AN EXPLORATION OF EXPRESSED EMOTION AND THE QUALITY OF LIFE RELATIONSHIP IN ISIXHOSA PEOPLE LIVING WITH HIV/AIDS IN EAST LONDON

Research Project By

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DECLARATION

I declare that "an exploration of expressed emotion and the quality of life relationship in isixhosa people living with HIV/AIDS in East London" is this author's original work and has never been submitted by the author or anyone else at any university for fulfilment of a degree. All the sources that i have used or quoted have been indicated and acknowledged by means of a complete reference list.

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PENWELL MUTIZE

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DEDICATION

This research project is dedicated to my dear departed wife Tambudzai Mutize who untimely passed away here in East London supporting me in my academic endeavour, may her soul rest in eternal peace.

To the special one Julian and my children Tinotenda, Tafara, Tsungirirai and Tanatswa for enduring long periods of time without me, guys I know we should be spending quality time together.

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ABSTRACT

The Level of Expressed Emotion (LEE) is a measure of perceived emotional climate of one's social environment. The measure has been used in previous studies in predicting relapse in schizophrenic patients and other psychological disorders. This study sought to investigate the relationship of the level of expressed emotion and the quality of life of people living with HIV/AIDS. The LEE scale and the World Health Organisation Quality of Life- HIV were administered to 72 participants who indicated to be HIV positive and a control group of 43 participants who indicated to be HIV negative. The LEE scale's four dimensions of intrusiveness, emotional response, attitude towards illness and tolerance/expectation was used to establish the overall level of expressed emotion of the participants. The quality of life of people with HIV was found out to be relatively higher than that of HIV negative participants. The results also indicated an inverse correlation between the level of expressed emotion and the quality of life that participants perceived themselves to have. Male participants were found to have higher EE than female participants and the quality of life was generally low for males than females. The findings suggest that future interventions in HIV positive people should take into account their home environment and issues of care and support in their families.

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CHAPTER 1: INTRODUCTION

Acquired Immune Deficiency Syndrome (AIDS) is a societal disease in the most profound sense because it is linked to specific ways of life. The disease is grounded in the conduct of social life and its potential to change norms, values, sex habits and lifestyles in the world is enormous. AIDS is caused by a virus called the Human immunodeficiency virus (HIV), transmitted through sexual intercourse, intravenous drug use, blood transfusion or passed to newborn infants at birth by pregnant mothers. By the end of 2008, United Nations Acquired Immune Deficiency Syndrome (UNAIDS, 2008) reported that an estimated 33 million adults and children were living with HIV/AIDS. On a regional basis two thirds of the people living with HIV/AIDS are in sub – Saharan Africa. Visser (2007) reports that 5.7million people in South Africa were infected by 2004, that is, 12% of the total population. Visser (2007) also reported that today South Africa has more infected people than any other country in the world.

He further states that HIV/AIDS is often accompanied by stigma and discrimination possibly because it is associated with many taboos, such as blood, death, promiscuity, homosexuality, drug abuse and sex work (Visser, 2007). Because of the stigma attached to HIV/AIDS people living with HIV/AIDS experience discrimination and a loss of traditional social networks. People sometimes prefer not to disclose their status and live in denial and secrecy. People living with HIV/AIDS (PLWHA) experience many emotions such as fear, loneliness, anger, anxiety, depression, shame, blame and hopelessness (Skinner & Mfecane 2004). For some people living with HIV/AIDS the shame and guilt of contracting the disease far outweighs the actual physical effects of the virus (UNAIDS, 2002). Thus the rate of depression among HIV positive individuals was found to be higher than the general population (Kaplan, Marks & Mertens, 1997). The emotional experience of an HIV positive diagnosis poses two aspects of self perception that can complicate positive coping abilities, that is, perception of self as undeserving and unworthy of care and the related tendency to see oneself as being responsible for contracting the disease (Visser, 2007). These negative perceptions about self make it difficult for the HIV positive person to deal with the host of problems that he/she needs to deal with. These include dealing with intimate relationships, family and friends, coping with losses, deciding about lifestyle, medication and social support.

HIV/AIDS impact has been felt in all social spheres. The Health sector report for the South African Department of Health (2003) revealed that the prevalence of HIV/AIDS in health workers was an estimated 15.7%. This is higher among young health workers (18-35 years) where the prevalence is 20%. It further asserts that without life prolonging drugs such as anti-retrovirals (ARVs) South Africa can expect to lose 16% of its health workers in the future. The health delivery system has additional pressure to bear with as the epidemic matures, the demand for care for those living with HIV increases, as does the toll of AIDS on the health sector. The report also highlighted that absenteeism was rampant among health workers and 16.2% of them were treated of stress related illnesses. This was caused by low staff morale where 33.8% of the workers had low morale due to stressful working conditions, heavy patient workload, staff shortages and low salaries. The education sector of Southern Africa has also been affected, with pupils and teachers being significantly affected. HIV research shows that it flourishes in areas with high unemployment, homelessness, illiteracy, welfare dependency, prostitution, crime and low levels of school attendance (Visser, 2007).

Social support is an important buffer for family caregivers of people living with HIV/AIDS (PLWHA). With limited formal options, these caregivers have to rely increasingly on informal networks. Yet this avenue is fraught with difficulty due to the stigmatization of the HIV infection (D' Cruz, 2002). This research focused largely on the sources of support and the circumstantial effects of the interaction between the PLWHA and their relatives. Little attention has been given to the understanding the emotional well-being of PLWHA in developing countries despite the fact that emotions may impact on people's sense of purpose and value, and ultimately their ability and resolve to hold livelihood and familial responsibilities together (Thomas, 2006).

