Gender Related Factors that Lead to Depression after Diagnosis with HIV/AIDS

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Abstract

People diagnosed as being HIV positive or having AIDS develop depression as they attempt to cope with their daily lives. Some studies have indicated the prevalence of depression and anxiety in people living with HIV/AIDS is higher than in the general population. An evaluation of gender related factors that lead to depression after a diagnosis with HIV/AIDS will highlight the incidences and frequency of what individuals experience in their daily lives.

The research is a descriptive study in which the factors that cause depression after HIV/AIDS diagnosis were identified and related to gender. Both quantitative and qualitative methods were used to analyse the responses elicited from the participants in the sample. Twenty five PLHAs who had been diagnosed with depression were selected from patients attending both Nthabiseng and Luthando Clinics at Chris Hani Baragwanath Hospital in Soweto, Johannesburg. A questionnaire was designed to gather demographic as well as information regarding family, social and economic history. A short interview was also conducted with selected patients to determine in their own words what causes their depression. The selected patient hospital charts were analysed to gain additional information to complete the equation. A semi structured interview was conducted with 13 selected health care professionals to gather information on how they see depression in the presence of HIV and whether they are adequately equipped to detect and manage this condition.

The findings from this study supported the view depression is present or develops after a positive HIV diagnosis and a difference was detected in the causes of depression in women and that of men. Common causes of depression after HIV diagnosis were denial, fear of death and social insecurity. Women were more likely to attribute their depression to denial and worry about work and family responsibility. Men attributed their depression to failure to provide for their family and loss of social status. Recognising the causes of and gender differences in the causes of HIV-related depression may help in designing more effective counselling strategies and improve management and care of PLHAs.

Opsomming

Daar is „n aantal mense wat nie aan depressie ly voordat hulle met HIV gediagnoseer word nie. Meeste studies dui aan dat die voorkoms van depressie en angstigheid by mense wat lewe met MIV en VIGS heelwat hoër is as die algemene MIV populasie. Baie mense, insluitende gesondheidsorgwerkers, neem aan dat depressie „n onontsnapbare newe-effek is van MIV/VIGS diagnose. Dus mag dit gebeur dat depressie ongesiens verby gaan, onbehandeld, met die gevolg van oneffektiewe behandeling, riskante optrede, swak bestuur van MIV/VIGS en „n lae lewenskwaliteit vir hierdie pasiënte. Hierdie navorsingsartikel kyk na die geslags-verwante faktore wat lei tot depressie na die diagnosering van MIV/VIGS.

Die navorsing is „n beskrywende studie waarin faktore wat depressie in MIV/VIGS gediagnoseerde pasiënte veroorsaak identifiseer en gedifferensieer word afhangende van geslag. Kwantitatiewe asook kwalitatiewe metodes is gebruik. Dertig PLHAs wat met depressie gediagnoseer is, word behandel in Nthabiseng asook Luthando Kliniek by die Chris Hani Baragwanath Hospitaal in Soweto, Johannesburg. Nthabiseng is die MIV Kliniek en Luthando is die psigiatriese kliniek vir MIV/VIGS pasiënte. „n Vraelys is saamgestel om demografiese asook familie, sosiologiese en ekonomiese inligting te verkry. „n Kort onderhoud is ook met sommige pasiënte gehou om in hul eie woorde te hoor wat hul glo hul depressie veroorsaak. Die geselekteerde pasiënte se hospitaal kaarte is geanaliseer, met die doel om die dokter se insette of redes te kry oor die pasiënte se depressie. „n Semi-gestruktureerde onderhoud was gedoen met gesondheidsorgwerkers in Luthando- en Nthabiseng klinieke om inligting te verkry oor hoe hierdie professionele gesondheidsorgwerkers depressie sien by MIV/VIGS pasiënte en of hul bevoegd is om dit te identifiseer en te behandel.

Die studie het bevind dat daar „n verskil is by oorsake van depressie by vroue en oorsake van depressie by mans. Mees algemene oorsake van depressie by MIV/VIGS pasiënte is ontkenning, vrees van dood en sosiale onstabiliteit. By die vroue het ontkenning en bekommernis oor werk- en familie verantwoordelikhede meestal bygedra tot hierdie depressie, en by die mans was dit meer asof daar „n algemene terleurstelling geheers het in hul gemoed. „n Terleurstelling deurdat hul nie vir hul families sal kan sorg nie asook die vernedering in die sosiale netwerk. Om die verskille in MIV-geassosieerde depressie gebasseer op geslag te kan herken mag bydra tot die ontwerp van meer effektiewe beradingstrategië.

Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
CNS	Central Nervous System
DNA	Deoxyribonucleic Acid
HIV	Human Immunodeficiency Virus
MDD	Major Depressive Disorder
MDE	Major Depressive Episode
MHD	Mental Health Disease
NIM-ART	Nurse Initiation and Management of Patients on Antiretroviral Therapy
NIMH	National Institute of Mental Health
PLHAs	People Living with HIV/AIDS
RNA	Ribonucleic Acid
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organisation

Chapter 1

Introduction

1.1 Background

A person with HIV is in a situation where the disease can be as much trouble for the mind as it is for the body. A person infected by HIV can experience a feeling of being helpless and overwhelmed (Woolston, 2009). Several of individuals' relatives and friends have passed on not because of HIV/AIDS itself but in retrospect, fast-tracked by undiagnosed depression. The highest prevalence of HIV is in Sub-Saharan Africa and yet in these cultures depression which is a by-product of the condition is not recognised as a disease.

Some Sub-Saharan communities are not supportive of PLHAs making them more vulnerable to depression. Depression as a result has a direct impact on the progression of HIV/AIDS through effects on the immune system and indirectly through poor adherence to medication (Ickovics et al, 2001). The health care professionals in both the primary and tertiary care settings in these communities are not adequately trained to diagnose depression except for a few specialised psychiatric units. The outcome results in poor treatment outcomes which may be attributed to drug resistance or virological failure. The scenario therefore can be interpreted where infected people are not aware they suffer from depression in addition to HIV/AIDS and the health care professionals are not able to help them due to their lack of knowledge of clinical psychology.

It is therefore vital to know what causes depression in patients that have been diagnosed as having HIV/AIDS, how the condition manifests itself in positive patients as well as risk factors that can make them more vulnerable to drift into the underworld of depression. Measures that can be taken to prevent depression in HIV positive patients should also be investigated as well as ways to increase knowledge and awareness of it in PLHAS in health care professionals. The aim in HIV management is to improve PLHAs quality of life to make living worthwhile. Management of mental health is critical in improving PLHAs quality of life by lifting the veil of darkness and despair manifested in the condition of depression; quality of life impacts on adherence and this impact on mortality.

Specially trained health care personnel are required to manage mental health problems in HIV positive patients. The shortage of health care professionals is a crisis prevailing and common in the developing world. HIV/AIDS has substantially increased the demand for

health care services to provide support to these people's lives on a daily basis (WHO, 2006). The increased demand for health care services is prevalent to such an extent that mental health in HIV positive patients has largely been ignored. Individuals suffering from depression are not identified at the clinics which are the primary health care level. There is congestion of patients at secondary and tertiary levels while support services at the primary level are weakened. There is need to provide assistance for community services as well as increased cost of services. Services such as voluntary counselling and testing, preventing mother-to-child transmission require additional resources and increase the system's inability to cope (WHO, 2006).

The South African Government recently made a policy decision to expand access to ARV treatment and ensure all health institutions in the country are ready to receive and assist patients through the nurse initiation and management of patients on ART (NIM-ART). Nurses will be left to shoulder the ongoing burden of rapid expansion without adequate training or support and within a health system that is already under marked strain (Colvin, 2010). The nurses are being trained on ARV treatment initiation only and not mental health needs for PLHAs. If mental health is not addressed this will worsen the problem of untreated mental illness including depression leading to discontinuation of treatment and poor healing outcomes.

This study was conducted at Chris Hani Baragwanath Hospital a large tertiary institution in Soweto Johannesburg. It is the largest hospital in Africa with a staff complement of approximately 6 822 and 3 200 beds. Most of the patients attended to need specialist care and referred from clinics and provincial hospitals. The catchment area therefore brings people from different areas and diverse cultures. The HIV clinic (Nthabiseng), and the HIV psychiatric clinic (Luthando) are at Chris Hani Baragwanath Hospital. Most patients at Nthabiseng Clinic are referred from the Chris Hani Baragwanath outpatients department and inpatients admitted for opportunistic infections while patients at Luthando Clinic are referred from other local institutions and other psychiatric hospitals. Luthando Clinic attends to approximately 350-400 HIV positive patients with psychiatric disorders on a monthly basis.

HIV infection is a condition where the mental health of the infected individual cannot be ignored (Thom, 2009). Depression is the most common mental illness in chronically ill patients as well as in HIV positive individuals. This study seeks to describe therefore among

HIV positive individuals who is mostly affected by depression, what makes them more vulnerable to this condition and what can be done to effectively manage such patients.

The study will assist in increasing awareness of health-care professionals to the problem of depression in HIV positive patients. Ability to diagnose depression can result in better care and management of infected patients. Patients will also be protected from pitfalls that might come with depression such as defaulting treatment and high risk behaviour. Health professionals can benefit from management strategies that can result from the study including situations where gender sensitive counselling could be a potential problem. The community will also benefit as most of them find it difficult to deal with HIV/AIDS and its related depression. The community has to be informed to accept and understand that depression is a medical condition in order to deal with it and seek support without feeling inadequate to deal with this condition.

1.2 HIV/AIDS

The Human Immune Deficiency Virus (HIV) is a retro-virus that cannot survive outside a host cell. HIV possesses a unique enzyme, reverse transcriptase which uses viral RNA as a template to make a DNA copy which then integrates into the chromosome of the host cell. HIV infects the body by entry through a mucosal surface or by introduction of the virus into the blood stream. On entering the body, HIV infects different cells of the immune system and destroys resistance to infections. There are different classifications of HIV based on the RNA sequence. The different types of HIV all fall under HIV 1 that is responsible for the global pandemic while HIV 2 is a minority condition. After an individual has been infected with HIV there are different stages of the disease; the acute retroviral syndrome followed by clinical, symptomatic HIV infection and lastly Acquired Immune-deficiency Syndrome (AIDS). AIDS is characterised by opportunistic infections and malignancies, prolonged fever and constitutional symptoms like diarrhoea and severe weight loss. The most common opportunistic infections include tuberculosis (TB), pneumocystis carinii pneumonia, herpes simplex virus and cryptosporidiosis. Auto immune diseases appear where the body attacks itself in the form of eczema. Progression from HIV to AIDS differs from one individual to the next and the average time to fruition is 8 to 10 years. Antiretroviral drugs are used in the treatment of HIV to control or suppress the disease (Van Zyl et al, 2009).

The UNAIDS Global Summary of the AIDS epidemic as at December 2009 indicates the total number of people living with HIV are approximately 33.4 million; 31.3 million are

adults and 2.1 million are children under the age of 15 years. The UNAIDS Global Summary further states the number of people living with HIV worldwide in 2008 was more than 20% higher than the number in 2000 and the prevalence is three-fold higher than in 1990. AIDS continues to be a major global health priority and demanding attention to increase the lifespan of people and increase their quality of life. According to the UNAIDS epidemic update of 2008, important progress has been achieved in preventing new HIV infections and lowering the annual number of AIDS related deaths; the number of people living with HIV/AIDS continues to increase. AIDS related illness remains one of the leading causes of death globally and are projected to continue as a significant worldwide cause of premature mortality in the future decades (UNAIDS, 2009).

In Sub-Saharan Africa about 22.4 million adults and children are estimated to be living with HIV. The number of new HIV infections is estimated to be 1.9 million and AIDS related deaths are approximately at 1.4 million. Sub-Saharan Africa remains the region's most heavily affected accounting for 67% of HIV infections worldwide (UNAIDS, 2009). Women and girls in Sub-Saharan Africa continue to be affected disproportionately by HIV. Women make up 50% of the global epidemic and 60% of the epidemic in Sub-Saharan Africa. In the nine countries in Southern Africa those most affected by HIV are among young women aged 15-24 years with an average of 3 times higher than men of the same age (UNAIDS, 2010). South Africa with 5.7 million infected is home to the world's largest population of people living with HIV (UNAIDS, 2009).

According to the World Health Organisation's women's health fact sheet (WHO, 2009) HIV/AIDS is the leading cause of death amongst women in their reproductive years between 15 and 44. Women especially when young are more affected by HIV due to biological factors, lack of access to information and health services, economic vulnerability and unequal power in sexual relations. The World Health Organisation Women's Health Fact Sheet further indicates women rather than men are more susceptible to depressive episodes and anxiety with an estimated 73 million adult females worldwide; suicide being the seventh top cause of death globally for women aged 20-59 years (Gehner et al, WHO 2009).

