HIV DISCLOSURE IN THE WORKPLACE AMONGST PUBLIC SERVICE WORKERS IN ZAMBIA

Rose M. Musumali

Student Number 2520839

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University of the Western Cape

Supervisor: Ms. Nikki Schaay

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DECLARATION

I declare that this study, "HIV Disclosure in the Workplace Amongst Public Service Workers in Zambia" is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

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Full Name: Rose Musumali

Date: 2012

Signed:

KEYWORDS

- HIV/AIDS
- Zambia
- Public service
- Workforce
- HIV-positive status
- HIV disclosure
- HIV workplace policy
- HIV workplace programme
- People Living with HIV/AIDS

• Stigma and Discrimination.

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ABSTRACT

With a prevalence of 14.3% among the 15-49 years age group, HIV/AIDS still constitutes a significant challenge in Zambia. In order to respond to the impact of HIV/AIDS within the workplace, government ministries have developed HIV-focused workplace policies and programmes that provide HIV/AIDS services. However, despite their availability, the number of employees accessing the services, especially those targetting HIV positive workers remains low. The fear (either perceived or real) of disclosing an HIV positive status is one likely reason for the low uptake of services. HIV-positive status disclosure is an important public health goal as it can create opportunities for an individual to access information and social and medical support, and this will affect career and workloadrelated decisions. This exploratory, qualitative study aims to identify and describe the HIV-disclosure experiences of 12 openly HIV-positive Zambian public sector workers living in Lusaka and working in four Zambian Ministries. Both male and female public sector workers were interviewed. The participants' experiences of disclosing their HIV positive status in the workplace were explored in depth in this study. With the aim of providing those responsible for overseeing and managing the Zambian public sector HIV workplace initiatives with some practical recommendations regarding the disclosure support needed by HIV-positive public sector workers.

The study found that whilst participants had an initial fear of disclosing their HIV-positive status in the workplace, their HIV disclosure actually proved to be very beneficial. Not only did it allow their health-related needs (such as accessing medication and visiting a doctor) to be met, but their disclosure also encouraged others to also disclose their status.

The recommendations are are aimed at creating a supportive working environment for people living with HIV within the Zambian public service, and offering suggestions to their managers on how best to support the process of disclosure amongst their staff.

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ABBREVIATIONS/ACRONYMS

AIDS Acquired Immune Deficiency Syndrome

ART Antiretroviral Therapy

ARVs Antiretroviral

CHAMP Comprehensive HIV/AIDS Management Program

CSO Central Statistical Office

FPP Focal Point Person

GRZ Government Republic of Zambia

HBC Home Based Care

HIV Human Immune Virus

HIVOS International Humanist Institute for Cooperation with

Developing Countries

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ILO International Labour Organization

MOH Ministry of Health

NAC National AIDS Council

PAW Positive Action by Workers

PLHIV People Living with HIV

PMTCT Prevention of Mother-to-Child Transmission

PSMD Public Service Management Division

SAfAIDS Southern Africa HIV and AIDS Information Dissemination

Service

SHARe Support to the HIV/AIDS Response in Zambia

UNAIDS Joint United Nations Programme on HIV/AIDS

WHO World Health Organization

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CHAPTER 1. INTRODUCTION AND BACKGROUND TO THE STUDY

1.1. Introduction

HIV/AIDS continues to be a global health challenge with 33.3 million people infected with the virus. Of this number 2.6 million were new infections; 1.8 million deaths were documented in 2009. There were 22.5 million infections and 1.3 million deaths in sub-Saharan Africa in 2009 (UNAIDS, 2010).

Zambia has not been spared by the HIV/AIDS pandemic. The last Zambia Health Demographic Survey by the Central Statistical Office (CSO, 2009) found the prevalence of HIV in the 15 to 49 year age group to be 14.3%. With this HIV prevalence, Zambia was ranks seventh among 15 other countries experiencing a mature generalised HIV/AIDS epidemic in Sub-Saharan Africa (National AIDS Council (NAC) 2010; UNAIDS, 2010). The prevalence is significantly higher in urban areas, where there is an HIV prevalence rate of 19.7%, compared to a rate of 10.8% in the rural areas. HIV prevalence is also higher among females, with rates of 16.1%, compared to a rate of 12.3% amongst males (CSO, 2009).

According to The National AIDS Strategic Framework (NASF) report of 2010, 15% of the Zambians aged 15-49 have tested for HIV and know their status (GRZ/NAC, 2010; ZDHS, 2009). More recently, in 2009, it was estimated that 82,681 adults (aged 15-49 years) and 9,196 children and adolescents (aged 0-14 years) were newly infected cases, with daily infections estimated at 226 among adults and 25 among children(GRZ/NAC, 2010). Mother-to-child transmission accounts for 80% of infections in children aged 0-14

years (GRZ/NAC, 2010). The NASF (GRZ/NAC, 2010) report further states that an estimated 1,027,626 people are living with HIV in Zambia; 285,000 (56% women and 44% men) of the total of 338, 992 people eligible for treatment were enrolled on Antiretroviral (ARV) treatment in 2009. During 2010, the number had increased to 344,407 people on treatment (Ministry of Health, 2011). Eligibility is determined by a Cellular Differentiation 4 (CD4) count of less than 350 cell/ml (NAC, 2004). A total of 47,175 (61%) pregnant women received ARVs in 2010, an increase from 25,578 (29.7%) in 2006 (Ministry of Health, 2011).

1.2. Impact of HIV/AIDs on the workplace

The impact of HIV on the workplace has been described by a number of authors in varying contexts; all agree that it has an impact on the workforce and productivity (Comprehensive HIV/AIDS Management Program (CHAMP), 2007; International Labour Organization (ILO), 2001). One of these authors is the President of Zambia, who addressed the National Prevention Convention in 2009 (National HIV/AIDS/STI/TB Council 2009). For some time the impact was not only described in terms of a reduction in worker productivity as a result of employees becoming sick and dying, but also in terms of the contribution of HIV to the decline in social and economic safety nets as workers began to lose income as a result of getting sick. Two agencies, International Humanist Institute for Cooperation with Developing Countries (HIVOS) and Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), provide technical support to a range of partners such as Governments, private sector organizations, Faith Based Organizations and Non-Governmental Organizations in Zimbabwe, Mozambique, Malawi and Zambia. They conducted a survey in Zimbabwe that provided information on the development of a workplace policy. The study found that the vast majority of its partners (88.5%) felt the impact of HIV on their workers, in particular through increased

staff turnover, extended periods of sick leave, time taken off to care for sick relatives or to attend to funerals, and through increasing requests for loans (SAfAIDS and HIVOS, 2007).

Similarly, the International Labour Organization (ILO,2001) notes that HIV-related illnesses and the deaths of workers caused reductions in productivity in the workplace through the loss of person-hours, the high cost of replacing lost skills and experience, and through the cost of mitigating the impact of the HIV epidemic.

1.3. Government's response to the impacts of HIV/AIDS

Although no studies have so far investigated the prevalence of HIV in the Zambian public service itself, the Zambian Government's HIV and AIDS Strategy for the Public Service 2010-2015 (GRZ, 2010a) suggests that the HIV epidemic in the public service closely mirrors the generalized, mature epidemic in the general population. The epidemic primarily affects young, economically active employees. To this effect, both the Government and the public sector, through the Public Service Management Division (PSMD), have put in place measures to mitigate the problem of HIV in the workplace: in particular, they have put in place a National HIV/AIDS policy (Ministry of Health (MOH), 2005) and a National HIV/AIDS Strategic Framework (National AIDS Council (GRZ/NAC), 2010)

Through the National HIV/AIDS policy and the National HIV/AIDS Strategic Framework, the Zambian Government calls upon the public and private sectors to participate in responding positively to the HIV/AIDS epidemic. The National HIV/AIDS policy document clearly outlines the various sectoral responsibilities of each Ministry, in line with the mandate of each ministry (MOH, 2005). The National AIDS Strategic Plan

2011-2015 (GRZ/NAC, 2010) outlines the drivers of the HIV/AIDS epidemic in Zambia as multiple concurrent relationships, low and inconsistent condom use, low circumcision levels, increased labour mobility and labour migration, and mother-to-child transmission. The plan suggests that all of these factors are compounded by the presence of stigma and discrimination. Stigma and discrimination can be a barrier to access and utilization of HIV/AIDS-related services; and can infringe on people's rights to privacy and dignity.

The Zambian national response to HIV/AIDS resolves around four pillars, namely: (i) the coordination and management of HIV/AIDS-related interventions; (ii) the prevention of HIV; (iii) HIV/AIDS impact mitigation; and (iv) HIV- related treatment, care and support. In addition, both the public and private sectors have been called upon to scale up workplace programs in order to manage and mitigate the effects of HIV/AIDS through effective workplace policies, plans and programmes (NAC, 2010).

1.4. HIV/AIDS workplace programmes

Between 2002 and 2004 the 23 Zambian line ministries started developing HIV/AIDS workplace policies. These workplace programmes were specifically aimed at reducing the effect of HIV/AIDS-related absenteeism and reducing the loss of skilled person-power as a result of the increasing number of AIDS-related deaths within the workforce. Service providers such as peer educators, psychosocial counsellors and palliative caregivers have been trained as part of these workplace programmes. The service providers ensure that educational activities, such as awareness raising with regard to HIV prevention, stigma and discrimination prevention, voluntary counselling and testing (VCT), and information on treatment and related services are provided to workers either in the workplace or at an outsourced site. Those found to be HIV-positive are referred to Anti-Retroviral Therapy (ART) clinics for possible treatment with Antiretroviral Drugs

(ARVs) and/or the treatment of opportunistic infections. ARVs are now accessible in a number of public health facilities in Zambia: for example, by the end of 2010, 454 of the total of 1, 883 health facilities were providing ART free of charge, and they were situated in all the 72 districts in the country (MOH, 2010).

These workplace programmes have not only created an awareness of the HIV/AIDS services available within and outside the workplace, but they have also helped to raise employees' awareness of HIV/AIDS. This was revealed by a study on the cost-benefit analysis of HIV workplace programmes in Zambia by the Comprehensive HIV/AIDS Management Programme (CHAMP) in Zambia (CHAMP, 2007). However, the study suggested that the employees' general awareness about HIV did not seem to translate positively into the uptake of services such as ART. Despite the availability of treatment for HIV, workers were reported to be reluctant to access this service for fear of being laid off if it became known that they were HIV positive.

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1.5. HIV/AIDS disclosure in the workplace

Whilst HIV disclosure within Zambian workplaces has not been formally assessed and documented, the National Aids Council has noted that stigma and discrimination is probably a major barrier in preventing HIV positive clients from accessing and utilizing available HIV/AIDS services (NAC, 2010). At national level, disclosure is only encouraged, by the Zambia Counselling Council (ZCC) through the Counselling Curriculum in the counselling of a person that receives an HIV positive result (ZCC, 2006). According to anecdotal information collected by HIV educators, using a simple questionnaire during worker sensitization meetings supported by the Support to HIV/AIDS Response in Zambia (SHARe) project, in the Ministry of Agriculture and Cooperatives, over 80% of the 300 staff members taking part in the survey did not know

their HIV status (SHARe, 2004). During these meetings (conducted between 2004 and 2006) the SHARe trainers, who were working with the Ministry of Agriculture and Cooperatives, noted that no worker in this Ministry had ever publicly disclosed that they were living with HIV (SHARe, 2004). The fear of stigma (gossip, name-calling, such as 'Kanayaka' [one burning], being laughed at and labelled a prostitute) and fear of discrimination (loss of employment, being looked over for promotion or selection for official trips and foreign missions) were among the reasons these workers gave for not wanting to know their status or disclose their status (if HIV- positive) in the workplace (SHARe, 2004).

Similarly a 2003 study by the Community Development Resources Association (CDRA) on the impact of HIV/AIDS on NGO workplaces in Zimbabwe revealed dramatic cases of staff that became ill because of HIV, but instead of disclosing their status and accessing treatment, they chose to deny their HIV-positive status, and subsequently died (CDRA, 2003, cited in SAfAIDS and HIVOS, 2007).

While acknowledging the fear of – and the negative consequences of – disclosure, a number of studies have, however, demonstrated the potential benefits of disclosure, including its role in HIV transmission prevention, and in enabling timely access to treatment, care and support. Disclosure of one's HIV positive status also facilitates the adaptation of his or her work to the needs of someone living with HIV/AIDS (ILO, 2003).

1.6. Research problem informing this study

In Zambia, HIV/AIDS information programmes and interventions, such as VCT, are encouraging people to know their HIV status and then to discuss the results with an

appropriate person (Zambia Counselling Council (ZCC, 2006). It is obviously easier to disclose an HIV-negative status; the disclosure of one's HIV-positive status is likely to be a challenge and many workers would prefer to keep this secret. This secrecy contributes to a delay in seeking appropriate medical care. As a result many people who are HIV-positive miss out on a range of supportive services, such as timely treatment, therapy or counselling.

To date, no studies in Zambia have been undertaken amongst ministry workers specifically to understand the factors that could either promote or inhibit the disclosure of their HIV-positive status in the workplace. This study was therefore undertaken to explore some of the factors that might contribute to HIV-positive disclosure in the workplace, and to consider what workplace strategies ought to be introduced to facilitate and support the disclosure decisions of HIV-positive workers.

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1.7. Study context

The study participants were five male and seven female employees drawn from four public sector ministries in Zambia, namely, the Ministries of Agriculture and Cooperatives, Home Affairs, Communications and Transport, and the Ministry of Tourism, Environment and Natural Resources. The headquarters of all four ministries are located in Lusaka; the various departments of each ministry are located in the nine provinces and 72 districts, spread across the country. These four ministries were selected from a total of 22 ministries within the public sector as these were the only Ministries in which workers living with HIV openly disclosed their HIV-positive status to other workers in the workplace; they were also the only ministries to have a workplace HIV policy in place and to offer HIV-related services to their workers. These services include HIV/AIDS

sensitization, VCT, treatment with ARVs, treatment of opportunistic infections and care and support through home visitations.

1.8. Overview of the research design and methodology of the study

A descriptive, exploratory study was conducted using a qualitative approach to identify and describe the HIV-disclosure experiences of 12 HIV-positive Zambian public sector workers, all of whom were open about their status in their respective workplaces. The participants were drawn from a group of approximately 153 HIV-positive civil servants, all of whom live and work in Lusaka and are members of the workplace HIV support groups within the four government ministries mentioned above.

A qualitative, as opposed to a quantitative, research approach was used as the former approach is considered to have the advantage of allowing a researcher to document and interpret the different ways in which people make sense of their experiences; it also allows for an empathic researcher-interviewee relationship (Teddlie, 2009; Malterud, 2001; Baum, 1995). As this study aims to explore the participants' experiences of living with HIV, and the process of how they disclosed their HIV positive status, specifically in the workplace, the choice of a qualitative approach was deemed most suitable. This would not only allow for a deeper understanding of the individual interviewee's perceptions and experiences (Pope & Mays, 1995), it would also lend itself to an exploration of the meaning of the social phenomena in relation to their context. This was particularly important for this study, given its focus on the workplace.

1.9. Report outline

This report comprises of six chapters: Chapter 1 introduces the study by providing an overview of the research issue and the study context. Chapter 2 reviews the current and

related literature on the topic. Chapter 3 describes the study design and methodology. Chapter 4 contains a description of the study results. Chapter 5 contains the discussion of these findings, and takes into account what other studies have found on the research issue. Chapter 6 concludes the report and contains a set of recommendations emanating from this study.



