their medication regiment than those with low concerns. It is not surprising stigmatization is one of the greatest barriers of efforts against HIV prevention amongst women. The impact of stigma involves dehumanisation, threat and sometimes depersonalization of others, furthermore, this impacts on the HIV treatment and prevention as a whole. Therefore clinical care directed to women living with HIV should include consideration for patient sensitivity to social stigma.

It can therefore be conceptualized that stigma leaves people with a mark that in many instances they have no control over. The labelling can either contribute to stereotypes, discrimination or loss of status. In some cases it can even result into loss of self-esteem or cause identity issues. Levine and Van Laar (2004:11) postulate that stigma can dis-empower people and in some instances cause social injustices. An example of this is

that in certain Arabian countries and in Egypt, when people from other countries are found to be HIV positive they are deported back to their countries of origin, a practice that is not coherent with the United Nations' declaration (UNAIDS, 2004:55).

From the analysis of the definition of the societal theory above it can further be inferred that the pressure that is put on people who are labelled different such as in the case of HIV and AIDS could leave them with various mental health issues, particularly when they have no control over stigma that are attached to them.

Theories of stigma are further expanded by (Major & O'Brien, 2005:395) to include six dimensions, which give a better understanding of the challenge from one's personal responsibility viewpoint. The dimensions are classified as:

- Concealable stigma- which means the extent to which others can see the stigma
- Course of the mark- whether the stigma becomes more pronounced
- Disruptiveness- the degree to which the stigma affects social interactions
- Aesthetics – other's reactions to the stigma
- Origin – whether others think the cause was from birth, accidental or deliberate
- Peril- the visible impact the stigma has to others.

From these dimensions one can infer that stigma is necessarily not based on facts but on one's perception, belief and judgement of others. If the researcher's assumption is true, treatment of HIV should include a multidisciplinary approach where a person is viewed in totality, from the society they come from to the understanding of themselves. Research from HIV and AIDS has indicated these various stigma dimensions as common amongst women living with HIV and AIDS (UNAIDS, 2007:362). In some cultures, especially African cultures, the role of women have previously been generalized to one as equal to that of children. With the HIV epidemic the social stigma has worsened this perception. Women who have the burden of HIV and AIDS may feel that the stigmatization is transforming them from whole person to nothing. They may feel devalued whether in the workplace or in the society. The role of women in these cultures

and societies affect their identity and contribute to their level of self-esteem in a negative way.

Literature on the HIV and AIDS stigma tends to conflate the causes, functions and effects of stigmatisation and reveals a continuing tension between individual and social explanation for the phenomenon. Furthermore, the area of HIV and AIDS, as well as racism has conceptualised prejudice as a problem of individual ignorance.

Stigmatisation is part of the attitudes and social structure that set people against each other; it is with this background that the theory of stigmatisation is investigated against women's emotional status in relation to societal structures, including workplace interactions. Several examples are seen where fear of stigmatisation is contributing to women's behaviour during pregnancy and parenting. Fear is causing women to continue breast-feeding because the mothers do not want to arouse suspicion of their HIV status by using alternative feeding methods. HIV-related stigmatisation directly hurts people; individuals may be isolated within their family, hidden away from visitors, or made to eat alone (Nyblade, Pande, Marthus, MacQuarrie & Kidd, 2003:53). Stigmatisation can present itself in two forms: An internalised stigma, where the infected person becomes one with the illness and looses a sense of self, and an external stigma where the person is labelled by others. The combination of external and internal stigmatisation on the self may impose a heavy burden.

In Zambia, Tanzania, Zimbabwe and Malawi, experience of some women in the workplace is presented as a heavy burden, which is often a downward spiral marked by fatalism, self-loathing, and isolation from others (Rankin *et al.*, 2005: 2). Internalised stigma may perpetuate anxiety concerning infected or affected women given the perception of the community they live in. Women, sex workers, and youth are frequently blamed for bringing illness into the family. If we agree that these groups are generally disempowered due to perceptions and societal beliefs, then it can be argued that the burden on women is great, that the self-stigmatisation would therefore be potent, particularly if they have just learnt about their status. If the woman has low self-esteem,

she may already hold punitive views of HIV infection, which will then in turn be an emotional pain on her identity. This will then result in the third level of stigmatisation, which are multiple stigmatisations. Multiple stigmatisations are as a result of already existing prejudice and social stereotypes (HSRC, 2005:25). This is when different kinds of prejudice are added together. An example is when a woman experiences stigmatisation by virtue of being a single woman and being HIV positive.