1.3 Depression

The National Institute of Mental Health USA (NIMH) describes depression as a medical condition that affects thoughts, feelings and the ability to function in everyday life. Symptoms include lack of interest in usual activities, fatigue, difficulty in concentration,

insomnia, thoughts of death or suicide and appetite loss or weight changes. Depression can occur as a result of an individual being diagnosed with HIV. Depression after HIV diagnosis can result in risky behaviour, non-adherence and non-compliance to treatment and poor management of the disease. Many people including health-care professionals may assume depression is an inevitable consequence of a positive HIV test result and if the mental condition is left untreated it results in poor quality health, treatment failure or fast progression from being HIV positive to suffering from AIDS (NIMH, 2006; Aidsinfonet.org, 2010).

Depression is likely to result from a combination of genetic, biochemical, environmental and psychological factors. Research indicates that in depressive illness and disorders parts of the brain responsible for regulating mood are different in people who suffer from depression showing biochemical causes (NIMH, 2010). Major depressive disorder (MDD) is a common psychiatric manifestation of the HIV disease. MDD in HIV patients can be a primary consequence of CNS effects of HIV or a reaction to the stigmatisation and emotional consequences of the diagnosis and coping with a serious medical illness (Owe-Larsson et al, 2009). Some types of depression tend to run in families and events such as trauma of a loved one, a difficult relationship or any stressful situation may trigger a depressive episode (NIMH, 2010).

Diagnosing depression can be difficult in someone with HIV because some symptoms of the infection and side effects of related drugs are the same as those with this mental condition. Such symptoms include fatigue, low sex drive, reduced appetite, confusion, nightmares, nervousness and weight loss. The ARV drug efavirenz for example can cause fatigue, nightmares and depression is often listed as a rare side effect of this medication. Depression therefore might be unrecognised and untreated in many patients with HIV infection because health care professionals may not be adequately trained to correctly diagnose the condition (Aidsinfonet.org, 2010), (Owe Larsson et al, 2009).

The National Institute of Mental Health USA also describes depression as a treatable disorder of the brain. Depression can be treated by different therapies and medications in addition to whatever illness a person might have contracted. There are anti-depressant medications that are generally well tolerated and safe for people with HIV. However, there are some possible interactions among some of the medications and side effects that might require careful monitoring. Specific types of psychotherapy or „talk' therapy can also relieve levels of

depression and assist individuals to improve their self image during the stages they might go through and experience.

The Joint United Nations Programme in its "AIDS in Africa, three scenarios to 2025" concludes that an adequate response to the AIDS crisis has to encompass and address issues of individual and community mental health. The impacts of the virus may be direct such as living with HIV or indirect in the form of nursing someone with the disease. Children of parents who are HIV positive and depressed can feel the direct impact due to the negative feelings and also do not receive the necessary nurturing (UNAIDS, 2005). A policy document in 2007 by the UNAIDS states involvement of PLHAs at work and in the community can improve self-esteem and boost morale, decrease isolation and depression and improve health through access to better information about care and prevention. Participation of PLHAs within organisations can change perceptions by providing valuable experiences and knowledge. In communities participation in education and enlightening talks can break down fear and prejudice and support groups can help PLHAs to deal with depression and manage their condition in a more effective manner (UNAIDS 2007). Placing an individual with diagnosed depression in context can highlight the importance of appropriate treatment to improve the view of the outside world.

Chapter 2

Literature Review

2.1 Non HIV Related Depression

Major depression is one of the most prevalent mental disorders and the number one cause of disability worldwide. Once a person experiences a major depressive episode the likelihood of recurrence is very high. A programme for prevention during the first onset of depression as well as protection against recurrence after recovery is an essential goal for the mental health field (Barrera et al, 2007). Depression affects both men and women; however, mental health services see far fewer men with this mental condition. Due to convention men are less likely to ask for assistance when depressed. Society has moulded men to be far more concerned with being competitive, powerful and successful and in control of their lives and emotions. Most men will not admit they feel fragile or vulnerable and are less likely to talk about their feelings with their friends, loved ones or their doctors (Croft, 2009).

A cross cultural survey of 29 countries from the 1990 World Values Survey for individuals 18yrs and older was used to determine the sex gap in depression (Hopcroft et al, 2007). The dependent variable was depression while the independent variable was sex. They found the sex gap in depression was wider in high gender equity countries all else being equal. Females were more significantly depressed than males in most countries. Women in high gender equity countries have greater expectations of gender equity than they actually experience in their lives while women in low gender equity societies have none of these expectations. Biological differences can also explain the sex gap in depression across countries. While all controls were in place, being male was inversely related to the probability of feeling sad or depressed; may have been related to sex differences in hormonal states and neurology. Important predictors of individual depression were socio-economic and marital status together with number of children. Biological nature and the social environment of individuals together account for the sex difference in depression.

Another study examined gender differences in socio-demographic military service and mental health characteristics among Operation Enduring Freedom (OEF) and Operation Iraqi Freedom Veterans (Maguen et al, 2010). The findings indicated female veterans had feedback of depression diagnosis more frequently while the male counterparts received identification of PTSD and alcohol use disorder more often. It was also found demographic differences

have significant implications for mental health services especially that young women may have competing priorities such as employment, school and sole responsibility caring for family members or children which presented specific barriers to accessing and engaging in mental health treatment. In terms of race, being black served as a protective factor for both men and women for a depression diagnosis (Maguen et al, 2010). Previous research suggested racial or ethnic minorities had stronger social support networks that serve as a protective factor against mental health illness such as depression compared to whites.

2.2 Risk Factors for Depression in HIV infected individuals

People with HIV/AIDS face significant threats to emotional well being and a reduction to the quality of life. The threats include physical effects of the illness and treatment, demands of treatment regimen and health care professionals, changes in roles with increasing disability and dependency, depletion of financial resources, loss of work, stigma and discrimination, decisions around disclosure, disruption of relationships and death awareness possibly at an early age. Possible risk factors for depression in HIV infected individuals include genetic predisposition, early childhood experiences, history of psychiatric disorder, psychosocial factors, co-existing disease and neurobiological factors (Makin, 2009).

Substance use, HIV CNS infection and suffering from opportunistic infections such as toxoplasmosis, herpes zorster, varicellar zorster and hepatitis are a possible risk factor. Personality characteristics such as a low self esteem, poor sense of mastery, avoidant or disengaged personality styles, insecure or anxious attachment and levels of perceived stress also increase the likelihood of depression after HIV/AIDS diagnosis (Thom, 2009).

Low self acceptance, poor social support and stress related to HIV/AIDS were found to be risk factors for mental health problems among Chinese PLHAS (Yu et al, (2009); such stress included negative life events and perceived discrimination. When individuals may be vulnerable to developing psychopathology, their risks increases when environmental stressors are present (Mourad et al, 2008). These individuals are more likely to be affected by domestic violence or negative life events. It was also revealed in a study that lower emotional social support was significantly associated with higher depression (Li et al, 2009). Social isolation and stigma attached to the disease can prevent PLHAS from seeking and receiving social support which can lead to depression.

Emotional distress in PLHAS is also related to symptoms associated with HIV infection. People with symptomatic HIV infection display more distress than both those who test negative for HIV and some who test positive but are asymptomatic (Neimeyer et al, 2005).

2.3 Causes of Depression after HIV Diagnosis

Depression after a positive HIV test can be caused by various factors such as fear of death. A comparison of death anxiety and quality of life of patients with advanced cancer or AIDS and their family members was conducted (Sherman et al, 2009). The results indicated AIDS patients expressed greater anxiety than cancer patients while this condition was the same in all caregivers. Greater death anxiety was associated with poor quality of life; people experience fear of death at one time or another. There is no direct link between fear of death and depression unless there are precipitating factors such as the knowledge of a terminal illness or death of a person close to an individual. Aids related death anxiety seems to involve the uncertainty from initial HIV diagnosis to managing debilitating symptoms of advanced stages of the disease. Precipitating factors that can increase death anxiety leading to depression include recent diagnosis of HIV/AIDS, switching of treatment regimens in patients due to failure of regimen or side effects and long term complications of HAART like lipodystrophy (Neimeyer et al, 2005).

HIV/AIDS is also associated with immorality leading to infected people being ostracised by family or their immediate society. After a positive diagnosis a person might not know how their loved ones, partner, friends and family may react if they know their status (Medley et al, 2004). In a study in the Winelands in Cape Town on the illness and experience of infected low income mothers, HIV/AIDS was construed as a stigmatised, incurable, deadly and shameful illness that someone should be blamed. It was also described as an illness of secrecy, silence, separation, pain and suffering, loss and loneliness (Kruger, 2006). People who should support the infected person the most, those with whom they are in a relationship will see themselves in a similar position the moment they know their partner's status and may not be supportive. This lack of support, understanding and love may result in the development of depression.

A social stigma associated with negative connotations is one of the prominent factors that may account for depression in HIV infected people. The withdrawal of people's support networks which often results from stigma compounds the problem of depression (Edgar et al, 2007). The handbook of social work and HIV states that persons and groups who have always

been vulnerable and marginalised in societies are especially susceptible to becoming infected with HIV (Poindexter, 2010). The author states after becoming infected with HIV regardless of how or whether PLHAs were previously marginalised or oppressed, they suffer from discrimination and are more likely to lose their shelter, employment and social support. The stigma results in segregation at work and in the community of these infected individuals. Work policies that do not offer reasonable accommodation and places of work and do not have an HIV/AIDS policy can result in frustration of the people living with the condition and lead to depression. Fear of disclosure born out of a stigma created by a community or greater society can be a cause of depression in PLHAs.

HIV disclosure has been identified as a key stressor for people living with the condition in Thailand, when patients do not disclose their sero-status the odds of becoming depressed increase three-fold (Li et al, 2009). Fear of disclosure in the event of contracting the disease may result in depression. Factors that result in apprehension of disclosure include the fear of domestic violence, partner's reaction and blame, accusations of infidelity, abandonment by partner, dread of family conflicts or expulsion from the marital home and fear of being rejected or abandoned. When there is disclosure to partners and family the treatment and management of HIV/AIDS becomes a challenge for the entire family. Emotional social support from family and loved ones has a protective effect on developing possible depression (Bor et al, 1993 & Li et al, 2009).

Loss of income, failure to provide for the family economically and socially can lead to depression. PLHAs that lack proper counselling, education and acquired life skills to deal with HIV/AIDS may end up being depressed. Poor health and inability to do tasks that were previously done with ease may also result in depression. Other social factors such as gender inequalities that influence HIV/AIDS risk and vulnerability may also increase defencelessness to depression after a positive diagnosis. In a sex gap study, feelings of depression and sadness were more a feature of less developed, low gender equity societies than the high counterparts because the aforementioned were more likely to have greater experience of untimely death, war, social unrest, disease, economic inequality and poverty (Hopcroft et al, 1990).

Depressive illness was found to be the most common psychiatric problem in both asymptomatic and symptomatic HIV infection. Its prevalence appears to be approximately twice that of a normal community sample and it rises with disease progression. However, it is

queried whether these high rates of psychiatric illness relate primarily to the viral infection itself or as a non-specific consequence of the effects of a terminal illness in the particular populations affected (Clark & Everall, 1997). The possibility that the depression could be a result of the viral infection itself supports the need to investigate further the incidence and the causes of depression in HIV positive patients.

Though there is a general agreement that depression is present in both male and female HIV positive patients, it is more common among women due to several factors including biological factors, life cycle, hormonal and psychosocial factors unique to women; may also face the additional stresses of work and home responsibilities. Men experience depression differently than women and may have different ways of coping with the symptoms. Men are more likely to turn to alcohol or drugs when they are depressed or become frustrated, discouraged, irritable, angry and abusive. Some men throw themselves into their work while women are more likely to use religion as a coping strategy. Therefore, it would be more likely that in HIV positive patients there is more depression in women than in men (Maj et al, 1995; Freeman & Patel, 2005; Olley et al, 2004; Owe-Larsson et al, 2008, the National Institute of Mental health, 2005; Gehner et al, 2009). However, the study by Olley et al, (2004) failed to show any significant gender differences though the incidence of depression was higher in the HIV positive population than in the negative diagnosed segment.

Drug abuse including alcohol misuse may also cause depression in individuals. Discrimination against drug users prevents them from learning about HIV and receiving the necessary support from friends, relatives and the community (Medley et al, 2004); drug and alcohol abuse also cause depression directly. Some drugs, for example, methyldopa and alcohol are known to decrease serotonin and nor epinephrine levels in the brain resulting in depression. Because of the stress related to a positive HIV diagnosis, some patients may start abusing alcohol and other drugs. Other drugs used daily by women such as contraceptive pills may also make them more susceptible to depression. It is therefore necessary to identify causes of depression in HIV positive patients and how it can be more effectively managed in positive diagnosed patients.