CHAPTER 2. LITERATURE REVIEW

2.1. Introduction

This literature review explores the findings of other studies that have explored HIV disclosure across a range of different relationships, such as those involving partners, family members and friends. These studies were conducted in a number of different settings, such as in communities and, importantly, in the workplace. The review explores and describes some of the issues associated with the disclosure of one's HIV positive status; it examines the benefits and consequences of disclosure, how people can be supported to disclose their HIV positive status, and in general what implications all of this has for the workplace.

Disclosure is defined by Saones (2004:408) as "making secret or new information known"; and it has been described in Makin et al. (2008: 908) "as a process that involves decisions about timing, to whom, how and under what conditions." For many years, given the negative associations that accompanied HIV/AIDS, the disclosure of one's HIV positive status was not something to be taken lightly or easily shared. Even today, with the changing perception of HIV as a chronic condition, and increasing levels of 'openness' and acceptance of those living with HIV, there is still a hesitancy regarding HIV disclosure. For example, a study by Kandowa and Nuwaha (2009) aimed to identify the factors influencing disclosure; it was conducted with 139 People Living with HIV/AIDS (PLWHA) in Mityana, Uganda. They found that in spite of the benefits of disclosure, some participants still chose to keep their status a secret; some chose to disclose their status to a select group of people; others decided to open up publicly – i.e. to openly talk about their HIV-positive status in their workplace or their community.

Theories around disclosure state that it can be influenced by either the progression of HIV into AIDS (as people are not able to keep their HIV positive status a secret any longer), and/or by the anticipated negative or positive consequences of such disclosure (Serovich, 2001). The anticipated benefits include improved access to treatment and support during illness, while the potential risks and anticipated negative consequences include things such as experiencing blame, stigma and discrimination, divorce, physical and emotional abuse, rumour-mongering and fear of being accused of infidelity. These factors help to explain non-disclosure.

Importantly, Kadowa and Nuwaha (2009:31) state that disclosure is not a one-step event but a process that consists of several steps, such as "adjusting to the diagnosis, assessing one's disclosure skills, deciding whom to tell, anticipating the recipients' reaction and having the motivation to disclose". Maman et al. (2003), in a study on the rates and outcomes of *HIV* – sero status disclosure to sexual partners among women in Dar es Salaam, Tanzania – found that the first person to be told was usually the primary partner, followed by a female confidante or close friend. Most (64%) of the participants took over three months to disclose their status to their sexual partners, while the remainder (36%) did not disclose their status to their sexual partners during the period of the study.

Another study that revealed the period of disclosure was that by Kalichman and Nachimson (1999). Their study focused on self-efficacy and disclosure of HIV positive status to sexual partners in Georgia, in the United States. The study found that six months after testing HIV-positive over 20% (of 266 participants) had not disclosed their HIV-positive status to their sexual partner(s). Disclosure therefore does not happen immediately once one is diagnosed with HIV; this can take a person some time, and the length of time obviously varies from person to person.

2.2. Importance and benefits of HIV-positive status disclosure

Kandowa and Nuwaha (2009) argue that HIV disclosure is to be encouraged as a preventative and rehabilitative intervention or strategy, with benefits for both uninfected and HIV-infected individuals. For example, HIV disclosure is recognised as being of benefit to the person living with HIV as it results in increased opportunities for social support, greater access to medical care and creates opportunities to discuss and implement appropriate arrangements regarding their work situation (WHO, 2004; ILO, 2001). Disclosure can also contribute to the improved psychological well-being of the HIV-positive person (Hays *et al.* 1993; Serovich, 2001), especially if those to whom the disclosure is made respond in a helpful manner and provide appropriate assistance.

Disclosure is also acknowledged as an important public health strategy for the prevention and control of HIV infection in uninfected partners. With disclosure, sexual partners may be motivated to get tested. Disclosure creates awareness of the risk of HIV for untested partners, and may change behaviour with regard to sexual practices, thereby reducing the risk of transmission (WHO, 2004; Kadowa and Nuwaha, 2009).

What follows is a more detailed account of the various benefits that authors have suggested may result from HIV disclosure – and which positively contribute to the lives of those living with, and those affected by, HIV.

2.2.1. Reductions in HIV sexual transmission

Disclosure helps to minimise the transmission of HIV to sexual partners by motivating people to reduce risky sexual behaviour and adopt safer sexual practices —such as use of condoms during sexual acts. In a study by Maman et al. (2003), which explored the extent of HIV-status disclosure to sexual partners among 245 HIV-positive and HIV-negative women living in Dar-es-Salaam, Tanzania, it was found that 65% of the 73 HIV

positive women had disclosed their positive status to their partners. The authors suggested that this put both partners in a better position to adopt safer sexual practices (Maman et al., 2003).

2.2.2. Access to support services

Disclosure creates opportunities for people living with HIV to access the available medical, social, spiritual, material and psychosocial support services and thus to improve their quality of lives (WHO, 2004; Kadowa and Nuwaha, 2009). Access to support and HIV-related services is likely to be a significant motivator for disclosure. For example, Kandowa and Nuwaha (2009) in their study of 278 participants (139 of whom were HIV positive) in the Mityana district of Uganda, found that one of the main reasons for HIV disclosure (to their parents, siblings, children and close relatives) was to obtain financial and social support, to access treatment, and to increase the chances that their partners will get tested.

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Similarly, in a study of 18 HIV positive people in two South African communities, disclosure was seen as a way of obtaining financial and material support from family members; it helped those living with HIV, and their families, to sustain themselves as a result of the material support they received in the form of cash and other goods and access to services that they would not have otherwise been able to afford. (Norman et al., 2007). Similarly, in a study by Akani and Erhabor (2006), conducted amongst 187 HIV-positive men and women in Nigeria, 77% of the respondents' decisions to disclose were associated with expectations of economic, spiritual and emotional support.

2.2.3. Facilitating timely initiation of treatment and adherence to medication

In the era of treatment with antiretroviral drugs (ARVs), disclosure can assist a person living with HIV to receive treatment in a timely manner, and to adhere to a course of medication treatment (Klitzman et al 2004: 636). For example, Klitzman et al. (2004) in a study on the intricacies and interrelationships between HIV disclosure and HAART, conducted amongst 150 HIV positive adults in four United States cities, found that HIV disclosure led to greater social support, and this in turn was thought to promote health, specifically starting and adhering to treatment.

2.2.4. Prevention of Mother-to-Child Transmission

HIV disclosure is important in encouraging women to participate in the Prevention of Mother-to-Child Transmission programs (PMTCT). This has proved to be an effective strategy in the prevention of HIV transmission to a child. Makin et al. (2008) studied the factors affecting disclosure among 293 HIV positive women attending an antenatal clinic in Pretoria. They found that of the 293 women who participated in the study, 173 had disclosed their status to at least one person. 124 of the 260 women with partners had disclosed their status to their partners. The study suggests that providing support for disclosure among such clients could lead to a decrease in both prenatal transmission to children and sexual transmission to partners.

2.3. Inhibitors of disclosure

While the positive benefits of disclosure are acknowledged, a number of factors also inhibit the disclosure of one's HIV positive status.

2.3.1. HIV-related stigma and discrimination

Stigma is defined as "a dynamic process that significantly discredits an individual in the eyes of others" (Sengupta et al., 2010:1075). Discrimination is defined as any distinction, exclusion or preference which has the effect of nullifying or impairing equality of opportunity or treatment (ILO, 2010:2); it results from stigma. Being HIV-positive carries with it a stigma, given that the transmission of HIV is associated with types of behaviour (having sex, taking drugs) that have traditionally been regarded as taboo. The fear of being known to be HIV-positive, given the existence of HIV-related stigma and discrimination (either perceived or real), continues to create a barrier to disclosure: people living with HIV fear rejection; they fear being blamed for infecting others, and they fear being beaten, divorced or abandoned (Serovich et al., 2007).

Timewell (1992), as cited in Paxton (2002), also states that HIV-related stigma creates secrecy, which in turn produces psychological isolation and depression. Holt et al. (1998) further state that disclosure is in itself a potent stressor; it creates difficulties associated with the discrimination and stigmatization that complicate the coping process of the HIV-positive individual. One difficulty noted by Holt et al. (1998) is that, upon disclosure, an HIV positive individual might have to contend with the disruption of their most personal relationships.

An association has also been found between not disclosing one's HIV-positive status to sex partners and engaging in sexual practices with a high risk of HIV transmission. In a study by Simbayi et al. (2007), conducted amongst 413 HIV-positive men and 641 HIV-positive women in Cape Town, South Africa, it was found that of the 85 % of sexually active participants, 42% had had sex with a person to whom they had not disclosed their HIV status to in the previous three months.

Fear of negative consequences such as divorce, domestic violence, and rumour-mongering can also inhibit disclosure, especially among women living with HIV, as indicated in studies by Kandowa and Nuwaha (2009) and Makin et al. (2008). Kandowa and Nuwaha (2009) found that clients who feared negative consequences arising from disclosure were less likely to reveal their HIV-positive status.

HIV disclosure carries the threat of the withdrawal of traditional familial and social support systems as a result of accusations of promiscuity or infidelity (Kadowa and Nuwaha, 2009) which bring shame to the family and the community. This was indicated by respondents in a study of concerns around disclosure among 19 Latino women in the San Francisco Bay Area, USA (Ortiz, 2005). Even among the Buddhists, who believe that individual suffering is an integral part of life, a study conducted amongst 200 people living with HIV/AIDS in Chiang Mai, Thailand, found that whilst many of the participants experienced grief and loss (and had in a sense come to accept this as part of living with HIV), they also experienced an intolerable loss of identity within their community and social structures (due to HIV-related stigmatization); this led to feelings of desperation (Ichikawa and Natpratan, 2006).

Disclosure of one's HIV positive status can also evoke feelings of anxiety related to one's physical well-being and safety. Two African studies, by Akani and Erhabor (2006) and Visser et al. (2008) reported that the fear, especially among women, of being abandoned and/or being beaten up by partners, was a key reason for non-disclosure of HIV-positive status. In the first study, conducted in Nigeria by Akani and Erhabor (2006), 43% of the 187 HIV-positive male and female respondents did not disclose their status for fear of stigmatization, abandonment, accusations of infidelity and victimisation. Visser et al. (2008) explored the reasons for the reluctance of 293 HIV-positive pregnant women to

disclose their status in two townships in Tshwane (South Africa). They found that 35 of the 173 women (20.2%) who had disclosed their HIV-status experienced adverse consequences as a result. These included feeling hurt by people's reactions, being abandoned by their partners, being physically harmed, and even being threatened with death.

Closer to the context of this study, in a cross-sectional study of mental health and the HIV disclosure of HIV among Zambian adolescents (there were 127 HIV-positive adolescents in the study), Menon et al. (2007) noted that the stigma and secrecy surrounding an HIV-positive diagnosis were potential barriers to the adolescents receiving psychological support from a peer-support programme.

Thus it is commonly accepted that the HIV-related stigma and discrimination that one might experience and/or anticipate as a result of being known to be HIV-positive might negatively affect a person's decision with regard to disclosure.

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2.4. HIV disclosure in the workplace

There are few studies on the issue of HIV disclosure in the workplace, particularly in an African context. In the workplace, HIV disclosure may create opportunities for someone living with HIV to obtain permission to receive medical attention and, where appropriate, to be considered for lighter duties or be given an alternative workload (the latter is known as "job accommodation"). An American workplace study, conducted in Boston by Fesko (2001), focused on disclosure experiences and strategies among 20 HIV-positive respondents, and reported that participants suggested that there were benefits to disclosure was sometimes motivated by the need to explain their career decisions, or by the need to share the emotional burden of the HIV-positive diagnosis, or by concerns

about their workload and their ability to be able to travel outside work stations or out of town. However, a rapid assessment undertaken with Zambian workers during HIV/AIDS sensitization meetings in the four line ministries that are covered in this study found that the fear of being stigmatised, if they were known to be HIV-positive, led workers to refusing to participate in VCT services and to refuse to disclose their status (SHARe, 2004).

2.5. Conclusion

The studies described above suggest that the decision to disclose (or not) is likely to be affected by both the anticipated and/or the imagined benefits as well as by the possible negative consequences of such an action. Thus, disclosure can be inhibited by the possibility of having to endure some form of HIV-related stigma – either perceived or real (Serovich, 2007) – and/or by the tangible adverse and discriminatory reactions of people to disclosure. These reactions may include abandoning or physically harming the person whose status has been disclosed. However, a number of benefits to disclosure have also been highlighted in this chapter. These include access to HIV-related services, such as treatment, care and support, appropriate work accommodation, and the prevention of new HIV infections (WHO, 2004; ILO, 2001).

Interestingly, the literature review revealed that little research has been conducted into HIV disclosure in the workplace, more specifically in the Zambian context. It is hoped that this study will help to fill this gap in knowledge.

CHAPTER 3. RESEARCH DESIGN AND METHODOLOGY

3.1. Research aim and objectives

The **aim** of this research study was to explore the disclosure experiences of HIV-positive workers in the Zambian public sector in order to enhance the capacity of the government's HIV/AIDS workplace programme to provide appropriate clinical and psychosocial support to HIV positive employees.

The **objectives** of the research study were:

- 1. To identify and describe the key factors that are perceived to assist HIV-positive public sector employees to disclose their status in the workplace.
- 2. To identify and describe what some of the positive and negative consequences of disclosure have been for public sector employees living with HIV.
- 3. To identify, based on the experiences of those living with HIV in the public sector, the various ways in which the public sector HIV/AIDS workplace programme could better support HIV positive employees to make appropriate decisions regarding disclosure.
- 4. To make recommendations to the Public Services Management Division as to how the Zambian public service HIV/AIDS workplace programme could be assisted to provide the necessary support to employees living with HIV, particularly with regard to disclosure.

3.2. Research approach and design

This study is an exploratory, descriptive study using a qualitative research approach. Given that the study aims to explore participants' account of their HIV-disclosure experiences within the workplace, a qualitative approach was considered most appropriate as this enables a researcher to obtain a deeper understanding of the opinions, feelings and perceptions of participants (Pope & Mays, 1995, Welman et al., 2005).

3.3. Study population, sampling procedures and study sample

3.3.1. Study population

The study population was comprised of male and female public service workers who were openly living with HIV, and who were members of a support group for public service workers living with HIV; they were based in the Lusaka district, and employed in one of the following four ministries: Home Affairs, Agriculture and Cooperatives, Communications and Transport and the Ministry of Tourism, Environment and Natural Resources.

All the 22 Ministries in the Zambian public service have started to implement HIV/AIDS workplace programmes, where services such as prevention through HIV sensitization, treatment with Antiretroviral (ARVs) and home-based care are provided. However, as part of their HIV/AIDS workplace initiative they have established slightly different types of HIV support groups:

- (i) The first type of HIV workplace support group focuses on home-based care; its members (both HIV-positive and HIV-negative) undertake home and hospital visits to sick public service workers.
- (ii) The second type of HIV workplace support group consists of both HIV-positive workers and those affected by HIV (for example, staff members who have HIV-

positive family members). Members of this group, as well as those in the third type of support group (see below), are able to access nutritional supplements, food parcels and (in one Ministry), monetary support.

(iii) The third type of workplace support group is one that is *only* comprised of HIV-positive public service workers, all of whom have voluntarily disclosed their status to the other support group members. These groups meet on a regular basis and share their experiences of living with HIV with one another and provide each other with peer support. It was from the third type of support group that the sample of participants for this study was drawn.

