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**Psychological wellbeing and health-related quality of life  
among low-income women living with HIV/AIDS in the  
province of KwaZulu-Natal, South Africa**

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Dissertation submitted in part fulfilment  
of the requirements of the degree

MASTER OF PALLIATIVE MEDICINE

School of Public Health and Family Medicine

University of Cape Town

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Submitted for examination: 9 November 2008

## ACKNOWLEDGEMENTS

I place on record my sincere gratitude to the following individuals:

The participants in this study who gave their valuable time to share their experiences with me;

The research assistants for the patient-centred manner in which they interacted with the participants in the study;

Ms C. Naicker for co-ordinating the data collection process;

The nursing staff at the HIV Clinic for allowing us the use of the premises during busy clinic hours, and their help in accessing patient records;

Miss N. Pather for providing refreshments for the patients and researchers on a daily basis;

Professor Nithi Muthukrishna, School of Education and Development, University of KwaZulu-Natal, for her expert research advice and support;

Dr L Gwyther for her assistance;

Mrs P Hariram for assisting with the literature search for this study;

Ms A. Grobler for her assistance with the data analysis phase of the study;

My parents, Harry and Savi Mannadiar, for their sustained support, encouragement and determination to see me bring this research to completion; (not a completion)

Finally to my wife Lulu and my children, Yashodhan and Makaira, for always giving me of their divine love.

## **DEDICATION**

To all the patients  
Affected by the HIV/AIDS pandemic,  
May there be a dawn  
When the disease disappears  
Making your body glow with renewal,  
Free of all the physical, psychosocial  
and spiritual stress associated with the disease.

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## **DISCLAIMER**

**I hereby declare that this dissertation is my original work, and that it has not been submitted previously for any degree at any institution for assessment purposes.**

**Signed by candidate**

**Researcher: Krishna Mannadiar Nair**

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## ABSTRACT

The study aimed to provide an understanding of health-related quality of life and psychological wellbeing amongst low-income women living with the Human Immunodeficiency Virus (HIV) or Acquired Immune Deficiency Syndrome (AIDS) in South Africa. The research examined the relationships among biomedical and psychosocial factors and health-related quality of life (HRQOL) and the levels of suicidality (psychological distress) of women with HIV and AIDS in the province of KwaZulu-Natal. One hundred and thirty three (133) women over the age of 18 years (average age 32.96 yrs) participated in the study. In order to assess psychological distress, participants completed a Suicidality Measure (SM). Psychosocial factors were accessed through participants' perceived social support as measured by the Multidimensional Scale of Perceived Social Support (MPSS). Information on social/contextual variables including income, marital status, employment status, number of children and number of family members in the household was obtained. Participants completed the Health-Related Quality of Life Survey (HRQOL) – SF-36. The two biomedical measures were *CD-4 count* and *time since diagnosis* information. The findings revealed that perceived social support was inversely related to suicidality, and there was a significant correlation between perceived social support and two SF-36 domains: vitality (VT) and mental health (MH). Overall, the findings indicated that the women did not have adequate social support in their lives. Certain social/contextual factors, for example low income; being employed; number of family members in the household and having a greater number of children negatively impacted on aspects of health-related quality of life of the women. CD-4 count was not a significant predictor of health-related quality of life and suicidality (psychological distress). The findings further indicated a compromised level of HRQOL (i.e. physical, social and emotional functioning) in the HIV-infected women in the study. After controlling for biomedical factors, all the psychosocial factors did not explain the majority of the variance in quality of life. This suggests that these may not have been the most suitable variables used to explain health-related quality of life. Similarly, the psychosocial variables did not account for the variance in suicide scale once the effect of the biomedical variables had been taken into account. Although the women seldom

thought of suicide, there was a significant negative relationship between time since diagnosis and suicidality. Newly diagnosed patients were less likely to think of suicide as an option than women who had been diagnosed some time before.

Key words: HIV/AIDS, women, quality of life, wellbeing, South Africa.

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## CHAPTER ONE: BACKGROUND TO THE STUDY

### 1.1 Introduction

Psychological distress is common among people with chronic, life-threatening illnesses. This is particularly true of people diagnosed with the Human Immunodeficiency Virus (HIV) or with the Acquired Immunodeficiency Syndrome (AIDS). It has been well documented internationally that HIV/AIDS patients encounter various psychiatric and psychological problems that arise from distress associated with the infection, and that the impact of an HIV-positive diagnosis is complex and still poorly understood (Alciati, Fusi, Montforte, Coen, Ferri & Mellado, 2001; Catz, Gore-Felton & McClure, 2002; Frierson and Lippman, 1990; Griffin & Rabkin, 1997; Siegal, Karus and Dean, 2004; Zibler, 2000). Catz, Gore-Felton and McClure (2002) explain that a person's seropositive notification is often accompanied by depression, suicidal ideation, suicide attempts, anxiety and other somatic and psychological symptoms of distress. They further explain that the most frequent psychiatric symptom associated with HIV/AIDS is an adjustment disorder with features of anxiety, depression or mixed mood. Sibnath (2002) undertook a study in India to explore the psychological dispositions of 32 HIV and 12 AIDS patients through an in-depth interview guide. Findings revealed that guilt feelings, anxiety and fear were more evident amongst most of the patients, followed by feelings of hopelessness, depression and severe withdrawal. Social support did not seem to be strong as most patients did not disclose their HIV status. Ten percent of the patients expressed suicidal ideation.

Organic mental disorders, particularly delirium and dementia, occur with increased frequency in AIDS patients as the disease advances. Depression is as important a factor in AIDS-related suicide as it is in suicide in general. Marzuk, Tierney, Tardiff, Gross, Morgan, Hsu and Mann (1988) reported that 50% of AIDS patients who committed suicide had been significantly depressed, and 40% had seen a psychiatrist within four

days before committing suicide. Perry, Jacobsberg and Fishman (1990) reported that suicidal ideation in HIV seropositive patients was primarily a function of concomitant depression. Hopelessness is a key variable linking depression to suicide. Past behaviour, multiple bereavements, isolation from family and friends and hopelessness are common factors of guilt resulting in many AIDS-related suicides. Rabkin, Williams, Nengebauer, Ramien and Goetz (1990) showed that absence of social support and depression correlated highly with hopelessness in HIV-infected persons.

Expression of suicidal thoughts or intent will often predate a suicide attempt in patients with AIDS. In the Marzuk et al. (1988) study, 25% of AIDS patients who committed suicide had made prior suicide attempts. Frierson and Lippman (1990) explain that AIDS patients in remission are the most likely to summon the necessary energy to complete suicide. In a more recent study conducted by Carrico, Johnson, Morin, Remien, Charleboie, Steward, Chesney and the NIMH Healthy Living Project Team (2007) with HIV positive individuals in four US cities, the findings were that suicidal ideation among HIV-positive individuals is relatively common and is associated with multiple factors including self-efficacy, drug use, medication side effects and affective symptoms of depression. Clearly, even debilitated patients with advanced AIDS have successfully committed suicide. Disease-related factors such as pain related with AIDS and other physical symptoms probably play a role in suicide. Substance abuse and pre-existing psychopathology heighten the risk of suicide with HIV-infected individuals, although further studies on the role played by these factors are required.

In South Africa, Olley, Gxamza, Seedat, Reuter and Stein (2003), Olley, Gxamza, Zeier, Seedat and Stein (2004) and Gxamza, Seedat, Theron, Taljaard, Reid and Reuter (2003) have argued that psychiatric disorders are common among HIV/AIDS patients. In their studies, they found a high prevalence of mood disorder among men and women, and increased alcohol and substance abuse and more risky sexual behaviour in men. This is common to other studies and is likely to be due to gender identity roles and related issues (Doyal, 1995). Olley et al. (2003) and Olley, Gxamza, Zeier, Seedat and Stein (2004)

examined psychopathology and psychiatric morbidity amongst HIV patients. The most prevalent psychiatric diagnoses were anxiety disorders and depression which the researchers suggest may be related to the high levels of stigmatisation the patients experience. Brandt (2009) conducted an extensive literature review on the mental health of people living with HIV/AIDS in Africa. The review indicated that in most studies conducted, half of the HIV-infected adults sampled suffered from some form of psychiatric disorder. Depression was found to be the most common individual problem.

## **1.2 Women, Psychosocial Wellbeing and HIV/AIDS**

The HIV/AIDS infection rate in South Africa is estimated at 1 500 new cases per day (Mattheyse, 2007). The total number of South Africans living with the virus by mid-2006 was estimated to be in the region of 5.4 million (Mattheyse, 2007). This annual survey uses a statistical model to estimate the prevalence of HIV in the population based on the prevalence among women tested at state antenatal clinics. The national average of HIV+ women attending antenatal clinics in 2005 was 30.2%. The province of Kwa-Zulu Natal continues to have the highest prevalence at 39.1%, followed by Mpumalanga at 34.8% (AIDS Foundation South Africa, 2005).

According to UNAIDS (2006), black African women comprise the largest single group of infected individuals in South Africa. Moreover, 1 in 2 women have a chance of being raped in their lifetime in this country. It has been documented that a woman is raped every 26 seconds, and in 40% of the cases the perpetrator is known to the rape survivor. One in 4 women is in an abusive relationship and can experience physical, verbal, emotional, psychological and/or sexual violence, and often live in fear of their male partner. Their partner frequently controls many aspects of their lives, including their finances, contact with others and their sexual and reproductive choices. These conditions increase women's risk of HIV (Baobab Connections, 2007).

In addition, women experience the brunt of the HIV epidemic's impact. They are most likely to bear the responsibility of providing care to relatives with HIV, to lose jobs, income and schooling as a result of the illness, and to face stigmatisation and discrimination. There is an increasing number of households that are run by single mothers, grandmothers and children due to the high incidences of HIV/AIDS amongst the female population. The UNAIDS 2004 Report on the Global AIDS Epidemic calls for the urgent need to address the many factors that contribute to women's vulnerability and risk, in particular, gender and cultural inequalities, violence and ignorance (UNAIDS, 2004).

As pointed out by Catz, Gore-Felton and McClure (2002), internationally very few psychosocial studies have focused on women living with HIV/AIDS, especially minority and low-income women. In South Africa, there have been few studies that have explored in depth the psychological wellbeing or the lack of it amongst women with HIV/AIDS, specifically. Gxamza, Seedat, Theron, Taljaard, Reid and Reuter (2003) did examine the role of gender by comparing psychiatric morbidity, coping responses and disability in male and female outpatients recently diagnosed with HIV/AIDS.

To contribute to this gap in research, the study presented in this dissertation investigated the quality of life and psychological wellbeing of low income HIV-positive women in the context of limited access to psychosocial resources.

The sample composition provided validity to this study as the participants were representative of women in KwaZulu-Natal - a province that has the highest rates of HIV infection in the world. This study focussed on how these women were exposed to the virus and the effect that it had on them socially, physically, emotionally and economically. Further, it explored whether the needs of HIV-positive females of low socio-economic status in a fledgling democracy that still experienced financial, infrastructural, racial and political constraints, were being met.

### 1.3 The Context of the Study

The participants in the study were from the Chatsworth area in Durban in the province of KwaZulu-Natal. During the apartheid era different race groups were allocated specific areas to reside in - hence the current demographics for the Chatsworth area. The Chatsworth area is made up of predominantly Indians (450 000). Two informal settlements have emerged during the past ten years in Chatsworth. These informal settlements house mainly lower socio-economic Black (African) South Africans.

The population of these settlements is estimated to be approximately 100,000 people, living in abject poverty. The majority of the population living in Chatsworth are of low socio-economic status earning less than R670 per month (Statistics South Africa, 2001). The residents live in shacks, that is, informal, make-shift homes made from waste cardboard, tins, planks, or anything that can provide shelter and protection from the wind and the rain. Further, many of these poor residents do not have access to a proper road transport system, running water, sanitation and waste disposal. During the emerging democratic era starting from 1994, other race groups began making use of public health services in areas that had initially been restricted to the Indian population group in this area only.

At present, the emerging SA democracy is facing a serious threat from the AIDS pandemic. In addition to all the problems stemming from past injustices and inequities that remain to be resolved, South Africa is being further traumatised by the impact that HIV/AIDS is having on the South African community, and in particular on women of low socio-economic status. The rate of HIV infection amongst the residents of these informal settlements in the Chatsworth area is around 60% (Chatsworth Regional Hospice VCT Clinic, 2005). The Medical Research Council of South Africa (MRC) in a recent survey in 2007 found high rates of HIV and AIDS infection among *women* in several parts of

KwaZulu-Natal, with provincial prevalence levels varying between 38% and 50%. In the greater Chatsworth area, the MRC found HIV-positive prevalences of around 40% in Welbedacht; 48% in Croftdene/Westcliff/Silverglen; and about 47% in Crossmoor. Much lower levels were found in Arena Park/Montford (19%); with 11 % in Woodhurst/Kharwastan (IOL HIV AIDS.co.za, 2006).

What is evident from these statistics is a strong cross-cutting of race (given the apartheid legacy), class and gender factors impacting on HIV and AIDS.

#### **1.4 Research Aims and Key Questions**

The present study aimed to provide an understanding of health-related quality of life and psychological wellbeing amongst low income women living with HIV/AIDS in the province of KwaZulu-Natal, South Africa. As in the study by Griffin and Rabkin (1997) health-related quality of life and psychological wellbeing were examined with an understanding that a diversity of factors can contribute to distress amongst low income women in a particular context. In addition, it was understood that differential availability of resources to cope with stressors would show an impact on the degree of psychological wellbeing and the quality of life among the infected women.

In the study health-related quality of life (HRQOL) was defined as those aspects of life directly affected by health status. HRQOL is multidimensional and covers physical, psychosocial and functional aspects. Psychological wellbeing or the lack of it, that is, psychological distress, is an issue of particular importance to individuals diagnosed with HIV and AIDS. In chapter two, these two concepts are examined in depth.

The key research questions were:

- What is the extent of quality of life and psychological wellbeing of low income HIV-positive women in the context of limited access to psychosocial resources;



- What is the relationships among biomedical factors, psychosocial factors and health-related quality of life (HRQOL) and suicidality (psychological distress) of women with HIV and AIDS in KwaZulu-Natal;
- Do psychosocial factors such as self-reported perceived social support, income, employment, number of children, number of family members and marital status contribute to the quality of life and psychological wellbeing beyond the effect of medical condition factors such as time since diagnosis and CD-4 count?

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## CHAPTER TWO: A REVIEW OF RELATED LITERATURE

### 2.1 Introduction

This chapter provides a review of literature related to the topic under study. Firstly, it examines key concepts in the study, namely health-related quality of life and psychological wellbeing. Secondly, the chapter examines empirical studies nationally and internationally that have explored psychological wellbeing and health-related quality of life amongst individuals with HIV and AIDS. Finally, debates on the issue of psychological wellbeing and health-related quality of life amongst women with HIV/AIDS are examined.