The concept of expressed emotion (EE) is a measure of the family environment that has been demonstrated to be a reliable psychosocial predictor of relapse especially in schizophrenia, depression and anorexia (Butzlaff & Hooley, 1998; Hooley & Teasdale, 1989). EE measures the quality of social interaction between the caregiver/relative and the index patient and can be rated as high or low. The attitudes expressed by caregivers or relatives have been found to affect the patient in a positive or a negative way (Hooley & Teasdale, 1989). In recent times, researchers who have investigated the concept of EE have remained with few exceptions, at a descriptive level, without trying to conceptualise why EE influences the course of a disorder. Most researchers rely on the concept of vulnerability, namely on the stress-diathesis model. In this framework, high EE is conceived as a stressor that can provoke relapse by increasing the patient's arousal beyond an optimal level. However, little is known about mechanism of relapse or precisely why emotions related to high EE supposed trigger arousal and relapse of schizophrenia (Migone, 1993).

High EE families are defined as those in which at least one family member is extremely critical of the index of the patient both verbally and non verbally, and low EE families as those who do not express hostility towards the index patient (Oltmanns, Neal & Davidson, 1991). EE is conceived as a stressor that sets up conflict relationship between patient and relatives. Studies have also revealed that high EE also impairs maximal benefits of medication and that the course of illness is worsened by an atmosphere of high EE (Cohen & Syme, 1985). EE may be considered as an indicator of the emotional "temperature" of the family, a sign of the intensity of the emotional level of a given relative in a given time period (Migone, 1993). HIV/Aids calls for the concerted efforts of all members within a family to relieve the patient of the psychological challenges that comes along with it and the stressful experiences that accompany it.

The stigma surrounding HIV/AIDS makes life more difficult for PLWHA and their families. Support groups have been set up to help in alleviate the loneliness, anxiety, stress, confusion, bitterness and depression that make people more vulnerable to their illness if they don't get support. PLWHA need a lot of emotional, spiritual, psychological, social, physical and clinical support. Different people have different institutions that can provide some support but it is important for PLWHA to come together and support one another (UNAIDS, 2006). In these support groups PLWHA would map out what would better their hopes, joys, anxieties, fears and needs and they can define how best they want to be understood and treated. The most common needs for PLWHA include health and medical supplies, skilled medical services, counseling to reduce isolation and promote acceptance. Community support groups provide safe places where feelings and advice can be shared, social acceptance, nutritional help and accurate information about HIV/AIDS (UNAIDS, 2006). This study explores the expressed emotions that characterize the families of HIV positive people and their quality of life and makes a comparison with HIV negative participant's family experiences.

1.1. Background to the study

The fact that there is no cure for the HIV/AIDS pandemic makes the understanding of expressed emotions within a family one of the pillars of hope in mitigating the effects of the disease and prolonging the lives of those living with the virus. Family members are de facto caregivers while willing or not, but there is stress that affects family dynamics (D Cruz, 2002). The concept of EE, a measure of attitudes expressed by caregivers or relatives is one of the most important discoveries in the field of psychosocial treatment of disorders like schizophrenia in the past few decades. EE consists of hostility, criticism and emotional over-involvement (EOI) by relatives that tend to be more intrusive; use of controlling behavior and inducing of feelings of guilt in the patient (William, 1993).

Psychotherapeutic techniques derived from EE studies use a psychoanalytic framework. In the decades after the concept of EE was introduced, the authors who have investigated the EE concept have remained at the descriptive level without trying to conceptualise why the understanding of EE influences the course of disorder in terms of treatment response and relapse (Migone, 1993). However, little is known about the mechanism of relapse or precisely why the emotion related to high EE supposedly trigger arousal and relapse in schizophrenia (Migone, 1993).

EE is conceived of as a stressor that sets up a conflictual relationship between patient and relative. Studies reveal that high EE also impairs maximal benefits of medication and that the course of illness is worsened by an atmosphere of high EE (Cohen & Syme, 1985). EE measures the quality of social interaction between the carer and the patient and it can be rated as high or low (Oltmanns et.al, 1991). In research involving schizophrenia, it has been established that the course and outcome of the illness are significantly influenced by the family's emotional environment as measured by EE. This background formed the foundation of this research in terms of the EE in isiXhosa speaking PLWHA in the East London town of South Africa.

1.2. Research Aim

This study aims at establishing whether there is an association between the level of expressed emotion in the families of PLWHA and the quality of life people living with HIV/AIDS who are on ARVs and those who are not on ARVs. The further aim is to establish the same associations across the gender divide in the isiXhosa speaking PLWHAs East London town of South Africa.

1.3. Research Objectives

This research seeks to:

a) Examine the relationship between Expressed Emotion (EE) and quality of life on male and female people living with HIV/AIDS in the Xhosa speaking community of East London town of South Africa.
b) Find out if there are gender differences on the impact of expressed emotion on people living with HIV/AIDS in PLWHA in the East London town of South Africa.

c) Find out if there are differences in the level of EE in PLWHAs who are on ARVs and those that are not on ARVs.

1.4. Research questions

Is there an association between the level of level of expressed emotion and the quality of life people living with HIV/AIDS across the gender divide in the isiXhosa speaking PLWHAs East London town of South Africa? Is the use of ARVs associated with low EE compared to non-use of ARVs?

1.5. Significance of the study

It is envisaged that this study may contribute to the discussion about HIV/AIDS emotional support and the quality of life of people infected or affected by HIV/AIDS. In absence of a cure for HIV/AIDS the correct attitudes and emotional involvement by family members and relatives will go a long way in prolonging the lives of those living with the virus. EE studies are a way in which what goes on in families is understood to affect the development and course of severe psychiatric syndromes. The study would show that family variables, which together with biological and psychological factors play a role in the development of severe disorders, and would show how EE is associated with being HIV positive. The study represents a model of clinical research that remind of the need for biopsychosocial models of dealing this pandemic because theories of the etiologies based on variables from a single domain (biology, psychology, or social systems) not only fail to capture the complexity of such syndromes, but lead to endless searches for simple explanations which are not to be found. The study is anticipated to also help in providing some valuable insights in the provision of home-based care services and the merits of being on ARVs when one is HIV positive.