The four Ministries listed above were selected to be a part of this study because they were the only Ministries in the public service that have the third type of workplace HIV support groups – i.e. where only HIV positive workers, who are openly living with HIV, meet collectively.

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Whilst there is a larger number of HIV-positive public service workers employed within these four Ministries, only some of those living with HIV have chosen to become members of a workplace support group. Across these four Ministries and countrywide, there are currently 400 HIV-positive public service workers registered as members of this third type of support group. Approximately 153 of these 400 members (38%) are based in the Lusaka district.

3.3.2. Sampling procedures and study sample

A purposive sampling method was used to select HIV-positive public sector workers, openly living with HIV, who would be willing to provide an account of their experiences regarding HIV disclosure within the workplace. A purposive sampling technique was used because it facilitates the selection of information-rich cases that provide material for an in-depth examination of meanings, understandings and interpretations (Rice, 1999; Patton, 1987). In this study HIV-positive public sector workers who are open about their HIV status in the workplace (as opposed to just being open about their status with family members and other HIV-positive group members) were chosen as participants for the study. This meant that only members of the third type of HIV workplace support group were considered as potential participants. Only support group members working in Ministry offices in and around Lusaka were considered as potential participants. The decision to limit the study to this urban area was based on logistical concerns: the researcher had limited resources and funding and was not therefore able to travel beyond Lusaka.

In terms of coordination and management, the person in charge of the HIV/AIDS workplace programme in each of the government Ministries is called the Focal Point Person, a position designated by the Office of the Human Resource Director in each of the Ministries. Each of the HIV/AIDS workplace support groups for people living with HIV has a support group Coordinator - selected from and by the members of the support group. The Coordinator is usually someone who has openly disclosed his or her status in the workplace. They are responsible for facilitating and arranging the activities of the support group.

In identifying and selecting participants for this study, the researcher first approached the Focal Point Person in each of the four Ministries; the FPP in turn informed the respective support group Co-ordinators about the study. The researcher was then invited to introduce the research study to the support group members in each of the four Ministries during one of their regular meetings. Information about the purpose and the process of the study, and the type of participants that were required was provided to all support group members. The Coordinators of each support group consulted with their respective support group members, and identified potential willing participants. In this way 22 support group members volunteered to participate in the study, 10 members from the Ministry of Home Affairs, six from the Ministry of Agriculture, four from the Ministry of Communications and two from the Tourism Ministry. The researcher contacted these potential participants, explained in greater detail the purpose and process of the research, and re-confirmed their willingness and availability to participate in the study. The researcher also responded to any further questions from the potential participants about the study. As a result of this follow-up process, a total of 16 individuals (eight males and eight females, finally agreed to participate in the study. They were not equally distributed across the four ministries, but each ministry was represented. A suitable time and venue for the interview with the participants was discussed and agreed to with the researcher at this point. Six of the initial number of 22 participants decided not to participate in the study as, upon further consideration, they felt uncomfortable at the prospect of being interviewed about their HIV status and disclosure.

As the research process unfolded, some of the 16 participants who had initially agreed to participate in the study were unable to make their scheduled appointments. This was for a variety of reasons, such as having urgent work assignments; having to travel out of town for work for long periods of time; and/or preparing for the presidential elections

(these took place on 22 September 2011). This meant that only 12 (seven females and five males) of the 16 identified participants were actually interviewed. The four possible participants who were not interviewed were not replaced as the researcher felt that, after the 9th interview, enough detailed information had been obtained from the 12 participants who were interviewed. It took about four weeks to recruit the participants, and this took place from July to August 2011.

3.4. Data collection instrument and procedures

Data was collected through in-depth individual interviews, and a semi-structured questionnaire was used. The data collection instrument and procedures are described below:

3.4.1. Data collection instrument

The semi-structured questionnaire (Appendix 3) was made up of key questions, each with related follow-up questions. The following issues were covered:

- Basic information was obtained about each interviewee (such as age, marital status, work responsibilities and experience and level of education);
- Experiences related to HIV testing were investigated (such as when they were tested; their experience of being tested and receiving an HIV-positive test result);
- Experiences of HIV disclosure (to family, friends and in the workplace); the negative
 effects or consequences of their disclosure in the workplace and the perceived
 benefits of disclosure);
- Awareness of and involvement in the various aspects of their HIV workplace policy and programmes;

 Perceptions and recommendations regarding the role of the HIV workplace support groups, and other aspects of the workplace programme.

3.4.2. The data collection procedures

The interviews were conducted during the months of August and October 2011. They were conducted in a private setting, acceptable to each interviewee, and free from distractions. All but two of the interviews were conducted at the participants' places of work. Two interview sites had to be changed during the interview as they proved to be too noisy.

Each interview started with the researcher introducing herself and the confirming the purpose of the study. Each participant was given detailed information about the study in line with the information contained in the Participant Information Sheet (Appendix 1). Prior to the interview, a Consent Form (Appendix 2) was shared and discussed with each participant. Their voluntary consent was obtained, and each participant either signed the consent form or provided a thumb print (the latter option was a requirement from the Zambia Ethical Committee). Permission was then sought from each of the participants to record the interview on tape. All the participants agreed to have their interviews recorded. With two exceptions, all the interviews were conducted in English, the official language of Zambia. Although all the participants were able to communicate in English, one female and one male participant specifically asked to be interviewed in Nyanja, one of the local languages. They said that whilst they understood English, they felt they would be able to express themselves more effectively in Nyanja. Nyanja is a language that the researcher was also able to communicate in, thus there was no need for a translator. In these two interviews, each question was first read out to the participants in English and then translated into Nyanja. Since the tools were constructed using simple English words

and phrases, they were easily translated into the local language (Nyanja) by the researcher.

Before the first question was asked (and before the recording began) each of the participants was asked if they wanted to use a pseudonym (rather than be identified by their real name in the recording). Participants were informed that recording was being made in order to ensure that the information that the participants provided was correctly documented. This would help the researcher obtain an accurate record of what the participants communicated during the interview. Ten of the 12 participants chose a pseudonym; two participants did not mind being identified by their real names as they did not conceal their HIV-positive status – even in their own communities. Each interview took, on average, an hour.

All the questions that were outlined in the questionnaire were asked in the same order. Whilst the use of follow-up questions changed slightly from one participant to the next, all the key questions were asked to each of the 12 participants. The recorded interviews were then transcribed by the researcher.

3.5. Data coding and analysis

The analysis of the results from the study involved a process of description, clarification and connection (Gifford, [n.d.]). As the data was being collected, sequential or interim analysis of the data was undertaken concurrently by the researcher. Data collection and analysis in qualitative research are not 'standalone' processes but, rather, feed into each other throughout the research process (Pope and Mays, 2000).

A broad framework for analysis, developed on the basis of the key questions asked of participants (see Appendix 3), was initially used by the researcher to guide her in her review, interpretation and analysis of the data. Within the boundaries of this broad

framework, an index of emerging themes or categories was established (based on the participants' description and/or expression of their feelings, experiences and accounts of incidents). Codes were allocated to key statements, phrases and important points raised during the interviews. The presentation of the results is based on both the overall framework (which mirrors the key issues asked of participants) and the identified themes, categories and codes which emerged in each of the focus areas – all of which are substantiated by direct quotations.

3.6. Rigour

Rigour in qualitative research is important in order to establish the credibility or trustworthiness of a study. Pope and Mays (2000) suggest criteria that can be used to assess the validity of a qualitative study. These include triangulation, reflexivity, respondent validation, attention to negative cases, fair dealing and a clear exposition of the methodology. To ensure the necessary credibility and trustworthiness in this research, these criteria by Pope and Mays (2000) were used as follows:

3.6.1. Triangulation

Triangulation entails comparing the results from two or more data collection methods such as individual interviews with a Focus Group discussion. While this study only used in-depth interviews with the participants as its method of data collection, triangulation was facilitated by, firstly, having the researcher's supervisor review two of the 12 interview transcripts. Her interpretation of the data was compared with that of the researcher, and agreement was reached on preliminary themes to be used in the analysis. Secondly, an independent researcher, working in the educational field in Zambia, read four of the interview transcripts. This educationalist was very instrumental in pointing out and highlighting some key aspects of the data that the researcher had initially overlooked

or had considered to be unimportant. These ideas were used to inform the selection of the final themes for use in the data analysis.

3.6.2. Attention to negative cases

This entails searching for and discussing elements that contradict the emerging findings of the study. An analysis of the data collected revealed no contradictory elements in the data.

3.6.3. Respondent validation

This was done through member checking, a technique as outlined in Mays and Pope (2000). This involves comparing the researcher's account with those of the research subjects to establish the level of correspondence between these two sets. Two of the participants (a male and female from different ministries) were given their transcripts to read while listening to the tape recording of their respective interviews. Both participants felt that the written transcripts were an accurate reflection of what they had said during the interview. After the preliminary findings were developed, the draft report was then also shared with these two participants to ensure that it was an accurate representation, interpretation and documentation of their experiences by the researcher. No contrary views were suggested by the two participants.

3.6.4. Exposition of methods of data collection and analysis

Care was taken during the research process to record each step taken by the researcher as she prepared, collected and analysed the data. These steps have been described earlier in this chapter. In addition, particular attention was given, during the transcription of the interviews, to writing down a description of the interview process so that the context and

tone of each interview could be recalled, as well as the actual content. Both the transcriptions and the researcher's notes on each interview are available for review.

3.6.5. Reflexivity

This refers to the sensitivity to the ways in which the research process was conducted; it includes an awareness of the way prior assumptions and experience could influence the research. This study involved only one researcher, who had been working for six years (from 2004 to 2010) as an HIV/AIDS Workplace Programmes Coordinator within the public sector workplace programmes of two of the four Ministries selected to be part of the study. This meant that care had to be taken to ensure that personal perceptions and biases did not affect the findings of the research. For this reason a researcher diary was kept in which the researcher recorded her observations and the thoughts that arose whilst collecting and analysing the data. Entries were made just after the completion of each interview. The researcher also recorded some of the dominant feelings or emotions that she experienced, such as the sadness she felt when listening to one of the female participants express her emotional pain when she recalled how she disclosed her HIV-positive status to her children.

3.7. Ethical considerations

3.7.1. Authority to collect data

Prior to the collection of the data the researcher obtained ethical approval from the University of the Western Cape (UWC), South Africa to conduct this study. Written permission was obtained from the National AIDS Council of Zambia (NAC) and from each of the four Ministries at which participants were located. The letter granting permission from UWC, along with letters of approval supporting the proposed study (obtained from the Zambian National AIDS Council and the four Ministries), as well as

the research protocol, were submitted to the Zambia Biomedical Ethics Committee for further approval. In July 2011 authority to conduct the study was granted by the NAC.

3.7.2. Obtaining informed consent from participants

Before the interview commenced, all study participants were given detailed information about the study through the participant information sheet (Appendix 1). This was read out to the participants by the researcher and also read by participants themselves. At no point, when the study was introduced to the support group members, were they told (either directly or subtly) that they had to participate in the study. All those that voluntarily expressed a willingness to participate in the study were asked to give their written and informed consent to participate. A consent form (Appendix 2) was used for this purpose, and each participant had to sign (or provide a thumb print – a requirement of the Zambian Ethics Committee).

3.7.3. Confidentiality

personally.

The participants were reassured that the content of the interviews, all the consent forms, tapes and all of the transcribed interviews would remain confidential. They were informed that this would be done by keeping all the research data, the consent forms and any other confidential or identifying information in a securely locked place that was only known to the researcher. The process of keeping this information safe was adhered to throughout the course of the study and will be maintained until all the transcripts and all tapes have been destroyed at an appropriate time after the completion of the study.

In the case of those participants that did not choose to use a pseudonym in the interviews, attention was given to removing any reference to their name (and the names of their family members), or any other identifier that would link their transcript to them

An appropriate referral arrangement was made to ensure that participants could obtain whatever support they might need following the interviews (such as counselling or debriefing or some form of clinical care). This arrangement was made prior to the interviews with a reputable HIV/AIDS organization (i.e. Latkings Outreach Counselling and Testing Services). However, none of the participants appeared to be adversely affected by their interview and no referrals were required during the process of the research.

3.7.4. Benefits

All participants were informed that there was no monetary gain attached to this study. However, to assist with transport to and from the interview venue, a transport refund of fifty thousand Zambian Kwacha (ZK 50,000.00) – the equivalent of 9.7 US dollars – was provided at the end of the interview to each participant who travelled to an interview site.

3.8. Limitations of study methodology

This study is limited in that it only describes the HIV disclosure experiences of a sample of HIV-positive workers, all of whom were members of a workplace HIV support group, in four of the 22 ministries in the Zambian public sector. It does not therefore account for what might have been experienced by HIV-positive workers who disclosed their status in the 19 other Ministries – and it does not take into account the experiences of those who are not members of the workplace HIV support groups in the Lusaka district. Thus, as with all qualitative research, the potential for the findings from this study to be generalized to other ministries – or to the Zambian public service as a whole, is limited. The study was also conducted in Lusaka, an urban centre, and the capital of Zambia, and usually selected participants with access to various HIV/AIDS services. Their

experiences will therefore differ from those of HIV-positive public sector workers living in more rural settings, who are likely to face a range of additional challenges.

Another limitation of this study has to do with the fact that the researcher had been working in, and was familiar with, the public service's HIV workplace policy programme. Some participants felt that it was not necessary to provide her with a very detailed response to some of the questions she asked them. In such situations, the researcher had to probe further and even rephrase the questions to get a more detailed response. However, there was also some benefit in having a researcher who was familiar with the workplace programme and with some of the participants. For example, many of the participants appeared to feel at ease and were comfortable sharing personal information with the researcher.



CHAPTER 4. FINDINGS

4.1. Introduction

This chapter presents an outline of the study findings. The chapter starts with a general description of the characteristics of the study participants and includes information on their age, marital status, employment status, family information and responsibilities. The chapter then describes the factors that (according to participants) enabled the disclosure of their HIV-positive status in the workplace; it examines both the positive and negative consequences of such disclosure, and the actions that participants took to deal with the negative consequences.

The chapter further describes the participants' opinions regarding what can be done to increase the involvement of HIV-positive workers in an HIV workplace program, and how workplace programs can support the disclosure and participation of other HIV positive workers in each of the ministries in the public service.

Though not the primary focus of this study, a section in this chapter has been dedicated to describing the experiences of the participants during their first HIV tests; this reveals how they learnt about and managed their HIV-positive status – all of which occurred prior to the disclosure of their status in the workplace. The researcher felt that it was important to include this information as it provided some context for the participants' subsequent disclosures in the workplace.

4.2. Ministerial placement and demographic characteristics of the participants

A total of 12 participants, comprising five males and seven females, were interviewed as part of this study. The participants were distributed among four ministries as follows: four participants from the Ministry of Home Affairs; four from Ministry of Agriculture; three from Ministry of Communications and Transport, and one from the Ministry of

Tourism, Energy and Natural Resources. The representation of participants in this study across the four Ministries mirrors the placement of workers living with HIV who are open about their status. For example, the Ministry of Home Affairs and the Ministry of Agriculture (Ministry of Agriculture has approximately 7,500 workers) are not only larger Ministries in terms of their workforce, they also have the highest number of workers who are open about their HIV-status. In comparison the Ministries of Communications and Transport only have nine members who are open about their status (in a workforce of about 200). The Ministry of Tourism, Environment and Natural Resources has a very small workforce of around 300 staff members, and only three members that are open about their status.