Available studies on psychiatric and neuropsychological complications of HIV had been conducted mostly in Western countries and on gay men (Maj et al, 1994). This gave birth to the WHO Neuropsychiatric venture which was a cross cultural venture. The project aimed to assess the prevalence and natural history of HIV1, associated psychiatric, neuropsychological

and neurological abnormalities in five different geographic areas. This study showed there was a significantly higher prevalence of mental conditions including depression in HIV positive individuals than in those negative individuals; more studies need to be done in Sub-Saharan Africa as it harbours most of the HIV pandemic.

Significant numbers of HIV infected people have or develop mental health problems and this often adversely impacts on HIV/AIDS treatment adherence. Integrating psychiatric and psychosocial interventions benefits both the mental and the physical health of people living with HIV/AIDS (Freeman & Patel, 2005). The following three broad recommendations in the "3 by 5" and other HIV/AIDS treatment programmes in developing countries were made by Freeman & Patel (2005). The 3 by 5 initiative launched by UNAIDS and WHO in 2003 was a global target to provide three million people living with HIV/AIDS in low and middle income countries with life prolonging antiretroviral treatment by the end of the year 2005. They recommended successful HIV/AIDS interventions must include assessment of mental disorders and their appropriate management as part of the normative service; an area that has largely been left out. Treatment of HIV/AIDS has only started now to include mental health as an additional variable needing attention. Even then, it is mostly tertiary hospitals where there is access to donor funded clinics and specialists where mental health is taken as part of the treatment. In many private institutions, rarely is treatment available for both HIV/AIDS and for depression.

The second recommendation was there is a need to support research on reasons for mental health and HIV/AIDS. There is limited research conducted in developing countries bearing in mind they carry 90% of the HIV/AIDS burden. It is now six years since this recommendation and there is still very little research on mental health in HIV/AIDS. Lastly, they recommended there should be advocacy by a range of stakeholders so as to highlight the role of mental health in HIV/AIDS treatment programmes. Though the recommendation was made in 2005, there is still need for advocacy regarding the role of mental health in HIV/AIDS treatment. Many health professionals overlook this area and there have not been enough advocacies.

2.4 Mental Health Studies in HIV/AIDS

A limited number of investigations or research has focused on the role of gender in the psychological responses to and the psychopathology associated with HIV/AIDS. A study was conducted to compare psychiatric morbidity, coping responses and disability in male and

female outpatients that had recently been diagnosed with HIV/AIDS (Olley et al, 2004). A total number of 149 patients, 44 male and 105 female with HIV/AIDS attending an infectious disease clinic at Tygerberg Hospital in Cape Town, South Africa were evaluated. Fifty six percent of the patients were diagnosed with a psychiatric disorder; common disorder was major depression represented by 34.9%. There were no significant gender differences in the prevalence of mood disorders in the sample. Men, however, were more likely than women to meet diagnostic criteria for alcohol abuse or dependence and to engage in certain risky sexual behaviours. Women were more likely to suffer from post traumatic stress disorder and to use coping strategies of planning and religion to deal with illness. The conclusion of this study indicated psychiatric disorders are common in recently diagnosed HIV/AIDS patients and clinicians should be aware of the high prevalence of mood disorders in both men and women. This study looked at patients who are HIV positive and have already been diagnosed with depression. Major depression was found to be the most common psychiatric disorder in HIV positive patients (Olley et al, 2004). It was therefore worthwhile to investigate depression after HIV diagnosis focussing mainly on its causes and whether these differ from men to women and to what extent is there a variation.

It has been shown in a study conducted in Australia that MHD was common in the population with HIV infection and was associated with increased health-care utilisation but not with reduced survival (Mijch et al, 2006). Survival can be reduced as MHD can lead to faster progression of HIV to AIDS and fast deterioration of the patients, reducing survival. These findings could explain that inhabitants of Australia a developed country, experience less stress than inhabitants of developing countries.

Supporting the argument that PLHAs had an increased rate of psychiatric illness, Owe-Larsson et al, (2008) reviewed the clinical features and current knowledge on the treatment of psychiatric symptoms and disorders in patients with HIV infection. They searched the Pub Med database from 1980 to 2008 combining HIV/AIDS with different key-words for psychiatric illness including, depression. The study showed major depressive disorder, depressive symptoms as well as anxiety disorder and substance abuse were more prevalent among the HIV infected population than among the general population. It is therefore important when completing the equation to screen for cognitive impairment as well as co-morbid mental disease in HIV patients.

There is supportive evidence from international research that the prevalence of depression and anxiety in people living with HIV/AIDS is higher than in the general infected population. It is critical people who are infected with HIV be screened for these disorders and that depression and anxiety should be treated with medication when necessary (Thom, 2009). A study was conducted by Thom (2008) at the Peri-natal HIV research unit associated well clinics and Nthabiseng Clinic at Chris Hani Baragwanath Hospital in which 302 individuals were interviewed. Over 30% of the participants had a current mental disorder, 17% had a current depressive disorder; 60% of participants with major depressive disorder had their first onset after being diagnosed and informed of their HIV status.

Chapter 3

Methodology

3.1 Research Problem

A number of people who did not previously suffer from depression showed these symptoms after they were diagnosed as being HIV positive or as having AIDS. In the developing countries some cultures do not recognise depression as an illness. Therefore people suffering from the symptoms may not present themselves for treatment or if they do, the diagnosis is often inaccurate. The situation is aggravated in PLHAs because the community, the workplace and health-care professionals may assume that depression is a normal consequence after a HIV diagnosis. There is need to investigate the factors that cause HIV/AIDS related depression as well as incorporate gender as a variable that could have an influence on the outcome. Counselling and prevention programmes are designed without taking gender influences into account and there is need to investigate differences if any between men and women on the causes of depression after they have been diagnosed with HIV. Gender controls to a certain extent the knowledge men and women have of the situation. It controls how they behave within their relationship and also affects their respective access to services and information and their ability to cope when their illness. Several studies have shown there is a higher level of correct knowledge of HIV/AIDS in men than in women. There is a need to investigate how gender related factors affect the occurrence of depression after a positive HIV test result.

3.2 Assumptions of the study

- HIV/AIDS diagnosis causes depression in some people
- There is greater depression in women than in men
- Health Care professionals do not diagnose or treat depression related to HIV/AIDS adequately.
- There is need for reform in the manner in which psychological illnesses are managed in the presence of HIV/AIDS

3.3 Research Question

What are the gender related factors that lead to depression after individuals being diagnosed with HIV/AIDS?

3.4 Aim of the Study

The aim of the study is to establish the gender related factors that lead to depression after an HIV/AIDS diagnosis in order to incorporate gender influences into the formulation of counselling and prevention strategies.

3.5 Objectives

- To establish whether people living with HIV/AIDS are depressed.
- To identify the factors which cause depression after a HIV/AIDS diagnosis.
- To differentiate the factors that lead to depression in men and women after HIV/AIDS diagnosis.
- To formulate counselling and prevention strategies that incorporate gender influences.

3.6 Research Design and Methods

A quasi experimental design was chosen in which there was no random allocation of subjects. Depression after HIV diagnosis will be described, which is affected, when it affects and the causes of related depression. Quantitative and qualitative approaches were used to elicit information to satisfy the problem statement. Two different questionnaires were designed to collect data from the selected patients at Nthabiseng and Luthando Clinic and from health care professionals who were dealing with the target population. Document analysis in the form of assessment of patient notes was done to collect qualitative data.

3.7 Research Strategy

Research can be conducted by using the following procedures:

- Questionnaire: A series of questions was designed so as to acquire personal as well as information regarding the participants HIV/AIDS status and depression since diagnosis of their HIV status.

- Document analysis: Systematic examination of documents was done. Information was gathered from specific selected patients' notes. Such information included demographic characteristics of the patients, diagnosis of HIV infection, reasons for depression and treatment being taken. The information was classified and relationships between the variables specified.

- Semi Structured Interviews: A semi structured interview which is conducted with a fairly open framework which allowed for focus, conversation and two way communications was used. An interview guide was prepared for the health care professionals and a separate interview guide was also prepared for the selected patients. General questions regarding HIV/AIDS and depression were formulated as a guide.

A survey was mainly used and focused on both factual information and opinions expressed. A questionnaire was administered to selected patients for the collection of data and a semi structured interview was conducted with the patients to collect their opinions. Qualitative data was also collected from interviews with selected health care professionals. Document analysis was carried out of the selected patients' hospital records.

3.8 Sample Selection

The study involved a sample of 25 HIV positive patients attending Nthabiseng and Luthando Clinic at Chris Hani Baragwanath Hospital in Soweto, Johannesburg, South Africa. Purposive sampling was used to select the participants; only those HIV positive patients who had been diagnosed as being depressed were recruited for the study. Males and females between the ages of 20 and 49 were selected. HIV positive patients who had been diagnosed as being depressed but with a co-morbidity illness such as diabetes and hypertension were excluded. PLHAs experiencing depression with a history of drug dependence and alcohol abuse were also excluded. It was possible to recruit a few male subjects to include in the study.

Purposive sampling was also done with thirteen health-care professionals. The health-care professionals were selected on the basis of whether they were either directly or not involved with HIV positive patients. The process was followed to distinguish between those who were directly involved could have more insight into HIV/AIDS and depression than healthcare professionals who were not working with these types of patients. The selected healthcare professionals included five medical doctors specialising in HIV/AIDS management, two

psychiatric doctors also specialising in management of HIV related psychiatric disorders, two nurses based at the HIV clinic, three pharmacists based at the HIV Clinic Pharmacy and a social worker. Information such as the health professional's opinion on whether HIV diagnosis was related to depression in these positive patients and what the possible causes of that depression could be was sourced.

3.9.1 Recruiting HIV Positive Patients

Doctors in Luthando and Nthabiseng Clinic assisted in identifying the HIV positive patients who had been diagnosed with depression; pharmacists working at the ARV pharmacy priced input at this level. The identified patients were given an explanation as to why they had been identified; study was explained and the patients were asked if they were willing to volunteer.

3.10 Ethical Considerations

Only those patients and health-care professionals willing to provide informed consent were recruited. Patients were asked for permission to use the information about their condition and personal information. They were also requested to read and understand the explanation of the purpose of the study and were given sufficient opportunity to ask questions before agreeing to take part in the study. All information obtained during the study including hospital records, personal data and research data was strictly confidential. Results of the study included personal details regarding age, date of birth, initials and diagnosis were anonymously processed into the study report. Data reported in scientific journals will not include any information that identifies a particular participant. The participants were made aware of their rights in the study which included their participation was voluntary and they could decline to participate or stop anytime without stating any reason. The study was approved by the Ethics Committee of Stellenbosch University and permission letters were sought from the Department of Health and Chris Hani Baragwanath Hospital.

3.11 Data Collection Methods

A self administered questionnaire with a few open ended questions was administered to people living with HIV/AIDS. The questionnaire was structured to elicit responses to gather biographical information on age, gender, marital status, home language, years of education and employment status. A short family or social history was also taken in the form of family members, relatives or other people staying with the individual and allocation, source and sharing of resources. A short interview was also conducted with selected patients to attempt

in determining what each of them thought what caused their depressive condition and any other factors that might be contribute other than being HIV positive.

A semi-structured interview was designed for health care professionals. The interview sought to describe how the health care professionals saw depression after an HIV diagnosis, whether it was viewed as a problem and how it was presented to these professionals. Health care professionals were also prompted to add their ideas according to their experience what they thought would benefit the study.

Patient notes of selected participants were analysed particularly viewing the doctor's notes from the diagnosis of depression and reasons for the condition; prescribed treatment and progress was also recorded.

3.12 Data Storage

All data collected was saved on a personal computer with a password to all documents in the study. Real names were not used in the report and were only known by the researcher.

3.13 Data Analysis

Descriptive statistics were used to develop and describe the variables recorded in the study. Demographic characteristics of participants were described. Participants' responses were classified, for example, the causes of depression after a positive HIV diagnosis were analysed and described using frequency distributions, histograms and pie charts were also used to present data. Use was also be made of statistical variables such as the mean; average is a measure of central tendency. Median, mode, standard deviation, variance and range were also used depending on the relevance of these statistical measures to data collected. The data collected from the document analysis and interviews was coded. Codes served to summarise, synthesise and type of observations made. Patterns and relationships within the data were reported.

3.14 Significance of Study

The study will increase alertness of health-care professionals to the problem of depression after a positive HIV diagnosis and will result in improved care and management of affected patients. Patients will also be protected from pitfalls that might come with depression such as defaulting treatment and high risk behaviour. Health professionals can benefit from management strategies that can result from the study including gender sensitive counselling

and better management of their patients. The community will also benefit as most resist dealing with HIV/AIDS related depression and do not accept that depression is a medical condition.

Chapter 4

Findings

4.1 Demographic Characteristics of Participants with Depression.

Twenty five subjects participated in this study where 20 (80%) were female while 5 (20%) represented males. Table 4.1 shows their ages ranged from 20 to 60 years; between the ages 31 and 40 and between 41 and 50 years. The least number of participants were above 50 and few participants were below 30 years of age. There were almost an equal number of single and married participants; ten and eight respectively. Only three participants were widowed and the rest were either divorced or separated.