The search was conducted using various search engines including Index to South African Periodicals (ISAP); South African ePublications; AIDSearch, Academic Search Premier, Medline, PubMed, ISI Web of Science, PsycINFO, PsycARTICLES, Science Direct, ProQuest and EBSCO Electronic Journals Services. The search strategy aimed to identify articles in the English language that had been published up to and including 2007. Additional articles were identified by scanning references from the relevant articles obtained. A limited number of articles from grey literature was also sourced. The keywords used were health-related quality of life; women, HIV; quality of life; psychological distress; depression; anxiety; social support; AIDS Africa / South Africa.

### 2.2. Key Concepts

In the literature reviewed, the term *'quality of life'* (QOL) sometimes is used interchangeably with *'health-related quality of life'* (HRQOL). However, QOL is a broader construct that encompasses aspects of life such as finances, the quality of the built environment and public transport which are not the direct concerns of health care services. The theoretical framework of QOL arose from the World Health Organization's

definition of health as a state of complete physical, mental and social wellbeing and not merely the absence of disease (O'Connor, 2004). This definition implies that a systematic, prospective collection of information about patients' and their families' subjective health is important. Most researchers and clinicians in the field of health agree that quality of life (QOL) is related to symptoms, functioning, psychological and social wellbeing. In the field of palliative care, clinicians and researchers agree that the goal of palliative care is achievement of the best quality of life for patients and their families.

Möller, Smit and Petr (2005) explain that quality of life refers to the extent to which an individual enjoys life in areas of being (physical being, psychological being, spiritual being), belonging (*inter alia* social belonging, community belonging) and becoming (related to, *inter alia*, hopes, goals, aspirations). Central to these three components is an individual's perceptions of health aspects of their lives that they value. It has been argued that patients should be given the opportunity to choose the domains that are important to their quality of life, at a given point in time (Waldron, O'Boyle, Kearney, Moriarty & Carney, 1999). The dimensions of QOL most commonly included in outcome measures are psychological functioning, physical functioning, disease- and treatment-related functioning, emotional functioning and social functioning. However, role functioning, cognitive issues, sexual functioning, spirituality, financial concerns, job satisfaction and living conditions may also be considered important to measure. This profile emphasizes individuals' physical, psychological and spiritual functioning; their connections with their environments, and opportunities for maintaining and enhancing skills.

Kaasa and Loge (2003) point out that in the end-of-life care stage, spirituality and existential issues become more important to patients, as well as to family members' perceptions of quality of care. These researchers explain that outcome measures in palliative care require constructs that reflect the specific goals of palliative care, such as improving QOL before death, symptom control, family support and satisfaction, as well as patients' views of the purpose and meaning of life. This approach includes in its

conception of quality of life one's philosophical perspectives on life. Quality of life has practical implications for health care in that researchers and clinicians can measure changes in subjective health brought about by a medical intervention.

As a consequence of these debates, the multidimensional health-oriented concept Health-related Quality of Life (HRQOL) emerged as the most appropriate term for QOL health dimensions which are within the area of health care services (O'Connor, 2004; Kaasa & Loge, 2003). It is accepted that HRQOL is a multidimensional construct that is strongly influenced by subjective factors such as past experiences, beliefs and expectations (Möller, Smit & Petr, 2005). Health-related quality of life (HRQOL) has been used to measure the effects of illness in order to better understand how an illness interferes with a person's day-to-day life.

***Health-related quality of life (HRQOL)*** refers to how a person's health affects their ability to carry out normal social and physical activities. In public health and in medicine, the concept of health-related quality of life refers to a person or group's perceived physical and mental health over time. Physicians have often used health-related quality of life (HRQOL) to measure the effects of chronic illness in their patients to better understand how an illness interferes with a person's day-to-day life. In other words, health-related quality of life refers to how well people are able to perform daily activities (functioning) and how they feel about their lives (wellbeing). Wilson and Cleary (1995) explain that health-related quality of life (HRQOL) is an individual's satisfaction or happiness with domains of life insofar as they affect or are affected by „health'. HRQOL can be distinguished from quality of life in that it concerns itself mainly with those factors that fall under the domain of health care providers and health care systems (Wilson & Cleary, 1995).

The assessment of HRQOL represents an attempt to determine how variables within the dimension of health (e.g. a disease or its treatment) relate to particular dimensions of life that have been determined to be important to people in general (generic HRQOL) or to

people who have a specific disease (condition-specific HRQOL). Ware (1994) explains that most conceptualizations of HRQOL emphasize the impact of disease on physical, social, psychological/emotional and cognitive functioning. Symptoms, health perceptions and overall quality of life are often included in the concept domain of HRQOL.

The notions of ‚*functional status*‘ and ‚*functional performance*‘ relate to the concept health-related quality of life. According to Wilson and Cleary (1995), *functional status* is an individual’s ability to perform normal daily activities required to meet basic needs, fulfil usual roles and maintain health and wellbeing. *Functional status* subsumes concepts such as functional capacity and functional performance. While functional capacity relates to an individual’s maximum capacity to perform daily activities in the physical, psychological, social and spiritual domains of life, functional performance refers to the activities people actually do during the course of their daily lives (Leidy, 1994). Thus, a maximal exercise test measures physical functional capacity, while a self-report of activities of daily living measures functional performance. Wilson and Cleary (1995) suggest that biological or physiological impairment, symptoms, mood and other factors can influence functional status. Leidy (1994) argues that functional status is also likely to be influenced by health perceptions. For example, a person who most people would consider to be well but who views himself or herself as ill may have a low level of functional performance in relation to his capacity.

Another key notion in the analysis of health-related quality of life is ‚mood‘. ‘Mood’ refers to emotional responses to short- or long-term stressors such as changes in health state. Mood describes a sustained emotional response that, when persistent, can distort a person’s view of the world. Depression, anxiety and anger are emotions that sometimes coexist with physical illness, and may affect the individual’s functional performance, symptom, health perceptions and quality of life (Anderson, 1995; Moody, McCormick & Williams, 1990). Conversely, Anderson (1995) argues that decreased functional status may contribute to depressed mood.

A „symptom’ indicates disorder or disease and may be defined as a person’s perception of an abnormal physical, emotional, or cognitive state (Poley, Stolk, Tibboel, Molenaar & Busschbach, 2004). A national study of persons with HIV infection in the USA was conducted by Lorenz, Shapiro, Asch, Bozzette and Hays (2001). The objective of the study was to estimate the association of HIV symptoms with health-related quality of life and with disability days. The conclusion drawn from this study was that several symptoms were associated with worse health-related quality of life and more disability days in persons with HIV infection. In such patients, targeting specific symptoms may improve health-related quality of life and reduce disability. Specific symptoms often indicate underlying conditions, and symptoms may be markers for the progression of HIV disease and may be ameliorated by antiretroviral therapy (Palella, Delaney & Moorman 1988).

The study by Lorenz et al. (2001) suggests the importance of monitoring and treating symptoms because of their adverse effects on health-related quality of life. However, the authors underscore the conflicts inherent in HIV therapy. Nausea was among the symptoms with the greatest detrimental impact on health-related quality of life and disability days. Nausea is infrequently a symptom of primary HIV infection but is commonly associated with many of the drugs used to treat it. This suggests that there may be important unavoidable tradeoffs when treating HIV-related conditions.

***Psychological wellbeing*** is assessed with measures of depression, quality of life and self-esteem. Although many people with HIV/AIDS may be fighting the diagnosis of HIV/AIDS and doing everything they can to cope with the disease, there are still powerful issues such as social stigma and economic devastation that make the psychological implications of living with HIV/AIDS just as difficult as the medical battle.

One of the most common causes of psychological trauma related to HIV/AIDS is the impact of social stigma on the infected individual, according to Phiri and Webb (2002). Stigma can lead to feelings of depression, guilt and shame, limited participation within

communities, and an increase in behaviour that may heighten the risk of further transmission (Fife & Wright, 2000). Stigma creates or reinforces social inequalities among individuals and leads to discrimination through actions that violate the very rights of those living with HIV and/or AIDS (Stein, 2003; United Nations Population Fund, 2005; Women in Health and Development, 2006). Prejudice, rejection, isolation or avoidance of people, communities or groups are just a few of the ways stigma occurs. As a result, individuals who have or are thought to have HIV or AIDS may be shunned, marginalised, denied jobs or opportunities and may even be refused treatment or care.

### **2.3 Researching the quality of life and psychological wellbeing of individuals with HIV/AIDS.**

In this section, *empirical studies* that explored the notions of quality of life and psychological wellbeing with respect to individuals affected by HIV and AIDS will be examined.

A study on stress and health-related quality of life among HIV-infected persons was conducted by Au, Chan, Li, Chung, Po and Yu (2004). These researchers examined the relationships among illness-related factors, stress, health-related quality of life (HRQOL) and psychological distress in persons infected with HIV and living in Hong Kong. In this study the number of symptoms was found to be inversely related to SF-36 general health and positively related to anxiety. Consistent with western findings, for example those by Franchi and Wenzel (1998), the results suggested that CD-4 count was not significant in predicting HRQOL and psychological distress.

In addition, the Au et al. (2004) study showed that after controlling for the biomedical factors, the psychosocial factors demonstrated a unique association with HRQOL in terms of the three particular SF-36 scores: general health, role-emotional and mental health. This was the only study located that used the SF-36 with HIV-infected persons to assess the concept HRQOL.

In her review of studies undertaken in the African context, Brandt (2009) found that there were high levels of mental health problems among men and women infected by HIV. Reece, Shacham, Monahan, Yebei, Ong'or, Omollo and Ojwang (2007) examined the nature of psychological distress among 397 individuals living with HIV in Kenya. This study is one of the most comprehensive assessments of psychological distress among individuals receiving HIV care in Kenya. The study found that the levels of psychological distress in the sample were moderate and a large number of the participants met the criteria that suggested a need for further psychiatric evaluation.

In South Africa, Tancred, Van Rensburg and Joubert (2000) conducted a study on the prevalence and severity of major depression in heterosexual male HIV-infected patients in the Orange Free State. The study showed that major depression was common among heterosexual HIV-positive men. Although most of the patients who complied with the DSM IV criteria could be described as mildly depressed, the inability of the health service to routinely identify these patients was listed as a concern. The study suggests that the liaison psychiatrist needs to adjust to the increasing problem of managing these patients.

Another interesting study was conducted by Olley, Gxamaz, Seedat, Reuter and Stein (2003) with recently diagnosed HIV patients in South Africa. The results of this study indicated that depression and anxiety disorders were common in the patients interviewed. Although the study did not employ a control group, the rates of depression were very similar to those seen in the developed world, where a rate of 48% was reported (Dew, Becker, Sanchez, Caldararo, Lopez, Wess, Dorst & Banks, 1997).

Olley et al. (2003) state that there is growing literature on the psychological responses to and the psychopathology associated with HIV/AIDS, but that few investigations have focused on the *role of gender*. Their study compared psychiatric morbidity, coping responses and disability in male and female outpatients recently diagnosed with HIV/AIDS. One hundred and forty-nine patients (44 male, 105 female) with HIV/AIDS



attending an infectious disease clinic at Tygerberg Hospital, Cape Town, were evaluated. Subjects were assessed using the MINI International Neuropsychiatric Interview (MINI), the Carver Brief COPE questionnaire and the Sheehan Disability Scale. In addition, negative life events and risk behaviours were evaluated. The results indicated that 56% of the patients had been diagnosed with a psychiatric disorder, 34% with major depression, 21.5% with dysthymic disorder, 14.8% with post-traumatic stress disorder, and 10.1% with alcohol dependence. There were no significant gender differences in the prevalence of mood disorders in the sample. Men, however, were more likely than women to meet the diagnostic criteria for alcohol abuse or dependence, and to engage in certain risky sexual behaviours. Women, on the other hand, were more likely to suffer from post-traumatic stress disorder and to use coping strategies of planning and religion to deal with the illness. There were no significant gender differences in disability. The findings in this study suggest that psychiatric disorders are common in recently diagnosed HIV/AIDS patients in South Africa. In addition, clinicians should be aware of the high prevalence of mood disorders in both men and women, and of gender-different responses such as increased alcohol and substance use and more risky sexual behaviour in men, so that gender-sensitive interventions can be planned.

Freeman, Nkomo, Kafaar and Kelly (2007), Kelly, Freeman, Nkomo and Ntlabati (2008) and Freeman, Nkomo, Kafaar and Kelly (2008) in their large-scale study investigated the prevalence of mental disorder amongst individuals living with HIV/AIDS in five provinces in South Africa, involving a sample of 900 participants. The prevalence of mental disorder was 43, 7% across this sample, though higher in stage 3 (49,7%) and in stage 4 (68%) of the disease. Depression was the most common disorder, followed by alcohol abuse disorder. The study found that the presence of mental disorder was significantly associated with gender, employment status, having children, and the clinical stage of the disease. Gender and stage of disease were the best predictors of mental disorder.

Möller & Smit (2004) conducted a comparative study that aimed to explore the quality of life of two sample groups in North West province of South Africa: members of the police in active duty (a healthy population) and a group of people living with AIDS. The *Health-Related Quality of Life Survey* (HRQOL) – SF-36: Version 2 (Ware, Kosinski & Dewey, 2002) was used as the measuring instrument. The study showed that there were statistically significant differences between people living with AIDS and members of the police force on all eight domains of the SF-36: Physical Functioning (PF), Role Limitations Physical (RL), Bodily Pain (BP), General Health (GH), Vitality (V), Social Functioning (SF), Role Emotional (RE) and Mental Health (MH).

In conclusion, several symptoms are associated with worse health-related quality of life and more disability days in persons with HIV infection. In such patients, targeting specific symptoms may improve health-related quality of life and reduce disability.

#### **2.4 Women, HIV/AIDS, quality of life and psychological wellbeing**

The number of women with HIV infections and AIDS has increased steadily worldwide. According to the UNAIDS/World Health Organization (WHO) 2005 epidemic update, 17,5 million women worldwide were infected with HIV by the end of 2005 (UNAIDS, 2005). Living with HIV/AIDS can destroy an individual's health, disrupt entire families, exacerbate poverty, lead to child neglect and create a whole array of physical, emotional and social problems. For the past two decades in the USA, the incidence of AIDS among women has been growing faster than for men (AVERT, 2007). Women comprised only 7% of all new AIDS cases in 1986, but they were 23% of all new AIDS cases by 2003 (Jeffrey & Kates, 2000).