1.6. Chapter Summary and overview

This chapter sought to set the research in motion by introducing the problem and its background. The chapter also attempted to elaborate on the link between expressed emotions within the families of PLWHA and the perceived quality of life that they would experience. The importance of support groups was also expounded on. The aims, objectives and the significance of this study were also discussed in this chapter.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter focuses on the theoretical formulations of the concept of expressed emotion and the origins of the concept. The HIV/AIDS pandemic is also extensively discussed in the chapter including the strains that it causes, estimates of people living with HIV/AIDS in the world, Africa and South Africa. The issues of family and health in view of expressed emotion also formed part of this chapter. Literature on the conceptualization of illness in the Xhosa culture is also discussed. This would help in understanding the kinds of expressed emotions that the participants would reveal as they are from a predominantly Xhosa community.

2.2 The Concept of Expressed Emotion

The concept of expressed emotion (EE) was introduced more than 50 years ago by Brown, Carstairs and Topping (1958) to explain why some individuals with schizophrenia who had been discharged to household characterized by criticism, hostility and emotional over-involvement, that is high levels of expressed emotion relapsed at significantly higher rates than those discharged to households that were not characterized by such attitudes, that is, low expressed emotion families. Behaving in a critical and hostile manner and behaving in an emotionally over-involved manner is non-conscientious (Butzlaff & Hooley, 1998). Hooley and Teasdale (1989), have also demonstrated that the more EE a patient's family and friends show, the greater the chance that a patient suffering from depression will relapse.

Previous research with respect to people living with HIV/AIDS has highlighted social support as an important determinant of health outcomes. Perceived support has been found to be associated with adjustment and coping in relation to HIV diagnosis and its potentially chronic, disabling course (Britton, Zarski, & Hobfoll, 1993; Crystal & Kersting, 1998; Friedland, Renwick, & McColl, 1996; Grummon, Rigby, Orr, Procidano, & Reznikoff, 1994)

The above will be considered in respect of people living with HIV/AIDS to establish the relationship between expressed emotion and their quality of life. Criticalness is the first aspect of EE and this is when friends or family members of patients act in a disagreeable way by using critical remarks, either explicitly or implicitly, which suggest disapproval of the patient's actions (Hooley & Gotlib, 2000). Hostility is another aspect of EE and this is when family members or friends of the patient criticise the patient for behaving badly because of the patient's internal characteristics or perceived character flaw (Hooley & Gotlib, 2000). Emotional over-involvement the other aspect of EE, is excessive and disproportionate involvement in the patient's life. Emotionally over involved relatives render self-sacrificing responses to the patient's illness, overprotection of the patient, and extreme worry when the patient is not around them (Hooley & Gotlib, 2000). The kinds of emotions that family members express would determine whether the index patient would be stigmatized or not.

Discussions of stigma, particularly in relation to HIV/AIDS, have taken as their point of departure in the now classic work of Goffman (1963), defining stigma as an attribute that is significantly discrediting which, in the eyes of society, serves to reduce the person who possesses certain distinctiveness. Drawing on research experience with people suffering from mental illness, possessing physical deformities, or practicing what has been perceived to be socially deviant behaviours such as homosexuality or criminal behaviour, Goffman (1963) argued that the stigmatized individual is thus seen to be a person who possesses an undesirable difference. He argued that stigma is conceptualized by society on the basis of what constitutes difference or deviance, and that it is applied by society through rules and sanctions resulting in what he described as a kind of spoiled identity for the person concerned (Goffman, 1963).

The theoretical analysis of the quality of life concept facilitates an exploration of the disparity between the ways that the healthy body is positioned within the medical discourse and the subjectively constituted notion of well-being. It is important to note that quality of life is a subjectively constituted notion rather than a clinical outcome (Wong & Ussher, 2008). They further assert that the concept of quality of life has been used in a wide range of contexts and has become a significant consideration in health care, including the care for those with HIV. Quality of life has been examined in relation to treatment use, side effects from treatment use and mental health issues relating to HIV infection.

2.3 HIV/AIDS

The estimated number of persons living with HIV worldwide in 2007 was 33.2 million, a reduction of 16% compared with the estimate published in 2006 of 39.5 million (UNAIDS/WHO, 2006). Sub-Saharan Africa has an estimated 22 million people living with HIV/AIDS, that translates to 67% of the total global estimates (UNAIDS, 2008). Of the total difference in the estimates published in 2006 and 2007, 70% are due to changes in six countries,

Angola, India, Kenya, Mozambique, Nigeria, and Zimbabwe. In both Kenya and Zimbabwe, there is increasing evidence that a proportion of the declines is due to a reduction of the number of new infections which is in part due to a reduction in risky behaviours (UNAIDS, 2007).
Every day, over 6800 persons become infected with HIV and over 5700 persons die from AIDS, mostly because of inadequate access to HIV prevention and treatment services. The HIV pandemic remains the most serious of infectious disease challenges to public health. Nonetheless, the current research would go along way in ameliorating the effects of this pandemic.

South Africa is the country with the largest number of HIV infections in the world (Visser, 2007). UNAIDS (2008) notes that South Africa's Department of Health estimates that 18.3% of adults (15–49 years) were living with HIV in 2006, rising to 38.7% in 2009. More than half (55%) of all South Africans infected with HIV reside in the KwaZulu-Natal and Gauteng provinces. Rising death rates lowered life expectancy at birth to 41 years for males and 46.5 years for females in 2008. HIV prevalence among pregnant women is highest in the populous KwaZulu-Natal province (37%) and lowest in the Western Cape (13%), Northern Cape (16%) and Limpopo (18%) provinces. In the five other provinces (Eastern Cape, Free State, Gauteng, Mpumalanga and North West) at least 26% of women attending antenatal clinics in 2006 tested HIV-positive (UNAIDS, 2008).