In some African countries, husbands have beaten or abandoned wives thought to be HIV positive despite the fact that many women contract the virus from their husbands. (Rankin *et al.,* 2005: 4) In addition, it is acceptable in Nigeria that if a husband should die, the wife's in-laws may seize her inheritance (Alumbo, 2002: 117).

For working women, stigmatisation can place a burden on the family. The family may recognise that she may become increasingly unproductive and that caretaking will sooner or later draw one or more family members away from providing for the family. This will in turn put an economic burden on the family. The belief that the person will die anyway can cause a caregiver to give up on the person. In addition, in the workplace, stigmatisation may result in discrimination or outright removal from a job (Nyblade *et al.*, 2003: 53). According to an article titled "HIV/AIDS the caregiver" The following are some of the reasons why caregivers experience burnout (Health 24.com):

- Stigma associated with HIV and AIDS
- Secrecy and fear of disclosure among people with AIDS
- Over-involvement with people with AIDS and their families
- Personal identification with the suffering of people with AIDS
- "Difficult" patients
- The terrible plight of children
- A demanding workload
- A lack of support from superiors
- Financial hardships (of both patients and caregivers)
- Training and skills lacking

- Isolation and no support (especially of family members who are also caregivers).

6.5 THE EMOTIONAL PAIN OF WOMEN WITH HIV AND AIDS

Most literature on women living with HIV is focused on medical factors or obstacles faced by women living with HIV. There is therefore a need for theoretical and empirical literature exploring how women live and cope with HIV, which would include research on stress management, psychological make-up, and cognitive coping styles. According to the Nursing Times magazine, a domiciliary sister at St Christopher's Hospice, visiting a 41 year old with appalling physical problems, responded that the mental anguish and emotional pain are more overwhelming than physical pain. The blaming model of stigmatisation suggests that negative meanings are associated with disease and people who contract it, in order to totally allay anxiety about the risk of infection (HSRC, 2005:22). It is further postulated that blaming is a result of internalised pain and thus either projecting to others or splitting a psychological mechanism of reducing anxiety during crisis and stress.

At the same time, opportunities created by new treatments have created new, potentially stressful uncertainties. For example, people benefiting from treatments may worry that returning to work will jeopardise their receipt of health insurance and their chances of regaining disability entitlements, should their health again begin to deteriorate. In addition, contemplating having a baby might raise concerns that the demands of parenting could compromise one's health, which is generally argued as a medical risk in the medical literature on HIV and AIDS.

A new paper published by the UNAIDS-led Global Coalition on Women and AIDS, shows that when women have an income and a safe place to live, they are much more able to negotiate abstinence, fidelity, and safer sex. Economic security, the paper explains, is a major factor in enabling women to protect themselves from HIV infection. Today, however, of the 1,2 billion people living on less than US$1 per day globally, 70% are women. Women also represent almost 50% of all people living with HIV globally. According to the paper, securing property rights and inheritance rights for women and

girls has clear value in HIV prevention. Many promising initiatives are using microfinance and skills training to improve women's access to economic assets such as land, property, and credit to reduce their vulnerability to HIV. (Haldenwang, 2006:1).

Education is the most effective weapon against AIDS. HIV is transmitted mostly by behaviour that individuals can modify. AIDS is the leading cause of death among women and is preventable. The goal of prevention education must be to reach those individuals most likely to be at risk of infection (Jones, 1996:14), such as women and those who are in an abusive relationship. It is evident that women are most vulnerable both as homemakers, employees, and caregivers. It is the business sectors' challenge to address women's needs in the workplace and the next chapter will attempt to investigate workplace interventions by various corporations.

6.6 SUMMARY

Women, as wives and sex workers, are at risk of HIV transmission. As mothers, women must deal with the implications of HIV infection for their unborn children. As mothers, aunts, sisters, grandmothers, and daughters, women will have to care for the children orphaned by the epidemic. As caregivers, women bear the burden of caring for the sick and dying partners, children, relatives, and neighbours and attempt to hold the family unit together in the face of sickness and death. All these accounts evidently show the impact of HIV and AIDS on women. Compounded to the burden of HIV is the stigma associated with it. Stigmatisation continues to undermine treatment and intervention to reduce the risk of HIV among women. However, interventions should be geared towards empowerment of women faced with HIV at both individual and at an affected level as caregivers.

"We need to put the power to prevent HIV in the hands of women. This is true whether the woman is a faithful married mother of small children, or a sex worker trying to scrape out a living in a slum. No matter where she lives or what she does, a woman should never need her partner's permission to save her own life". (Bill Gates)