The trends in HIV prevalence amongst women in sub-Saharan Africa suggest a *feminization of the pandemic* (UNAIDS, 2006). In South Africa, one in five South African women is HIV infected (Shisana, Rehle, Simbayi, Parker, Zuma, Bhana, Connolly, Jooste & Pillay, 2005). According to the Department of Health (2006), figures

based on attendance of antenatal clinics show that more than a quarter (25%) of pregnant women in six of the nine provinces in South Africa are HIV positive. Brandt (2007) explains that the higher prevalence amongst African females compared with women in general suggests the high representation of poor women. The author bases this argument on the fact that the African population represents the poorest sector of the South African population.

Women are more vulnerable to HIV/AIDS than men, both epidemiologically and biologically, as research suggests that there are effects of both *gender* and *sex* on the experiences of HIV/AIDS amongst women (Doyal, 1995; Brandt, 2007). *Sex* refers to the biological characteristics that categorise someone as either female or male. The effects of *sex* relate to women's greater biological or physiological vulnerability to HIV. There are physiological reasons why women are more vulnerable to infection than men, for example, the fact that much of the female genital tract is more permeable to fluids compared with the male's anatomy. Moreover, semen contains a higher concentration of the HIV virus than female secretions. *Gender* on the other hand is a social construct, and refers to the socially created ideas and practices of what it is to be female or male (Baden & Reeves, 2000). It is about „power relations' between females and males in which males tend to have more power. Gender strongly influences the roles people play in society and the home, the identities they have, and social and cultural norms regarding masculinity and femininity - that is, what is seen as acceptable behaviour if you are male or if you are female. Gender and its social processes result in women's disempowerment and oppression (Doyal, 1995; Brandt, 2007). For example, women are frequently less educated than men throughout the developing world. This disparity is important for women because literacy rates are strong predictors of fertility choices and decisions (Womenwatch, 2006). Linked to this is the fact that gender-based violence makes women vulnerable to rape, and powerless to negotiate safe sex with their partners and to refuse unwanted sex (Kalichman, Simbayi, Kaufman, Cain, Cherry, Jooste & Mathiti, 2005; Dunkle, Jewkes, Brown, Gray, McIntyre & Harlow, 2004).

Research on gender differences and mortality rates has indicated that women with HIV/AIDS have a shorter survival rate than HIV/AIDS-infected men (Walker, 2002). Worldwide, more than 90% of all adolescent and adult HIV infections has resulted from heterosexual intercourse. Women are particularly vulnerable to heterosexual transmission of HIV due to substantial mucosal exposure to seminal fluids. This biological fact amplifies the risk of HIV transmission when coupled with the high prevalence of non-consensual sex, sex without condom use and the unknown and/or high-risk behaviours of their partners. Women suffer from the same complications of AIDS that afflict men but they also suffer gender-specific manifestations of the HIV disease, such as recurrent vaginal yeast infections, severe pelvic inflammatory disease (PID) and an increased risk of pre-cancerous changes in the cervix - including probable increased rates of cervical cancer. Women also exhibit different characteristics from men for many of the same complications of antiretroviral therapy, such as metabolic abnormalities.

In the section below, issues of quality of life and psychological wellbeing will be examined through the experiences of women living with HIV/AIDS. Few studies on this issue could be traced in the literature.

A study conducted by Catz, Core-Felton and McClure (2002) examined psychological distress among 100 minority and low-income women with HIV in Louisiana, USA. The researchers used various measures to explore predictors of psychological distress including depression, anxiety, life stress, social support and coping. The findings in this study revealed that the women were experiencing significant psychological distress. However, the women's emotional distress was a reflection of factors unrelated to HIV such as poverty as found in other studies (Hlatshwayo, Gennrich & Njenga, 2004; Wallace, 2004). The high levels of psychological distress were related to major life events, lack of social support and poor coping strategies. The researchers concluded that it was not clear how distressed these women would have been had they not been affected by HIV, but that it was reasonable to assume that this diagnosis played an important role in their psychological wellbeing.

These findings are very interesting from a *gender perspective* in that gender relations in society tend to mean that women have less power and therefore perhaps less „mastery’. Internationally it has been shown that women (especially those in women-headed households) have less economic resources than men. Brandt (2005) explains that apart from women being overrepresented amongst HIV infected people, the epidemic has a disproportionate social and economic impact on women. This author points out that the prevalence of AIDS in households and communities in South and Southern Africa has resulted in an increase in both the number of female-headed households and the economic strain experienced by those households. Therefore women are being disadvantaged from a gender perspective. Women have to negotiate many roles: the role of being a person who is HIV positive, caring for children, negotiating economic demands and survival needs to maintain households, taking in orphaned children, caring for the sick, and in general dealing with multiple stressors.

Another perspective in debates is that women’s economic dependency within the context of migrancy in Southern Africa, and in South Africa in particular, has led to a greater economic dependency by women on men in this context (Ramphela, 1986; Ramphela, 1989; Smith, 2002). This has also made women more vulnerable to HIV acquisition and in negotiating protective sex and other issues while HIV positive (Jewkes, Levin & Penn-Kekana, 2003; Caldwell, Caldwell & Quiggin, 1989). Hence once again there is a cross-cutting of the effects of gender, socio-economic status on health and HIV, in particular.

Perspectives generated by *cognitive adaptation theory* and *conservation of resources theory* with regard to positive and negative changes associated with HIV infection have been examined and reported in the literature. It is useful to explain the relationship between benefit-finding and psychological adjustment that has been described in two influential theoretical perspectives, namely Taylor’s (1983) *cognitive adaptation theory* and Hobfoll’s (1989) *conservation of resources theory*. First, Taylor’s (1983) *cognitive adaptation theory* views people as active agents in restoring equilibrium after a stressful

life event. According to the theory, stressful events take their toll by challenging at least three basic beliefs people have about themselves and the world: people's sense of meaning, their sense of mastery and their self-esteem. In the aftermath of a traumatic event, the theory posits that people are motivated to restore their self-esteem and sense of meaning and mastery by the production of self-enhancing cognitions (Taylor & Brown, 1988). Causal attributional search or a rethinking of attitudes and priorities may assist the individual to regain a sense of meaning. A sense of mastery can be preserved by selectively focusing on domains of one's life where one continues to experience control. Self-esteem can similarly be preserved by focusing on aspects in which one's self-concept is unaffected or improved by the experience or by engaging in social comparisons with less fortunate others (Taylor & Lobel, 1989). Furthermore, the processes by which meaning, mastery and self-esteem are re-established are believed to be critical for mental health and adjustment (Taylor & Brown, 1988). Taylor's perceptions of stress-related growth are as a result of the natural products of a person's motivation to enhance his or her self-perception but are not thought to be necessarily related to one's social and economic resources.

On the other hand, Hobfoll's (1989) *conservation of resources theory* suggests that perceptions of stress-related growth and adjustment are heavily determined by a person's pre-existing personal, social and economic resources. This theory is about people who strive to retain, protect and build resources and that resources include money, education, employment and free time as well as personal characteristics such as mastery, optimism, self-esteem, health status and social support. This theory predicts that people with greater initial resources will be able to mobilize them in a time of stress to effect a greater net gain than those with fewer resources (Hobfoll, 1991). Furthermore, such gains appear to be important in moderating the effects of resource losses on psychological adjustment (Wells, Hobfoll & Levin, 1999).

Few studies, however, have focused specifically on how socio-economic status (SES) may contribute to people's perceptions of stress-related growth. Most research exploring stress-related benefits in HIV-positive populations have used samples of fairly affluent, educated gay men who have a number of community resources available to help them in dealing with their infection (Bower, Kemeny, Taylor & Fahey, 1998). Accordingly, the purpose of the study by Updegraff, Taylor, Kemeny and Wyatt (2002) was to examine the self-reported consequences of an ongoing stressful event in an ethnically diverse, low SES sample of HIV-positive *women*. The researchers chose to examine this phenomenon in such a population because they believed that women would have limited access to a number of resources, such as financial and community resources and support groups that might ordinarily facilitate the adjustment and stress-related growth documented in more privileged samples. This research examined the relationship between socio-economic status (SES) and *benefit finding* in two ways: by both assessing the prevalence of positive and negative HIV-related changes in a low SES sample, and by measuring the degree to which SES predicted these changes. A second purpose of this study was to identify and compare the unique predictors of positive and negative HIV-related changes to the predictors of more standardized adjustment measures such as depression and anxiety. Lifetime trauma and chronic stress are especially important to examine as predictors because greater levels of distress found in lower SES groups may be attributable to greater exposure to traumas and chronic daily stresses (Myers & Durvasula, 1999; Turner & Lloyd, 1995). A final purpose of this study was to examine the relationship between reports of HIV-related changes and adjustment. Although most studies that have examined the relationship between benefit finding and adjustment have found increased benefits to be associated with less distress, the exact nature of the relationship remains unclear. An interest of this study was to determine whether *women* who reported a mix of both positive and negative changes showed lower levels of both depression and anxiety than women who reported mainly positive changes.

Overall, the results provided support for the hypotheses generated by both Hobfoll's (1989) conservation of resources theory and Taylor's (1983) cognitive adaptation theory.

The results were consistent with Hobfoll's (1989) theory and showed that benefit-finding in being HIV positive appeared to be a socio-economic phenomenon. Although the measures of negative outcome (negative changes, depression and anxiety) were predicted by optimism, health status and chronic burden, the measure of positive changes was best predicted by education and income. These results appear to be robust, as the most plausible mediators of any socio-economic effects on benefit-finding - ethnicity, optimism, health status and chronic burden - were controlled in the analysis and shown to have no unique association with positive changes.

Consistent with Taylor's (1983) theory of cognitive adaptation, in the Updegraff et al. (2002) study HIV-related benefits were reported significantly more often than losses. Even though the women in the sample were of a low socio-economic status, lacked financial, educational and community resources, and showed a higher prevalence of both depression and anxiety than samples of HIV-negative women, they nevertheless reported that being HIV positive resulted in more benefits than detriments, especially in their views of themselves and life priorities. The common themes of benefit included becoming stronger, wiser, less involved with drugs, more understanding and more focused on priorities such as family, helping others and living life to the fullest.

The results of the above study suggest that although the ability to benefit from negative life events may be to a degree contingent on socio-economic resources, it is not necessarily the case. Even among those with limited socio-economic resources, the capacity to benefit from adversity is linked strongly to the resilience of the human spirit.

## **2.5 Conclusion**

This literature review examined the key concepts in the study, namely, health-related quality of life and psychological wellbeing. The chapter also examined empirical studies nationally and internationally that have explored psychological wellbeing and health-



related quality of life amongst individuals with HIV and AIDS. The review finally focussed on key debates on the issue of psychological wellbeing and health-related quality of life amongst women with HIV/AIDS.

Although it is evident from this review that there is growing literature on psychological responses to and the psychopathology associated with HIV/AIDS, few investigations have focussed on the experiences of low income women. The aim of the study reported in this dissertation was to gain an understanding of health-related quality of life and psychosocial wellbeing among low income HIV-positive women in the Chatsworth region in KwaZulu-Natal.

University of Cape Town

## **CHAPTER THREE: RESEARCH DESIGN AND METHODOLOGY**

### **3.1 Introduction**

In this chapter the research methodology and design of the study will be presented. The research design is the plan or the protocol for a particular piece of research, and includes the paradigm, purpose, context, research methods and ethical considerations.

### **3.2 Research Design**

#### ***3.2.1 Research paradigm***

The study design was a cross-sectional descriptive study. It was conducted as a quantitative study and was exploratory in nature, being located in a positivist paradigm.

The study investigated the extent of health-related quality of life and psychological wellbeing of low-income HIV-positive women in the context of limited access to psychosocial resources. The research examined relationships among biomedical factors (time since diagnosis and CD-4 count), psychosocial factors and health-related quality of life (HRQOL) and suicidality (psychological distress) of women with HIV and AIDS in KwaZulu-Natal.

#### ***3.2.2 Research site***

The research site was an HIV/AIDS outpatients clinic at a public hospital in the province of KwaZulu-Natal. The clinic provides medical and auxiliary social, psychological and health education services for patients with HIV/AIDS. The clinic serves a population of

men and women who come from low socio-economic backgrounds and who have no private medical insurance.

### ***3.2.3 Research procedure***

The sample was intended to include all seropositive women who were patients at the HIV/AIDS out-patients clinic, who were at least 18 years of age and who agreed to participate in the study on a voluntary basis. In all, 133 women agreed to participate in this study. Of the 142 women in the age group above 18 years who were approached by the matron of the clinic and 133 agreed to take part in the study. The matron of the clinic discussed the study with the women and sought their consent.

The study did not have a direct control group. This was found to be a limitation in the design. However, there are complexities with identifying a direct control group. Given the fact that the prevalence rates of HIV in South Africa are high, it was very likely that a number of individuals assessed as part of the general population group might be HIV positive.

The sensitive nature of the topic of research and the characteristics of these participants necessitated that particular attention be paid to ethical issues. Ethical research practice includes consideration of the three major ethical principles: i.e. autonomy, non-maleficence and beneficence (Israel & Hay, 2006; Emmanuel, Wendler & Grady, 2000; Mason, 2004). These principles are seen as necessary for research to be both scientifically and socially acceptable. They are especially important considerations when one works with disempowered and vulnerable population groups, such as women with HIV and AIDS, and with sensitive topics such as HIV/AIDS.

Participants provided written informed consent (refer to appendix 5). All interactions with the participations were conducted in a respectful, supportive, and in a non-

judgmental way The matron of the clinic explained to participants that their responses would be kept confidential and that their anonymity would be assured. Neuman (2000) contends that the relationship between the researcher and subjects most often involves power and trust. This was an important consideration in the context of this study since the subjects were accessed through an HIV/AIDS outpatient's clinic. The matron assured participants that if they made the choice not to participate in the study, their care and support from the clinic would not be negatively impacted in any way. The patients would continue to receive standard care. The risk that the researcher might place participants in an anxiety-provoking situation and cause psychological discomfort and stress was present. However, this research was conducted in the context of counselling support and care – i.e. the HIV/AIDS outpatient's clinic which provided a safety net of professionals. At all stages of the research, that is, before, during and after the study was completed, the women had the support of the clinic professionals, including a psychologist and a social worker. These professionals worked with the women and were on hand to support them. The support programme included issues such as promoting healthy sexuality and safer sex skill building; nutrition counselling and support; reducing the risk of mother-to-child transmission of HIV; promoting the rights and gender specific empowerment of HIV positive women; managing symptoms; reducing susceptibility to opportunistic infections; and reducing high-risk sexual behaviours that increase risk of re-infection.

Israel and Hay (2006) stress that researchers are obligated to take into account the principle of beneficence. In this study, the aims of the research were explained to the participants in some depth. It was explained that the study had the potential to contribute to the general body of knowledge on HIV/AIDS, and that the group of people who make up the participants may benefit from the research. In other words, the field of care for women with HIV and AIDS could benefit from the study with respect to interventions for care and support.