Table 4.1

Demographic Characteristics of Participants

Gender		**Age (Years)**		**Marital Status**		**Employment Status**		**Education Level**	
Male	5	21-30	6	Single	10	Employed	5	Primary Level	9
Female	20	31-40	9	Married	8	Self Employed	2	Secondary Level	13
		41-50	8	Divorced	2	Unemployed	18	Tertiary Level	3
		51 and above	2	Separated	2			University	0
				Widowed	3				

4.1.1 Employment and Depression

A high percentage of the participants 18 (72%) were unemployed, 5 (20%) had formal jobs while two were self employed.

Figure 4.1 Employment Status

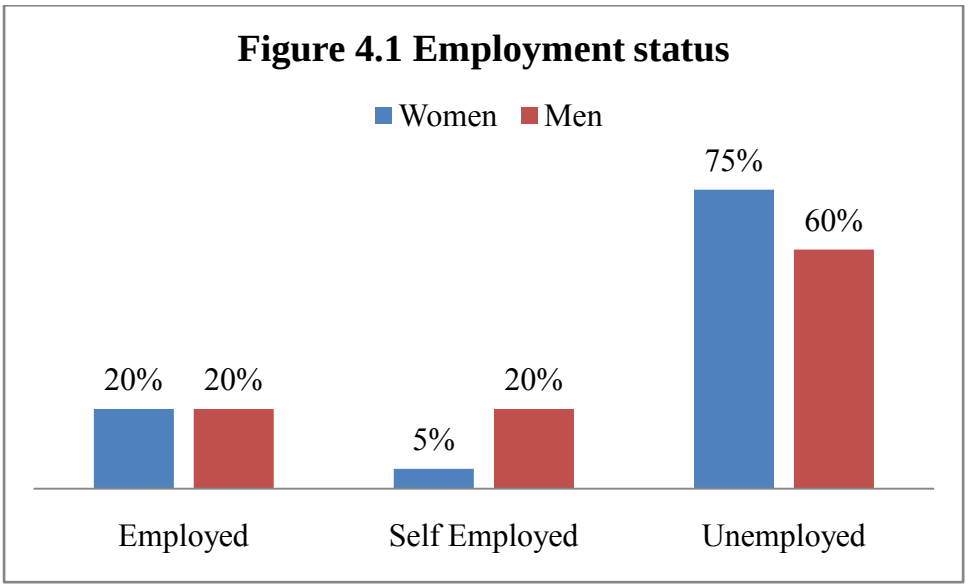
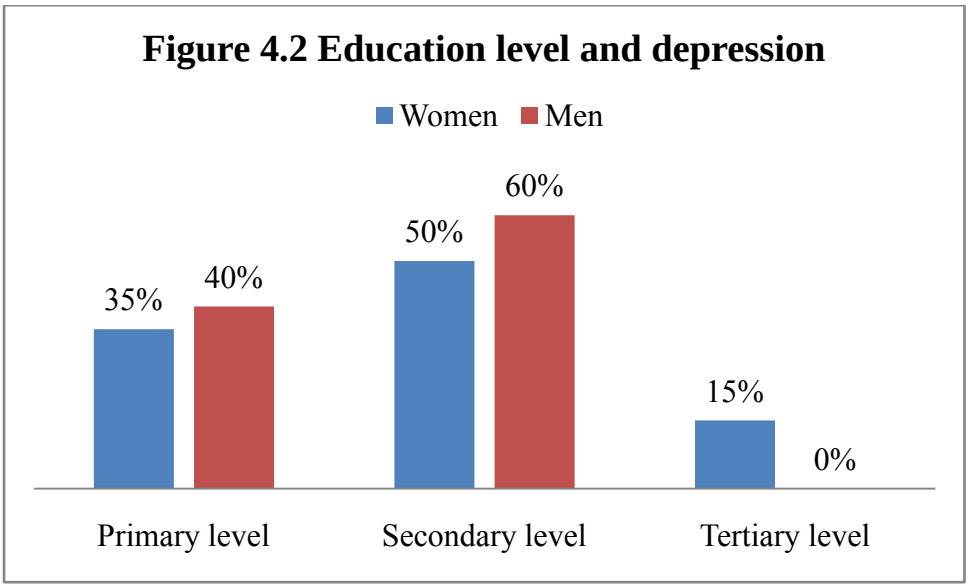


Figure 4.1 shows the percentage of men and women who are employed is 20% in each category while the percentage of self employed individuals is higher in men than in women. In both men and women the greatest percentage suffering from depression is the unemployed.

4.1.2 Education Level and Depression

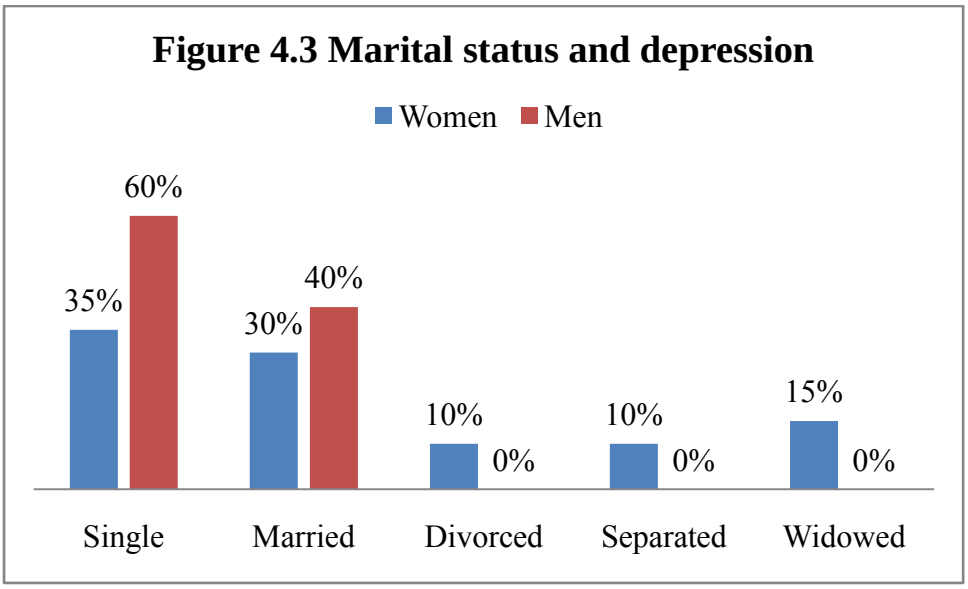
Despite the high unemployment rate most participants had acquired a certain level of education. Figure 4.2 shows 16 (64%) of the participants had completed a secondary education and only 9 (36%) had progressed to primary level. Three male participants had completed secondary education and two had reached primary level. Most female participants had completed secondary education 13 (65%) and out of these 3 (15%) had completed tertiary education. A few female participants 7(35%) had reached the primary level.



Lower levels of education, namely primary and secondary there is a greater prevalence of depression when compared with tertiary level. The general understanding or perception of what it means to be HIV positive can also vary due to the level of education. Whether one falls into depression may also depend on what knowledge and perceptions they have about HIV.

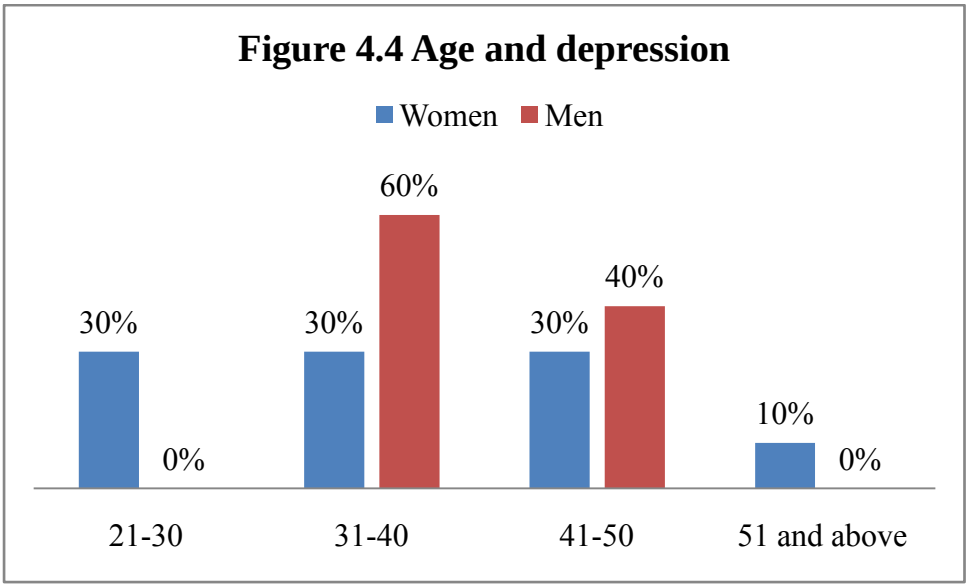
4.1.3 Marital Status and Depression

According to figure 4.3 the most depressed participants are single followed by those that are married. Married participants might worry about infecting their spouses and those that are single might want to marry someday and their HIV status may be perceived as a hindrance to getting a spouse.



4.1.4 Age and Depression

Figure 4.4 shows the most depressed age group is between 31 and 40 years of age.

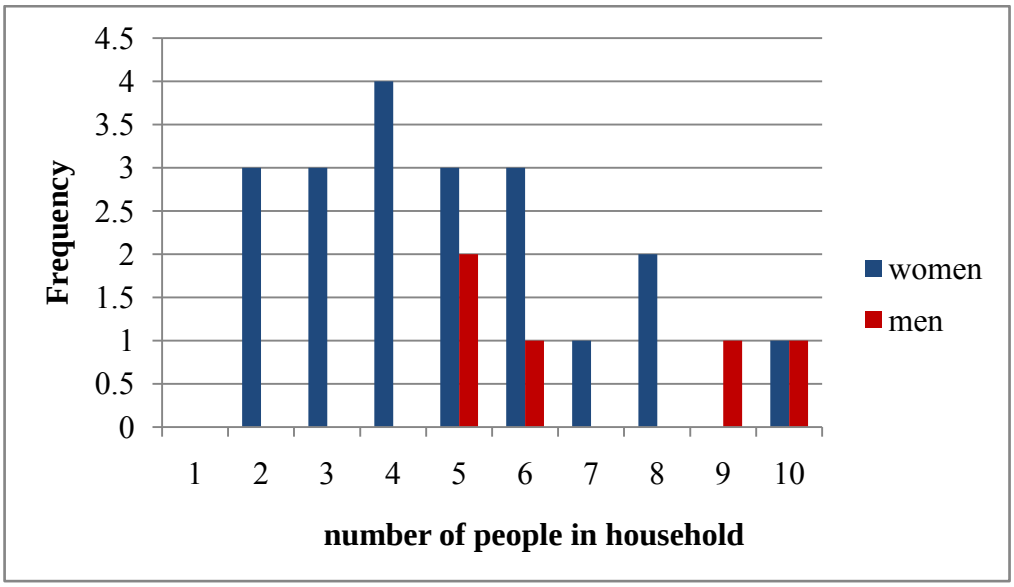


4.1.5 Household Responsibility and Depression

The average number of people in a household was 5; average of 2 children. A participant had the highest number of children had 11 while three individuals had no children. Most participants 18 (72%) were totally dependent on a government grant for their survival. These participants also relied on their parents' pension and or support from a working relative for their needs. The participants that were employed relied only on their jobs. One self employed participant also received a government grant.

Figure 4.5

Household Responsibility and Depression



According to figure 4.5 the proportion of depressed people decreases with the increase in the number of people in the household. The increased number of people in the household might mean a PLHA has more social support. The chances of a patient being depressed given the number of people in a household also depends on whether this person is either the breadwinner or not and also the relationship with the people in the household.

4.2 Diagnosis and Depression

Voluntary counselling and testing was not a popular method by which the participants had discovered their HIV status as only 7 (28%) of the participants had known about their status through voluntary counselling and testing while 18 (72%) were diagnosed through other events such as: pregnancy related testing 6 (24%) and after admission for opportunistic infections in the hospital represented 7 (28%). The other participants 5 (20%) had discovered their HIV status through illness or death of a child. Only one participant had been tested at work and one other established the status after a rape incident.

Most of the participants 18 (72%) could not specify any complaints or had no family problems such as feuds, loss of employment and abuse before diagnosis. However, two participants had employment problems and another two participants had abuse related problems. Three of the participants had marital or relationship problems.

After diagnosis, most participants noted a great change in their eating 18 (72%) and sleeping 17 (68%) habits. A change in lifestyle was experienced by 9 (36%) participants while 5 (20%) experienced a change in their church going practices. Participants were asked to explain why there were such changes; 15 (60%) could not give any reasons. A few participants 3 (12%) specifically attributed the changes to depression. Two participants said it was because they were stressed while an equal number said they were thinking too much. One participant attributed the changes to having had many problems and the remaining two attributed the change to anger.