The 12 participants were aged between 29 years and 50 years in age. Seven of the participants were married, one was a divorcee, two were widowed and two were single (i.e. had never married). Eleven of the 12 participants had children of their own. Ten participants had other people in their care, such as brothers, sisters, grandchildren and 11 of the 12 participants are taking care of one or both of their parents. Responsibilities for these various dependents included financial and material support, and in the case of children, support with school attendance. One of the participants described the level of his responsibilities as follows:

I have so many other responsibilities; I am responsible for two of my stepchildren, my sister in law, my two elderly parents and my divorced cousin with her four children.

(Participant # 5)

The characteristics of the participants that have been described above are summarized in Table 1 below:

Table 1: Participant's characteristics

Participant No.	Sex		Marital status				People under participants' care			
	M	F	Married	Divorced	Widow/ Widower	Single	Own children	Parent(s)	Other family members	
1.	-	1		-	-	-	2	V	1	
2.	-		-	-	$\sqrt{}$	-	1	-	4	
3.				-	-	-	8		1	
4.	-		-	-	-		0		7	
5.	-		-	-		-	5		0	
6.	-			-	-	-	2	$$	2	
7.				-	-	-	2		5	
8.	-				-	-	2		0	
9.		-		-	-	-	4		2	
10.				-	-	-	10	$$	3	
11.	-		-	-	-		2		10	
12.		-		-	-	- u	3		2	

It is clear that all of the study participants had considerable personal responsibilities, and were taking care of one or both of their parents, their siblings and/or other extended family members. Given that public sector salaries are relatively low, 11 of the participants reported that they had to supplement their basic income by taking on another job or income-generation activity to raise the income needed to support their families. These activities included selling foodstuffs like maize, fish, chickens or goats (which they had either reared themselves or bought for reselling) and undertaking consultancies with other organizations. One female participant described this as follows:

Over the weekend I go out to buy fish and goats and come to sell (them) to the workers and other people to top up on what I get from my job.

(Participant # 2)

4.3. Level of education and work backgrounds

All the participants had attained a primary education (grades 1-7) and 11 had attained a secondary education (grades 8-12). Of the 11 that had completed secondary school, 9 had obtained a certificate or a diploma in some professional field, and one participant had a Master's degree from a university. All the participants have worked for a number of years in the Ministry in which they were placed at the time of the interview. The shortest length of service within that Ministry was five years and the longest 20 years. The average length of service amongst the 12 participants was 13.6 years.

Ten of the participants had people under their supervision and had thus assumed some form of supervisory role within the workplace. The number of people under the participants' supervision ranged from three to over 100 – the latter in the case of participants who held senior management positions. The management categories used to describe participants' positions within the public service were characterised in four ways:

- Senior management is defined as having at least an undergraduate university degree and/or holding at least the rank of an Assistant Director;
- Middle management is defined by having a diploma and/or holding the rank of a program supervisor; and
- Lower management is defined as being in possession of a certificate-level qualification and would be generally at the rank of a copy typist or a registry clerk.
- Those within the 'support staff' category were generally those without a professional
 qualification and would take responsibility for jobs like Office orderlies and drivers.
 The table below shows the educational levels and work backgrounds of all of the 12
 participants:

Table 2: Participant's educational levels and work backgrounds

Participant No.	Sex		Education level attained (Pri = Primary; Sec = Secondary; Univ = University)				Level within management/workplace structure				Years worked in the Ministry
	M	F	Pri.	Sec. Sch.	College.	Univ.	Senior	Middle	Lower	Support	
										Staff	
1.	-	$\sqrt{}$	1	V	V	-	-	V	-	-	5
2.	-	1	V	1	V	-	-	-	-	1	12
3.	V		1	√	V	-	1	-	-	-	13
4.	-	V	1	-	-	-	-	-	-	1	10
5.	-	V	1	√	V	-	_	V	-	-	11
6.	-	V	1	√	V	-	-	V	-	-	20
7.	V		1	1	1	1		V	-	-	10
8.	-	V	1	1	V		-	V	-	-	13
9.	V	-	1	V	V	-	<u>-</u>	-	V	-	14
10.	1		V	√ UNI	VERSI	TY of t	he	V	-	-	20
11.	-	V	V	√ WES	KERN	CAP	V	-	-	-	16
12.	V	-	V	√	-	-	-	-	-	V	19
TOTAL	5	7	12	12	10	1	1	6	1	3	

4.4. HIV Testing and the first disclosure experience

While the focus of this study is on disclosure in the workplace, part of the interview process asked participants to describe their experiences when they first tested for HIV. They were also asked about their reasons for taking the HIV test, who they first disclosed their HIV positive status to after testing positive, how long it took to first disclose their status to another person, and the reactions of those people to the news that they were HIV positive.

The rationale for focusing on these experiences was to help the researcher gain an insight into the participants' disclosure experiences away from the workplace, and to consider how this might link with their disclosure experiences *in* the workplace.

At the time of being interviewed (August - October 2011) the 12 study participants had known that they were living with HIV for between nine years (the maximum) and six years (the minimum period).

The 12 participants had different reasons for taking an HIV test. However, three key reasons emerged from the interviews. These were: (i) as a result of becoming sick themselves; (ii) because a partner or child became sick; and (iii) as a result of activities within the workplace such as HIV-awareness meetings or the provision of mobile VCT services. Of these three key reasons; (i) was most commonly cited: the participants' illness might take the form of having Kaposi Sarcoma, high blood pressure, unexplained fevers or the symptoms of pulmonary tuberculosis. Seven of the 12 participants suggesting that it was their own ill-health that had motivated them to access care and undergo an HIV test. Diagnostic testing for HIV is encouraged under the current clinical management guidelines in Zambia. The medical personnel therefore advised the participants to undertake an HIV test; this was to rule out HIV as the underlying factor for their presenting condition of ill-health. As one female participant narrated:

The day that I went [for testing] I was sick. Then the clinical officer told me that before he could do anything, maybe I could go to the VCT [Voluntary Counselling and Testing] centre and do an HIV test. Then they said asked, are you ready for the VCT? I agreed. Thereafter, I went outside and I came back and they told me that my results were positive.

(Participant # 2).

Testing as a result of a sick partner or sick child was cited as a reason by two participants. The participant with the sick child willingly took the test when the doctor suggested that they should both take an HIV test as the child's condition was not improving. When the results come out positive, the participant described how shocked she was:

My son was sickly. So one day the doctor asked both of us to undertake the test.

We both did the test and results were positive. I never suspected to be positive, so

I was shocked and felt very bad when my results came out positive.

(Participant # 5).

For the participants who were tested through workplace programmes, the decision to test was influenced by the fact that they were engaged in the programme and wanted to lead by example. As one participant narrated:

I was part of a training team and in that training programme, and I was busy telling people to go for Voluntary Counselling and Testing (VCT) yet I did not know my status. Since the VCT was just within the place where we were doing the training, I decided to test and know my status.

(Participant #7).

Receiving positive HIV test results was understandably met with some form of emotion, such as fear, silence or shock, on the part of the participants. Even in cases where their health status was poor, a positive result was not what they had expected. This was expressed as follows by one participant:

20 minutes before I knew my results, I was mostly sure that I was okay, and I was not expecting to be told that I was positive. But when I went back and I was told that I was positive, I felt like the world had finished, I did not know what to do, where to start from. I was disturbed actually.

(Participant # 5).

From the interviews it became clear that once they had received their results, all 12 participants were inclined to first disclose their status to a close family member (either their spouse, a sister or their parents), before they disclosed this to someone in the workplace. The timing of the disclosure varied: some participants told their partners immediately. According to one participant:

After I had the test, just within the clinic grounds, I just called my husband on the phone and he said don't tell me over the phone. He then knocked off early and came home early to hear the results of the test. Just the same day, I didn't wait for another day. I didn't even have plans of thinking of how I am going to tell it to him.

(Participant #1).

Other participants took as long as six months to disclose their status to their partners. One participant explained that it was so difficult to tell his partner of the positive test result that he had to pretend that he had not taken the test. He then asked his wife to go with him for an HIV test, while pretending that he did not know his status. He narrated his experience as follows:

I hid the results from my wife for about six months or so. First of all I was researching as to how I would give her the information. But the blood pressure was giving me problems so I decided to tell her that I was going to have an [HIV] test. She even encouraged me that I should go for the test and she would go with me. So I pretended to be tested for the first time and we all tested. That's how I even disclosed to my wife.

(Participant # 10).

The participants suggested that the reaction of the people to whom they first disclosed their status played a big part in how they dealt with their HIV diagnosis and how they took further disclosure decisions. For nine of the participants their fears of being diagnosed HIV-positive were allayed when they received support from the people that they first disclosed their HIV positive status to. As one female participant put it, having disclosed her status to her niece just after she had taken the HIV test, the support she received proved to be a relief:

My niece was very encouraging when I told her. She was not shaken because she had seen the way I was very sick. I felt relieved [with her reaction] because I at least had someone to share [the diagnosis] with.

(Participant # 2).

Some participants, however, experienced negative reactions to their disclosure. For example, one male participant experienced the break-up of his marriage, while another participant's spouse was offended when she shared her HIV positive test results with him:

My spouse was very offended and angry as to why I had gone on to do the test the before discussing the issue at length and agree that we take the test. Yet we had been discussing the issue for some time and he was just never ready to undertake the test.

(Participant # 5)

The experiences described above helped the researcher to understand the circumstances and the context in which participants first disclosed their HIV-positive status; they alerted her to factors that might influence HIV disclosure in the workplace.

4.5. Disclosure in the workplace

The data revealed little variation in the extent of HIV disclosure amongst participants: the majority (11) were open about their HIV status – regardless of their colleagues' HIV

status. Only one participant had only disclosed his or her positive status to other HIV-positive colleagues.

When participants were asked to whom they first disclosed their status in the workplace, and why they made this disclosure, 11 of the participants said they initially disclosed to their immediate supervisors. This was done primarily to facilitate shifts in their work load related to their state of health. Given that they were living with HIV, they anticipated that they might get sick more frequently and/or more severely. By disclosing to their supervisor, participants felt that they might be assigned lighter duties when they were not feeling so well. According to one participant:

I told my supervisor because I needed support as my health was worsening. I needed to reduce on some of the work that I was involved in.

(Participant #10).

Disclosure in the workplace was also prompted by the need to get permission to participate in training workshops for staff members living with HIV or to attend to their various HIV-related medical appointments (such as collecting drugs, undertaking tests, or visiting hospital suddenly in the event of a medical crisis – and thus having no time to complete a leave application form).

Eleven of the 12 participants had already commenced taking antiretroviral drugs (ARVs). The one participant who had not started taking ARVs had a CD4 count that was higher than that recommended for the commencement of ARV treatment (i.e. when the CD4 count is less than 350 ml). Each of the 11 participants generally has a routine monthly medical check-up which lasts a whole day. This is because that the government clinics they attend are usually crowded and have long waiting times. A supervisor was therefore the obvious, and often the first, person to whom the participants revealed their HIV positive status in the workplace. One participant noted:

I told the Director [about my HIV-positive status] because I knew that I would need time to go for my reviews and collect medication. I needed someone who is higher [in position] to know my status so that I am protected in the times when I am not feeling well and have to immediately go to the clinic even without first asking for permission.

(Participant # 2).

Some participants suggested that another reason for revealing their HIV positive status to others in the workplace was so as to enable other workers to get involved in activities that were only provided for those who were openly living with HIV. This was illustrated by one of the participants:

I was supposed to go for a workshop I remember. The workshop was a capacity-strengthening workshop for people living with HIV. Then how do I get permission? [Laughs] How do I get the necessary financial support that I needed to travel? I needed to attach the [invitation] letter that was written to me to get the permission. So before giving the letter, I just had to say, before this letter can go, it can't go into accounts because accounts is an open office and everyone would know. So I had to tell him [the accountant] then ask [him] for advice [about] how best I can put in the letter [submit letter to accounts without all the other workers in the accounts section knowing about my status.

(Participant #1).

The participants reported that their disclosure to their supervisor was generally met with surprise, and sometimes disbelief. However, after disclosure the majority of the participants reported receiving support and encouragement from their supervisors. For example, many of the participants said that their supervisors had thanked them for confiding in them and disclosing their status to them, given the sensitivities around HIV and disclosure. This was followed up by some words of encouragement, with the

supervisors assuring the participants of their support. This is illustrated by one participant:

The boss [supervisor] was very, very surprised and he really encouraged me. He said there are very few people who would openly talk about their status the way you have done to me. So he got very encouraged with me that he started using me to encourage other people who were like me [HIV-positive].

(Participant # 1).

Among the 12 participants, seven reported that prior to their testing for HIV they had suffered various opportunistic infections and were so sick that they were bedridden. It was at this time that they were advised, usually by the health workers attending to them at the clinic, to take an HIV test. After they received their positive HIV test results, they started on antiretroviral treatment (ARV) and treatment for the other infections. When they reported back for work after their sick leave, they first told their supervisors about their HIV-positive status. Subsequently (over different time periods) they also disclosed their status to other colleagues in the workplace.

However, four of the participants reported never having been seen as obviously sick by their supervisors. In the case of these four participants, the fact that they were HIV-positive appeared to come as a surprise to their supervisors. Their supervisor's perception of what an HIV-positive person ought to look like was related by one of the participants:

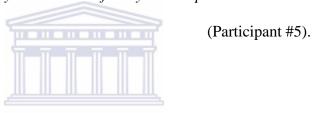
I think my supervisor could not believe that I was HIV-positive seeing the person that he had known me to be. At the time I was telling him, I was just myself, not somebody showing that I could be ill or something. For him, he thought someone who is HIV-positive is supposed to show that a person is HIV-positive. I looked very normal like everybody else.

(Participant # 1).

Disclosure in the workplace was not only limited to workers opening up to

their supervisor. Seven of the 12 participants reported that they had also told their fellow workers, usually during workplace sensitization or awareness- raising meetings, that they were HIV positive. Participants suggested that the reasons for disclosing their HIV positive status to others in the workplace included (i) the need to support other people that were still having difficulty with disclosure; (ii) wanting to encourage other workers to go for HIV testing; (iii) wanting to share their own HIV experiences with fellow workers; as well as (iv) the desire to prevent gossiping among workers. This was explained by one of the participants as follows:

I disclosed my status because I did not want people to be questioning when I go to the clinic. When I am open about my status, I can tell anyone that I am going to the clinic to collect my medicines or for my check up



4.6. The positive and negative consequences of disclosure in the workplace

One positive aspect that all the participants suggested that disclosing their status in the workplace had assisted them to come to terms with their situation; talking about their status (in the workplace) had given them "encouragement and a free mind." Participants stressed that this did not, however, mean that they never faced challenges as a result of their disclosure, but that it had eased some of the burden they experienced before disclosing their HIV-positive status to their colleagues.

The positive consequences of disclosure (which are also seen as benefits) and the negative consequences (including the participant's reactions to these), are described below.

4.6.1. Positive consequences of disclosure

Participants were asked to describe the benefits that they experienced as a result of disclosing their status in the workplace. Some of the key benefits (some of which have already been described above) were as follows:

4.6.1.1. Getting time off from work to go for medical visits

All the participants reported that it was easier for them to get permission from their supervisors for clinic visits because their supervisors knew their status. As these routine clinic check-ups sometimes took longer than was necessary, they felt free to inform their supervisors if they needed more time at the clinic; sometimes they even asked for permission not to report back for work on that day.

4.6.1.2. Being able to get involved in PLHIV programmes

Some participants reported that once they had disclosed their status in the workplace they felt supported by their supervisors when they asked for permission to attend a meeting that involved people living with HIV.