Official permission to undertake the study at the site was obtained from the Department of Health, Province of KwaZulu-Natal. Ethical approval was granted by the University of Cape Town (UCT) Research Ethics Committee.

### ***3.2.4 Data Collection***

Two research assistants who are fluent in isiZulu and in English and who had been trained by the principal researcher engaged in the data collection process. The training included research ethics and the implication of conducting research in a vulnerable population. Individual interviews were conducted with each of the participants in order to obtain demographic information. This was done in a private room at the clinic. The interviews were conducted either in English or in isiZulu depending on the participants' home language. All African participants in the study were Zulu speaking.

In individual sessions, each participant completed various self-report measures aimed at evaluating health-related quality of life and psychological wellbeing. Prior to administration, all measures had been translated into isiZulu by two Zulu speaking research assistants. These translations had been discussed with the researcher who has a working knowledge of isiZulu. However, there is a potential limitation in this approach. On reflection, the translated measures ought to have been translated back into English by an independent isiZulu speaking individual to ascertain whether the translated version was close to the original English version. This process would have ensured greater face- and content validity.

In view of low levels of literacy, each item on the self-report measures was read to participants, and they were required to indicate their response verbally. The research assistant recorded the responses on the response sheets.

### **3.2.5 Measures**

This study can be described as an example of survey research. According to Neuman (2000), survey research was developed within a positivist approach to social research. Survey research produces information that is statistical in nature. Neuman (2000) explains that surveys are appropriate for research questions about self-reported beliefs, opinions, expectations, knowledge, characteristics and behaviours. It is possible to measure many variables. Survey researchers sample many respondents who answer the same questions. According to Cohen, Manion and Morrison (2007), surveys usually follow a deductive approach; that is, the researcher begins with an applied research problem and ends with empirical evidence and data analysis. In other words, the researcher translates a research problem into questionnaires, and then uses these with respondents to create data. A survey researcher usually conceptualises and operationalises variables as questions which are organised into questionnaires. In this study various instruments were used to measure the key variables.

#### **3.2.5.1 Personal information questionnaire**

##### *Biographic Information*

A questionnaire was used to collect data on the biographic characteristics: age, gender, race, education, work status, income, number of household members, marital status, employment status and religion.

##### *Biomedical Information*

This information collected data on the number of sexual partners since diagnosis, the number of sexual partners currently, time since diagnosis, current treatment, perceived mode of infection and current treatment (whether on anti-retrovirals or not).

The CD-4 count was verified by written documentation by case medical officers at the clinic. Lower CD-4 counts reflect a more advanced stage of disease progression at the

time of assessment. All women had tested HIV positive before receiving treatment at the clinic. Time since diagnosis was assessed by asking the women when they were first notified that they were HIV positive. (refer to appendix 1 for questionnaire).

Although there is limited evidence supporting a direct relationship between psychological wellbeing and health-related quality of life and AIDS progression, well-controlled, large-scale epidemiologic studies have documented a relationship between depressive symptoms and CD-4 cell count declines (Burack, Barrett, Stall, Chesney, Ekstrand & Coates, 1993; Ickovics, Hamburger, Vlahov, Schoenbaum, Schuman, Boland & Moore, 2001). Several studies do not support this association (for example, Lyketsos, Hoover, Guccione, Senterfitt, Dew, Wesch, Vanraden, Treisman & Morgenstern, 1993 ; Au et al., 2004). In their meta-analysis study Zorrilla, McKay, Luborsky and Schmidt (1996) found that depressive symptoms and not stressors were longitudinally related to symptoms of HIV infection, but neither stress nor depressive symptoms were related to changes in CD-4 cell count. Despite these contrasting findings in other international contexts, the decision was made to include CD-4 count as a biomedical factor in the present study as it was conducted within a South African context. A further rationale was that in HIV-infected individuals, CD-4 cells are important biomedical predictors of disease status and progression, and vulnerability for opportunistic infections. According to Remor, Penedo, Shen and Schneiderman (2007), few studies have addressed conclusively whether perceived stress (and psychological wellbeing) may be associated with HIV disease course or declines in CD-4 cells.

The second biomedical variable included was time since diagnosis. International studies have demonstrated that a significant association exists between time since diagnosis and psychologically maladaptive responses to HIV infection (McClure, Catz, Prejan, Brantley & Jones, 1996; Nicholson & Long, 1990). In contrast, other international studies have found that patients with low CD-4 counts and/or AIDS are not necessarily more depressed than those in the early phases of infection (Lipsitz, Williams, Rabkin, Remien, Bradbury, el Sadr, Goetz, Sorrell & Gorman, 1994; Rabkin, Goetz, Remien,

Williams, Todak & Gorman, 1997). In the present study, time since diagnosis was included to examine the trends in the South African context.

On reflection, the selection of these two biomedical variables (time since diagnosis and CD-4 count) in the study may be considered a limitation. Future research should examine other biomedical factors such as time on treatment or presence of opportunistic conditions.

### ***3.2.5.2 Multidimensional Scale of Perceived Social Support (MPSS)***

Perceived social support was measured with the Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet & Farley, 1988). This is a twelve-item questionnaire with a scale of 0-7 (refer to appendix 3). The scale is divided into factor items relating to source of social support, namely: family, friends, or significant others. The above items indicate that the scale also assesses psychological dimensions of functioning. Social support is multidimensional information that an individual is a member of a complex network of affection, mutual aid, and obligation. The total support score ranges from 0 to 84. Higher scores represent greater perceived availability of social/psychological support. Lower scores indicate lower levels of support. The scores across the participants were averaged for the purpose of interpretation (Louw, 2007; Myint & Mash, 2008).

The effectiveness of the MPSS has been demonstrated in diverse samples. Although the present study had a different population group, Bruwer Emsley, Kidd, Lochner and Seedat (2008) found the MPSS to be a psychometrically sound instrument that can be applied to South African youth (age 11,3 - 23,5 years). The study found that the MPSS had good internal consistency. Perceived social support was positively correlated with resilience and negatively correlated with depression, exposure to community violence and other potentially life-threatening traumas. In their study, females and youth of white and mixed race reported significantly higher levels of perceived social support than males and



black youths, respectively. The unique features of this scale are: first, it is short (12 items in total); second, it is ideal research that requires assessment of multiple variables, and for subjects who may not be able to handle a long questionnaire; and third, the items are easy to understand.

**3.2.5.3 Suicidality Measure (SM)** (adapted from Sheehan, Lecrubier, Harnett-Sheehan, Amorim, Janavs, Weiller, Hergueta, Baker, & Dunbar, 1998).

This measure is used to assess whether respondents have suicide tendencies. In the study, the measure was used to assess the degree of *psychological distress* in the women. Many studies have identified the relationship between HIV infection, mental and social adjustment, psychological distress, and potential suicide (see for example: Gielen, McDonnell, O'Campo & Burke, 2005; Moultrie & Kleintjes, 2006; Rosario, Schrimshaw & Hunter, 2005; Wright, Lubben & Mkandawire, 2007).

More specifically, there have been studies which showed that individuals who had thoughts of suicide had greater psychological distress and depressive symptoms. Kalichman, Heckman, Kochman, Sikkema & Bergholte (2000) conducted a study to examine the prevalence and characteristics of suicidal ideation among middle-aged and older persons who have HIV infection or AIDS. Twenty-seven percent of respondents reported having thought about taking their own life in the previous week. A key finding was that those participants who had considered suicide reported greater levels of emotional distress and poorer health-related quality of life than those who had not considered suicide. Similarly, Heckman, Miller, Kochman, Kalichman, Carlson & Silverthorn. (2002) examined suicidal thoughts among 201 HIV-infected persons living in rural communities of eight U.S. states. Thirty-eight percent of HIV-infected rural persons had engaged in thoughts of suicide during the past week. The study found that participants who reported thoughts of suicide had more depressive symptoms, less coping self-efficacy, more frequently worried about transmitting their HIV infection to others, and experienced more stress associated with AIDS-related stigma.

Based on these findings, the decision was made to use the Suicidality Measure (SM) adapted from Sheehan, Lecrubier, Harnett-Sheehan, Amorim, Janavs, Weiller, Hergueta, Baker, & Dunbar (1998) in the study (refer to appendix 3). The three items were scored on a scale of 0 to 3 (with 0 indicating high risk of suicide and 3 low risk of suicide). The score that would indicate a very high risk of suicide would be zero, and a very low risk of suicide would be 9.

#### ***3.2.5.4 Health-Related Quality of Life Survey (HRQOL) – SF-36***

The version 2 of the SF-36 Health Survey (Ware, Kosinski & Dewey, 2002) was administered in order to obtain the health profile of the participants. The 36-item Health Survey 1.0 (SF-36) is a generic measure of HRQOL, composed of 36 items evaluating functional status, wellbeing and perceptions of health status.

The SF-36 yields a profile of 8 domains: Physical functioning (PF); Role Limitations Physical (RL); Bodily Pain (BP); General Health (GH); Vitality (V); Social Functioning (SF); Role Emotional (RE) and Mental Health (MH). A higher score on the SF-36 indicates perception of better *quality of life*, with raw scores linearly transformed to a 0-100 scale. According to Kimmel (2000) US-population means for the scales vary from 61 to 84. Scores above 50 are above average and scores below 50 are below average.

Although there is a variety of quality of life instruments available, one of the most commonly used ones is the 36-item Short-Form Health Survey (SF-36). This survey is widely used in monitoring population health and assessing treatment outcomes and disease burden. It is the subject of more than 4,000 published studies (Gandek, Sinclair, Kosinski & Ware, 2004; Riley, Bangsberg, Perry, Clark, Moss & Wu, 2003; Velanovich, 2007). The SF-36 is a multi-purpose, short-form health survey with only 36 questions. The questionnaire items represent multiple operational indicators of health, including behavioural function and dysfunction, distress and wellbeing, objective reports

and subjective ratings, and both favourable and unfavourable self-evaluations of general health status. The SF-36 reflects a shift by researchers from disease-specific evaluations to assess health status prior to and after medical intervention to examining a patient's health-related quality of life (Moller, Smit & Petr, 2005).

A few South African studies, including those investigating people living with AIDS, have documented the usefulness of the SF-36 in assessing quality of life and health-related quality of life. Based on the results, interventions could be implemented to improve quality of life (Benitha & Tikle, 2007; (Möller & Smit, 2004; Möller, Smit & Petr, 2005).

### ***3.2.6 Validity and Reliability***

Validity is an important issue in effective research. In quantitative research validity is a demonstration that a particular instrument measures what it is supposed to measure. Cohen, Manion and Morrison (2007) state that validity should be viewed as a matter of degree rather than as an absolute state. Neuman (2000, p.167) explains that the reason a researcher cannot achieve absolute validity is that “constructs are absolute ideas whereas indicators refer to concrete observation”. Content validity is a special type of face validity. According to Neuman (2000), it examines the question: Is the full content of a definition represented in a measure? In the present study, it was possible to examine face validity through the judgment of the research community that a particular measure really measures the construct. All the measures above have been validated and used in previous studies by international researchers in the field. However, a limitation in this study is that the instrument was not validated in South Africa with the specific patient population in this study, in particular one with a different language.

Reliability means dependability. The question to ask is: Are the measures stable and dependable? Terreblanche and Durrheim (1999) argue that reliability is a key concept in positivist research because it addresses the problem of objectivity. Neuman (2000, p.164)

explains that it means that "...the numerical results produced by an indicator do not vary because of the characteristics of the measurement process or the measurement instrument itself". Cronbach's alpha is a coefficient of reliability (or consistency). Cronbach's alpha measures how well a set of items measures a single unidimensional latent construct (Nunnally, 1978).

The reliability and validity of the measures used in the present study have been verified in other studies (Au et al., 2004; Prezza & Giuseppina Pacilli, 2002; Wang, Adair & Patten, 2006). The Cronbach alpha values are presented in the next chapter for each of the measures used in the study. The reliability coefficients reported are considered acceptable in most social science research situations.

### ***3.2.7 Statistical Analyses***

First, the data on the SF-36, the Suicidality Scale and the Multidimensional Scale of Perceived Social Support (MPSS) were examined on a descriptive basis.

Second, Spearman correlation coefficients were computed to explore the relationships of the SF-36 (quality of life), Suicidality (degree of psychological distress) and the MPSS (perceived social support). Pearson correlations were computed to examine the relationship between the two biomedical variables: time since diagnosis and CD-4 count.

Third, Pearson correlations were computed to examine the relationship between the biomedical variables and the SF-36 sub-scales.

Fourth, Pearson correlations were computed to examine the relationships between SF-36, Multidimensional Scale of Perceived Social Support (MPSS), and suicidality to the biomedical variables: CD-4 count and time since diagnosis.

Finally, hierarchical regression analyses were conducted on the main effects of the biomedical and the psychosocial variables on SF-36 and suicidality scores. Multiple regression analyses were used to explain HRQOL scores – that is, scores on each item of the SF-36 questionnaire. Each of the nine SF-36 scores was used as a *dependent* variable, and the independent variables were grouped into two blocks. *The biomedical block* included time since diagnosis and CD-4 count. *The psychosocial block* included perceived social support, income, employment, number of children, number of family members and marital status. Employment was coded as unemployed or employment. Marital status was coded as either with partner or without partner. All the other variables were continuous.

In step 1, the biomedical variables (time since diagnosis and CD-4 count) were entered as the first block to establish their impact on the dependent variable (SF -36).

In Step 2, the psychosocial variables were entered as a second block to determine their unique contribution.

The objective was to examine the following questions:

- When all the biomedical variables are accounted for, is there a unique association between the psychosocial variables and HRQOL in terms of any particular SF-36 scores (scales). For example, are there some underlying constructs linking any two or three of them?
- How much of the variance in the SF-36 scores (in each scale) is accounted for by the psychosocial variables?

With respect to CD-4 count data and time since diagnosis, the analyses reflected missing data. Missing data in a study are attributed to patients missing clinical visits owing to transport and other difficulties, the recording of data in clinic files in illegible handwriting; missing data in clinic files; and errors by data capturers when imputing the information into the database..

The suicide scale, the perceived social support scale and the SF-36 questionnaire also reflected incomplete data. It was evident that certain subjects were unable or unwilling to answer some of the questionnaire items. In certain cases the problem occurred in the recording of a response on the questionnaires in that more than one box was rated or items were left blank.

### **3.3 Conclusion**

This chapter dealt with the style and approach of the study and the way the research was conducted. It provided an overview of the research design, that is, the research context, sample, the research instruments, the research procedure, data analysis approach and ethical considerations. The chapter also drew attention to certain limitations in the study. The next chapter will focus on the results of the study.

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## CHAPTER FOUR: RESULTS OF THE STUDY

### 4.1 Introduction

The results of the study are presented in this chapter.