South Africa is currently experiencing one of the most severe AIDS epidemics in the world. At the end of 2007, there were approximately 5.7 million people living with HIV in South Africa, and almost 1,000 AIDS deaths occurring every day (UNAIDS, 2008). The suffering that HIV has caused in South Africa is enormous. UNAIDS (2008) statistics shows that almost one in five adults are infected, HIV is widespread in a sense that can be difficult to imagine for those living in less-affected countries. For each person living with HIV, in South Africa and elsewhere, not only does it impact on their lives, but also those of their families, friends and wider communities. The prevalence of misinformation about AIDS in South Africa has not only hampered efforts to increase access to treatment, but has also created a climate of confusion in which prejudice towards people living with HIV thrives. HIV is sometimes seen as being a disease of the poor. In South Africa, there is some correlation between extreme poverty and high HIV prevalence, although HIV is prevalent across all sectors of society (Inter Press Service, 2000).

2.4 Families and health

Other factors in the development of psychological problems may include family interactions. Studies have shown that women with eating disorders come from families where there is low nurturance (Humphrey,1986), high conflict, low warmth, low cohesiveness, poor tolerance of independent behavior or expression of feelings (Johnson & Flach, 1985) or needs, low involvement and support, and high levels of disorganization (Humphrey, 1986). Expressed emotion is a particular combination of family interaction patterns, which predicts course of illness and recovery in several psychiatric disorders including eating disorders. Studies have shown that expressed emotion, which consists of critical comments, hostility, emotional overinvolvement, and lack of warmth or positive comments, is associated with treatment outcome for women with eating disorders (Kog & Vandereycken, 1989).

The American Association for Marriage and Family Therapy (AAMFT), (2002) says schizophrenia has a devastating impact on all members of the family. Schizophrenia is a severe and persistent mental disorder that affects 1% of the population. The disorder is marked by the distortion of experiences, thoughts, and feelings, and often weakens the ability to function in such areas as education, work, interpersonal relations, and self-care. Schizophrenia poses significant challenges for both clients and families. For example, family members usually need to cope with their caregiving responsibilities, their own emotional distress, the symptoms of schizophrenia, increased stress and disruption, the mental health system and social stigma. As caregivers, families share three essential needs, that is, need for information about schizophrenia and the mental health system, for skills to cope with the disorder and its consequence for their family, and for support for themselves. Of course, each family has unique concerns and needs, which are likely to change through time. Even within a given family, the needs of individual members differ for parents, spouses, siblings, and offspring of people with schizophrenia. Communities differ as well. Some communities offer excellent services for clients and families, while others offer relatively few.

AAMFT (2002) opines that depression as a mood disorder, but also recognizes that its symptoms can vary widely from one person to another. It is also accurate to think of depression as a complex problem that can affect many different aspects of the sufferer's life. It can affect the body, and generate such physical symptoms as insomnia, fatigue, appetite disturbances, diminished sex drive, and anxiety. It can affect the mind, interfering with the ability to think clearly, notice and remember details, and make good decisions. It can affect emotions, causing feelings of sadness, despair, guilt, worthlessness, and apathy. It can affect behavior, leading to alcohol or drug abuse, suicide attempts, and other socially or self-destructive behaviours. It can affect interpersonal (social and family) relationships, leading to aggression, withdrawal, or marital and family distress. It further states that the hopelessness and helplessness that people experience when they are depressed is more than just a frame of mind at such times, it is an entire way of being. People stop trying, they stop caring, they withdraw from life, and of course, this makes them feel even worse. Their lives deteriorate, and it affects others as well. Family members are not immune to the depressive's negativity, the never-ending complaints, the steady stream of criticisms, the lack of emotional closeness, and the loss of the ability to have fun together. Spouses can feel hurt and alienated, and children may feel guilty, resentful, and as if they are to blame. In turn, family relationships can also exacerbate depressive symptoms.

2.5 Family and HIV

HIV/AIDS disproportionately increases the vulnerability of families. As soon as one family member is affected, everyone in the family suffers, not only because of the human tragedy but also owing to economic difficulties resulting from rising healthcare costs and decreasing income. Therefore, supporting the strength of families and family networks is instrumental to improving the capacity of this future generation to cope with the disease and its consequences. The social stigmatisation of victims by community and family members of HIV/AIDS infected persons into their daily activities needs to be on the integration programmes run by governments and AIDS organizations (UNAIDS, 2008). Stigma directed at PLWHA not only makes it more difficult for people trying to come to terms with and manage their illness on a personal level, but also undermines the ability of individuals, families and societies to protect themselves and provide support and reassurance to those affected. In the majority of developing countries families are the primary caregivers when somebody falls ill. There is clear evidence that families play an important role in providing support and care for PLWHA. However, not all family responses are positive. HIV-infected members of the family can find themselves stigmatised and discriminated against within the home. There is concern that women and non-heterosexual family members are more likely than children and men to be mistreated (Woudenberg, 1998).

The education sector of Southern Africa has also been affected with pupils and teachers being significantly affected. Children dropping out of school because of orphanhood. HIV/AIDS robs the smallest unit of society which is the household with "social security" as productive members of the family are taken out of the equation when they become ill and die, leaving children and the elderly to take care of themselves. UNAIDS (2002) says some strategies adopted in Malawi for example in the light of this situation children marry earlier, drop out of school and take on informal labour schemes. In the event that the children are abandoned by the extended family they tend to become street children and engage in antisocial behavior and prostitution. Without sufficient social and welfare structures uncared for orphans can result in significant problems with juvenile crime in communities. Dr Peter Piot UNAIDS Executive Director (2004) has predicted that reaching the top of the bell for some of the African societies means national bankruptcy, pushing households into poverty and starvation, people ending up in streets and then UNAIDS will be giving food aid instead of investing in HIV prevention .The compound effect of the AIDS crisis is to encompass national development and household economies plus a whole range of challenges surrounding poverty and inequality. HIV research shows that it flourishes in areas with high unemployment, homelessness, illiteracy, welfare dependency, prostitution, crime and low levels of school attendance (Visser, 2007).