4.6.1.3. Supporting the HIV workplace programme

Participants also suggested that by disclosing their status in the workplace they became more involved in motivating people to go for voluntary counselling and testing and, in some cases, to start taking medication. Some participants suggested that by sharing their own experiences they were seen as providing a resource in their workplace: they were able to help other workers come to terms with living with HIV:

When some people ask you a question, you answer them giving references to your condition and what you have experienced from your condition.

(Participant # 5).

4.6.1.4. Challenging HIV-related stigma and discrimination

Some of the participants who made their HIV status known to other workers in the workplace said their disclosure helped them to challenge incidents of HIV-related stigma and discrimination in the workplace. Disclosure helped the participants talk freely about their own HIV-positive status, thereby removing the secrecy surrounding their status or illness, and removing a source of gossip. Participants suggested that now that their HIV positive status was known to others they even felt comfortable questioning certain actions or decisions made regarding their involvement in HIV-related activities in the workplace. These included participation in a "march past" during World AIDS Day events. A "march past" is a key ceremonial event on World AIDS Day activities: workers from various ministries and other Non-Governmental Organizations march past a group of important Government and donor dignitaries to register their participation in the World AIDs Day event each year.

4.6.1.5. Access to medical schemes

Some of the participants reported that disclosure helped them to access medical schemes that were available for workers who were diagnosed with HIV. Participants from three of the four workplaces said their Ministries had a medical scheme with a private medical provider which supported HIV-related treatment, including Antiretroviral (ARV) medication and routine HIV-related check-ups. As one participant put it:

Disclosing my status has given me access to the medical scheme that the ministry has at a private clinic where I go for treatment and routine HIV check-ups.

(Participant #7).

Participants said disclosure also helped to encourage those living with HIV when they met to support one another in facing the different problems that encountered with regard to HIV. One of these problems was adherence to treatment:

When we meet in meetings as workers that have disclosed, people come up with different experiences and this helps to solve similar problems that others may be having.

(Participant # 4)

4.6.2. Negative consequences of disclosure

Participants were also asked to describe any negative consequences that they may have experienced as a result of disclosure in the workplace. They were specifically asked to describe how the other workers reacted to their disclosure, and how they themselves felt about their decision to disclose. As has been shown, while disclosure brimgs many tangible benefits, all the participants also narrated at least one negative experience resulting from their disclosure. These included the following:

4.6.2.1. Gossip and offensive remarks

Seven of the 12 participants described how fellow workers would pass an offensive remark when they saw them as a result of knowing that they were HIV positive. Two participants from the same ministry narrated a specific experience that deeply affected all of the members of their support group. This was described as follows by one of these participants:

There was a time when we were going on a bus as a support activity for workers living with HIV. Since all the workers on the bus were open in the workplace about their status, we were accompanied by one member of the general HIV/AIDS workplace committee whose status was not known. Before he came to the bus, he was heard shouting to other workers outside saying, 'Mwabaona baja, niba

AIDS' [have you seen those, they are the AIDS people], pointing at the bus. We were very offended and we felt bad.

(Participant # 5)

4.6.2.2. HIV-related stigma and discrimination

Some participants recounted how they had experienced instances of HIV-related stigma and discrimination. They provided some examples of such instances:

(i) being denied the chance to participate in duties out of town since they were perceived to be unwell (as they were HIV positive); or (ii) never being put on schedules to work away from their work station – such going on patrols (for those in the Ministry of Home Affairs) – thereby losing some financial allowances; or (iii) being left out of HIV/AIDS activities such as participating in the "march past" parade because they were HIV-positive. A participant narrated how he heard one worker in their Ministry remark as follows when preparing for World AIDS Day activities:

This one cannot participate in a march past activity preceding the main event as he is HIV-positive – he will be tired and will not make it.

(Participant # 10).

Another participant narrated that at one time HIV-related stigma was so rife in her workplace that fellow workers did not even want to eat with her during lunch break:

During lunch hour, when you want to eat with your friends, they would say "takuta" [we are satisfied], because they thought when you are positive, even sharing a cup would make somebody get it [HIV]. Stigma was very high from my fellow workers.

(Participant # 2).

Another participant suggested that because of the high levels of HIV-related stigma, fellow workers would avoid any physical contact. A number of participants said that the

use of stigmatizing names like "kanayaka" (a local word which translates as "one on fire") was commonly used in the workplace to describe those who were HIV positive.

I felt so embarrassed about being positive when I had just disclosed my status because some people were even saying this one is sick. They also used words like kanayaka! Kanayaka!

(Participant #9)

4.7. Reactions to the barriers or consequences faced

Participants were asked how they dealt with such negative consequences and whether they ever regretted having disclosed their status in the workplace. They said they never regretted disclosing their status although they had to deal with the negative consequences of disclosure by taking bold steps, such as bringing complaints regarding stigmatizing and discriminatory actions to the attention of their supervisors. One of the participants reported as follows.

I told my supervisor how my colleagues were talking and laughing about my positive status. The supervisor then called a meeting where I openly told everyone about my status and then the supervisor informed the participants to stop the talk that has been going on amongst them pertaining to my status.

(Participant #9).

Some participants dealt with the negative consequences of disclosure through their interactions with other people who were HIV-positive. Nine of the participants mentioned that being a member of a support group for workers living with HIV, called Positive Action for Workers (PAW), had encouraged them to deal with the negative consequences. Through this group they were able to meet with other HIV-positive people and share their challenges and experiences – and share how they were able to overcome these challenges.

4.8. Participants' knowledge and involvement in the development of their HIV/AIDS workplace policies and programmes

The HIV/AIDS workplace programmes in the Ministries provide all their staff with opportunities to access the various HIV/AIDS activities and services that are aimed at mitigating the impact of HIV/AIDS in the country.

To provide an understanding of the HIV/AIDS programmes and services offered by the four Ministries – and the levels of involvement of HIV positive workers – participants were asked about the availability and implementation of HIV/AIDS workplace policies in their particular ministries. What types of HIV/AIDS related activities and services were on offer in their workplaces? Obviously, the accounts recorded provide the perspective of the 12 study participants, all of whom were living with HIV.

All the participants from the four ministries represented in the study stated that HIV/AIDS workplace policies and programmes had been launched between 2010 and 2011. The involvement of staff members living with HIV in the development of the HIV/AIDS workplace varied from participant to participant. All eight participants at a senior or middle management level had been actively involved in the development of the draft HIV/AIDS workplace policy; they were part of the policy development team and contributed to the content of the policy. The other four participants, at a support and lower management level, were not engaged in the development of the policy. While guidelines were given regarding the development of the workplace policy (these demanded the inclusion of all staff in discussions), not all staff, especially at lower levels, were in fact involved. They were usually represented by their supervisors or by senior staff.

All 12 participants knew of the existence of an HIV/AIDS workplace policy. Interestingly, the eight participants who had been involved in the development of this policy had copies of the final policy and had read it: the four participants that were not involved in the development of the policy had not read it.

4.9. Participants' understanding of the HIV-related services offered by their ministry

In terms of prevention, all the participants reported that HIV/AIDS information was

provided through HIV/AIDS sensitization meetings in all four ministries. Information provided included information regarding behaviour change, male circumcision, voluntary counselling and testing, cervical cancer screening, Prevention of Mother to Child Transmission (PMTCT) as well as basic HIV/AIDS information. Condoms were also distributed in the workplace as part of the prevention service. The information detailed above was provided by staff trained as peer educators in all four ministries. Following, or as a result of these sensitization meetings, members of staff were referred for actual clinical and counselling services to Non-Governmental Organizations like the Society for Family Health (SFH) for male circumcision and cervical cancer screening; and the Latkings Outreach Program (LOP) for VCT services. PMTCT services are provided by all Government clinics (under auspices of the Ministry of Health). In the case of the Ministry of Home Affairs, these services can also be accessed through their own medical clinic. Workers in this Ministry therefore have a choice of either accessing services from their clinic or from any other Government clinic in the town. The history of establishing a clinic within this Ministry was not explored by the researcher in this study. Afya Muzuri, an Information Resource Centre, was also mentioned as a source of

materials such as leaflets.

We also get booklets and posters for information from Afya Muzuri. Condoms are also given to workers and some are put in toilets.

(Participant # 1).

In terms of treatment, all participants interviewed had access to the free ARV treatment programme which is available in all government hospitals and urban clinics in the Lusaka district. The Ministry of Home Affairs also has a medical clinic where workers can obtain medical care, including ARV drugs. The Ministry of Agriculture pays a private clinic where the workers go for treatment and routine HIV monitoring.

Care and support services for those who are HIV-positive or those that are suffering from AIDS in homes and hospitals are provided through home visitations by fellow workers in all Ministries. In this way, food supplements such as high energy protein supplements, vitamins and mineral supplements are provided.

The Ministry of Communications and Transport also supports all positive workers who have disclosed their status by providing financial support (in the form of vouchers) to buy medication and groceries (the vouchers may be exchanged at a particular pharmacy and a particular department store). This is the only Ministry that provides this kind of support to its HIV positive workers. This was described by one of the participants:

The ministry is supporting us by supplementing the HIV-positive workers with a cheque of K150 000.00 (US \$50) for medical supplies from one of the pharmacy stores and K350, 000.00 (US\$70) in form of a voucher for groceries from Shoprite Checkers every month.

(Participant # 5)

While the package of services is the same in all the Ministries, it is noted that the provision of some of these services differs from ministry to ministry. Provision of HIV

information through sensitization is basically the same in all the Ministries, while care, support and treatment are provided in different ways. In the case of treatment services, HIV positive workers have the option of either accessing services available within their ministries or accessing the same services at the public clinics. Resources for care and support are also provided differently, with some ministries actually supplying specific needs (such as additional medicines or groceries for those with HIV).

The table below provides a summary of the services that are available in the respective ministries:

Table 3: HIV/AIDS services offered in the ministries

Ministry	HIV/AIDS Sensitization	UNIVERS	Male Circumcisio n and Cervical Cancer Screening	PMTCT	Care and Support (Supplement ation, Home- based Care, Palliative Care, Home visits)	HIV Treatment (Including ARVs, Blood tests, CD4 counts, Viral Load Test, drugs for treatment of opportunistic Infections)
Agriculture	$\sqrt{}$	Outsourced	Referral	Referral	$\sqrt{}$	Outsourced
Home Affairs		V	√	$\sqrt{}$		√
Communicati ons and Transport	√	Outsourced	Referral	Referral	√	Outsourced
Tourism, Environment and Natural Resources	V	Referral	Referral	Referral	√	Referral

[N.B: $(\sqrt{})$ means that the Ministry provides the services; outsourced services are those that are available on site, but provided by other service organizations; Referral means that workers are sent to a site such as a clinic to obtain the necessary services]

4.10. Participation in the HIV/AIDS workplace activities by PLHIV

Participants were asked to describe the activities that they are involved in within the workplace programmes in their Ministries, at what level they are involved, and what factors facilitated or hindered their involvement.

The major activities in which the participants were involved included sensitization meetings for workers and participation in the World AIDS Day celebrations (on 1st December of each year) and in the National VCT Days which take place in June each year. Seven of the participants were trained as peer educators, and of these seven, four had also been trained as psychosocial counsellors and were thus involved in peer education, care and support activities.

Regardless of training, however, 11 of the participants reported that because they are openly living with HIV, they are called upon by the Focal Point Persons (FPPs) for the Workplace HIV/AIDS programmes in their Ministries to share their HIV experiences with other workers in the Ministries; they were asked to discuss the importance of treatment adherence amongst those who were taking medication; they were also asked to visit other sick workers, regardless of their HIV status, so that they could be encouraged to take an HIV test (if they had not already done so – to rule out the possibility of being HIV positive). One of the participants in this study was actually a Focal Point Person as he/she was in a senior Human Resource Management position.

It is important to note that The Focal Point Persons in the workplace programmes are not necessarily People Living with HIV. The FPP responsibilities are vested in the Office of the Human Resource Director; this is a requirement in all the Government ministries' HIV Workplace Programmes. Thus whoever is designated as the Director of Human Resources automatically assumes the responsibilities of a Focal Point Person.

A number of suggestions were made by participants to facilitate the involvement of workers living with HIV in workplace HIV/AIDS programs. The participants felt that if these factors were addressed, there would be greater involvement of the workers who were living with HIV. These factors included; (i) the need to expose most of the workers who were known to be HIV positive to more training workshops; (ii) the need to identify some HIV-positive to workers as Focal Point Persons in the workplace programs; and (iii) the need to allocate resources (such as financial resources) to enable the HIV-positive workers carry out specific tasks in the workplace programs. The aim would be to assist other HIV-positive persons who were having problems with treatment issues such as adherence.

Among the factors that were reported to discourage involvement in the workplace HIV/AIDS programs were the negative consequences of an HIV disclosure in the workplace. For example, the stigma that could accompany disclosure was cited as a factor:

People are not free to get involved because they fear to be known and fear to be stigmatised. People still have that thinking that one used to move around.

(Participant # 6)

Stigma is not only characterised by gossip and name calling, but also by a loss of identity experienced by those living with HIV, such as when he or she is referred to as "that sick one". As one participant put it:

Workers fear to be always referred to as "balwele" (The sick one).

(Participant #7)

In ministries such as Home Affairs, where HIV/AIDS services such as treatment are provided within a work setting, workers sometimes do not access these services for fear that this will reveal their HIV-positive status. One participant explained:

Some people do not go to the police clinic to get their medication. They go to other health centres to get their medication because they are scared of being known from the police clinic. They want the information they have shared with the medical personnel to be kept secret.

(Participant #5)

While the participants may have disclosed their status in the workplace, they might not want this to be known by the clinic staff for fear that their status might be disclosed outside the workplace. As a result some HIV positive workers avoided accessing services from these clinics.

4.11. Role of support groups in the disclosure process

During the interviews participants were asked about the availability of support groups in their workplaces, the role of these support groups, their own membership and role in the support groups, and whether support groups were helpful in encouraging disclosure. All the participants suggested that support groups were very beneficial in that they have helped them to be recognised and become involved in programs as HIV-positive people. They also emphasised that they experienced them as supportive as they had helped with disclosure by encouraging members to share their experiences:

Support groups are important as they can enhance disclosure.

(Participant #7)

All the participants found these groups to be a source of support and encouragement as they provided members with a forum in which they could learn from each other through sharing their experiences. They also felt that for these reasons workers living with HIV should be encouraged to join support groups: such groups helped their members deal with any fears they might have regarding the issues affecting them. For example, on participant reported as follows:

When you join a support group, you are free and able to share with one another. The support group helps as you are able to find that you are not alone. I joined because I knew it would help me to be open about my status.

(Participant # 4)

Participants felt that support groups were helpful in supporting disclosure, as sharing of one person's experience of disclosure encourages others:

There are people who are not able to disclose their status, but after hearing from those that are open, they also begin to develop that courage of openness. It helps them to reach a level where they are encouraged to disclose.

(Participant # 12).

Having recognised the role of HIV-positive workers and the role of support groups, all participants alluded to the need for financial support for the support groups. This would enable these groups to provide appropriate workplace activities so that workers could share their experiences and encourage disclosure by giving a human face to the HIV pandemic. Four participants also felt that those in senior management positions could support disclosure in the workplace if they were seen to be engaging with those workers who were open about their status.

The next chapter will consider these results in light of the literature review and then consider what implications the results may have for the further development of HIV/AIDS workplace programmes in the Zambian public service – specifically in relation to providing a supportive workplace environment in which civil servants can disclose their HIV positive status.