### 4.2 Results

#### *4.2.1 Demographic characteristics and HIV-related variables*

Tables 1A-C present the demographic and biomedical characteristics of the 133 participants in the study. Ninety seven percent of the respondents were African and 3% were Indian. The personal profile details reflect that respondents represented a low-income group - the mean income was R631.17 per month. These demographic characteristics and income levels were representative of the predominantly lower SES population of women who attend the clinic. The mean age was 32.9 years (the youngest participant being 18 years, and the oldest 56 years). Other data revealed that 72.9% had some secondary school education, 69.2% were unemployed and 77.4% were single (unmarried).

On average the women had been diagnosed with HIV/AIDS within 32 months preceding the investigation. The average CD-4 count was 189.

Ninety seven percent of the women indicated that the probable mode of infection was sexual.

**Table 1A: Demographic variables and HIV-related (Biomedical) variables (N=133)**

<i>Characteristic</i>		<i>Frequency (Number)</i>	<i>%</i>	<i>Mean ± SD</i>
Age				32.9 ± 7.3
Gender	Female	133	100.0	
Race	Black	129	97.0	
	Indian	4	3.0	
	White	0	0.0	
Language	English	4	3.0	
	Xhosa & isiZulu	6	4.5	
	Zulu	121	91.0	
	Sesotho & isiZulu	1	0.8	
Marital status	Single	103	77.4	
	Divorced	1	0.8	
	Married	18	13.5	
	Partner	10	7.5	
	Widow	1	0.8	
Education	No schooling	5	3.8	
	Primary	24	18.0	
	Secondary	97	72.9	
	Tertiary	7	5.3	
Employment	Employed	25	18.8	
	Unemployed	92	69.2	
	Temporary	10	7.5	
	Casual	2	1.5	
	Volunteer	1	0.8	
	Student	1	0.8	
	Self-employed	2	1.5	
Number of sexual partners since sexually active				4.5 ± 2.4
Number of sexual partners currently				0.7 ± 0.6
Number of children				1.9 ± 1.4
Number of household members				5.5 ± 3.1
Income per Month				R631.17 ± R643.90
Time since diagnosis in months				32.8 ± 32.4
CD-4 count				189.1 ± 123.9



**Table 1B: Biomedical data of mode of infection: N=133; non-responses=23**

<i>Probable mode of infection</i>	<i>Frequency Number N=133 non-responses=23</i>	<i>% of 110 responses</i>
Sexual	98	89.1
Blood transfusion	2	1.8
Helping HIV-infected people	5	4.5
Unsure	1	0.9
I do not know	1	0.9
Needle prick	1	0.9
Raped	2	1.8

**Table 1C: Antiretroviral treatment of respondents (N=133)**

<i>Current treatment</i>	<i>Frequency Number</i>	<i>%</i>
On antiretrovirals	121	91.1
Not on antiretrovirals	12	9.0

#### ***4.2.2 Psychometric data for the SF-36, Suicidality and Perceived Social Support Scores***

All three scales displayed satisfactory levels of internal consistency as reflected in the Cronbach alpha values in Table 2. Cronbach's alpha is not a statistical test - it is a coefficient of reliability (or consistency). In other words, Cronbach's alpha measures how well a set of items measures a single unidimensional latent construct. It measures the extent to which item responses obtained at the same time correlate highly with each other. Table 2 captures the Cronbach values, the means and standard deviations for responses to the various items on the three scales. A reliability coefficient of .70 or higher is considered acceptable in most social science research situations. Evidence for a high degree of internal consistency was evident for parameters: Physical Functioning, Role Limitation, Bodily Pain and Role Emotional – exceeding 0.80. It was marginal for General Health (0.66) and Mental Health (0.62) sub-scales. Poor internal consistency was evident in the case of the sub-scales Social Functioning (0.51) and Vitality (0.48). It is conceded that these low values may have been a limitation in the study. However, it was not within the scope of the present study to further investigate the reason for the above trends. Additional studies are needed to evaluate the internal consistency of the SF-36 scales among South African population groups.

**Table 2: Results of SF-36 scores, Suicidality scores and Perceived Social Support scores.**

<i>Measurement</i>	<i>Variable</i>	<i>Cronbach's Alpha</i>	<i>Means</i>
SF-36	Physical functioning (PF)	0.91	59.9 ± 29.1
	Role Limitations Physical (RL)	0.91	56.9 ± 27.6
	Bodily Pain (BP)	0.83	47.4 ± 33.7
	General Health (GH)	0.66	66.3 ± 21.9
	Vitality (V)	0.48	55.8 ± 19.6
	Social Functioning (SF)	0.51	64.8 ± 31.7
	Role Emotional (RE)	0.90	58.2 ± 28.2
	Mental Health (MH)	0.62	61.5 ± 20.2
Suicide		0.91	7.1 ± 2.5
Perceive social support		0.85	56.1 ± 18.3

#### **4.2.3 Psychosocial wellbeing and distress among women living with HIV/AIDS**

Psychosocial wellbeing and distress were assessed by examining scores on the SF-36 Mental Health (MH) scale, the Suicidality measure and the Perceived Social Support scale.

The mean *Mental Health* (MH) score and standard deviation was  $61.5 \pm 20.2$ . Raw scores were linearly transformed to a 0-100 scale.

The mean *Suicidality* score was  $7.2 \pm 2.5$ . *This suggests that the women seldom thought of suicide.* The three items were scored on a four-point scale of 0 to 3 (with 0 indicating high risk of suicide and 3 a low risk of suicide). The score that would indicate a very high risk of suicide would be zero, and a very low risk of suicide would be 9.

The mean Perceived Social Support score was  $56.1 \pm 18.3$ . The participants rated the degree of support on a scale of 1 to 7 – the highest score that would suggest high levels of social support would be 84. This suggests that the women did not have adequate social support in their lives.

#### ***4.2.4 Relationship of Perceived Social Support to SF-36 and Suicidality***

The relationship between SF-36 and Perceived Social Support showed a *statistically significant* correlation for *Vitality (V)*,  $r = 0.28$ ,  $p < .01$  and *Mental Health (MH)*,  $r = 0.26$ ,  $p < .01$  (refer to Table 5). High levels of social support from family, friends and significant others were related to good mental health in the participants. The findings suggest that low levels of social support could be associated with feelings of tiredness and constant lack of energy, or lack of vitality.

Furthermore, the analyses indicated a *statistically significant* correlation between perceived social support and suicidality (Table 3). High levels of social support were related to minimal suicide tendencies (which reflected a high suicide score):  $r = 0.22$ ,  $p < .01$ .

#### ***4.2.5 Relationship between biomedical variables and SF- 36 and suicide***

The study examined the relationship between the biomedical variables and SF-36 and suicide. The results are presented in Tables 3 and 4. An analysis of the findings is provided below.

**Table 3: Relationship between biomedical variables, suicidality and perceived social support.**

		<i>Suicide score</i>	<i>Perceived social support score</i>	<i>Time since diagnosis</i>	<i>CD-4 count</i>
+ Suicide score		1	(**).022	(**)-0.21	-0.03
	Sig. (2-tailed)	.	.01	0.02	0.72
	N	131	125	129	126
+ Perceived social support score		(**).022	1	0.01	-0.02
	Sig. (2-tailed)	0.01		0.91	0.81
	N	125	125	123	120
** Time since diagnosis	Pearson Correlation			1	-0.04
	Sig. (2-tailed)			.	0.66
	N			131	127
** CD-4 count	Pearson Correlation			-0.04	1
	Sig. (2-tailed)			0.66	.
	N			127	128

\* Correlation is significant at the 0.05 level (2-tailed).

+ Spearman correlation

\*\* Pearson correlation

**Table 4: Relationship between biomedical variables and Health-related Quality of Life (HRQOL)**

		<i>CD-4 count</i>	<i>Time since diagnosis</i>
CD-4 count	Pearson Correlation	1	-0.04
	Sig. (2-tailed)	1	0.66
	N	128	127
Time since diagnosis	Pearson Correlation	-0.04	1
	Sig. (2-tailed)	0.66	1
	N	127	131
Physical Functioning (PF)	Pearson Correlation	0.03	(*)-0.18
	Sig. (2-tailed)	0.77	0.04
	N	128	131
Role Limitations physical (RL)	Pearson Correlation	0.01	-0.12
	Sig. (2-tailed)	0.88	0.20
	N	124	127
Bodily Pain (BP)	Pearson Correlation	-0.01	-0.03
	Sig. (2-tailed)	0.94	0.75
	N	126	129
General Health (GH)	Pearson Correlation	0.08	-0.08
	Sig. (2-tailed)	0.36	0.35
	N	126	129
Vitality (VT)	Pearson Correlation	0.09	(*)-0.22
	Sig. (2-tailed)	0.29	0.01
	N	127	130
Social Functioning (SF)	Pearson Correlation	-0.11	-0.09
	Sig. (2-tailed)	0.24	0.31
	N	128	131
Role Emotional (RE)	Pearson Correlation	-0.00	-0.06
	Sig. (2-tailed)	0.98	0.54
	N	123	126
Mental Health (MH)	Pearson Correlation	-0.01	(*)-0.18
	Sig. (2-tailed)	0.87	0.04
	N	127	130

- \* Correlation is significant at the 0.05 level (2-tailed).
- \*\* Correlation is significant at the 0.01 level (2-tailed).

The CD-4 count did not show any significant correlations with SF-36 scores. This implies that, in this study, the CD-4 count was not a significant predictor of HRQOL (as measured by SF-36) (Table 4). With regard to suicidality, there was no correlation evident between suicide scores and CD-4 count.

However, there was a statistically significant negative correlation between *time since diagnosis* and *suicide*. This implies that a greater number of years/months since diagnosis is associated with low scores on the suicide scale – that is, with high levels of suicide tendencies – suggesting that recently diagnosed patients might be less of a risk for suicide ( $r = -0.212$ ,  $p < 0.05$ ).

There was a statistically significant negative correlation between three SF-36 scores and time since diagnosis (Table 4):

Physical Functioning (PF):  $r = -0.18$ (\*),  $p, 0.05$

Vitality (V):  $r = -0.22$ (\*),  $p, 0.05$

Mental Health (MH):  $r = -0.18$ (\*),  $p, 0.05$

*Time since diagnosis* was inversely related to *physical functioning*, *vitality* and *mental health* of the patients (Table 4). Newly diagnosed patients scored high on these domains. With respect to the relationship between *mental health* and *time since diagnosis*, the mental difficulties/psychological distress of newly diagnosed patients were highlighted.

In this study, as is evident each sub-scale was assessed separately for significance. It could be argued that one would find something significant using this approach. Since there were multiple dependent variables, a multivariate approach should have been used. This is a limitation that needs to be addressed in any future research.

**4.2.6 Relationship between contextual/social variables and SF-36 scales and suicidality (dependent variables).**

Table 5 reflects the relationship between the various contextual/social variables (i.e. *social support, employment, income, number of children, marital status and number of family members*) and HRQOL and suicidality. Employment was coded as unemployed or employed. Income was coded as low income and high income. Marital status was coded as either with partner or without partner. All other variables were continuous.

**Table 5: Relationship between contextual/social variables and SF-36 scales and suicidality.**

	<i>Perceived social support</i>	<i>Employment</i>	<i>Low Income</i>	<i>Number of children</i>	<i>Marital status</i>	<i>Number of family members (household)</i>
+Suicide scale	*0.29	0.17	-0.15	-0.15	0.11	0.07
Physical functioning	0.08	0.15	-0.01	*-0.25	0.08	0.03
Role limitations physical	0.09	0.06	-0.03	-0.03	-0.01	-0.11
Bodily pain	0.17	*0.25	0.11	-0.07	0.02	-0.08
General health	0.10	*0.22	-0.08	0.02	-0.09	*-0.20
Vitality	*0.28	0.13	-0.12	-0.02	-0.03	-0.12
Social functioning	0.14	0.11	-0.07	-0.04	0.06	0.00
Role emotional	0.13	0.13	-0.06	0.03	-0.04	-0.03
Mental health	*0.26	0.07	*-0.22	-0.05	-0.05	-0.04

\* p-value < 0.05

+ high score means „seldom thought of suicide’



*Perceived social support* was positively associated with suicidality – in other words, the women with high social support scored high on the suicidality scale. This implies that they seldom thought of suicide.

The results indicate that *perceived social/psychological support* was associated with two HRQOL variables. Lower social support resulted in feelings of tiredness and constant lack of energy (V). Both social support and income were related to feelings of nervousness and depression all the time (MH).

Being employed was associated with *intensity of bodily pain* (BP) experienced by the women, and with the extent to which bodily pain interfered with normal work. The results indicate a significant positive association between being employed and the women's subjective sense of *general personal health* (GH). The results revealed that low income resulted in poor mental health - that is, feelings of nervousness and depression all the time.

The number of family members in the household negatively impacted on the women's subjective sense of *general health* (GH) – that is, the larger the family in the household the lower was the women's perception of their personal health. Similarly, having a greater number of children had a negative impact on the physical functioning of the women.

#### ***4.2.7 Hierarchical regression analyses of the main effects of biomedical variables and the psychosocial variable (Perceived Social Support) on the SF-36 and suicidality scores***

Multiple regression analyses were utilised to explain health-related quality of life scores – that is, scores on each of the SF-36. Each of the nine SF-36 scores was used as a *dependent* variable, and the independent variables were grouped into two *blocks*. The

*biomedical block* included *time since diagnosis* and *CD-4 count*. The *psychosocial block* included *perceived social support, income, employment, number of children, number of family members in the household, and marital status*. Employment was coded as unemployed or employment. Marital status was coded as either with partner or without partner. All other variables were continuous.

In step 1, the biomedical variables (*time since diagnosis* and *CD-4 count*) were entered as the first block to establish their impact on the dependent variable (SF -36).

In Step 2, the psychosocial variables were entered as a second block to determine their unique contribution.

The objective was to examine the following questions:

- When all the biomedical variables have been controlled for, is there a unique association between the psychosocial variables and HRQOL in terms of any particular SF-36 scores (scales)? The purpose was to determine if there were some underlying constructs linking any two or three of these variables.
- How much of the variance in the SF-36 scores (in each scale) is accounted for by the psychosocial variables?

Of particular interest was *mental health* (MH) which assessed *psychological wellbeing*, or lack of it (psychological distress). The question explored was: How much of the variance was accounted for by the psychosocial variables?

Similar questions were explored in respect of the suicide scores as a dependent variable. The independent variables again were grouped into two blocks. The *biomedical block* included *time since diagnosis* and *CD-4 count*. The *psychosocial block* included *perceived social support, income, employment, number of children, number of family members in the household and marital status*.

Table 6 and Table 7 below present the results.