2.6 HIV/AIDS home based care

Africa has of late experienced a shift in the model of care for people living with HIV/AIDS from hospital care to home based. A large number of people living with HIV/AIDS find themselves seeking more medical attention than any other person. Even though this might be the case, the hospitals that should be the ones providing them with such attention, have found themselves in shortage of staff, medicines and space. This therefore means that the patients will have to be taken care of at home (Akintola, 2004). He further state that countries with a high prevalence of HIV are found to be having an overstretched health system, a shortage of resources, lower number of beds and health workers. This therefore contributes to the overburdening of health sectors and has therefore resulted into HIV people being treated at home.

As much as there is a benefit to home based care (being surrounded by the people they love and are familiar with) there is also some hardship that the people caring for them might be faced with. As people living with HIV/AIDS may require assistance in most of what they do this might end up overwhelming the people taking care of them and might result in the psychological needs of the person living with HIV being disturbed (Akintola, 2004). Thus, it is this result in different kinds of emotional states in the home that tend to have a bearing on the patient's recovery outcome.

2.7. HIV/AIDS and Antiretrovirals

In 1996, a breakthrough occurred in HIV treatment (UNAIDS, 2002). The development of antiretroviral therapy (ART) has dramatically lowered morbidity and mortality in countries where it is widely available. In New York City, for example, with the highest incidence of HIV and AIDS in the United States, death rates from AIDS and new AIDS cases have both been reduced by half since the introduction of ART. Similar reductions are seen everywhere that therapy is available including South Africa. ART is complicated, however; the treatment does not cure HIV and therapy is lifelong. A combination of drugs must be used. To avoid the development of drug resistance, people must adhere strictly to the regimen without missing doses and take pills on time, once, twice or more a day. Thus, a regular and reliable supply of drugs must be available.

UNAIDS (2002) further opines that despite these difficulties, the need for and benefits of treatment are undeniable. ART and other HIV treatment not only keep people alive longer, they also provide a better quality of life, allowing people to return to work and school, take care of their families, and contribute to their communities.

2.8. Conceptualisation of illness in Xhosa culture: Implications for HIV/AIDS and expressed emotion

Life in African societies is modelled in collective communities that value ubuntu and the Xhosa culture is no exception. The concept of "ubuntu" according to Alia (2006) is not easily translatable but roughly meaning 'kindness, humanity, sharing" and often used to stress the corporate nature of African societies; the individual never takes precedence over the group. In Xhosa society this is expressed as "umntu ngumntu ngabantu" (a person is a person through other people) usually guides the nature of interaction amongst people in the Xhosa community.

According to Cheetham and Cheetham (1976) rural Xhosa people of South Africa have retained social cohesion through traditional custom, purity of language and the dominant role of ancestor worship, traditional medicine and witchcraft in lifestyle, beliefs and ceremonies. Abstract concepts are limited and ego defence mechanisms include projection, displacement and rationalization but cognitive disturbances per se are not regarded as important. Major attention is paid to severe cognitive and affective disturbances, ascribed to object or spirit intrusion, witchcraft or sorcery, which necessitate treatment by a traditional "witchdoctor". Therapy is community orientated as far as possible unless uncontrollable violent behaviour necessitates referral to a hospital. This understanding would to some extent influence the participants who in one way or the other constantly look up to their culture in search of solutions to problems.

Studies have suggested that up to 80% of the South African population consult with traditional healers before psychiatric hospitalisation (Mzimkulu & Simbayi, 2006). In response to this fact, there has been an increasing acceptance of the need for a more holistic approach by western-type psychiatric health services to include alternative medicine practices such as traditional healing as an adjunct to the treatment that is provided to patients. Some understanding of the conceptualisation of diagnosis, aetiology, and treatment of psychosis especially by African traditional healers is important to communication between western and traditional approaches to the management of psychosis in multi-cultural environments such as that found in South Africa.

Mzimkulu and Simbayi (2006) revealed that due to the strong traditional influences among Africans, who form the overwhelming majority of the population, western-trained healers often tolerate traditional medicine within the western health care settings as some patients and/or their relatives insist on it. This occurs with both in-hospital and out-of-hospital patients, including among those who are highly educated and/or prominent in politics and business. This is an issue that is a major challenge in modern-day Africa, as it is throughout the rest of the world, as often there is a clash between traditional and western or modern ways of treating illnesses.

The above understanding of illness amongst the Xhosa community is very important as it would inform the kind of life that respondents would reveal. The cohesiveness and the community centeredness among the Xhosas and the traditional belief in the culture make it very interesting to follow up on the variety of emotions that the respondents would be experiencing. Illness in a family would be traced to ancestral displeasure that needs to be atoned for. The shared responsibility within the family and the communal beliefs in whatever happens in the family would cause a pattern of EE that would be unique to this sub-African culture.

2.7 Chapter Summary and overview

This chapter covered the concept of expressed emotion chronicling its origins and the studies that have been undertaken with schizophrenic and anorexics. The concept was tied to the HIV/AIDS pandemic with a view to find out how expressed emotions would help in mitigating the ease with which PLWHA and their families can find a common understanding in the quest for a better quality of life with the index patient. The family's involvement in health and HIVAIDS issues were also part of this chapter. This literature on the conceptualisation of illness in the Xhosa culture was also reviewed to put into context the implications that it would have on the HIV/AIDS illnesses within the population.

CHAPTER 3: METHODOLOGY

3.1. Introduction

This research was a quantitative cross- sectional survey on the relationship between of expressed emotion in urban HIV positive individuals in the town of East London in male and female participants who are in a support group and not in support group who would have a control group of HIV negative participants. The design, measuring instruments, sampling method and procedure that were followed in conducting this study would be discussed below.

3.2. Design

This research was a self reporting study in people living with HIV/AIDS on the expressed emotion in their lives and the quality of life they perceive themselves to be having in view of such expressed emotion. The study focused on participants in the HIV positive category who are on (ARVs) and those who were not on ARVs from support groups and those not in support groups in the urban setting of East London. There is also a control group of HIV negative participants that participated for the purposes of comparisons and generalization of the study. The inclusion and exclusion criteria was that participants should have been 18 years and above in the Xhosa speaking community. This was to do away with issues of having to seek consent from parents or guardians for respondents hence the legal age of consent at 18. This ensured that consent can be sought from the participants themselves.