Most of the participants 23 (92%) had accepted their status. A few of them 2 (8%) were not sure whether they had really accepted their position. Reasons were they were afraid of death and would time and again remind themselves they are ultimately going to die. The other participant was still very young and could not accept they had contracted the disease having been with only one partner.

There was selective disclosure among participants; some to certain members of the family and not the others. Most participants 22 (88%) had disclosed to their family while 18 (72%) had disclosed to their spouse. Disclosure to friends or workmates was fairly low with 12 (48%) and only 3 (12%) had disclosed to their pastor or church members. Most participants did not disclose to their children, only 7 (28%) had shared the situation with them.

Most families and spouses sharing their conditions were supportive of the situation. A few of the families displayed negative behaviour and others were indifferent. No spouses were negative but a few of them disclosed to were indifferent. Most friends and workmates disclosed to were supportive while very few were indifferent. Pastors and church members were mostly supportive when informed of the condition. Those who had not disclosed or had partially given various reasons for not acknowledging their status included individuals that had something bad and negative to say about HIV people. Some were ashamed to disclose because they believe people say HIV is dirty and others were afraid of discrimination. Most did not disclose to their children being too young or sensitive and would not be able to keep a secret. Others did not disclose to relatives they are very close to because they would be heartbroken while others only disclosed to close family members and friends. Others said they had not disclosed because it was their problem and felt they did not want to involve other individuals.

Participants were asked whether they had any current life stressors. Most participants indicated they were worried about their children and family. A few were concerned about work while very few were anxious about their partner or spouse. Other participants had various other possible stressors including the possibility of treatment failure, illness, HIV related loss, marital problems and other people's behaviour around HIV positive people.

The most common factor selected by participants as contributing towards their depression was loss or lack of income 15 (60%). None of the participants denied or expressed failure to accept their status while 5 (20%) selected lack of moral support. An equal number of participants 3 (12%) selected fear of death, fear of disclosure and poor heath as factors that contributed to the depression. Stigma and discrimination were cited by 4 (16%) while 10 (40%) of the participants added other reasons which were not listed; bereavement, marital problems and employment related issues, fear of divorce and taking care of an ailing spouse. Most participants were worried about their children's future and not having enough money to support them or the family. A couple were not being treated fairly at work while others were angry at being infected.

4.3 Patient Interviews

Responses from various conditions were recorded from the study.

- **Depression**

Most participants knew what depression was and recalled several symptoms with most mentioning thoughts of killing themselves, being moody, not able to sleep and thinking too much. Other factors mentioned included isolating themselves, feeling lonely, always sense being tired and having negative beliefs. The least common factors included feeling angry or sad, stressed, loss of memory, unable to function properly, fear, severe headache, unable to talk and loss of concentration. However, not eating well was mentioned by only one participant though most of them had said they noticed a change in their eating behaviour after diagnosis. Self hatred and that the body does not feel fine were also mentioned.

- **Diagnosis of depression**

The participants were asked how their depression was diagnosed; 8 (32%) had spoken to their doctor about the symptoms and were referred. Some of them 6 (24%) had been admitted to the hospital after attempting to commit suicide. Other participants 4 (16%) had been referred from the local clinics after speaking to nurses about their symptoms and 3 (12%) had been diagnosed after having been admitted to the hospital with a serious headache. Only one participant had been diagnosed of depression after childbirth and 3 (12%) could not say when and how they were diagnosed of depression.

- **Causes of depression**

The reasons for the causes of depression in the semi-structured interview were similar to the reasons given in the questionnaire. A few other reasons such as the weather and refusal of a partner to be treated were mentioned in addition. Many participants said that gossip within the community made their depression worse, while others mentioned being a single parent and failure to get a partner or get married worsened their psychological wellbeing. Negative events like seeing a spouse suffer, no place to stay, making mistakes at the workplace and neighbours' kids were also mentioned as factors that increased levels of depression. Most participants said family fights or feuds worsened their depression while a few recalled that nothing at home, work or within the community was responsible for making them feel negative..

- **Current sources of stress and coping mechanisms**

Current sources of stress included being abandoned by a spouse, unfair treatment at the workplace, financial problems and fear of death, inability to meet children's demands, lack of family support, watching a spouse ailing and mourning the death of a husband. Also mentioned was abuse by an ex-boyfriend and failure to get a divorce. A few participants had no new or current sources to bring about stress. Most participants said they would take a walk or exercise when feeling stressed and depressed. Others would sleep while a few read a magazine, wrote in a journal, talked to someone or went to church. A few participants would isolate themselves, watch TV or listen to the radio or socialise in the form of attending a soccer match. Very few participants would do beadwork or sewing, sing or smoke cigarettes or use snuff. Individuals also mentioned other things done to help relieve stress included praying, drinking lots of water, eating, screaming, crying and drinking.

- **Vulnerability to depression after a positive HIV/AIDS diagnosis**

Less than half of the participants thought women were more vulnerable to experience depression than men after a positive HIV diagnosis. The reasons given were that women have more responsibilities, are emotional and fragile and men do not take responsibility. A sizeable number of participants thought that women and men were equally vulnerable. Their reasons were God made men and women differently and depression would affect them according to situation and not gender. These participants also mentioned vulnerability was the same only those men put up a front to be tough. Very few participants thought men were more vulnerable because they are the family bread winners and cannot stay at home and not work. They also reasoned the perception that men cannot cry makes it difficult for them to be open and therefore pretend to be fine. A couple of participants did not know whether or not there was a difference between the sexes.

4.4 Health Care Professional Interviews

Relative information derived from the responses of this group in the sample will be highlighted.

4.4.1. Demographic Characteristics

The total number of 13 health care professionals was interviewed; three quarters were female and a quarter male. Most health care professionals were between 31 and 50 years of age; two were above 50 years of age. Five White, six Black and two Indian health care professionals were interviewed. The total was divided between five medical doctors, two psychiatric specialists, three pharmacists, two nurses, and a social worker. The health care professional's experience working with HIV ranged from 1 to 20 years with the youngest age group 21-30 having the least experience. The average number of years experience for the 31-40 and 41-50 age groups was 4. Health care professionals aged above 51 had the most experience of 15 years.

4.4.2 Depression in HIV positive patients

All the health care professionals agreed HIV positive patients suffer from depression and that it was something they should be concerned about. Their reasons were that HIV positive patients suffer from psychiatric disorders including depression; current treatment focus was on acute opportunistic infections and physical symptoms. Depression would only be treated if the symptoms were quite obvious. Some health care professionals mentioned the patients cry now and again and talk about their financial problems, work or family related concerns but in the absence of obvious symptoms, a keen sense was therefore required to detect depression. Diagnosed patients may suffer from depression especially just after diagnosis and coming to terms and accepting the condition as well as in the long run on changing treatment or loss of a partner. The stigma attached to HIV, lack of education can result in depression in the positive patients.

- **Depression after a positive HIV diagnosis**

The health care professionals agreed that a positive HIV diagnosis can cause or result in depression. They gave several reasons including that any news of a terminal disease with no cure may result in depression. Other reasons were that HIV is a significant psychosocial pressure and can precipitate depression in patients who do not have social support and when

the first time patients find out, some get depressed and others go into denial. There were examples of patients who leave their files and do not come back for years. The health care professionals added that getting depressed also depends on the lifestyle of infected individuals. If a person was in a stable monogamous relationship then a diagnosis can definitely lead to depression. Some patients also get depressed because they do not know what the future holds for them. Pregnant mothers for example will wonder whether their baby is also infected and they are concerned about the future of that child. Some patients will face the difficulty of disclosure and the possible stigma they may have to face. A positive HIV diagnosis can also cause or result in depression because of the way the community views the disease. A patient might not get depressed with other chronic illnesses such as diabetes because it is considered a clean disease. The health care professionals also mentioned the incidence of depression after a positive HIV/AIDS diagnosis would depend on the society one lives in and on whether there is knowledge about the condition. The quality of counselling, lack of support and economic difficulties may also result in depression. Social factors, stigma and the effects of HIV itself on the brain and co-morbid conditions like tuberculosis and granuloma which damage the brain can cause depression.

- **Causes of Depression**

The causes of depression identified by the healthcare professionals included the news of the illness would itself cause the depression. HIV positive patients are faced with significant changes in their life including receiving treatment and depending on taking tablets daily. Disclosure is a major decision with social stigmatization and rejection as possible consequences of confession; cause depression. Rejection can be by the spouse, family and work mates, by friends or the community. People tend to underestimate recurrent loss associated with HIV. This may include loss of employment, good health, relationships, bereavement and all this can result in depression; inability to disclose can be a contributing factor.

Patients can get depressed if they have to change treatment because of resistance or side effects; additional drugs for other conditions might contribute to the condition. The use of methyldopa for example for high blood pressure can result in depression. Frequent admissions for opportunistic infections, chronic pain and fear of death can also be a cause. Ignorance, poverty, unemployment and diagnosis on pregnancy were identified as causes for depression after a positive HIV/AIDS diagnosis.

Anger directed towards spouse and unanswered questions such as „why me' could also cause or result in depression. Some patients would have abstained from sex for a number of years only to meet a partner and get infected or will not appreciate the virus can be latent in a body and the individual only start feeling ill after some years.

Lack of a care provider could also cause depression especially for women who look after children and they are not around to look after a parent when they are ill. Most women worry about their children's welfare and future. Single people get depressed because they wonder if they will be able to get a partner or marry in light of their status. Some patients present late for treatment and HIV would have affected the brain causing psychotic conditions and depression.

- **Signs and Symptoms of Depression**

Many responses were given of how depression manifests itself in HIV positive patients. The signs and symptoms included looking or feeling down, a low self esteem, no confidence, altered interactions with the health care provider; few complaints and short answers, looking tired, isolation, tearful and de-motivated; some become angry, aggressive and insulting. Other patients have poor treatment adherence, neglect themselves and may come to the clinic dirty and yet they were well kept before; some are withdrawn and reluctant. Patients may also complain they sleep all day while some in contrast experience a lack of sleep. The patients may present with non-specific somatisation and complain about a general illness which the doctor cannot identify or for which prescribed treatment does not help. Some patients will eat too much while others have no appetite. The depressed patients may also present with hysteria and have anxiety reactions while some with psychosis. A number of patients especially women verbalise their feelings while others do not want to communicate. Other signs and symptoms mentioned included memory loss and talking too much.

- **Cultural Differences in accepting depression after HIV/AIDS diagnosis**

Most health care professionals agreed there were differences culturally in accepting depression as a disease. Black patients especially would find it difficult to accept depression as a disease because of other cultural beliefs especially beliefs in „sangomas' and that anything to do with the mind is a sign of being bewitched or your ancestors calling for you to become a traditional healer or to perform appeasing ceremonies. A few Black health care professionals did not themselves believe that psychiatric conditions existed in their people.

The fact that there is no local or vernacular word for depression and doctors found it difficult to describe the term to their patients made them believe Black patients would find it difficult to accept it as a disease. The nurses also confirmed there is ignorance amongst Blacks of the condition. Whites are exposed to relevant information, most are educated and come forward for treatment early while their Black counterparts delay action and come for treatment after many complications.

There are differences in acceptance of depression across all cultures. Many of the health care professionals believed that psychiatric illnesses were not seen on the same plane. They said it depended on the level of education and different religions would also deal with depression differently. Acceptance depends on exposure and access to information. When there is no information made available people tell the infected individuals to get them self together when in actual fact they cry out for assistance.

Other health care professionals thought there would be cultural differences between men and women. Men are culturally affected because manhood requires that they must be strong, so they deny depression and see it as a personal failure. Men would also be less open and do not express their feelings while females display opposite behavior patterns.

A few healthcare professionals did not know about any differences as they dealt only with a particular group of people which did not complain. However, some of them thought there was no difference or that there should be none as it was the healthcare practitioner's duty to make the patient aware and understand the illness. Others thought there was no difference because many people across cultures did not understand depression including the educated ones. The healthcare professionals also highlighted that recognized depression was missed at HIV clinics and patients would only be referred should a serious problem arise. It was therefore important for the health care professional to be empowered to diagnose and treat depression.

- **Gender effect on the incidence of depression after HIV/AIDS diagnosis**

Most health care professionals thought gender has an effect on the incidence of depression after a positive HIV diagnosis because female patients find it easier to express their feelings. Women are seen to be honest in sharing their emotions while men will not cry or admit they are depressed. Women are more emotional and it is acceptable for them to nurse their feelings; healthcare professionals identify less depression amongst men. Most women also test early but are scared to disclose because their partner might abandon them.