CHAPTER 5. DISCUSSION

5.1. Introduction

This chapter draws together a discussion of the findings of the study. It compares the findings of the literature review with the findings of this study and reflects on some areas that could inform and improve future practice in relation to HIV disclosure in the workplace. The study specifically aimed to identify and describe the factors that assisted the HIV disclosure of public service workers in Zambia.

By exploring the disclosure experiences of five male and seven female public service workers living with HIV, the study has provided new insights into the challenges, the decision-making and the consequences associated with HIV disclosure in the Zambian public service. It has also provided some insights into how HIV workplace policies and programmes can better serve to support the involvement and the psychosocial needs of HIV-positive workers.

While the major focus of this study was on the HIV-disclosure experiences of civil servants in the workplace, some interesting insights were provided by the participants regarding the process of disclosure outside of the workplace.

5.2. The context of HIV disclosure in the Zambian workplace

While HIV prevention services (such as information about behaviour change, promotion of correct and consistent condom use and treatment with antiretroviral drugs (ARVs) are available in Zambia through both national and workplace HIV/AIDS programmes, disclosure of an HIV positive status is still problematic in Zambia. This affects people's willingness to access available services such as HIV testing and HIV treatment. This is as shown by the low testing rates: only 15% of Zambian people have been tested and know their HIV status. The Government cannot ensure that all the people who are eligible for or in need of treatment are reached (GRZ, 2007).

However, despite a potentially hostile workplace environment where HIV-related stigma is pervasive, the participants in this study demonstrated that it is possible for workers to disclose their HIV-positive status in the workplace. If one compares this to the SHARe

study (2006), where not one of the 300 study participants had openly disclosed their status in the workplace, this is an achievement of note: approximately four years later there is a small group of workers who are openly living with HIV in the Zambian public service.

5.3. The motivation for and process of HIV disclosure in the workplace

The participants' disclosure decisions were to some extent motivated by the kind of responsibility they carried at home: all the participants indicated high levels of family responsibility: they were all an important source of support, not only for their nuclear families, but also for extended family members and parents as well. Disclosure of their status was not only beneficial for the health of the HIV infected workers, but would also benefit their families. As was found in the study by Kandowa and Nuwaha (2009), conducted in Mityana, Uganda, HIV disclosure is particularly encouraged because of the benefit to those living with HIV as well as for those affected by HIV.

When asked about the process of disclosing their HIV status, the study participants indicated that it never *started* in the workplace. All the participants first disclosed their HIV positive status outside of the workplace, either to their parents or siblings or to their partners. Disclosure, as described in Makin et al. (2008) is a process that starts with the person's decision to go for HIV testing. The first step, even before a decision to disclose, is to decide to go for HIV counselling and testing. It is only *after* disclosure that the benefits can be accessed. These include receiving psychosocial support from others and receiving treatment, as other studies have shown (WHO, 2004; Norman et al. 2007, Akani, 2006). Ideally, workers need to be encouraged to know their HIV status: if found to be HIV positive, they then need to be supported to disclose their status in order to maximise the opportunities for support and, where appropriate, to access the material benefits (such as grants).

However, as stated by Green et al. (2003), an HIV-positive diagnosis creates significant anxiety and distress with regard to one's health, self-identity, and close relationships. As evidenced in this study, a positive diagnosis was typically met with the following reactions: crying, trembling, secrecy, fear of the anticipated outcome (death), and the fear of leaving behind children. As has been noted by Holt (1998), being told that one is HIV-positive can be one of the most stressful experiences an individual has to face –

something which the participants of this study demonstrated as they recounted their reactions to the news that they were living with HIV.

The role of HIV counselling before and after testing is therefore critical in supporting an individual's disclosure decisions. As the Zambia Counselling Council (ZCC) acknowledges in their psychosocial counselling curriculum (ZCC, 2006), the training of counsellors should be focused on providing them with the skills to support clients who receive a positive test result – and they should understand what may be needed by way of additional support and encouragement after disclosure. Interestingly, the counselling curriculum does not include guidelines on how the trained counsellors should encourage disclosure. This is usually left to the discretion of the client. While people should not be coerced into disclosing, they should be encouraged by being provided with the information that may help them make an informed decision.

It appeared that one of the most important personal and circumstantial factors that might impact on the workers' willingness to disclose was the need for them to stay healthy in order to keep their jobs and also be able to continue with other income-generating activities. For workers to be productive and for them to stay in employment, they clearly need to be healthy. Studies have shown how HIV has negatively impacted on productivity: it not only results in the loss of years of experience (through the death of trained and experienced persons); it also means additional costs to the employer when workers are sick (CHAMP, 2007; ILO, 2003; NAC, 2009). As demonstrated in this study, some of the participants have been in their positions for as long as 20 years; during this time the Government is likely to have made a considerable investment in their training. Such long-serving employees have considerable institutional knowledge and experience in their fields of work; an AIDS-related death thus has a significant impact in the workplace.

While the participants in the study were drawn from all the three management levels (ie. senior, middle and lower), it is important to note that only one participant at a senior management level could be reached for an interview. During the recruitment process, four senior members had initially agreed to be interviewed. However, when the time came, three of them dropped out. Explanations for this were not provided – apart from informing the researcher that they were 'too busy'. One area where further research could

be undertaken would be to explore the disclosure experiences amongst senior staff in particular.

As other studies, such as that by Kalichman (1999) have suggested, disclosure decisions are easy to make where the disclosure does not result in regret, or where the one making the disclosure feels that his or her decision will be supported. This study found a variety the reasons for testing. These included advanced sickness due to the HIV infection, the sickness of partners or children, or agreeing to test as an outcome of a workplace programme or as part of the Prevention of Mother to Child Transmission (PMTCT) programme.

In this study, eight of the participants undertook a VCT test and agreed to disclose their status because of advanced sickness among six of the participants; in one case this was because their child was sick; in another case it was because their spouse was sick. This study further revealed that the participants were encouraged to get tested by the medical workers who were attending to them at the time. This shows that it *is* possible to integrate VCT into other curative care services – as opposed to always expecting clients to go to a specially designated VCT site, as is the general practice in HIV-testing services and programmes in Zambia. The decision to undertake an HIV test should therefore be encouraged, even in health care settings when patients are receiving other screening and care services during illness – as suggested by Kalichman (1999). Medley (2004) also suggests that there should be innovative ways of providing HIV testing; and providing testing during illness can be seen as one such innovative way as it can improve the quality of life for individuals who are not only infected with HIV but are also sick due to HIV-related illnesses.

Disclosure decisions following an HIV-positive diagnosis can also be facilitated if people are not afraid of getting negative reactions from the people that one discloses to. Contrary to the finding by Holt (1998), that participants were more likely to adopt a policy of non-disclosure immediately after diagnosis, this study revealed that the workers in fact disclosed their status to someone in the family just after diagnosis. The reactions of the person they first disclosed to were a key factor in their ability to deal, not only with the emotional consequences of the diagnosis, but also to gain increased self-acceptance, especially given that most participants were sick at the time of their diagnosis. While the people first disclosed to were often alarmed to discover that a dependable family member

or employee had been diagnosed with HIV, their fear was followed by supportive actions, such as encouragement to adhere to treatment—or general words of encouragement.

It is important to note that while this study focused on disclosure by workers who were living with HIV in the workplace, disclosure was first made in a family setting – disclosure in the workplace followed later. The family provided them with an opportunity to come to terms with their diagnosis before making the disclosure in the workplace.

5.4. Factors that enabled or inhibited HIV disclosure in the workplace

It has been suggested by various authors that HIV disclosure is driven by a number of factors. These include the need for increased material, emotional and/or social support, access to medical care, and opportunities for discussing appropriate job accommodations (Norman et al., 2007; Akani, 2006; WHO, 2004; ILO, 2001; Fesko, 2001).

This study found a set of similar reasons for HIV disclosure amongst the participants. These included the need to avoid lengthy explanations each time the worker had to visit the clinic, (either for review or collection of ARV drugs). As HIV treatment requires a long-term course of medication and routine monitoring, workers often made the initial disclosure to their immediate supervisors so that their absence from work could be explained.

Another reason for disclosure in the workplace was so that the participants could receive the material support that was available to them. This included assistance with transport to attend the clinic and access to food. Often people could not afford to purchase supplements on a regular basis because of their limited government salaries.

Despite the participants' experience of stigma and discrimination in the workplace, when asked what motivated them to disclose their status in the workplace, they all mentioned the need to help other workers who were not only struggling not only with disclosure, but with the whole complex notion of HIV and AIDS.

Disclosure was facilitated by the satisfaction that the participants got from seeing fellow workers go for HIV counselling and testing following the participants' disclosure decisions. Disclosure also helped to give a "face" to HIV and make it real in the lives of

other workers in the workplace. The presence of someone that had opened up about living with HIV provided other workers with a real person they could relate to. Fellow workers are able to ask questions about living with HIV and even refer other people to the person who had disclosed his or her status. In this way, as stated in Paxton (2002), disclosure helps to challenge the myths and misconceptions around HIV infection. As stated by Paxton (2002), it enriches the person who discloses as well the community to which the disclosure is made (in this case to fellow workers).

Another reason for participant's disclosure in the workplace was the requirement to participate in activities that were designated for people living with HIV. Because the participants were open about their status, they could easily be easily identified by their supervisors and asked to participate in various meetings or workshops for those who were living with HIV.

While the participants experienced a number of positive reactions in the workplace following their disclosure, they also described other adverse reactions. For example, the study revealed that the participants were faced with hostility from other employees in the form of stigma, discrimination and prejudice. As noted in other studies (UNAIDS, 2000; Serovich, 2007; Holt, 1998), disclosure of a positive HIV status can be a potential stressor, contributing to denial of the infection, and perpetuating stigma and discrimination. This study found that the participants suffered stigma in the workplace as a result of their disclosure. For example, other workers gossiped about their ability to participate in certain workplace events, such as World AIDS Day and Voluntary Counselling and Testing Days. They also experienced name calling and being referred to as *kanayaka* ('one who is burning'); they would be pointed at and referred to as *the sick one*.

Some of the workers were ostracised by their fellow workers at times when workers would meet together socially, such as at lunch time. Their colleagues would refuse to sit and eat with them. They would even claim not to be hungry to avoid being close to a person who was HIV positive, or to avoid sharing their food.

Discrimination was also experienced with regard to out-of-station activities by workers who had disclosed their status. These activities are very popular among public workers as they brought in extra income in the form of allowances. HIV-positive workers were

denied these opportunities as supervisors and other fellow workers felt that they were not in a healthy enough state to undertake or participate in these activities.

All these factors could inhibit employees' initial willingness to disclosure their status; they could also discourage disclosure by other positive workers in the public service. In other words, as other workers who are positive see what other workers go through following disclosure, this may discourage them from revealing their own HIV status.

Other studies (Akani, 2006; Rutenberg, 2003, Kadowa, 2009) have found that HIV disclosure can disrupt personal relationships. In this study HIV disclosure contributed to the break-up of the marriages of two participants. Other participants were accused of infidelity and or experienced victimisation from their spouses.

Disclosure is not only stressful for the person who discloses; it is also stressful for partners who may fear that they too could be infected. As was the case with another study (Maman, 2003), this study revealed that disclosure could initiate an angry response from a spouse. One of the participants recalled how, after her disclosure, her spouse refused to undertake an HIV test himself despite being very ill. The spouse said that since he had not given the study participant (his partner) permission to go for an HIV test, he would not test himself. In this particular case the spouse later did test for HIV – but died a month afterwards.

Such negative consequences might have the effect of discouraging disclosure decisions by other HIV-positive workers. They might, for example, hear of incidents of HIV-related stigma or prejudice and/or witness incidents of HIV-related discrimination and decide that it was preferable to remain silent about their own status. This would mean that they would miss out on the various benefits that might assist them as people living with HIV (such as counselling and medical support and appropriate job accommodations).

Others in the workplace – who might hear about or witness such incidents (and who did not yet know their HIV status) might decide, for fear of experiencing such negative consequences, to delay testing – or not to test at all. This would have the effect of reducing the numbers of employees who know their HIV status – and were potentially willing to disclose their status in the workplace. This would obviously be counterproductive for efforts to establish a supportive workplace environment.

While the findings in this study illustrated many of the negative and positive effects of disclosure that are mentioned in the literature, the study did reveal one unique factor that other studies did not mention. This study found that the workers who had disclosed their HIV-positive status in the workplace had no regrets about doing so. Despite the stigma and the incidents of discrimination they experienced subsequent to their disclosure, they took it upon themselves to help other workers come to a greater understanding of their condition and to deal with the various issues associated with living with HIV. Some participants choose to report discriminatory incidents to their supervisors and to speak out or challenge those responsible for such incidents in the workplace. They suggested that they felt that this assertiveness not only helped and benefitted them, but also helped other people living with HIV in the same workplace.

5.5. Reactions to disclosure decisions are supportive of both the person who discloses and the one who receives the disclosure

One important finding of this the study has to do with the reactions of the people to whom disclosure was first made in the workplace. The study revealed that five of the participants' supervisors reacted with shock, manifested by a long silence and a deep stare as the worker disclosed his or her status. Some supervisors and colleagues could not believe that someone could talk so openly about their status, whilst others cried, and then thanked the worker for disclosing to them.

Further research is needed to deepen and extend the initial findings of this study. It would be helpful, for example, to find out why the supervisors reacted with shock: was it the fear that their subordinate was sick, or could it be the pervasive stigma and discrimination surrounding HIV/AIDS; or might there be other reasons? This study did not of course interview the supervisors, so was unable to explore the reasons for their reactions

After the initial reaction supervisors often went out of their way to provide support to the worker that had disclosed. Participants often reported that the initial reaction was followed by their supervisor's taking action to provide whatever support the workers in question needed. This included surrendering their official vehicle to enable an HIV-positive worker go to the clinic, or personally ensuring that the worker was provided with

a more comfortable working space, or even checking on the worker's health status each morning when reporting for work.

These reactions (as described by Holt, (1998)) indicate the dual role of disclosure in cases of HIV infection. It not only helps the individual that discloses to get support, it also helps others around them to openly respond in a more positive and open way because they know the person's status.

5.6. The role of public service HIV/AIDS workplace programmes in Zambia

Workplace programmes play a key role in providing information and services to all workers and ensuring that those who have disclosed their status receive the necessary support.

The HIV/AIDS workplace programmes in the Zambian public sector line ministries have been operating since late 2002, with the scale-up of these programmes occurring in 2004. As indicated by this study's findings, all the participants in this study were tested between 2002 and 2006; a time when workplace programs were introduced in the public sector workplaces. This suggests the importance of workplace programmes in reaching out to employees, providing them with information and a site where they can get tested, and enabling them to access on-going clinical and psychosocial care.

While HIV/AIDS workplace programmes are critical in providing the necessary services to the workforce, more still needs to be done to increase the reach of the HIV services to workers in the public service in Zambia through workplace programmes. The study's findings show that some HIV-related activities – such as sensitization meetings where information on HIV is given to workers – and VCT services, are not undertaken or provided on a regular basis. Workers thus do not always obtain access to the information they need on a regular basis, - nor are they always provided with important items (like condoms) which help to prevent HIV infections.

In the recent past, before ARVs became more widely available through the public health system, the frequent occurrence of long HIV-related illnesses (and the eventual death of workers) was of great concern to many employees because of the resulting loss of skills

and experience (CHAMP, 2007:10). The death of an experienced and skilled worker ultimately leads to additional costs as the employer has to replace the skills and experience that were gained over the years (ILO, 2001).