The participants were divided into groups, namely those with high expressed emotion and those with low expressed emotion as determined by the scores produced from the Level of Expressed Emotion scale (LEE scale); those on ARVs and those not on ARVs and those who were members of support groups and those who are not members of support groups. The research further sought to establish whether gender is associated with high or low EE and whether membership in a support group was associated with low EE. The groups would be compared and contrasted in terms of the quality of life as determined by the World Health Organisation Quality of Life Scale (WHOQOL HIV). The research sought to establish the correlational effect between the expressed emotion and the quality of life of the participants in the groups.

The research was dealt with in two studies that were in the following hypotheses:

Study 1

H1: Participants rated high on the level of expressed emotion (LEE) scale would have a lower quality of life.

H2: Participants rated low on the LEE would have a high quality of life.

H3: Participants who are HIV negative would have a low EE and high quality of life.

H4: Participants who are HIV positive would have a low quality of life.

H0: Level of expressed emotion and one's HIV status does not have an effect on the quality of life of participants.

Study 2

H1: PLWHA and are members of support groups would have a high quality of life.

H2: PLWHA who are not members of support groups would have a low quality of life.

H3: Participants who are on ARVs would have a high quality of life.

H4: Participants who are not on ARVs would have a low quality of life

H0: Being a member of a support group and use of ARVs does not have an effect on the quality of life of PLWHA.

3.3. Sample

72 participants that are in the category of being HIV positive and 43 in the HIV negative status completed the questionnaires in a purposive sampling method. The participants consisted of 40,9% (n=47) male participant and 59,1 % (n= 68) female participants.

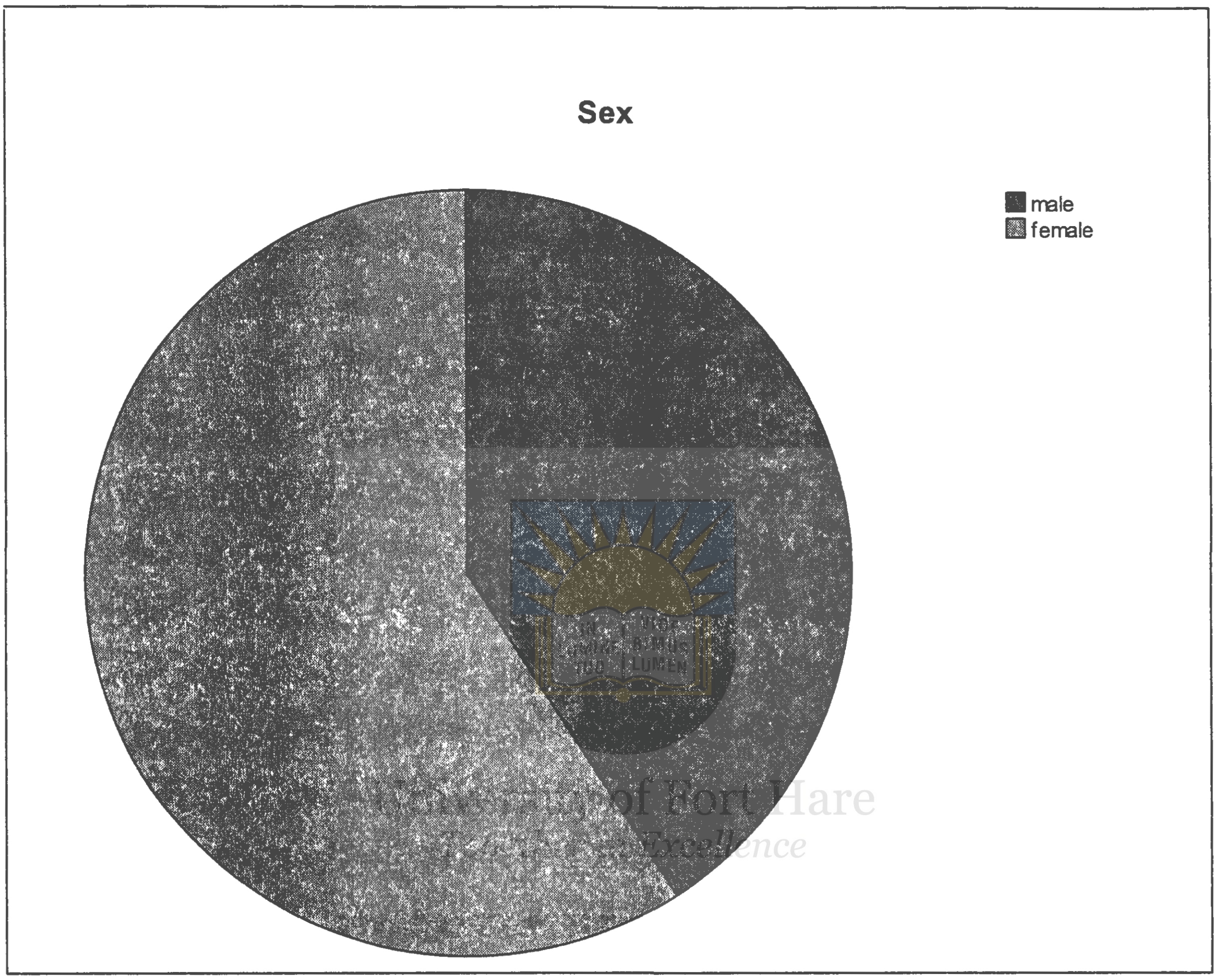

Figure 1. Descriptive statistics for the people that participated in this study, males (47) and females (68), (N=115).

Most of the participants that took part in the study were females and a few males also participated as compared to the females.