The healthcare professionals also mentioned women carry the major burden of raising children and will therefore find the diagnosis more stressing unlike the opposite sex. Some women will get depressed because their partner moved away after infecting them and most of the healthcare professional's female patients thought they had received the HIV from the husband or partner. The nurses especially mentioned men who do not want to come to the clinics for diagnosis and women who experience problems to convince men to use condoms, tell lies and do not admit being HIV positive. Women are also made more vulnerable according to their culture which makes them subservient to men and this makes them feel inferior. Unemployed women are especially vulnerable and at the mercy of others.

Some health professionals said there was no difference on the incidence but on the diagnosis. The impact is the same but it is more acceptable for females to be depressed; for both men and women there is no offer of special support. Others said there is no difference; however, there are also many more female patients than males because they refuse to subject them self to testing and only resort to it when they are sick. Men also experience depression when they lose their jobs and cannot support the family.

Only one male health care professional thought men were more vulnerable to depression after a positive HIV diagnosis. Men are more prone to depression because when they fall they are told to get up and they find it more difficult to go and seek help and therefore in comparison more women are diagnosed.

- **Health care system adequacy to detect and manage depression in HIV positive patients**

Most health care professionals said the health care system was not adequately prepared to detect and manage depression in HIV positive patients. Most said psychiatric conditions required time to counsel the patient and that clinics are busy and there is no time to make assessments for depression unless it is specifically raised.

Some healthcare professionals said they could detect depression but there was not adequate staff and their time was taken up to manage the huge workload. At the primary health care clinics, there is no anti-depressant medication and all the patients were referred to the tertiary institutions; there is no integration between primary and secondary health care. Depressed patients are de-motivated hence they are reluctant to go to another institution when referred for treatment.

The healthcare professionals also said the focus in the consultation rooms was on viral loads and CD4 counts. Many cases of depression are missed and only picked up in retrospect. Assessment at the tertiary level of care is also at intervals and not continuous which makes it even more difficult to identify depression. Most of the patients do not have access to organizations like life-line which could help them to obtain the necessary treatment and support.

Some healthcare professionals, especially nurses said the health care profession was adequately prepared to detect and manage depression in HIV positive patients. The nurses said through in-services and mental health training they could identify and manage mental health problems. Training of counselors would assist them while doing ward rounds and post treatment visits would be able to detect depression and refer patients for treatment and counseling. The social worker also thought the system was adequately prepared through teamwork with the doctors referring the patient to the social workers and them in turn to the psychologist.

- **Experiences to help understand and manage depression**

Depression is an illness like any other where it includes an organic component which requires medical therapy to correct. Medical therapy enables patients to cope and be able to engage in psychological interventions. Early initiation of ARVs will stop HIV crossing over into the brain and causing psychosis. Health care professionals must be able to identify, be aware and have the extra eye to watch out for depression. Depression will become less common as people get ARVs sooner. There will be no decline in health over time as experienced before and this will improve the condition of depression. Patient provider relationship will also improve and there will be more time to spend with patients and provide appropriate care.

Couples need to be invited together for HIV tests because of the difficulties faced after results are divulged; disclosure and acceptance. Once the findings are made available to a couple at the same time they can be there to support each other and provide the needed understanding.

People in the rural areas are a group which has been forgotten and has unfortunately been left out of the equation. There is more that can be done for rural populations to gain understanding of HIV/AIDS and depression. Providing care for people with HIV also needs to be assessed and treated for depression as a patient access them late and have to carry a burden and process their own emotions.

There is also a need to address depression in the health care provider taking care of the HIV positive patient by arranging psychological sessions and wellness programmes. Healthcare professionals may mismanage a patient because they themselves are depressed; cannot focused on patients and forget important details.

Chapter 5

Discussion

5.1 Are People Living with HIV/AIDS Depressed?

A total of 25 patients who had been diagnosed with depression and on treatment were interviewed. The HIV/AIDS Psychiatry clinic sees about 468 patients of which 336 are female and 132 male. The total number of patients who had suffered from MDD is 163 (35%) and the numbers of people who had the condition mood disorders secondary to HIV and had progressed to MDD were 44 (9%). A total of 207 patients (44%) had at one time suffered from a depressive disorder. PLHAs suffer from depression and figures might be higher in the general population because there are very few service providers able to diagnose and manage depression in HIV positive patients. In Thom's study of 2009 the occurrence of a current depressive disorder was 16.87%. Emphasizing of those, two thirds of the patients had their first major depressive episode after a positive diagnosis of HIV.

The healthcare professionals also agreed from their experience that HIV positive patients suffer from depression for several reasons. They also conferred the diagnosis itself could cause or result in depression. The healthcare professionals referred to the psychosocial stages of the HIV disease from the pre-testing stage, the possibility of being infected, post testing, the knowledge of being positive, emotional responses, coping as well as counseling issues.

5.2 Factors which cause depression after a positive HIV diagnosis

According to the study participants, they were depressed because of an inability to learn and take care of themselves and the families especially their children. Amongst most participants additional negative events triggered or worsened their depression. The health care professionals attributed the patients' depression to family rejection or lack of support, inability to disclose and illness. Illness was hardly mentioned by the participants because at the time of the interview they were of good health. However, additional social stressors such as family fights and disagreements worsened their depression highlighting the need for and the protective effect of social support. This need for social support was highlighted by the health care professionals as a possible cause for depression.

5.3 Gender Differences in factors that cause depression after a positive HIV diagnosis

The findings in the study could not effectively support the assumption that there is a difference in the factors that cause depression in men and women due to the small sample size of men. The major cause of depression for both men and women was lack of income. However, due to the an inadequate number of men in the sample supports the assumption there is greater depression in women than in men. According to Croft (2009) mental health services see fewer men with depression because they are less likely to ask for help. Results from the South African Stress and Health Study indicated the prevalence of MDE in the general population regardless of HIV was significantly higher among female respondents; 1.75 times more likely to experience lifetime depression than males (Tomlison, et al, 2009).

Most participants thought women were more vulnerable to develop and experience depression than men though a sizeable number of women thought both sexes were equally vulnerable. The healthcare professionals also supported the notion that gender had an effect on the incidence of depression after a positive HIV diagnosis with more women being depressed. Depression is not accepted as a disease in most communities. Mentally ill people including those suffering from depression are vulnerable because most communities and cultures do not understand mental illness. Black people attribute any type of mental illness to witchcraft or ancestral calling.

5.4 Strategies to incorporate mental health care into HIV/AIDS treatment, care and management

The health care professionals agreed the health care system was not adequately prepared to detect and manage depression in HIV positive patients. Most of the recommendations supported Lund et al (2009) who recommended there is need for stronger national leadership to develop a national mental health policy which provides a clear framework for public mental health service development. Such a policy would facilitate capacity building, setting up of facilities, programme design and monitoring and evaluation of the designed programmes.

5.5 Study Limitations

The size of the sample and the method of recruitment place a limit on the impact of obtaining data. The experimentally accessible population was not the same as the target population as

people who had already sought help and treatment were used for the study. It was also difficult to determine gender differences in the factors that cause depression between male and female because only 20% of the participants were male.

Some depressed participants may not have interacted freely with the researcher. Important detail the patient would not have mentioned to the researcher was found in the patient hospital notes. Such patients could now be embarrassed to reveal information given at diagnosis. A few patient hospital notes could not be analysed as patients had lost their old records and new hospital notes would not have diagnosis information but only current therapy and prognosis.

Some healthcare professionals recruited for the study wanted to be ideal for the study and studied the proposed subject of research; opinions might have been shifted after studying. The study findings therefore cannot be generalized to all people living with HIV/AIDS and all health care professionals. However, the results have important implications for future studies, interventions and treatment programmes for people living with HIV/AIDS.

5.6 Suggestions for future studies

There is limited research on depression and other psychiatric conditions in PLHAS. There is a need for information on factors that cause depression and the management of depression in HIV positive patients. Health care professionals also need to be included and made aware of studies on psychiatric conditions in PLHAS including depression. Studies should be done to assess health care professionals' knowledge as well as how to improve their knowledge and equip them with skills to manage depression and other psychiatric conditions in PLHAS. Studies at a large scale where both HIV positive and HIV negative patients are used in a randomized trial could determine more accurately what factors cause depression after a positive HIV/AIDS diagnosis.

Chapter 6

Conclusion

Depression after a positive HIV diagnosis affects both men and women, however, with different causes. The common cause in both men and women is economic pressure resulting in failure to fend for themselves and the family. Negative life events such as death of a spouse or child precipitate such depression. Women were more likely to attribute their depression to denial and worry about work and family responsibility. Men attributed their depression to failure to provide for their family and loss of social status. Recognising the causes of and gender differences in the causes of HIV related depression may help in designing more effective counselling strategies and improve management and care of PLHAs.

There is need to formulate effective strategies to manage depression and other psychiatric illnesses in HIV/AIDS patients. Many psychiatric illnesses including depression are overlooked as being a consequence of HIV instead of being managed together with the condition. There is a need for more research on causes of depression and psychotic illnesses in patients with HIV with the aim to improve management of the disease and improve quality of life of people living with HIV/AIDS.

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Appendices

Appendix 1: Gender related factors that lead to depression after HIV/AIDS diagnosis : Patients'Questionnaire

Name: .....

Home Area and Language: .....

Section A: Background information

Please answer the following questions by placing an X

1. Age: ☐ 21-30 ☐ 31-40 ☐ 41-50 ☐ 51 and above

2. Gender: ☐ Female ☐ Male

3. Marital status: ☐Single ☐Married ☐Divorced ☐Separated ☐ Widowed

4. Employment Status: ☐Employed ☐Self Employed ☐Unemployed

5. Education level: ☐ Primary level ☐ Secondary level ☐ Tertiary level ☐ University

Section B: Family Background

6. Who are you staying with?

.....

.....

7. Give us a brief history of your family. Where are your children and siblings?

.....

.....

8. Who is responsible for your family's finances, children's education, food, rent, etc.

.....

.....

Section C: Diagnosis and Depression

9. Did you go for Voluntary Counselling and Testing? ☐ Yes ☐ No

10. If not, how were you diagnosed?

.....

.....

11. Did you have any problems before diagnosis, for example, family problems, loss of employment, abuse, etc.

.....

.....

12. Did anything change after the diagnosis: Mark with an X

☐Life-style ☐ church ☐ drinking ☐ eating habits ☐ sleep ☐ other

13. If any of the above (question 3) changed, why do you think it changed?

.....

.....

14. Have you accepted your status ☐ Yes ☐ No

15. If not, why not?

.....

.....

16. Have you disclosed your status to your

spouse or partner ……☐ Yes ☐ No

children……☐ Yes ☐ No

family……☐ Yes ☐ No

friends or workmates……☐ Yes ☐ No

pastor/church members..... ☐ Yes ☐ No

17. If yes(question 16), Describe their attitude to your disclosure. Mark with an X

family's, ……...negative☐ indifferent☐ supportive☐

spouse/partner…….. negative☐ indifferent☐ supportive☐

friends' or workmates'……. negative☐ indifferent☐ supportive☐

pastor or church members … negative☐ indifferent☐ supportive☐

18. If not, why haven't you disclosed?

.....

.....

19. After your diagnosis and disclosure/non disclosure, what worries you? Mark with an X

Spouse or Partner…….....☐

Children…….☐

Family……☐

Work……☐

Community……☐

None of the above.....☐

20. How do these factors (question 19) worry you or what other factors worry you?

.....

.....

21. List possible causes of your depression: Mark with an X.

Lack of moral support…….....☐

Stigma and discrimination…….....☐

Fear of disclosure……...☐

Denial/ failure to accept status….....☐

Loss of income……☐

Poor Health……☐

Fear of death..... ☐

22. Please explain your answers in question 21 above.

……

……

……

……

……

Thank you

Appendix 2: Gender related factors that lead to depression after HIV/AIDS diagnosis : Interview Guide for Patients

1. Do you know what depression is?

2. How were you diagnosed of depression?

3. What do you think causes your depression?

4. Are there any factors at home, work, community that worsen your depression?

5. What are your sources of stress?

6. How do you deal with the stress?

7. Do you think being a man or woman makes you more vulnerable to depression?

Appendix 3: Gender related factors that lead to depression after HIV/AIDS diagnosis : Health Care Professional Questionnaire

Profession.....

Qualifications.....

Section A: Background information

Please answer the following questions by placing an X

1. Age: ☐ 21-30 ☐ 31-40 ☐ 41-50 ☐ 51 and above

2. Gender: ☐ Female ☐ Male

3. Race: ☐ Black ☐ White ☐ Indian ☐ Coloured

Section B: Career Background

1. Have you worked with HIV patients and for how long.

.....

.....

2. Give us a brief history of your

career.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

Appendix 4: Gender related factors that lead to depression after HIV/AIDS diagnosis : Interview Guide for Health Care Professionals

1. Do you think HIV positive patients suffer from depression?
2. Do you think a positive HIV diagnosis can cause or result in depression?
3. What are the causes of depression in HIV positive patients?
4. How does depression manifest itself in HIV positive patients?
5. Do you think there are any differences culturally in accepting depression as a disease?
6. Do you think gender has an effect on the incidence of depression after a positive HIV diagnosis?
7. Is the health care system adequately prepared to detect and manage depression in HIV positive patients?
8. Is there anything else from your experience that you would like to add to help us understand depression and HIV?