Most of the participants were very well educated: 10 participants (of the total 12) had college degrees, and one participant had completed a university degree as well as a Master's degree. Seven of the 12 participants occupied middle and senior management positions and had worked in the civil service for between five and twenty years (with an average length of service of 13.6 years).

These long years of service bring with them an accumulation of valuable skills and experiences that contribute to the economic gains made by the public service and by Zambia in general. Therefore, any decisions made by the workers relating to improvements in their wellbeing, especially with regard to disclosure, are extremely important for securing the sustained well-being of the workers and should be supported at all costs. As indicated in the literature by Kandowa (2009) and UNAIDS (2000), disclosure of HIV status needs to be encouraged so as to maximise the benefits not only for the infected, but also for the uninfected. This study shows that, while the HIV-positive worker improves his or her quality of life (by maximizing the benefits that come with disclosure), the employer also benefits as workers remain in productive employment and this contributes to achieving work-related outputs.

The findings of this study indicate that while HIV positive people in the workplace still suffer stigma and experience discriminatory practices from their fellow workers, they were aware of the benefits that come with disclosure and chose to overcome or deal with the negative effects of disclosure.

This study also demonstrates that supervisors in the workplace play a critical role in the disclosure process as they are always the first point of contact for the participants when the decision to disclose in the workplace has been made. Workplace programmes should be strengthened to include mechanisms that not only support disclosure, but also help to prepare people in supervisory positions to deal with disclosure and provide them with advice regarding the support of people who have disclosed. This will help them to manage the disclosure process.

Furthermore, the study has demonstrated that disclosure itself is one step towards an improved quality of life for HIV-positive workers. Eight of the study participants were sick when they tested for HIV and disclosed their status. Disclosure not only helped them to access the available services, but also formed a step in the healing process as it led the participants to talk about their experiences. The participants were a valuable human resource in the workplace as they continued to contribute to productivity.

5.7. Study limitation

It is important to note that the experiences documented in this study are only representative of a select number of participants (12 workers) from four (of a total of 22) Government Ministries; all four ministries provide support groups for workers living with HIV. Whilst the study gathered important information that can guide implementation of programmes for PLHIVs in the workplace, the experiences of those interviewed cannot, of course, be generalized to all public servants in Zambia. For example, this study did not explore the experiences of public servants who were living with HIV but who did not belong to workplace support groups, or those who have not disclosed their HIV status in the workplace.

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The study also interviewed only one public servant in senior management. All 'categories' of staff are crucial to informing the study question and to developing a response to disclosure that is more inclusive.

The findings of this study are also limited to one district (Lusaka), an urban district that houses the headquarters of all the line ministries. This was the site from which all the participants were drawn. Being at the headquarters of their ministries meant that the participants were more likely to have access to a greater number of services, e.g. to NGOs offering support, treatment and information and to a range of support groups. Many of these services would not be so readily available in smaller rural towns. Hence the findings of this study do not adequately reflect the disclosure experiences of public servants in rural sites.

The next chapter concludes the study and outlines some key recommendations that the author believes should be addressed in the workplace in order to provide HIV-positive Zambian public service workers with greater support in the process leading up to, and following, the disclosure of their HIV positive status.

CHAPTER 6. CONCLUSION AND RECOMMENDATIONS

This chapter presents some conclusions and makes some recommendations that could assist the public service in Zambia – and specifically HIV workplace programmes which encourage and facilitate a positive process of HIV disclosure amongst employees.

6.1. Conclusion

This study reveals that though HIV positive workers face challenges in disclosing their HIV-positive status in the workplace, such disclosure is quite possible. The benefits of disclosure far outweigh the negative consequences. This has been shown in the various testimonies that participants shared during the course of their interviews.

Despite the pervasive HIV- related stigma and discrimination that still exists in the public sector workplace, the participants shared how they had turned such negative perceptions into a positive force and how they had used their own strength to reach out to and help other workers who had not yet disclosed their status publically.

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HIV disclosure in the workplace is also important as such a decision helps to ensure that workers receive the appropriate social, medical and economic benefits. The other workers including the employer in the workplace also benefits as a result. Disclosure enables workers to access the HIV services that will improve the quality of their lives and enable them to make the necessary job accommodations.

For this to happen it is critical that workers living with HIV receive the necessary support, The understanding and supportive reactions of spouses, family members and supervisors help people living with HIV/AIDS to reach a point where they can disclose their status and adjust to living with their condition.

This is important because, as this study and many other studies have shown, disclosure also has some unfortunate consequences and workers need the support of people around them.

As was noted in the Introduction and the literature review, greater efforts are needed to reach people and enable them to get tested, as HIV testing is the entry point for the HIV/AIDS-related services such as treatment, care and support. As has been noted in this study, workers who disclose their status in the workplace can play a pivotal role in encouraging other workers to access Voluntary Counselling and Testing services; they also act as a source of support for those who may wish to disclose their status.. This could help to increase the number of people that can be reached through HIV testing. It could also increase the number of people who seek early treatment and who continue with treatment, and could reduce the incidence of sickness and death caused by unattended or poorly managed HIV infections. In their turn, workers would then continue to contribute to the economic development of the country, as they would be able to continue working even when HIV positive.

The study further reveals that disclosure is a process which starts within families before it reaches the workplace. With the support and encouragement of people in the workplace, workers can go through this process of disclosure without any feelings of regret. Other workers, as well as family members, need to be equipped with the skills and the knowledge to enable them to support others in their disclosure decisions.

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Some key recommendations follow.

6.2. Recommendations

6.2.1. Create a working environment that supports HIV disclosure

HIV/AIDS programmes in the workplace need to create environments that are supportive of disclosure decisions. The workplace plays a critical role in the provision of supporting HIV programmes. This study finds that workplace programmes encourage workers to know their HIV status and to take appropriate action. Conducive environments in the workplace can assist in the following ways:

- They can help to put in place policies that not only support disclosure but also engage those living with HIV as active partners and participants in implementing workplace policies and programmes.

- They can help to ensure that workers living with HIV are part of the Workplace HIV/AIDS Committees; in this way these workers will participate in the planning and implementation of workplace programmes.
- They can help to establish clear channels for reporting HIV/AIDS-related grievances. In the event that HIV positive employees feel stigmatized, discriminated against or victimised, there should be a channel of communication and support in the workplace, so that incidents can be reported and dealt with. All employees ought to be informed of the disciplinary measures that have been taken.

Workplace HIV/AIDS programme activities include sensitization meetings, the provision of HIV counselling and testing and treatment (either within the workplace or through referral to an external service provider). These activities ought to be made available to all workers on a regular and sustained basis. Activities such as HIV sensitization and counselling should also engage workers who have disclosed their positive status as part of the team that provides these services. In this way, the workers will be able to share their experiences of living with HIV and also allay the fears of other workers; these fears that often contribute the perpetuation of HIV-related stigma in the workplace.

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6.2.2. Involve HIV-positive workers in workplace policy development and programme Implementation

The workers who have disclosed their status should be included as active participants in all workplace programmes. They should be involved in the development and review of HIV/AIDS workplace policies, and trained as service providers (for example as peer educators or as psychosocial counsellors). They should become committee members and act as coordinators within workplace programme management structures. This will help to expand their supportive role in the workplace, and counter some of the myths and misconceptions surrounding HIV. This should help to avert or reduce with HIV-related stigma and discrimination in the workplace.

6.2.3. Promoting supportive spaces in which workers living with HIV can meet

Support groups for workers who are HIV-positive need to be strengthened within each ministry. Through these groups, workers who have just learnt their status can find support and encouragement to help deal with their disclosure decisions. Those who have been

living with the HIV for some time can share their experiences and so strengthen and encourage new members in their efforts to live positively with HIV, and to manage its disclosure in the workplace.

6.2.4. Senior managers need to be equipped to support the process of disclosure among their staff

In the case of all the participants in this study, the first person in the workplace to learn about their HIV positive status was their immediate supervisor. This illustrates how important public servants in supervisory and senior management positions are to the process of disclosure on the part of their staff. Senior managers therefore need to be actively engaged in workplace programmes. They need to be empowered with information and skills that will help them to support disclosure on the part of workers, and they must understand how to take the appropriate action in the event that disclosure has negative consequences..

6.2.5. Workplace programmes need to reach beyond the worker

Family members play a critical role in disclosure decisions and provide important follow-up support after disclosure. Workplace programmes need to be extended to address the needs of the worker within his or her family setting; if possible, they should even reach out to other family members. In other words, family members need to be empowered with the information and skills that will help them support workers with their disclosure decisions in the family setting. Family members need information on creating supportive family environments that are devoid of stigma and discrimination, as well as information on how to deal with shame, guilt and/or denial, on how to support adherence, and on how to promote safe practices (such as the use of condoms).

As most workers are married, strategies to engage spouses in workplace programs need to be explored and implemented. More effort needs to be made to strengthen HIV/AIDS sensitization and counselling for couples. This will help to make disclosure between partners easier. As noted in the study, it was difficult for some workers to disclose to their spouses that they were HIV positive: they often had to pretend that they had not been tested (before going with their spouse to get tested).

Among the workers there were couples that were in sero-discordant (i.e. one partner is negative while the other is positive). There is need to develop appropriate support mechanisms for such couples as part of the overall workplace programme.

6.2.6. The need to include disclosure as a key element in the National HIV/AIDS response

At national level, overall HIV/AIDS policies, National Strategic plans and the various operational plans should support disclosure of HIV status to ensure that the benefits that follow disclosure can be accessed. The national response should consistently provide the necessary human, material and financial resources for PLHIV-led programmes

6.2.7. The need to empower workers with entrepreneurship skills.

Government should put in place policies that lessen the social and economic burden on those who are HIV positive by increasing and providing opportunities for empowering lower-income employees (such as office orderlies) and some of their family members.

The participants in this study had huge family responsibilities: they had to take care of their elderly parents, support siblings who might also be sick, support unemployed family members, take care of the children of their deceased brothers and sisters (as well as of their own nuclear families). They had to engage in other work outside of their formal employment to earn the extra income needed if they were to meet these responsibilities. Programmes to mitigate the impact of HIV/AIDS should be put in place to cushion and support workers who have to carry the burden of these responsibilities.

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Policies that mitigate the impact of HIV include supporting HIV-positive workers with loans, and supporting the development of cooperatives and income generation projects such as poultry and livestock rearing, vegetable growing, etc. Policies should also ensure that support is provided for orphans and vulnerable children (OVCs). Such measures would include some financial contribution to orphans school fees or uniforms and entrepreneurship skills empowerment (to mention just two).

Through private sector social responsibility initiatives, businesses such as banks could be encouraged by Government through Public Private Partnerships (PPP) to provide vulnerable women, youths and people living with HIV with flexible loan repayment plans or start-up grants to assist PLHIVs and others made vulnerable as a result of HIV infection (such as orphans).

6.2.8. Need to undertake follow-up studies

There is need for more extensive research on the subject of disclosure among workers in Zambia. Further information could be obtained by using a much bigger sample and an appropriate design. This would help to generate recommendations that were more generally applicable. This study has revealed a number of areas that need further research, and this will help to provide a more holistic understanding of the relevant issues. The views of family members, supervisors, and other workers in the workplace who have not disclosed their status need to be explored; this will enhance the body of knowledge around disclosure decisions.

This study has created a strong platform or baseline for engaging in more detailed studies on the subject of disclosure, even beyond the workplace. It has also provided information that can assist in the planning of HIV/AIDS programmes to support workers who have disclosed their HIV-positive status in the workplace.

One strong message to emerge from this study is that disclosure of ones HIV-positive status is not only possible, but also beneficial, and should be wholeheartedly supported by the public service in Zambia.

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APPENDICES

Appendix 1: Participants Information sheet



UNIVERSITY OF THE WESTERN CAPE

School of Public Health

Private Bag X17 ● **BELLVILLE** ● 7535 ● South Africa

Tel: 021- 959 2809, Fax: 021- 959 2872

Participant Information Sheet

August, 2011

Dear Participant,

UNIVERSITY of the WESTERN CAPE

Thank you for your time and willingness to hear and read about the research I intend to do. What follows is an explanation of the nature of the research and an outline of your potential involvement in the project. This study will be done as part of my fulfilment of the master's degree program requirements with the University of the Western Cape, South Africa. If there is anything you need clarity on, please feel free to ask me or my supervisor Ms. Nikki Schaay. At the end of this information sheet you will find my contact details as well as those of my supervisor.

Title of the research

HIV Disclosure in the Workplace amongst Public Service Workers in Zambia.

Purpose of the study

The purpose of this study is to explore the opinions of public service workers who are openly living with HIV about their experiences of disclosing their HIV positive status in the workplace. It is hoped that with your, and other's participation, a better understanding of the variety of issues that public sector workers face in relation to disclosing their HIV positive status in the workplace will be identified. This information will be used to improve the HIV-related services and programmes offered to workers in the public service.

Description of the study and your involvement

The study will be based on individual interviews with workers that are openly living with HIV in the workplace. The interview will cover questions on issues pertaining to disclosure, such as dealing with stigma and discrimination in the workplace, your views, attitudes and beliefs towards the negative and positive aspects of disclosure, the positive and negative outcomes of your disclosure decision, how the workplace has responded to your disclosure decision, how you feel disclosure can impact on the workplace programs and if they are any suggestions you can make in line with disclosure based on your own experiences.

Confidentiality

At all times, I will keep the source of the information confidential and refer to you or your words by pseudonym or invented name which I would like you to choose. I shall keep all records of your participation locked away at all times, and destroy them after the

research has been completed.

Voluntary participation and withdrawal

Your participation in this study is entirely voluntary and should you wish to withdraw

from the study at any time you may do so without giving reasons. The interview may

touch on issues that you may not be comfortable to discuss. If there is anything that you

would prefer not to discuss, please feel free to say so. I will not be offended and there

will be no negative consequences if you would prefer not to answer a question. I would

appreciate your guidance should I ask anything which you see as intrusive.

Benefits

You may not get any direct benefit from this study. However, the participants in this

study will help to make recommendations that will help with the support given to workers

that are HIV positive in workplace programmes. However, a token of ZK50, 000:00 will

be given to you to help with your transport to and from the interview site.

Informed consent

Your signed consent is required for you to participate in this study. You may decide to

participate or not. The consent form is attached to this participant information sheet.

Contact details

Ms. Rose Musumali

Student number: 2520839

Cell phone: 260-979638730/260-211-260731

E-mail: rosemlungu@yahoo.com.

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My supervisor's details are as follows

Ms. Nikki Schaay

The School of Public Health, University of the Western Cape, South Africa

Mobile: +27 842 115 544

Work/home office & fax: or +27 217 884 186

E-mail: schaay@mweb.co.za





Date:



School of Public Health

Private Bag X17 ● **BELLVILLE** ● 7535 ● South Africa

Tel: 021- 959 2809, Fax: 021- 959 2872

RECORD OF INFORMED CONSENT TO CONDUCT AN INTERVIEW

The memory of the state of the
Interviewer's name:Ms. Rose Musumali
UWC student no:2520839
Cell phone: 260-979638730/260-211-260731
E-mail: rosemlungu@yahoo.com.
Interviewee's pseudonym:
Place at which the interview will be conducted:, Lusaka.
Thank you for agreeing to allow me to interview you. What follows is an explanation of
the purpose and process of this interview. You are asked to give your consent to me on
tape, for me to conduct an interview with you and to use this data for my research project
in partial fulfilment of the requirements of the MPH program with the School of Public
Health, UWC, South Africa.