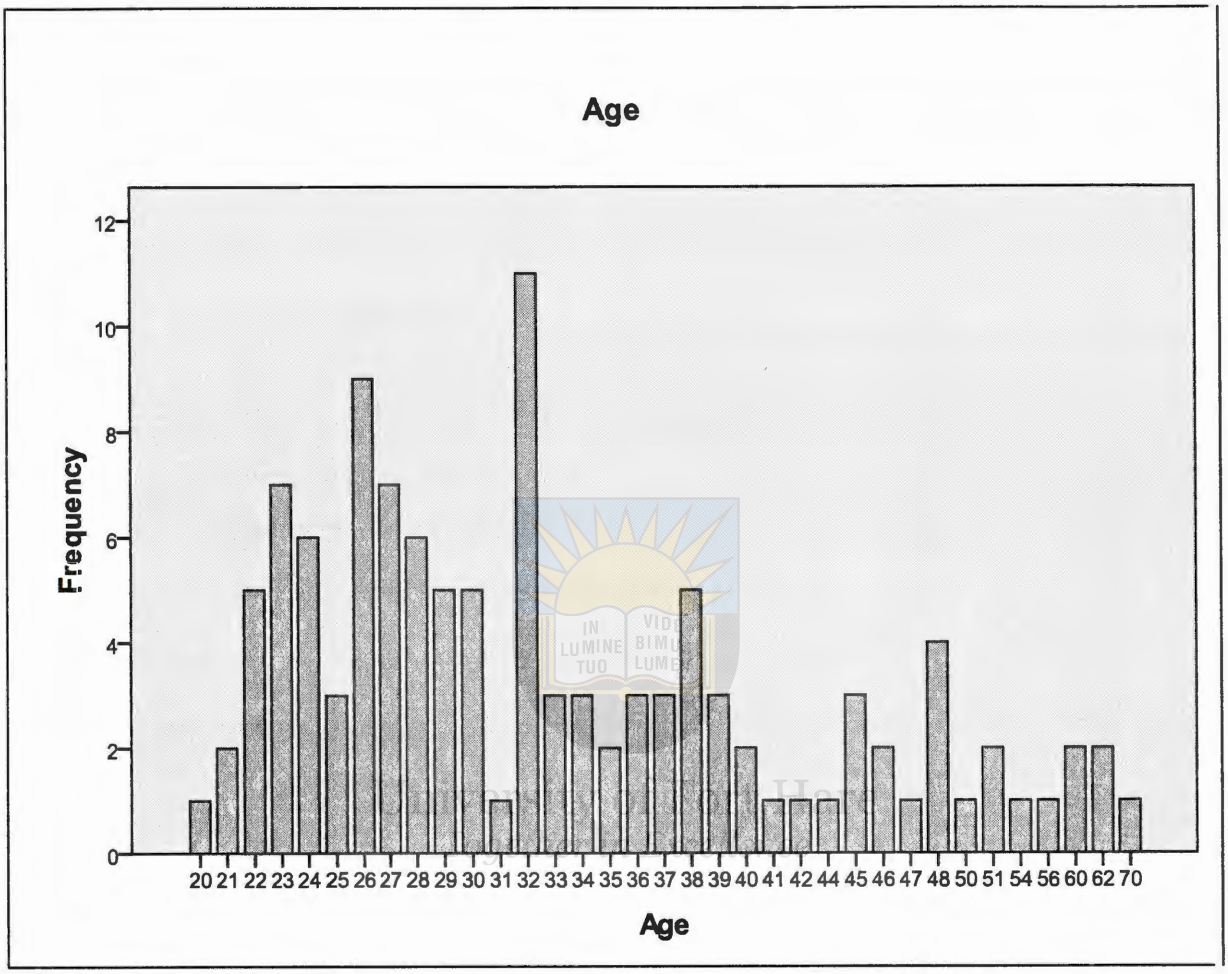

Figure 2. Descriptive statistics for the ages of people that participated in this study, (N=115). The participant's ages ranged from 20 years to 70 years of age most people were in their late twenties and in the early thirties (n=53) and the minority of the participants were in their early twenties and above 60 (n=3).