Appendix 5: Gender related factors that lead to depression after HIV/AIDS diagnosis: Female Participants' Responses

Question 6, 7, 8: Who are you staying with? Brief family history, Family finance

Number of people per household	Number of Children	Relatives	Family History	Family Finances
2	2	1	Stays with young Brother. Own Children stay with parents in the Free State	Employed Children's grant
2	1	1	Stays with 21year old disabled son	Son's grant
2	0	2	Children married and stay on their own. Son works in a saloon and daughter is a domestic worker. Cannot support parents.	Social grant
3	2	1	2 Children, 19year old finished matric, not working. 15year old in grade 11, Used to work as a cutter & designer.	Social Grant
3	0	3	Stays with mom and 20 year old brother	Employed Mom Domestic worker
3	1	2	Stays with Boyfriend and 5 year old child. Husband was HIV +ve and died in 2009	Social grant

4	2	2	Husband & 2 children	Husband Self employed. Fixes electric objects
4	3	1	2 Children, 19 and 9 in school. Small child not yet in school.	Self employed. Decorate earrings and steel spoons. Grant
4	1	3	6year old son, grandmother, sister just finished matric.	Employed Pre-school teacher
4	2	2	Husband and 2 children, 10 and 5year old. Husband works as I.T Technician	Husband I.T Technician
5	2	3	Parents and 2 children. 19 and 5yr old	Social Grant
5	2	3	Parents and 2 children. 21 years old in University.	Father's pension, disability grant
5	2	3	Parents and 2 children. I child is late. Sometimes stays with husband.	Parents pension, Husband works as a driver
6	3	3	Mother, twin brother, 3 Children. 21 year old child works as a cashier	Social grant, mother and self
6	2	5	Sister and her 4children. Have 2 children, 11 and 2year old staying	Sister and children Social grant

			with their mother. Does not support them	
6	2	4	Partner, late sister's 2children, 2 own children	Foster grant, disability grant, Partner employed and also supports
7	2	5	Mother, Sister, Brother, Sister's daughter, Children 22year old epileptic, can't afford special care school, 15year old in school.	Child disability grant. Mother's grant
8	0	8	Mom and Mom's late sister's children	Grant. Husband also pays for food and rent sometimes
8	0	8	Mother, 2siblings, nephews and nieces	Mother employed. Self and sister also employed
10	2	8	Mom, Stepfather, 4Brothers, Sister	Mother employed

Section C: Diagnosis and Depression

9. Did you go for Voluntary Counselling and Testing? Yes 5 No 15

10. If not, how were you diagnosed of HIV?

i) Pregnancy related testing.....6

ii) Admission for opportunistic infections.....5

iii) Other.....4

- illness or death of child 3
- rape 1

11. Did you have any problems before diagnosis for example, family problems, loss of employment, abuse etc.....

- Employment related problems.....2
- Marital/Relationship problems.....2
- Abuse.....2
- No problem/could not specify any particular problem.....14

12. Did anything change after the diagnosis: Mark with an X

9☐Life-style 5☐ church 0☐ drinking 16☐ eating habits 14☐ sleep 2☐ other

13. If any of the above (question 12) changed, why do you think it changed?

- Depressed 2
- Stressed 2
- Thinking too much 2
- Angry 2
- I do not know why. 14

14. Have you accepted your status 18☐ Yes 2☐ No

15. If not, why not?

- Sometimes I think I am going to die

- I try, but it's hard. I am young and this is the only man I have been with.

16. Have you disclosed your status to your

spouse or partner ……...13 ☐ Yes 7 ☐ No

children……5 ☐ Yes 12 ☐ No

family……..17 ☐ Yes 2 ☐ No

friends or workmates……..9 ☐ Yes 7 ☐ No

pastor/church members.....8 ☐ Yes 6 ☐ No

17. If yes(question 16), Describe their attitude to your disclosure. Mark with an X

family's, ……...negative 3☐ indifferent 3☐ supportive 10☐

spouse/partner…….. negative 0☐ indifferent 4☐ supportive 8☐

friends' or workmates'……. Negative 0☐ indifferent 1☐ supportive 7☐

pastor or church members … negative 0☐ indifferent 1☐ supportive 6☐

18. If not, why haven't you disclosed? ……

- People gossip and say bad things about HIV positive people: 3
- Close people, mother, brother , child will be heartbroken: 3
- Ashamed to disclose or people think if you have HIV you are dirty: 1
- Children are very close and sensitive. May lose concentration in school and can tell anyone: 2
- Afraid of discrimination: 1
- It's my problem not anyone else's: 1
- I only told close family and friends: 2

19. After your diagnosis and disclosure/non disclosure, what worries you? Mark with an X

Spouse or Partner……..3 ☐

Children……..7 ☐

Family…….5 ☐

Work……4 ☐

Community……..0 ☐

Other.....7 ☐

20. How do these factors (question19) worry you or what other factors worry you?

- What will happen to my children? 5
- Financial problems. I don't have enough to pay rentals, take care of my children. 4
- I am not employed. I need a job. 3
- Marital problems. 2
  i. Engagement broke after disclosing status.
  ii. Separated after diagnosis. Husband passed on, relatives want to take away everything.
- Other.
  i. I am always fighting with my sister
  ii. I need to take treatment so I can be there for my children. What if the treatment stops working?
  iii. I don't like men, a man told me that he loved me but not that he was HIV positive
  iv. Father of last child positive, but he does not want treatment,
  v. Loss of my twins after childbirth
  vi. I am always ill. 15year old girl has an affair. She is a lesbian.
  vii. Everybody at home treats me like a patient and they weigh what they say around me. I was taken for tests at work to see if I was still fit to perform my duty. They have no sympathy at work and are no; longer willing to accommodate me.

21. List possible causes of your depression: Mark with an X.

Lack of moral support…… 4 ☐

Stigma and discrimination……3 ☐

Fear of disclosure……..2 ☐

Denial/ failure to accept status……...0 ☐

Lack/Loss of income……12 ☐

Poor Health……..2 ☐

Fear of death.....2 ☐

Other.....9 ☐

22. Please explain your answers in question 21 above.

- I am worried about the my children's future 3
- I do not earn nor receive a grant enough to support children, family, in respect of food, school fees and a decent place to stay. 7
- I cannot work as I used to or cannot find a job. 3
- My family does not care about me. 2
- Other

i. Bereavement: Loss of my children

ii. `My engagement broke and I am still in love with the man

iii. The fact that my partner cheated and gave me this disease makes me angry

iv. I am afraid that my husband will divorce me.

v. My late husband's relatives want to take away everything.

vi. My 1year old boy's father raped me.

vii. The work environment depresses me. Everyone asks if you have taken the happy pill. You can't be well if people around you think you are not. People think I can't think for myself.

viii. My husband needs extra care.

Appendix 6: Gender related factors that lead to depression after HIV/AIDS diagnosis : Male Participants' Responses

Family Background

Question 6, 7, 8: Who are you staying with? Brief family history, Family finance

Number of people per household	Number of Children	Relatives	Family History	Family Finances
5	11	2	Stays with Girlfriend and 3 children. 1 stepchild. 6 children with late wife. Does not support the six children. 2 children with another woman. Does not know where they are.	Employed.
5	3	2	Girlfriend and 3 children. All children in school	Self employed. Sells fruit. Children not receiving grants
6	2	4	Sister and her 2 children, 2 own children. All in school	Children's Social grant
9	7	2	Partner, 7children in school.	Support grant for 2children & part time jobs
10	2	8	Parents, 6siblings and 2children	Parents pension, grants, piece

				jobs

Section C: Diagnosis and Depression

9. Did you go for Voluntary Counselling and Testing? Yes 2 No 3

10. If not, how were you diagnosed of HIV?

iv) Admission for opportunistic infections.....2

v) Other.....1

- work

11. Did you have any problems before diagnosis for example, family problems, loss of employment, abuse etc.....

- Marital/Relationship problems.....1
- No problem/could not specify any particular problem.....4

12. Did anything change after the diagnosis: Mark with an X

0☐Life-style 0☐ church 0☐ drinking 2☐ eating habits 3☐ sleep 2☐ other

13. If any of the above (question 12) changed, why do you think it changed?

- Depressed 1
- Many problems 1
- I do not know why. 1

14. Have you accepted your status 5☐ Yes 0☐ No

15. If not, why not?

16. Have you disclosed your status to your

spouse or partner ……...5☐ Yes 0 ☐ No

children……2 ☐ Yes 3 ☐ No

family…….5☐ Yes 0 ☐ No

friends or workmates……..3 ☐ Yes 2 ☐ No

pastor/church members.....2☐ Yes 3 ☐ No

17. If yes(question 16), Describe their attitude to your disclosure. Mark with an X

family's, ……...negative 1☐ indifferent 1☐ supportive 3☐

spouse/partner…….. negative 0☐ indifferent 1☐ supportive 4☐

friends' or workmates'……. Negative 0☐ indifferent 0☐ supportive 3☐

pastor or church members … negative 0☐ indifferent 0☐ supportive 2☐

18. If not, why haven't you disclosed? ……

- Close people only. 2
- Ashamed to disclose or people think if you have HIV you are dirty: 2
- It's my problem. 1

19. After your diagnosis and disclosure/non disclosure, what worries you? Mark with an X

Spouse or Partner……..0 ☐

Children……..1 ☐

Family…….2 ☐

Work……2 ☐

Community……..0 ☐

Other.....0☐

20. How do these factors (question19) worry you or what other factors worry you?

- Financial problems. I don't have enough to pay rentals, take care of my children. 2
- I am not employed. I need a job. 2
- Marital problems. 1

iii. Failed marriage and I cannot divorce.

21. List possible causes of your depression: Mark with an X.

Lack of moral support…… 1 ☐

Stigma and discrimination……1 ☐

Fear of disclosure……..1 ☐

Denial/ failure to accept status……...0 ☐

Lack/Loss of income……3 ☐

Poor Health……..1 ☐

Fear of death.....1 ☐

Other.....1 ☐

22. Please explain your answers in question 21 above.

- I do not earn nor receive a grant enough to support children, family, in respect of food, school fees and a decent place to stay. 1
- My family does not care about me. 1
- Other

ix. People take HIV/AIDS as a sin. Things may change, but people never change.

x. Not in the mood. 2

Appendix 7:Gender related factors that lead to depression after HIV/AIDS diagnosis: Patient Interview findings

1. Do you know what depression is?

Thinking too much	6	Cannot function normally	2
Feeling lonely	5	Cannot talk	1
Moody	7	Always feeling tired.	4
Isolate yourself	5	Self hatred: feel like a looser	1
Loss of memory	2	Negative feelings	4
Not able to sleep	7	Body does not feel fine	1
Thoughts of killing yourself	8	Fear	2
Stressed	3	Severe headache	2
Not eating well	1	Loss of concentration	2
Angry/Sad	3	Not comfortable among people	2

2. How were you diagnosed with depression?

- I spoke to the doctor about symptoms and I was referred. 8 patients
- I was admitted after attempting to commit suicide. 6 patients
- I spoke to the nurses at the clinic and they referred me to the hospital. 4 patients
- I was admitted for serious headache. 3patients
- After childbirth in 2003
- Doctor spoke in English. I did not understand.