1. Information about the interviewer.

I am Ms. Rose Musumali, a student at the SOPH, University of the Western Cape, South Africa. As Part of my Masters in Public Health, I am doing an operational research project. I will be focusing on the experiences of public workers openly living with HIV and what their experiences have been in disclosing their HIV positive status in the workplace. I would like your opinion, perceptions and feelings on this topic.

I am accountable to Ms Nichola Schaay who is my supervisor and is contactable on Mobile: +27 842 115 544; Work/home office & fax: +27 217 884 186. E-mail: schaay@mweb.co.za

2. Purpose and contents of the interview

The purpose of this study is to get the views and disclosure experiences of people that are living with HIV and working in the Zambian public service. It is hoped that by getting a better understanding about the experiences of people living with HIV and working the public service – especially about how they disclosed their HIV positive status in the workplace issues of disclosure that workers face and their suggestions will be known. This information will be used to enhance the support given to workers living with HIV in workplace programs.

3. The interview process

The interview will be carried out in a quiet place in one of the offices in Lusaka.

Questions about your views, feelings and perceptions towards disclosure in the workplace will be asked and will guide the interview. The interview will last for approximately one hour. After the interview you will be given a token of

KZ 50,000.00 for help meet your transport costs to and from the session.

4. Anonymity of contributors.

At all times, I will keep the source of the information confidential and refer to you or your words by pseudonym or invented name which I would like you to choose. I shall keep all records of your participation locked away at all times, and destroy them after the study has been completed.

5. Things that may affect your willingness to participate

The interview may touch on issues that you may not be comfortable to discuss. If there is anything that you would prefer not to discuss, please feel free to say so. I will not be offended and there will be no negative consequences if you would not answer a question. I would appreciate your guidance should I ask anything which you see as intrusive.

6. Agreement		
6.1. Interviewee's agreem	ent	
I		(Full name) do agree to take
part in the research intervi	ew.WESTERN CAPE	
Date:		
Place:		
Signature:	Thumb Print	

6.2. Interviewer's agreement

I shall keep the contents of the above research interview confidential in the sense that the pseudonym noted above will be used in all documents which refer to the interview. The contents will be used for the purposes referred above, but may be used for published or unpublished research at a later stage without further consent. Any change from this agreement will be renegotiated with you.

Signed:							
oignou.	 	 	 	 	 	 	 •

Date: Place:



QUESTIONNAIRE GUIDE

Study Title: HIV Disclosure in the Workplace amongst Public Service Workers in Zambia.

1.0: Basic Information

- Date of interview:-----
- Interviewer: -----
- Location: -----
- Language:-----
- Description of setting:

2.0: Introduction

- Thank the interviewee for participating.
- Introduction of the interviewer
- Provide purpose of the interview, give information sheet and read out consent.
- Obtain consent and have consent form signed.
- Provide interviewee with information on the need for recording the interview.
- Ask for permission to record.
- Set the recorder if interviewee comfortable with recorder being used.

3.0: General Questions:

3.1: Can you please tell me a little information about yourself?

Find out about

- a. Age (How old are you?)
- b. Marital status

- Widow/Widower					
- Single (ask if the	ey are single l	pecause the	y have neve	er married, divo	rced, widowed,)
- Co habiting(liv	ing with som	eone but not	married)		
c. Financial respon	sibilities / Ho	ousehold?			
Ask:					
- how many childs	ren of their o	wn that they	have and h	nave to care for.	. How many oth
110 11 1110111 7 11111011			nave and i		•
children are in th					·
-	neir care (nuc	lear and exte	ended)		
children are in th	neir care (nuc	lear and exte	ended)		
children are in the	neir care (nuc	lear and exte	ended) at home (
children are in the - Are there any o Indicate below)	neir care (nuc	lear and extend their care	ended) at home (Y of the	parents, sibling	s other relative
children are in the	neir care (nuc	lear and extend their care	ended) at home (os other relative
children are in the - Are there any o Indicate below)	ther people i	lear and extend their care	ended) at home (Y of the	parents, sibling	s other relative

Ask if they are:

your home?)

Find out about:

3.2:

- Married

Can you tell me about your education and work back ground?

a.	The highest	level of	academic	education
----	-------------	----------	----------	-----------

University level	College Certificate or diploma)	Secondary school (Upper or lower)	Primary school (upper or lower)	No education

b. What are you employed as in this ministry and at which level are you?

Current	Director	Senior	Middle	Lower	Technical	Support
position		Management	management	Management	staff	Staff
and level						
in the						
ministry						

Can you tell me a little about the training that you did to reach this position? You mentioned that your highest qualification was (X), but did you do any further training after that prior to getting appointed to this position?

In service / on the job training as they worked CAPE	
Attended some/ various courses as they worked	
Currently in training course	
Other	

- c. Are there any people under your supervision? How many? Where are they located (within, the office, in the district, in the province/s)
- d. How long have you worked in this position?
- e. How long have you worked in this Ministry?

- f. Did you work in any other public sector department before this current job? (Find out where, when and how long)
- g. Have you worked in any other sector *other* than the public sector?
- h. Do you do any other work other than the work in the ministry (Probe why or why not, what they do, how they cope with double work)].

4.0: Experiences of HIV testing

[Can I take you back to the time you went for your HIV test. Please note that for some of the questions in this section, I would like to take you back to a time in your past and so I would like to know what happened or what you felt at that time not necessarily what you feel now]

- a. When did you first go for HIV testing? Explain.[Probe whether health center or through mobile; why they tested]
- b. Could you share with me what happened from the time you entered the place you tested to the time you left place you were tested from?
- c. At that time, what did you feel about the testing exercise?[Probe whether counseling was done]
- d. How long did it take for you to get the results?
- e. Could you describe what you felt after the test was done and the time you were waiting for your results?
- f. Was this the time when you first learnt that you were HIV+? How did you feel when you were first informed that you were HIV+? Describe.

5.0: First disclosure experiences

- a. Whom did you first tell about your HIV+ test? [Probe, how long did it take to tell the first person; What was their reaction?]
- b. How did you feel about the reaction of the person you first told about your result?
- c. Are there any other people that you shared your HIV+ result with? Explain
- d. How long did it take to share with the other people? Explain.

5.1: Employees disclosure of their status in the workplace.

- a. Who knows about your positive HIV status in the workplace? Explain (Only friend/s, only supervisor, only those that are HIV-positive in the support group for workers living with HIV, everyone in the workplace)
- b. How long did it take you to tell someone in the workplace/ and or the other workers about your HIV positive status from the time you knew about your positive status? [Probe: Whom did you first tell? What made you decide to tell them?]
- c. What do you think this person felt? [Probe what the person/s said or did at that time]
- d. How did you feel after sharing your HIV positive status with this person?
- e. Have you told anyone else in the workplace? Explain how it happened.

 If appropriate: How do you think your fellow workers took your disclosure? Probe: why they thought so?]
- f. Did you know about your status in your previous job?
- g. If so, did the workers in your previous job know about your status?

5.2: Consequences of disclosure in the workplace

- a. What is the reaction to your disclosure now among your fellow workers within the workplace (supervisor, fellow workers, and other HIV- positive workers).
 Describe.
- b. Are there any negative consequences that you have experienced within the workplace (such as, stigma, prejudice or discrimination) since you disclosed your status? Explain.
- c. How did you deal with these barriers? Explain
- d. Do you think that your disclosure has in anyway helped other workers or the workplace program as a whole? Why not or In what way. Explain.
- e. How do you feel now about having disclosed your HIV positive status among your fellow workers? Describe. (Probe whether they would have done it differently, whether they have regrets, self-stigma or they wish they had done it earlier).

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5.3: Benefits of disclosure

- a. Do you think there are any benefits of disclosure in the workplace? If so, explain what they are.
- b. To what extent did or has your HIV positive status disclosure helped you as a worker in your workplace? Explain. [e.g. recognition as a source of support, identified as a coordinator for HIV program, adequate time to get medication, other job accommodations etc.]

6.0: Awareness and involvement in the HIV workplace program

a. Can you tell me about the HIV/AIDS workplace program in this Ministry? Ask about:

6.1: Workplace policy

- a. Does your ministry have an HIV workplace policy? When was it developed? Has it been launched?
- b. Who developed the policy for the Ministry? Did you participate in the development of the policy?
- c. Have you seen and read through the workplace policy of your Ministry?
- d. Is there anything in the policy that you think needs to change or improve? If so, what? How do you think this ought to be done? (for example, would they see themselves involved in changing this and how?)

6.2: Services offered in relation to HIV in the Ministry

a. What services are offered by the ministry, who provides them and how regularly are they provided

(Go through each service area and type of service with the respondent)

SERVICE AREA	Types of service	Who provides the	When is it
	UNIVERSITY of the	service? (Is it within	done?
	WESTERN CAPE	the ministry or outsourced?)	
PREVENTION	HIV/AIDS sensitization		
	• VCT		
	Male Circumcision		
	• Prevention of Mother to Child		
	Transmission		
TREATMENT	Antiretroviral Therapy (ART)		
	Opportunistic Infections treatment		
CARE and	Home Based Care services		
SUPPORT	Palliative Care services		
	Home visitations		
	Support groups		
OTHERS	e.g.		
(specify)	Diabetes screening		
	High blood pressure screening		
	Malaria testing		

- b. To what extent do you participate in HIV/AIDS activities in your workplace? Describe the activities that you participate in and describe your role in the programs or activities.
- c. To what level (and how?) do workers living with HIV participate in the workplace activities? Explain
- d. What factors do you think would facilitate HIV positive workers to get involved in the workplace programs?
- e. What do you think would hinder HIV positive workers from participating in workplace programmes?

7.0: Role of support groups in the disclosure process.

- a. What programs are there that supports workers living with HIV in your workplace?
 Do you belong to any? Explain and describe the programs. (Such as treatment programs or support group).
- b. If support groups, how frequently do they meet as a group.
- How long has the group been in existence?
- How long have you been part of the group?
- What is your role in the group?
- What do you see as a purpose of this group?
- How does the group benefit or support you?
- c. What encouraged you to join the support group?
- d. Do you think other workers living with HIV should be encouraged to join a support group in the workplace? Why and How? Explain.
- e. Do you belong to any other support group outside the workplace? Explain
- f. How does it differ from the workplace support group? Explain.

g. Do you think that support groups are helpful in supporting disclosure? Explain.

8.0: Recommendations

a. What do you think workplaces should do to help workers disclose their status in the

workplace?

b. What do you think workplaces through HIV/AIDS workplace programs should do to

support workers that have disclosed their HIV positive status? Explain.

c. Lastly, what do you feel about people disclosing their positive status in the

workplace? Should it be or not be encouraged. Give reasons for your answer.

9.0: Closing the interview

a. Is there anything more you would like to add?

b. Do you have any questions?

c. Thank you so much for your time.

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10.0: Referral/ Follow up.

Record of referral or follow up to an appropriate service user such as Latkings Outreach

program if any issues of support arose.

Interview Closed at:

Time: ----- Date: ----- Interviewers signature -----

Appendix 4: Copies of Approval letters.



THE UNIVERSITY OF ZAMBIA BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753
E-mail: unzarec@unza.zm
Assurance No. FWA00000338
IRB00001131 of IORG0000774

Ridgeway Campus P.O. Box 50110 Lusaka, Zambia

10 June 2011.

Your Ref: 004-05-11.

Ms Rose Musumali, Stand No. 30200, Buluwe Road Woodlands, Lusaka.

Dear Ms Musumali,

RE: SUBMITTED RESEARCH PROPOSAL: "HIV DISCLOSURE IN THE WORKPLACE AMONGST PUBLIC SERVICE WORKERS IN ZAMBIA"

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee for ethical review on 01 June, 2011 and the following changes were recommended prior to approval.

CORRECTIONS:

- Include budget and timeline for the activities.
- Submit approval letter from the University of the Western Cape.
- Provide space for thumb print on the consent form.
- Seek approval to conduct study in the four Ministries mentioned

Approval will only be granted after the above concerns are addressed. Please re-submit one copy of the revised proposal, which should be highlighted with the changes made and a cover letter.

Yours sincerely,

Dr. E.M Nkandu CHAIRPERSON

In	reply	please	quote:
No			



REPUBLIC OF ZAMBIA MINISTRY OF HOME AFFAIRS

INDEPENDENCE AVENUE P.O. BOX 50997

MHA/7/6/1

6th July 2011

The Chairperson UNZA Research Ethic Committee Ridgeway Campus P.O. Box 501101 LUSAKA

Dear Sir/Madam,

RE: SUPPORT LETTER FOR MS. ROSE MUSUMALI

Reference is made to the above mentioned subject.

I write to you in support of Ms. Rose Musumali's study on HIV disclosure in the workplace. As Ministry of Home Affairs we have really appreciated her work especially the most grateful programme she initiated and introduced as positive workers at work place (PAW) which runs with appreciation in all the departments of Home Affairs involving positive living workers and their spouses. This study will widely help her in her work on the thesis for her master's degree in the Public Health with the University of Western Cape, South Africa.

The Ministry of Home Affairs is in full support of this study as it will build her widely and hence it will accommodate every one in the capacity building.

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Yours faithfully,

Gezepi Chakulunta – S/Supt Focal Point Person HIV/AIDS for/Permanent Secretary

MINISTRY OF HOME AFFAIRS

Wednesday, July 20, 2011

The Chairperson, University of Zambia, Research Ethics Committee, Ridgeway Campus, P.O.Box 50110, LUSAKA.

RE: SUPPORT LETTER FOR MS. ROSE MUSMALI.

Reference is made to the above captioned subject.

I write to bring out our support as a Ministry to Ms. Rose Musmali's Study on HIV and AIDS disclosure in workplaces among Civil Servants in Zambia. This study is part of the requirement needed for her Masters Degree thesis in public health.

On behalf of the HIV and AIDS workplace committee I fully support this study as it is not only in line with the revised Ministry of Agriculture and Cooperatives' Workplace Policy but will also contribute to National Strategic Framework on HIV and AIDS (2011 – 2015)

Your support to her will be greatly appreciated.

UNIVER R.Chibiya the Assistant Focal Point Person For/Permanent Secretary

MINISTRY OF AGRICULTURE AND COOPERATIVES



26th April 2011

The Chairperson, UNZA Research Ethic Committee Ridgeway Campus PO Box 50110 LUSAKA

Dear Sir/Madam,

RE: SUPPORT LETTER FOR MS ROSE MUSUMALI

We write to accentuate our support to Ms Roes Musumalis' study on HIV disclosure in workplace amongst Public Service Workers in Zambia. This study is part of the requirement needed to fulfill her work on the thesis for a Masters degree in Public Health with the University of Western Cape, South Africa.

As National HIV/AID/STI/TB Council, we are in full support of this study as it will not only build to the current body of knowledge but will also contribute to the overall objectives of the National Strategic Framework on HIV and AIDS (2011-2015.

Your support to her will be greatly appreciated.

Your National AIDS Council

Dr B U Chirwa DIRECTOR GENERAL

OFFICE OF THE DEAN DEPARTMENT OF RESEARCH DEVELOPMENT

Private Bag X17, Bellville 7535 South Africa Telegraph: UNIBELL Telephone: +27 21 959-2948/2949 Fax: +27 21 959-3170 Website: www.uwc.ac.za

21 February 2011

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape has approved the methodology and the ethics of the following research project by: Ms R Musumali (School of Public Health)