**Table 6: Regression analysis of biomedical variables and psychosocial variables on SF-36**

	<i>Physical functioning</i> (N = 115)		<i>Role physical</i>		<i>Bodily pain</i> (N = 113)		<i>General health</i> (N = 113)		<i>Vitality</i> (N = 114)		<i>Social functioning</i> (N = 115)		<i>Role emotional</i> (N = 111)		<i>Mental health</i> (N = 114)	
Predictor variable	Step 1 Beta	Step 2 Beta	Step 1 Beta	Step 2 Beta	Step 1 Beta	Step 2 Beta	Step 1 Beta	Step 2 Beta	Step 1 Beta	Step 2 Beta	Step 1 Beta	Step 2 Beta	Step 1 Beta	Step 2 Beta	Step 1 Beta	Step 2 Beta
<b>Biomedical variables</b>																
Time since diagnosis	*-0.18	*-0.22	-0.09	-0.11	-0.030	-0.045	-0.030	-0.035	-0.134*	-0.139*	-0.086	-0.097	-0.034	-0.026	*-0.115	*-0.119
CD-4 count	0.01	-0.00	-0.00	-0.004	-0.019	-0.018	0.005	0.009	0.006	0.010	-0.045	-0.047	-0.008	-0.0003	-0.010	-0.007
<b>Psychosocial variables</b>																
Perceived social support		0.15		0.19		0.325		0.128		0.329*		0.208		0.139		*0.292
Income		0.01		0.002		0.007		-0.0008		-0.003		0.003		-0.004		-0.003
Employment (0)		0.58		0.45		-11.46		-11.03*		-3.770		-4.376		-9.241		-1.773
Number of children		*-6.06		-1.11		-1.018		-0.118		-0.587		-1.388		0.692		-0.763
Number of family members (household)		-0.40		-1.59		-1.048		*-1.691		*-1.504		-1.008		-0.407		*-1.230
Marital status (partner)		3.60		3.90		-0.073		8.154		5.832		-1.025		7.153		6.928
R <sup>2</sup>	<b>0.045</b>	0.134	0.013	0.055	0.005	0.094	0.004	0.166	0.054	<b>0.200</b>	0.034	0.070	0.003	0.041	0.042	0.157
R <sup>2</sup> change		0.089		0.042		0.089		0.162		0.146		0.036		0.038		0.115

\* p-value < 0.05

The  $R^2$  gives the proportion of the variation in the outcome variable that is explained by the variables in the model.  $R^2$  will always be larger when more variables are added. It is therefore not surprising that Step 2 would have larger  $R^2$  than Step 1. The  $R^2$  for Step 1 is very low, with the SF-36 score on *Vitality* (5%) the greatest amount of variance described by the biomedical variables (Table 6). Even the full model, with all the psychosocial factors (*perceived social support, income, employment, number of children, number of family members in the household, marital status*) included, does not explain the majority of the variance in the SF-36 scores – there were no significant results. At best, about 20% (for one of the SF-36 scores, *Vitality*) is explained – but it did not prove significant at the significance level of .05. ***Whether these variables were the most suitable to explain health-related quality of life is therefore questionable.***

(N.B. The amount of variance in SF-36 scores and suicide accounted for by all the variables in the model is given in the  $R^2$  row, and the amount of variance accounted for by the psychosocial variables is given in the  $R^2$  change row. )

#### ***4.2.7.1 Results for each of the SF-36 domains***

The biomedical variables accounted for 4.5% of the variation in the ***physical functioning (PF) score***. When the psychosocial variables were added, all the variables in the model (*time since diagnosis, CD-4 count, perceived social support, income, employment, number of children, number of family members (household) and marital status*) explained 13.4% of the variation in physical functioning (PF) score. **Variables that were significantly associated with the physical functioning (PF) score, taking into account the effect of all other variables in the model, were *time since diagnosis* and *number of children*. The psychosocial variables described 8.9% of the variance in the physical functioning (PF) score once the effect of the biomedical variables had been taken into account.**

In the **role physical (RP) score**, 1.3% of the variation was accounted for by the biomedical variables. When the psychosocial variables were added, all the variables in the model (*time since diagnosis, CD-4 count, perceived social support, income, employment, number of children, number of family members (household) and marital status*) explained 5.5% of the variation in the role physical (RP) score. **No variables were significantly associated with the role physical score. The psychosocial variables described 4.2% of the variance in the role physical score once the effect of the biomedical variables had been taken into account.**

The biomedical variables accounted for 0.5% of the variation in the **bodily pain (BP) score**. When the psychosocial variables were added, all the variables in the model (*time since diagnosis, CD-4 count, perceived social support, income, employment, number of children, number of family members (household) and marital status*) explained 9.4% of the variation in bodily pain (BP) score. **No variables were significantly associated with the bodily pain (BP) score. The psychosocial variables described 8.9% of the variance in the bodily pain (BP) score once the effect of the biomedical variables had been taken into account.**

In respect of the **general health (GH) score**, the biomedical variables accounted for 0.4% of the variation. When the psychosocial variables were added, all the variables in the model (*time since diagnosis, CD-4 count, perceived social support, income, employment, number of children, number of family members (household) and marital status*) explained 16.64% of the variation in the general health (GH) score. **Variables that were significantly associated with the general health (GH) score, taking into account the effect of all other variables in the model, were *employment and number of family members in the household*. The psychosocial variables described 16.2% of the variance in the general health (GH) score once the effect of the biomedical variables had been taken into account.**

The biomedical variables accounted for 5.4% of the variation in the *Vitality (V)* score. When the psychosocial variables were added, all the variables in the model (*time since diagnosis, CD-4 count, perceived social support, income, employment, number of children, number of family members (household)* and *marital status*) explained 20.0% of the variation in the vitality (V) score. **No variables were significantly associated with the Vitality (V) score. The psychosocial variables described 14.6% of the variance in the vitality (V) score once the effect of the biomedical variables had been taken into account.**

With regard to the *social functioning (SF)* score, the biomedical variables accounted for 3.4% of the variation. When the psychosocial variables were added, all the variables in the model (*time since diagnosis, CD-4 count, perceived social support, income, employment, number of children, number of family members (household)* and *marital status*) explained 7.0% of the variation in the social functioning (SF) score. **No variables were significantly associated with the social functioning (SF) score. The psychosocial variables described 3.6% of the variance in the social functioning (SF) score once the effect of the biomedical variables had been taken into account.**

The biomedical variables accounted for 0.3% of the variation in the *role emotional (RE)* score. When the psychosocial variables were added, all the variables in the model (*time since diagnosis, CD-4 count, perceived social support, income, employment, number of children, number of family members (household)* and *marital status*) explained 4.1% of the variation in the role emotional (RE) score. **No variables were significantly associated with the role emotional (RE) score. The psychosocial variables described 3.8% of the variance in the role emotional (RE) score once the effect of the biomedical variables had been taken into account.**

Variation in the *mental health (MH)* score (4.2%) could be accounted for by the biomedical variables. When the psychosocial variables were added, all the variables in the model (*time since diagnosis, CD-4 count, perceived social support, income,*

employment, number of children, number of family members (household) and marital status) explained 15.7% of the variation in the mental health (MH) score. **Variables that were significantly associated with the mental health (MH) score, taking into account the effect of all other variables in the model, were time since diagnosis, number of family members in the household and perceived social support.** The psychosocial variables described 11.5% of the variance in the mental health (MH) score once the effect of the biomedical variables had been taken into account.

**Table 7: Regression analysis of biomedical variables and psychosocial variables on the suicide scale**

<i>Predictor variable</i>	<i>Suicide scale (N = 115)</i>	
	<i>Step 1 Beta</i>	<i>Step 2 Beta</i>
Biomedical variables		
Time since diagnosis	*-0.022	*-0.020
CD-4 count	0.001	0.002
Psychosocial variables		
Perceived social support		*0.031
Income		-0.001
Employment (0)		-0.441
Number of children		0.028
Number of family members in household		-0.037
Marital status (partner)		-0.150
R <sup>2</sup>	0.105	0.183
R <sup>2</sup> change		0.078

\* p-value < 0.05

The biomedical variables (*time since diagnosis* and *C-D4 count*) accounted for 10.5% of the variation in the suicide scale. When the psychosocial variables (*perceived social support, income, employment, number of children, number of family members (household) and marital status*) were added, all the variables in the model explained 18.3% of the variation in the suicide scale. Table 7 above shows that **the psychosocial**

**variables described 7.8% of the variance in the suicide scale once the effect of the biomedical variables has been taken into account. Variables that were significantly associated with the suicide scale, taking into account the effect of all other variables in the model, were *time since diagnosis* and *perceived social support*.**

### **4.3 Conclusion**

The results of the study indicated in this chapter reflect some interesting trends in the data. The next chapter presents the discussion of these findings.

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## CHAPTER FIVE: DISCUSSION OF FINDINGS

### 5.1 Introduction

This exploratory study examined the relationships between biomedical and psychosocial factors (self-reported *perceived social support, income, employment, number of children, number of family members in the household, marital status*) and health-related quality of life (HRQOL) and suicidality (psychological distress) of women with HIV and AIDS in the province of KwaZulu-Natal. The aims and objectives of the study have been met as the findings yielded interesting insights which are discussed in the sections below.

### 5.2 Examining Health-Related Quality of Life (HRQOL)

The results based on the SF-36 indicated a *compromised level* of HRQOL (i.e. physical, social and emotional functioning) in the HIV-infected women in the study. When compared to the Hong study by Au et al. (2004) and the Hong Kong norms by Lam, Lauder and Lam (1999), the participants in this study demonstrated a very poor quality of life on all nine SF-36 domains: *physical functioning, bodily pain, general personal health, mental health, role emotional, vitality, role physical and social functioning*.

The study reported by Möller & Smit (2004) undertaken in the North West Province of South Africa, would have been useful in interpreting the findings in the present study in order to provide points of comparison. This is the only South African empirical study which could be located that used the SF-36 as a data collection instrument with individuals living with AIDS. Unfortunately, the article by Möller and Smit (2004) does not report means and standard deviations. However, the researchers state that the participants living with AIDS attained lower scores on all 8 domains and were less satisfied with their health-related quality of life than the participants who were members of the police force (deemed the healthy population).

If the Au et al. (2004) study is used as a comparison point, the similar low score on the SF-36 bodily pain (BP) scale in the present study highlights the intensity of bodily pain experienced by the participants, and the extent to which bodily pain interferes with normal work.

The study by Catz, Gore-Felton and McClure (2002) in Louisiana, USA, explored psychological distress in a sample of minority and low-income women living with HIV. The study found that the women were experiencing significant psychological distress – 75% reported mild to severe depressive symptoms, and their anxiety levels were high in comparison with those of community norms. The findings also showed that the women experienced a wide range of stressors. The majority of the women were living below the poverty level, and on average the women had experienced approximately seven major traumatic life events in the six months prior to the study.

Similarly, Reece et al. (2007) examined the nature of psychological distress among 397 individuals living with HIV/AIDS in Kenya. The majority of the participants (284 = 71.5%) were women. The study found that the levels of psychological distress in the sample were moderate, yet the authors concluded that a large number of the participants met the criteria that suggested a need for further psychiatric evaluation.

Freeman et al. (2008) explored the prevalence of mental disorder in individuals living with HIV/AIDS in South Africa. The sample comprised 235 (26%) men and 662 (74%) female participants. A number of the participants had diagnosable mental disorder with depression being the most prevalent.

Despite similar findings when comparing the South African situation with regards to HIV/AIDS with the situation elsewhere in the world, Spangenberg and Pieterse (1995) and Eaton, Flisher and Aaro (2003) argue that in South Africa, HIV/AIDS patients may be at greater risk for reduced health-related quality of life and psychopathology than patients in certain parts of the more developed world, given their additional and

potentially stressful living conditions which include high rates of unemployment and poverty; poor and unstable housing; inadequate social services and high rates of crime and domestic violence.

With respect to the CD-4 count as a biomedical factor, the findings of the current study suggest that CD-4 count is not significant in predicting HRQOL, which is similar to the findings by Au et al. (1999) and Franchi and Wentzel (1998). On the other hand, this contrasts with the findings of a study by Riley, Bangsberg, Perry, Clark, Moss & Wu (2003) that was conducted in the USA among HIV-homeless and marginally-housed individuals. These researchers found that the physical scales were associated with CD-4 count.

A low CD-4 count response to treatment was observed. The study did not explore why the women had a low average CD-4 count despite the fact that 91% were currently on anti-retrovirals. Possible explanations for this condition could be the age of the women, interrupted treatment regime and a low baseline immunological and virological status. Further, the study was not designed to explore the psychological impact of the low CD-4 counts on the participants.

In the case of the other biomedical factor, *time since diagnosis*, the findings indicate that *time since diagnosis* is inversely related to the *physical functioning*, *vitality* and *mental health* domains of the patients. In other words, newly diagnosed patients scored high on these domains. With respect to the relationship between the domains *mental health (MH)* and *time since diagnosis*, the findings suggest that mental health problems and psychological distress (such as feelings of nervousness and depression all the time) are experienced by newly diagnosed patients. Similarly, Riley et al. (2003) found that all the SF-36 scales, including the mental health (MH) scale, were associated with depression.

This finding may be related to contextual factors such as poverty. There is little doubt that growing poverty in many developing countries, particularly in sub-Saharan Africa, is exacerbated by the impact of HIV-related illnesses on adult members of households, who

are usually the breadwinners. Illnesses associated with HIV/AIDS have a negative impact on the socio-economic structure of households, communities and societies in general. Smith (2002) explains that these patterns of vulnerability exacerbate existing poverty and gender inequalities. The illness of the main breadwinner adds the burden of care to the workload of women who eventually may become sick themselves.

The present study found that certain *social variables*, for example *low income, being employed, number of family members (household), marital status* and *having a greater number of children* significantly impacted in a negative way on certain aspects of the health-related quality of life of the women in the study. Olley et al. (2003), in their research on recently diagnosed HIV patients in South Africa, found that HIV/AIDS patients may be at greater risk for psychopathology than patients in certain parts of the developed world, given their additional and potentially stressful living conditions which include high rates of unemployment and poverty; poor and unstable housing and inadequate social services.

The current study showed that both low income and being employed impacted negatively on the health-related quality of life of the respondents. In South Africa, poverty, underdevelopment, poor living conditions, large families; limited access to care and support services are intersecting risk factors for poor mental health status. Although individuals may be employed, their income may be low and families (particularly large families who live in one household) may still live in conditions of poverty. In addition, working women still have domestic responsibilities and may find the burden of work in both settings (formal work and domestic work) impacts negatively on health-related quality of life.

This experience has been found to be *gendered*. Wallace (2004) argues that many women, especially in rural sub-Saharan Africa, define poverty as their prime concern above all others, including the risk or reality of HIV. This experience is gendered as women have less control than men over economic assets, yet they are responsible for the care of children and other family members. Poverty affects men and women

differentially (Hlatshwayo, Gennrich & Njenga, 2004). Women are particularly vulnerable as they directly experience the pressure to feed their children and families and to meet the gendered carer roles in families. Brandt (2007) found that "...poverty was the underlying narrative through which women's experiences of living with HIV was continually filtered" (p. 215).