3. What do you think causes your depression?

People's behavior around me	1	Bereavement: HIV related loss of children	2
Summer/hot weather	1	Rape: post trauma	2
I am not working	1	How did I get HIV?	2
Partner does not want treatment	1	Marital problems	2
I am angry at partner for infecting me	1	Abusive husband	3
Late husband's relatives want to take away everything	1	Financial problems	3
HIV diagnosis	1	Worried about children	6
No family support	2		

4. Are there any factors at home, work, community that worsen your depression?

Seeing spouse suffering	1	Making mistakes at work because I am worried	1
Negative events	1	Gossip	2
Failure to get married	1	I don't mix with people so nothing worsens.	2
No place to stay	1	Work, work environment	3
Neighbors' kids	1	Nothing	5
Being a single parent	1	Family fights, disagreements	6

5. What are your sources of stress?

Watching spouse ailing	1	Fear of death	1
Mourning husband	1	Financial problems	2
work	1	Family	4
Ex-boyfriend abuse	1	Children's welfare	5
Spouse abandoned me	1	Nothing	6
I can't get a divorce	1		

6. How do you deal with the stress?

Prayer	1	Beadwork, sewing, work hard	2
Drink lots of water	1	Isolate myself	3
Eat	1	Watch TV or listen to radio	3
Scream	1	Socialise, groups, soccer match	3
Cry	1	Read magazine, write journal	4
Drink occasionally	1	Talk to someone	4
Smoke snuff/cigarette	2	Go to church	4
Sing	2	Sleep	5
		Take a walk, exercise	6

7. Do you think being a man or woman makes you more vulnerable to depression?

I don't know	Equally vulnerable	Man	Women
2	8	2	10
	God made man and women differently and depression affects them according to situation not gender	Men are the ones who posess and cannot stay at home and not work	Women have more responsibilities.
	It's the same, man just try to be tough about it	The perception that men do not have to cry makes it very difficult for men to be open and they pretend to be fine	Women are emotional and fragile
	All are human beings		Men do not take responsibility, they just eat and sleep
	Depends on the situation		

Appendix 8: Gender related factors that lead to depression after diagnosis with HIV/AIDS: Interview findings for Health Care Professionals

Gender			Profession		
	Male	3		Nurse	2
	Female	9		Pharmacist	3
Race	White	5		Medical Doctor	5
	Black	5		Psychiatrist	1
	Indian	2		Social worker	1
Age	21-30	3	Years of Experience	1	
	31-40	3		6,4,2	
	41-50	4		5,5,5,1	
	51 & above	2		10,20	

1. Do you think HIV positive patients suffer from depression.

- Yes, patients suffer a lot of psychiatric disorders including depression.
- Yes, but treatment focus is on acute opportunistic infections and physical symptoms.
- Yes, patients cry now and again and tell you all their problems, financially, work or family related.
- Yes, but we stick more to HIV unless the depression symptoms are quite obvious
- Absolutely, I diagnose a lot of depression but it requires a keen sense to detect

- Yes, especially just after diagnosis, coming to terms and accepting. Also in the long run on changing treatment regimens and or loss of a partner.
- Yes, after being diagnosed
- Yes, because of the stigma attached to HIV, lack of education and thinking it's a death sentence.
- Yes, being diagnosed and learning to live with it.
- Yes, the rate is about 20-40%. Amitryptylline used for peripheral neuropathy also works for depression
- Yes, lack of support, the diagnosis itself

2. Do you think a positive HIV diagnosis can cause or result in depression?

- True, any news of a terminal disease with no cure may result in depression
- Yes, HIV is a significant psychosocial pressure and can precipitate depression in patients who do not have social support.
- Yes, first time to find out patients do get depressed, others go into denial, leave the files and don't come back for at least three years or until they fall sick.
- Yes, faced with a "death sentence", maybe cannot work, thinking about stigma and the task of disclosing to a partner.
- Yes, also depends on lifestyle. If a person was stable in a monogamous relationship then a diagnosis can definitely lead to depression.
- Yes, Wondering about the future, for pregnant mothers wondering whether their baby is infected too, if sick, wondering if they will continue to work, the difficulty of disclosure and thinking about the stigma.
- Yes, the immediate reaction is that HIV is a life sentence. Acceptance is only

after proper management.

- Yes, because of the way the community looks at the disease. With other chronic illnesses for example diabetes, a patient might not get depressed because its considered a clean disease and HIV is dirty.
- Yes, depends on the society one lives in. If there is knowledge then the person can say yes I do but I can rise above it. Others will be shocked, think about children or even have suicidal thoughts.
- Definitely, social factors, stigma, effects of HIV itself on the brain and co-morbid conditions like TB and granuloma which damage the brain.
- Yes, HIV precipitates life stressors and is not such a straightforward disease. Being an "acute" hospital, most patients seen have already been diagnosed and gone through the emotional turmoil and upset. Therefore there is no full assessment of depression.
- Yes, the realization, the quality of counseling, lack of support and economic difficulties.

3. What are the causes of depression in HIV positive patients?

- The news. 2
- Starting treatment, depending on tablets daily.
- Changing from one regimen to another
- Incidence of side effects
- Uses of other drugs
- Social stigmatization and rejection 4
- Family rejection/ lack of support 7
- Loss, underestimate recurrent loss in HIV 2

- Relationship with partner 2
- Inability to disclose 5
- Illness, especially for women who look after children and children who are not around to look after you when very ill. 3, chronic pain 1, frequent admissions before treatment 1
- Fear of death 3
- Ignorance
- Poverty 2
- Why me? 2
- Anger directed to spouse
- Unemployment
- Diagnosis on pregnancy
- Marital chances if single
- Children's welfare.
- Why today? I have not had a partner in 5years.
- Late diagnosis, HIV might have affected the brain.
- Bereavement

4. How does depression manifest itself in HIV positive patients?

Feel or look down	1	Suicide attempt	2
Low self esteem, no confidence	1	Fight with care-givers or intentionally frustrate the care-giver	1
Few complaints	1	Altered interactions with the health care provider, short answers	2
Hangover effect/look tired	3	Isolate	1
Tearful	4	Sense of despondency, feeling hopeless	2
De-motivated, don't enjoy things	2	Angry, aggressive, insulting	1
Poor treatment adherence	3	Neglect themselves, may come to the clinic dirty and yet they were smart before	1
Withdrawn, reluctant	5	Sleep all day	1
Lunar medical complaints, non specific, somatisation	4	Eat too much	1
Psychosis, hysteric	3	No appetite	11
Do not want to talk	3	Verbalise feelings	1
Talk too much	1	Memory loss	1
Lack of sleep	5	Anxiety reactions	1

5. Do you think there are any differences culturally in accepting depression as a disease?

- Black people and psychiatric conditions never mix. For any psychiatric condition they either go to church, see your grandmother or a traditional healer. A white person on cilift will present with improved mood while a black person on cilift becomes hyperactive.
- There are differences across all cultures. Psych illnesses are not seen on the same plane. It also depends on the level of education. Different religions also deal differently.
- Yes, some patients believe they were bewitched by a jealous neighbor and want to take herbs from inyanga.
- I see only black patients and most of them don't complain. I don't know any cultural differences.
- There is no difference or there should be no difference. The healthcare practitioner should make the patient aware and understand the illness.
- Definitely. In my practice you need a translator to describe depression. There is no local/vernacular word for depression. Men are culturally affected because manhood requires that they must be strong, so they deny depression and see it as a personal failure.
- Definitely, males are less open and do not express their feelings while females are more open. It also depends on exposure and access to information. When there is no information, people will tell you to get yourself together when you need help.
- Almost the same. There is a lot of ignorance with blacks. Whites are exposed to a lot of information most are educated and come forward for treatment early. Blacks are late and come for treatment after a lot of complications. At home they hide their cards under mattresses.
- Yes and No. A lot of people don't understand what depression is, even educated people. It is difficult because most people want to tell the person to get up and pull themselves together. There is very little understanding of the

illness.

- There are no differences. The only problem is that depression is often missed in HIV clinics and a patient might only be referred if there is a problem of non-adherence or when the patient becomes psychotic. Healthcare professionals are not empowered.
- No difference
- No difference. If we can recognize it. Workload does not allow us to interview the patient unless the patient volunteers the information. Counselors also do not pick it up.

6. Do you think gender has an effect on the incidence of depression after a positive HIV diagnosis?

    - Yes, women are more accepting. Men are more prone to depression because when they fall they are told to get up. Men find it more difficult to go and seek help and therefore more women are diagnosed.
    - Yes, there is more depression in female patients because they find it easier to express their feelings. Women will be honest while man will not sit and cry or admit that they are depressed. Therefore health care professionals pick less depression in men. Women also carry the major burden of raising children and will therefore find the diagnosis more stressing unlike men.
    - Yes, women get depressed because the partner ran away after infecting her. Some partners disappear for years and come back for a few months and leave them infected. Men do not want to come to the clinic for diagnosis and women also struggle with men who do not want to use condoms. Most men do not care and they lie and say they are HIV negative.
    - Most patients seen at this clinic have already accepted their status. There may be more depression among females because they carry most of the burden. There are also much more female patients than male patients because men refuse testing and test only when they are sick. Women test much earlier. Men

also get depressed when they lose jobs and cannot support the family.

- Yes, mostly women, rare for men. Women are more emotional and nurse their feelings. Men will not accept.
- No, there is no difference on the incidence but on the diagnosis. The impact is much the same but it is more acceptable for females to be depressed. For many people there is no offer of special support.
- Females are emotional and attach everything to feelings while males are practical. Females are also scared to tell the husband because the husband might think they brought it.
- Yes, females are more depressed. A man will stay for long knowing status not telling spouse. Most females think they got HIV from the husband. Housewives depending on men are more vulnerable. Women are also shy or scared to tell their husbands because the husband might abandon them. Culture makes women to be under men, therefore women feel inferior and are even more vulnerable if unemployed.
- Yes. A woman would cope better with depression than men. Men would battle with depression.
- Yes, I have never seen a man depressed, only women especially unemployed women.

7. Is the health care system adequately prepared to detect and manage depression in HIV positive patients?

- No, Psychiatry is a very difficult field. There is need for structures to be put in place.
- No, the problem with psychiatric conditions is that they need time. You need to sit with the patient, discuss issues. Clinics are busy and wards are busy therefore there is no time to assess for depression unless the patient

specifically brings it up.

-What can be done

i. Staff education

ii. Improve number and quality of counsellers. Currently counsellers work under a lot of pressure. They give information only, no discussion and they do not explore patient issues.

iii. Set up facilities at peripheral clinics to identify and refer patients. (A psychiatric sister or psychologist could be in charge. Sometimes appropriate social intervention would be adequate.

- Yes, through in-services. We had mental health course training in October 2010 on how to pick and manage mental health problems. We work together with the psychologist. However, wellness clinics can be increased. Health care professionals need to go out and invite people to the clinics. TV, radio and other media are not adequate.

- No, we can detect but workload is too much. You need to spend much time with the patient, explore social history to pick it up and then refer to a psychiatrist. More people can be employed to enable health care professionals to spend more time with the patient. The language barrier also makes a consultation long and its difficult to get translators.

- Yes, through teamwork. The doctor should refer a patient to the social worker who then refers the patient to the psychologist.

- No, not at all. At the primary healthcare clinics, there are no antidepressants and patients have to be referred to the psychiatry clinics. There is also no integration between primary and secondary healthcare. Depressed patients are not motivated to seek treatment so when referred to another institute they may not go. Nurses are already bombarded with lots of work and it's a completely neglected area.

  -What can be done?

  i. Improve access to support groups

ii. A five day nurse training is not adequate. There is need for topics to build up experience with

iii. Government needs to supply adequate drugs. Depression can lead to social dysfunction which can lead to crime.

iv. There is need to follow up on patients with post natal depression once patients are discharged. Mental health should be followed up on baby cards

v. There is need to address depression in the health care provider taking care of the HIV positive patient. For example, psychological sessions, wellness programmes. Healthcare professionals may mess up patient management because they are depressed. Depressed healthcare professionals are not focused on patients and forget important detail.

- No, in the consultation rooms focus is on CD4 counts and viral load. There is no room to do a psychological assessment.

  -what can be done

  i. Patients should be encouraged to ask or indicate to the doctor so that if an investigation is necessary it can be done later on.

  ii. Support groups

  iii. Scheduled psychological visits say once every six months after diagnosis

  iv. Include psych in the treatment programme.

- Yes, with training and counselors, it is easy to identify depressed patients and to refer them. Nthabiseng nurses and counselors go towards for post test counseling. New patients consult on Wednesdays where vital observations are recorded and the counselors reinforce health education. Follow up is done in two weeks to check adherence. Some patients are depressed because of lack of information. Continuously motivate. Love, warm environment and health-care professional attitudes are important.

- No, there is lack of staff and therefore limited time with patients. Patients have no access to organizations such as life-line. Many patients are only discovered after an

attempt to commit suicide or admission with serious headaches.

-what can be done

i. There is not enough education on ground level. A separate department must take care of mind health and such education for patients.

ii. Resources must be increased, staff, education

iii. Whether or not you are HIV positive, depression is an illness that people are scared of.

- No, a lot is missed. Depression is picked in retrospect. There is a large number of patients and no personnel. Assessment at this level is also at intervals, not continuous making it difficult to pick. There are also constraints on patients telling the health care practitioner.

  -what can be done

  i. Depression should be brought to the attention of health care professionals at all levels and appropriate training undertaken.

  ii. Down-refer patients and patient access to clinics and appropriate management should be improved.

8. Is there anything else from your experience that you would like to add to help us understand depression and HIV?

- Depression is an illness like any other. It includes an organic component which requires medical therapy to correct. Medical therapy enables you to cope and be able to engage in psychological interventions.
- People in the rural areas are forgotten. Couples need to be invited for tests as couples because of the difficulties faced after results. Everything must be on the table so they can support each other.
- Health care professionals must be able to identify, be aware and have the extra eye to

watch out for depression. From the clerks, counselors, pharmacists, nurses and doctors.

- Depression will become less common as people get ARVs sooner. There will be no decline in health over time as experienced before which will improve depression. Patient provider relationship will also improve and there will be more time for patients.
- „Carers' of people with HIV need to be catered for. Patients access care late and „carers' have a big burden.
- Early initiation of ARVs will stop HIV crossing over into the brain and causing psychosis.