However, in the regression analyses in this study, it emerged that even the full model, including all the psychosocial variables (*perceived social support, income, employment, number of children, number of family members (household) and marital status*), did not explain the majority of the variance in the SF-36 – the amount of variance was not significant. *This suggests that these variables, when combined, may not be the most suitable variables to explain quality of life.* Au et al. (2004), in their sample of 48 men and 7 women, found that after controlling for all biomedical factors, the psychosocial variables accounted for significant amounts of variance in three of the SF-36 scores: general health (GH) (35%); mental health (MH) (28%); and role emotional (RE) (27%). Judging from the correlation coefficients among these three scales, there could be some underlying constructs linking them, for example, general health may be closely linked to mental health and the way emotions affect everyday functioning. However, for their study Au et al. used the Modified HIV Stressor Scale (HIVSS) as the independent psychosocial variable developed by Thompson, Nanni and Levine (1996). This scale consists of 25 negative life events that are relevant to HIV-infected individuals. It is likely that this scale would have been a better measure of psychosocial factors impacting on the lives of individuals with HIV/AIDS than the measures used in the study reported in this dissertation. Further research should explore this option.

The question of whether individuals currently living with HIV/AIDS experience levels of psychosocial distress comparable to the levels experienced by individuals living with the disease before the advent of antiretroviral therapy is an important one.

In the present study, 121 of the 133 women (91%) were on anti-retrovirals. In future studies, it may be interesting to examine the health-related quality of life and psychosocial characteristics of HIV-infected women *before and after* antiretroviral therapy. Despite much speculation about the potential effect of antiretroviral availability on the psychosocial wellbeing of infected individuals, empirical investigations of this issue are few. Siegal, Karus and Dean (2004) point to the widely held but unexamined assumption that living with HIV/AIDS in the era of antiretroviral therapy may be significantly less distressing than before the advent of protease inhibitors. The danger is that there may emerge a growing tendency to overlook the psychological needs of infected individuals or to reduce mental health resources. Siegal, Karus and Dean (2004) conducted a study on the psychosocial characteristics of HIV-infected women in New York City before and after the advent of highly active antiretroviral therapy (HAART). The findings in their study did not support the notion that the women living with HIV experienced lower levels of psycho-social distress than similarly situated women who had been living with HIV before the availability of HAART. The findings revealing few differences were surprising, given the improved survival afforded by HAART and the diminished stigmatization of AIDS. The findings, however, do not preclude the possibility that HAART availability has improved the quality of life and wellbeing for HIV-infected women in other ways that the study did not measure, for example, women's enhanced sense of control over the disease.

With the group of women in the study reported in this dissertation, it is likely that similar findings may prevail. This may stem from the fact that the women were of lower socio-economic status with a likely heavy burden of poverty, with the burdens of caring for family, low self-esteem and lower social status in their families and communities. Due to *gender-related* cross-cutting factors, their lives may have been of rather low quality and psychologically depressing even *before* they became HIV positive and placed on antiretrovirals.

Despite improved treatments for HIV/AIDS, the findings of the research suggest that there is still a very substantial proportion of HIV-infected women who are psychologically distressed and have difficulty adjusting to illness (Brandt, 2007; Siegel, Karus & Dean, 2004). In her study in South Africa, Brandt (2007) found that inconsistent household income, poor perceived physical health and avoidance coping predicted high levels of depression amongst HIV-infected women. However, longer term use of antiretroviral therapy was associated with reduced depression. This is a key area for further research.

### **5.3 The issue of suicidality (psychological distress) amongst participants**

The results on the suicide scale used to assess the degree of psychological distress indicated that the participants in the present study seldom thought of suicide. However, there was a significant relationship between suicide and perceived social support and time since diagnosis.

In the study, the biomedical variables (time since diagnosis and CD-4 count) did not account for the variance in the suicide scale. Similarly, all the psychosocial factors together accounted for only 7.8% of the variance in suicide scale once the effect of the biomedical variables had been taken into account – suggesting minimal variance. Variables that were significantly associated with the suicide scale, taking into account the effect of all other variables in the model, were *time since diagnosis* and *perceived social support*. There was a significant positive relationship between suicide and the biomedical variable, time since diagnosis. Newly diagnosed participants were less likely to think of suicide as an option. However, debates around this issue are varied. Zibler (2000) argues that psychopathology associated with the HIV/AIDS disease, in particular in the early stages of diagnosis, may reflect a negative impact on patients as they learn that they suffer from a stigmatizing disorder. It is likely that they may begin to anticipate the

traumatic experiences of the medical symptoms, the consequences of losing relationships and support, and possible job loss as a result of the diagnosis.

However, in contrast, Frierson and Lippman (1990) found that AIDS patients *in remission* (that is, some time after diagnosis and treatment) are the most likely to have the necessary energy to complete suicide. In contrast, a study by Brandt (2007) in South Africa found that HIV-positive women displayed higher levels of depressive symptoms than HIV-negative women, *regardless of the stage of their disease*. No difference in depression was evident between HIV-positive women who were asymptomatic, symptomatic and AIDS-sick. Her study suggests that higher levels of depression were predicted by being HIV positive but not by being more seriously ill, and that depression was a function of HIV status and not the severity of the illness. This is clearly an area that needs further research.

The study of psychological distress among HIV-infected individuals can be meaningful and essential for at least three reasons, according to Au et al. (2004). First, the authors state it is important to understand the exact nature of the stressful events contributing to psychological distress. Second, some stressful events may at times be more amenable to intervention than the biomedical factors. Third, a correct understanding of the nature of stressful events is essential in designing and tailoring appropriate psychological intervention for distressed individuals. A *gender perspective* would be useful when designing interventions for what would be most appropriate to the differential (and sometimes the same) needs of women and of men. Seedat (2004) explains that women in the developing world generally face more stigmatization and suffer more negative life events than men, and there is reason to suspect that being diagnosed HIV-positive could lead to more psychological problems among women. However, as the present study comprised of only female participants, no comparisons could be drawn with men's experiences. This is a need for more research on this issue.



In the Au et al (2004) study, stress count, that is, the number of stressful events reported, was found to be strongly associated with HRQOL. The stress count (i.e. the number of stressful events reported) was found to be strongly associated with most measures on HRQOL and psychological distress. In another study, it was interesting to note that the stress count did not appear to have an effect on the SF-36 *mental health* score, though it was positively related to the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). According to Au et al. (2004), one possible explanation could be the relatively better sensitivity of the HADS over the SF-36 in the assessment of psychological distress. The results of the current study suggest that the SF-36 revealed a general measure of HRQOL which might not have been best suited to identifying specific psychological distress elements. Au et al. (2004) suggest that further investigation is needed to examine whether instruments like the HADS will have incremental value in this aspect.

The use of the Suicide Measure to assess psychological distress is a limitation in the present study in that it is not a comprehensive indicator of psychological distress. Au et al. (2004) used the Hospital Anxiety and Depression Scale (HADS) to assess psychological distress which proved to be a more sensitive and comprehensive measure. Martin (2008) in her study that examined psychological distress among a sample of individuals recently diagnosed with HIV used the Hopkins Symptom Checklist (Nettlebladt, Hansson, Stefansson, Borgquist & Nordstrom, 1993). Martin points out that this measure of psychological distress has been used in studies to assess anxiety and depression in a number of cross cultural settings, including in South Africa. Future studies should explore these and other more comprehensive measures of psychological distress.

A further limitation in the present study was that it did not examine closely factors that might precipitate psychological distress, namely thoughts of suicide. In the study by Au et al. (2004) *disclosure* was found to be the most frequently reported stressful event in newly diagnosed participants. Phiri and Webb (2002) suggest that in the initial stages of

diagnosis, the fear of social stigma, fear of experiencing isolation, rejection, marginalisation, being denied jobs or opportunities can lead to feelings of depression, guilt and shame. Such information would help to structure counselling and support interventions in the early stages of diagnosis to help HIV patients reduce stress.

However, it cannot be stressed enough that these interventions must take on a *gendered perspective*. As stated earlier, there are important differences between men and women in many contexts in respect of the underlying mechanisms of the HIV/AIDS infection and the social and economic consequences of HIV/AIDS. These stem from biological factors, sexual behaviour, social norms and the socially constructed gender differences between men and women with respect to access to resources, roles and responsibilities, decision making power, extramarital and premarital sexual relationships and the ability to negotiate safe sex practices. Stigma associated with HIV/AIDS is a major factor which prevents both men and women from accessing health services. But women may be more affected by stigma because of social norms concerning acceptable sexual behaviour and because women tend to be more economically vulnerable than men. However, there are also risks associated with HIV disclosure which can include loss of social, emotional and economic support, blame, discrimination, abandonment and social isolation, physical and emotional abuse and disruption of family relationships (Women in Health and Development, 2006). Women are also sometimes blamed by the family for bringing the disease into the family as they are often the first to be diagnosed, for example, during ante-natal care. When the virus is detected, they may even be rejected or abandoned by their families (United Nations Population Fund, 2005). The data indicate a very low incidence of rape as a probable cause of infection amongst this group of women. Given that South Africa has a very high incidence of rape, it is likely that rape was under-reported by the respondents.

In this study, *social support* was positively associated with *suicidality*. In other words, the women with high social support scored high on the suicidality scale, which means that they seldom thought of suicide. It is likely that social support may have served as a buffer

to the stress of HIV/AIDS in the lives of the participants. However, the *potential* for gaining positive support needs to be considered in the analysis of this issue. Green (1993) points out that social support theories distinguish between three basic types of support that appear most important for people with chronic illnesses: informational, emotional and tangible. Informational support helps people stay grounded in the realities of their condition. Emotional support is offered through affection and empathy. Both informational and emotional support have been shown to reduce the distress of having a chronic illness, including HIV/AIDS, according to Hayes, Turner and Coates (1992). Tangible support is also important for people with HIV/AIDS, particularly at the later stages of disease, when they need help with meals, house keeping, shopping, transportation and other tasks of daily life (Catania, Turner, Choi & Coates, 1992). Counselling can be extremely useful in helping HIV-positive patients discover ways to reduce psychosocial stress and anxiety. Exercise can also be important as a way to reduce stress. Proper nutrition is important in living healthier. Issues related to food and eating, for example, the effects of weight loss on self-esteem, preoccupation with food safety and so forth, need to be brought into counselling, according to Wachtel, Piette, Mor, Stein, Fleishman, & Carpenter (1992).

Again these issues in interventions need to include *gender specific* components. The above social issues may affect women more than men due to their often lower social status and the gendered roles they play in making meals, housekeeping, accessing food sources and other general activities in the domestic sphere. In some societies men are supposed to eat the food first as more value is placed on men. For example, in a study among women in Tanzania and Kenya, Hyder, Maman, Nyoni, Khasiani, Teoh, Premji and Sohani (2005) explored intra-household food distribution. One of the findings was that the husband was served first and the wife ate later with the children. This pattern reflected both a process within households but also differential amounts or quality of food served to men. The researchers conclude that this unequal pattern of food distribution between genders within the household from childhood through adulthood may have long-term nutritional and health implications for women and female children. Such patterns in

households of women with HIV/AIDS may have serious implications for the nutrition and health of women.

#### **5.4 Limitations of the study**

In planning the research study, the number of sexual partners and probable mode of acquiring the infection were included in the questionnaire. As the research progressed it became clear that this data was not relevant to the aims of the study. The researcher recognises the ethical concerns that are raised in collecting data that is not relevant to the study especially when these questions may be sensitive. The questions were deemed relevant during development of the questionnaire.

It may have become evident through piloting the questionnaire prior to embarking on the research that the questions were not relevant and lack of a pilot study is an important limitation. It was recognised that these were particularly sensitive questions, and were handled in a supportive, non-judgemental and respectful manner. Participants were also told that they could ignore the questions if they felt uncomfortable about answering them.

The study design did not allow for exploration of factors that may predispose to suicidality and this investigation was beyond the scope of the study. However, as described in methodology the professional support structures at the facility were available to assist participants identified as experiencing psychosocial distress.

The study did not have a direct control group and would have been strengthened either by collecting data amongst women who were HIV negative or amongst men from similar socio-economic status.

Translation of the measurement tools into isiZulu was done by two Zulu speaking research assistants and discussed with the researcher who has a working knowledge of isiZulu. However, there is a potential limitation in this approach. On reflection, the translated measures ought to have been translated back into English by an independent

isiZulu speaking individual to ascertain whether the translated version was close to the original English version. This process would have ensured greater face- and content validity.

All the measures above have been validated and used in previous studies by international researchers in the field. However, a limitation in this study is that the instrument was not validated in South Africa with the specific patient population in this study, in particular one with a different language.

In the analysis of the results of the study, each sub-scale was assessed separately for significance. However, since there were multiple dependent variables, it would have been more informative to use a multivariate approach to identify significant differences .

## 5.5 Summary

The following picture regarding HIV/AIDS-infected women in the study emerged:

- There was a compromised level of HRQOL (i.e. physical, social and emotional functioning) in the HIV-infected women in the study.
- Perceived social support was inversely related to suicidality, and significantly correlated with two SF-36 domains: *vitality* (V) and *mental health* (MH). Overall, the findings indicated that the women did not have adequate social support in their lives.
- The results indicated a significant positive association between being employed and the women's subjective sense of general personal health (GH). The number of family members negatively correlated with the women's subjective sense of general personal health (GH) – that is the larger the family, the lower the women's perception of their personal health. Similarly, having more children was associated with low levels of physical functioning of the women. Low income

was associated with poor mental health, that is, feelings of nervousness and depression all the time.

- The CD-4 count was not a significant predictor of HRQOL and suicidality.
- Although the women seldom thought to suicide, there was a significant negative correlation between *time since diagnosis* and *suicidality*. Newly diagnosed patients were less likely to think of suicide as an option.
- The biomedical variables (*time since diagnosis* and *CD-4 count*) did not account for the variance in the suicide scale. Similarly, all the psychosocial factors together only accounted for 7.8% of the variance in suicide scale once the effect of the biomedical variables had been taken into account.
- Variables that were significantly associated with the suicide scale, taking into account the effect of all other variables in the model, were *time since diagnosis* and *perceived social support*.

## CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

The study explored the following research questions:

- What is the extent of quality of life and psychological wellbeing of low-income HIV-positive women in the context of limited access to psychosocial resources?;
- What is the relationships among biomedical factors, psychosocial factors and health-related quality of life (HRQOL) and suicidality (psychological distress) of women with HIV and AIDS in KwaZulu-Natal;
- Do psychosocial factors such as self-reported perceived social support, income, employment, number of children, number of family members in the household and marital status contribute to the quality of life and psychological wellbeing beyond the effect of medical condition factors such as time since diagnosis and CD-4 count?

The main finding in this study is that this group of low income women experienced a compromised quality of life and psychological wellbeing. This is consistent with findings in other studies of low income women (for example, Catz et al., 2002; Freeman et al., 2007 & 2008; Souvannarath, 2005; Updegraff et al., 2002). A key recommendation arising from the study is that future research and health care interventions need to continue in efforts to understand and address the needs of this at-risk population group in South Africa. There is also a need to identify specific protective factors that can prevent the risk of developing mental health disorders so that these can be made an integral part of public health interventions for women living with HIV/AIDS.

The biomedical factor, *time since diagnosis* and the psychosocial factor, *perceived social support*, seem to be associated with psychological wellbeing (or extent of psychological distress as measured by the *Suicidality* scale) in this group of women. The psychosocial

factors in this study that did not account for the variance in the suicide scores suggest that there is a need to explore the use of more robust measures to determine both psychosocial factors and psychological distress/wellbeing. This was a limitation in the present study. Similarly, in terms of health-related quality of life, the psychosocial factors in the study did not account for all the variance in health-related quality of life in the participants.

One has to be cautious not to generalise from a small group of women in a particular context, but the findings do have some implications for care and support. The findings point to the need for stress management and coping skills, particularly in the *early stages* of diagnosis. Catz et al. (2004) caution, however, that having such services in isolation is not adequate, but that health care workers need to ensure that low-income women have the support and social power to access these services. Although not a direct focus of this study, the findings point to the need for a *gender-specific approach* aimed at incorporating and benefiting *low-income* women into all HIV/AIDS strategies. The findings indicate that the women in this study did not have adequate psychosocial support from friends, family and community. In addition, certain social/contextual factors, for example low income; being employed; the number of family members in the household; and having more children negatively impacted on aspects of quality of life of the women. These are factors associated with low socio-economic status and are likely to compound psychological distress and negative influences on health-related quality of life in domains measured in this study. The issue of adequate psychosocial support is critical to interventions with this group of women. Brandt (2009) points out in her literature review that although women were well represented in the samples, only 8 of the 23 studies reviewed focussed specifically on women's issues. A recommendation is that this is an area that needs to be prioritised in future research.

It must be noted that a gender perspective would also be useful in interventions to ascertain what would be most appropriate to the differential (and sometimes the same) needs of women and of men. Womenwatch (2006, p. 4) points out that developing countries have not addressed the difficulties that arise on social, psychosocial and moral



grounds to ensure that women, who are deemed a subordinate class in such countries, will not continue to undergo ‚stigmatised suffering’. Increased awareness-raising of how social norms relating to masculinity and femininity may increase risky sexual behaviour, especially targeted to the youth, is necessary. A key recommendation from this study is that there has to be a continued effort made to develop, evaluate and disseminate these gender-specific interventions aimed at improving women’s mental health and quality of life.

Chesney and Folkman (1994) contend that patients need help in reframing their planning processes. They need to feel entitled to set goals and focus on *quality* rather than quantity of life. It is useful to anticipate and expect a patient to respond to the diagnosis of HIV/AIDS infection with a wide range of feelings, for example shock, disbelief, panic, fear, guilt, anger, despair, hopelessness and numbness (Folkman, Chesney, Pollack, & Phillips, 1992). Most people infected with HIV struggle with issues of disclosure to others, particularly when first diagnosed. Interventions need to take into account the gendered nature of the experience of HIV/AIDS. For example, owing to *gender-related factors*, women may experience difficulty in disclosing their status to their partners for fear of abandonment or violence as has been documented in various studies (Gielen, McDonnell, Burke & O’Campo, 2000; Finney & Njoko, 2000; Mathews, Kühn, Fransman, Hussey & Dikweni, 1999). A multi-country World Health Organisation (WHO) study revealed that fear of violence was a barrier to HIV disclosure for an average of 25% of the women, and in some countries the proportion was as high as 86% (Global AIDS Alliance, 2006).

A recommendation is that primary care physicians can play an important role in helping patients adjust to the news of a positive test result. The patients need to address this new information in the context of their *existing identities*, according to Taylor (1983). This involves questioning assumptions about many aspects of their lives, rethinking priorities and goals, and acquiring new skills to accomplish these goals. Goal setting is important because living with HIV is characterized by pervasive uncertainty about the future.

However, one has to be cautious about generalising these findings to women in all contexts in South Africa. This study included a particular group of women who were attending an HIV/AIDS outpatients' support clinic at a public hospital. Furthermore, they were women who were willing to provide self-reports of their psychological wellbeing and health-related quality of life. Thus, there were embedded selection biases in the study. Self-reports have additional limitations such as intentional misrepresentation, inaccurate recall, inaccurate responses due to psychological distress caused by items seen as personal and sensitive, the issue of social desirability impacting on responses, etc. (Reece et al, 2007; Catania, Gibson, Chitwood & Coates, 1990).

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## APPENDICES

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### APPENDIX 1: QUESTIONNAIRE: DEMOGRAPHIC INFORMATION

1. Name:
2. Surname:
3. Address:
4. Age:
5. Date of Birth:  
Height: \_\_\_\_\_  
Weight: \_\_\_\_\_
6. Sex:  
Waist: \_\_\_\_\_
7. Race:
8. Home language;
9. Marital status:
  - Single
  - Divorced
  - Married
  - Partner
10. Number of sexual partners since sexually active:
11. Number of sexual partners (current):
12. Employment:
  - Employed
  - Unemployed
  - Temporary
  - Casual
  - Other: \_\_\_\_\_

13. Place of employment and type of work:

14. Education Level (write grade or qualification, where necessary):

- No schooling
- Primary
- Secondary
- Tertiary (university/technikon)
- Other

15. Religion:

- Christian
- Hindu
- Other \_\_\_\_\_

16. Number of children:

17. Income per month:

18. Source/s of income:

19. Members in household (list number and relationship to participant below)

20. Date of diagnosis:

21. CD-4 count:

22. Probable mode of HIV infection

23. Current Treatment:

- On anti-retrovirals
- Not on antiretroviral

Thank you. Any additional information can be written on back of this questionnaire

**APPENDIX 2: MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT (MPSS) (ZIMET, DAHLEM, ZIMET & FARLEY, 1988)**

- 1-very strongly disagree
- 2-strongly disagree
- 3-mildly disagree
- 4-neutral
- 5-mldly agree
- 6-strongly agree
- 7-very strongly agree

	1	2	3	4	5	6	7
1. There is a special person who is around when I am in need.							
2. There is a special person with whom I can share my joys and sorrows.							
3. My family really tries to help me.							
4. I get emotional help and support I need from my family.							
5. I have a special person who is a real source of comfort to me.							
6. My friends really try to help me.							
7. I can count on my friends when things go wrong.							
8. I can talk about my problems with my family.							
9. I have friends with whom I can share my joys and sorrows.							
10. There is a special person in my life who cares about my feelings.							
11. My family is willing to help me make decisions.							
12. I can talk about my problems with my friends.							

Factor Items: family, friends, significant others.

FAM: 3, 4, 8, 11.

FRI: 6, 7, 9, 12.

SO: 1, 2, 5, 10.

**APPENDIX 3: SUICIDALITY MEASURE\* (SM)** (Adapted from Sheehan, Lecrubier, Harnett-Sheehan, Amorim, Janavs, Weiller, Hergueta, Baker & Dunbar (1998) )

\* A HIGH score reflects LOW suicide tendencies

	0	1	2	3
<p>1. I think that it would be better off to be dead or I wish I were dead</p> <p>0 often 1 sometimes 2 not often 3 very seldom</p>				
<p>2. I think about suicide</p> <p>0 often 1 sometimes 2 not often 3 very seldom</p>				
<p>3. I want to harm myself</p> <p>0 often 1 sometimes 2 not often 3 very seldom</p>				

**APPENDIX 4: INFORMED CONSENT: INFORMATION SHEET AND  
CONSENT FORM.**

Date:

Dear Ms/Mrs \_\_\_\_\_

I am a student at the University of Cape Town, and I am carrying out a small study to try to find out what difficulties women with HIV/AIDS have once they have been diagnosed as HIV positive, and what support women might need so that we can better help them at the hospital in the future.

Any one of our patients will be picked for the interview. Everything that you tell us will be kept very confidential, and your name will be kept anonymous.

If you do not want to participate, please tell us. Please understand that you will still receive the same care at the hospital if you do not agree to be interviewed. Although we would like you to answer all the questions, but if there are any questions, you feel you do not want to answer, please feel free to tell us. We will skip the question and this will not be a problem.

If you have understood all of these things, and if you are ready to make your decision about whether you will take part in this research, please read the next sheet.

Yours sincerely,

---

Dr K M Nair



**CONSENT FORM**

---

I, (Please write in your full name) .....

Please tick:

Agree

I understand the information given to me and agree to take part.

Do not agree

I understand the information given to me and I have decided that I do not want to take part.

Signature: .....

Date: .....

University of Cape Town

**APPENDIX 5: HEALTH-RELATED QUALITY OF LIFE SURVEY (HRQOL) SF-36:  
VERSION 2 (Ware, Kosinski & Dewey, 2002)**

This survey asks for your views about your health. This information will help you keep track of how you feel and how well you are able to do your usual activities.

Answer every question by selecting the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

- |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <b>Excellent</b>      | <b>Very good</b>      | <b>Good</b>           | <b>Fair</b>           | <b>Poor</b>           |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

2. Compared to one year ago, how would you rate your health in general now?

- |  |  |   |   |   |
|--|--|---|---|---|
| <b>Much better<br/>now than one<br/>year ago</b> | <b>Somewhat better<br/>now than one<br/>year ago</b> | <b>About the<br/>same as one<br/>year ago</b> | <b>Somewhat worse<br/>now than one<br/>year ago</b> | <b>Much worse<br/>now than one<br/>year ago</b> |
| <input type="radio"/>                            | <input type="radio"/>                                | <input type="radio"/>                         | <input type="radio"/>                               | <input type="radio"/>                           |

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

- |   | <b>Yes,<br/>limited<br/>a lot</b> | <b>Yes,<br/>limited<br/>a little</b> | <b>No, not<br/>limited<br/>at all</b> |
|---|-----------------------------------|--------------------------------------|---------------------------------------|
| a <u>Vigorous activities</u> , such as running, lifting heavy objects, participating in strenuous sports  | <input type="radio"/>             | <input type="radio"/>                | <input type="radio"/>                 |
| b <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | <input type="radio"/>             | <input type="radio"/>                | <input type="radio"/>                 |
| c <u>Lifting or carrying groceries</u>  | <input type="radio"/>             | <input type="radio"/>                | <input type="radio"/>                 |
| d Climbing <u>several</u> flights of stairs   | <input type="radio"/>             | <input type="radio"/>                | <input type="radio"/>                 |

- e Climbing one flight of stairs
- f Bending, kneeling, or stooping
- g Walking more than a mile
- h Walking several hundred yards
- i Walking one hundred yards
- j Bathing or dressing yourself

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

- |   | All<br>of the<br>time   | Most<br>of the<br>time | Some<br>of the<br>time | A little<br>of the<br>time | None<br>of the<br>time |                       |                       |                       |                       |                       |
|---|---|------------------------|------------------------|----------------------------|------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| a | Cut down on the <u>amount of time</u> you spent on work or other activities                       |                        |                        |                            |                        | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b | <u>Accomplished less</u> than you would like  |                        |                        |                            |                        | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| c | Were limited in the <u>kind</u> of work or other activities                                       |                        |                        |                            |                        | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| d | Had <u>difficulty</u> performing the work or other activities (for example, it took extra effort) |                        |                        |                            |                        | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

5. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

- | All<br>of the<br>time | Most<br>of the<br>time | Some<br>of the<br>time | A little<br>of the<br>time | None<br>of the<br>time |
|-----------------------|------------------------|------------------------|----------------------------|------------------------|
|-----------------------|------------------------|------------------------|----------------------------|------------------------|

- a **Cut down on the amount of time you spent on work or other activities**
- b **Accomplished less than you would like**
- c **Did work or activities less carefully than usual**
- 

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

- Not at all**      **Slightly**      **Moderately**      **Quite a bit**      **Extremely**
- 
- 

7. How much bodily pain have you had during the past 4 weeks?

- None**      **Very mild**      **Mild**      **Moderate**      **Severe**      **Very severe**
- 
- 

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- Not at all**      **A little bit**      **Moderately**      **Quite a bit**      **Extremely**
- 
- 

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks...

- All of the time**      **Most of the time**      **Some of the time**      **A little of the time**      **None of the time**

- a Did you feel full of life?
- b Have you been very nervous?
- c Have you felt so down in the dumps that nothing could cheer you up?
- d Have you felt calm and peaceful?
- e Did you have a lot of energy?
- f Have you felt downhearted and depressed?
- g Did you feel worn out?
- h Have you been happy?
- i Did you feel tired?

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

- |                            |                             |                             |                                 |                             |
|----------------------------|-----------------------------|-----------------------------|---------------------------------|-----------------------------|
| <b>All<br/>of the time</b> | <b>Most<br/>of the time</b> | <b>Some<br/>of the time</b> | <b>A little<br/>of the time</b> | <b>None<br/>of the time</b> |
| <input type="radio"/>      | <input type="radio"/>       | <input type="radio"/>       | <input type="radio"/>           | <input type="radio"/>       |

11. How TRUE or FALSE is each of the following statements for you?

- |  | <b>Definitely<br/>true</b> | <b>Mostly<br/>true</b> | <b>Don't<br/>know</b> | <b>Mostly<br/>false</b> | <b>Definitely<br/>false</b> |
|--|----------------------------|------------------------|-----------------------|-------------------------|-----------------------------|
| A I seem to get sick a little easier than other people | <input type="radio"/>      | <input type="radio"/>  | <input type="radio"/> | <input type="radio"/>   | <input type="radio"/>       |
| B I am as healthy as anybody I know                    | <input type="radio"/>      | <input type="radio"/>  | <input type="radio"/> | <input type="radio"/>   | <input type="radio"/>       |
| C I expect my health to get worse                      | <input type="radio"/>      | <input type="radio"/>  | <input type="radio"/> | <input type="radio"/>   | <input type="radio"/>       |

**D My health is excellent**



*Thank you for completing these questions!*

University of Cape Town

## APPENDIX 6: The Eight SF-36 Scales by Item Number

SCALES	ITEMS
Physical Functioning	3a+3b+3c+3d+3e+3f+3g+3h+3i+3j
Role-Physical	4a+4b+4c+4d
Bodily Pain	7+8
General Health	1+11a+11b+11c+11d
Vitality	9a+9e+9g+9i
Social Functioning	6+10
Role-Emotional	5a+5b+5c
Mental Health	9b+9c+9d+9f+9h

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