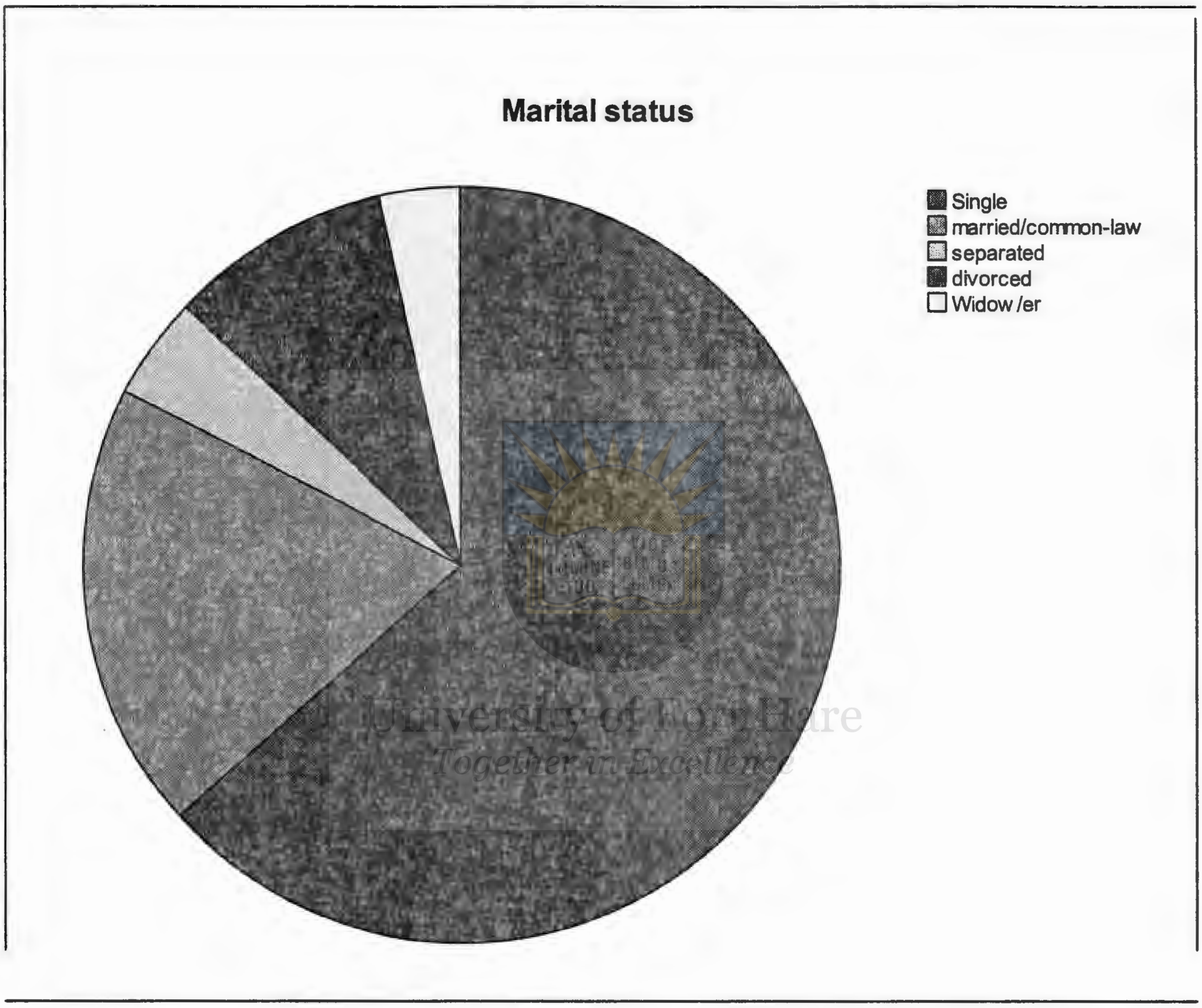

Figure 3. Descriptive statistics for the marital statuses of people that participated in this study, (N=115).

Most participants were single 63,5% (n=73), participants who were married were 19,1% (n=22), separated 4,3 % (n=5), divorced 9,6% (n=11) and widowed 3,5% (n=4) .

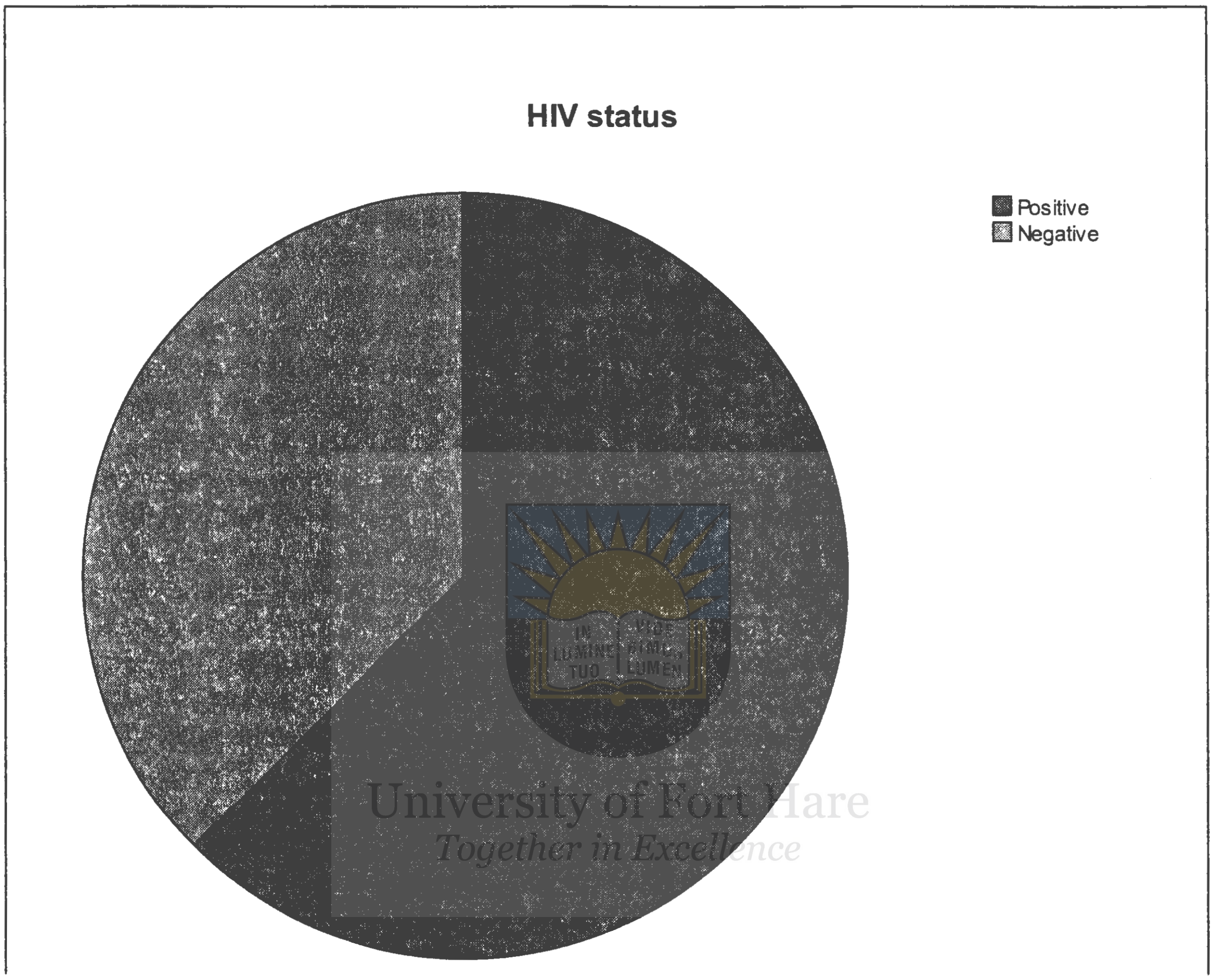

Figure 4. Descriptive statistics for participants' HIV status in this study, (N=115).

Most of the participants were HIV positive 62.6% (n=72) while 37.4% (n=43) were HIV negative.

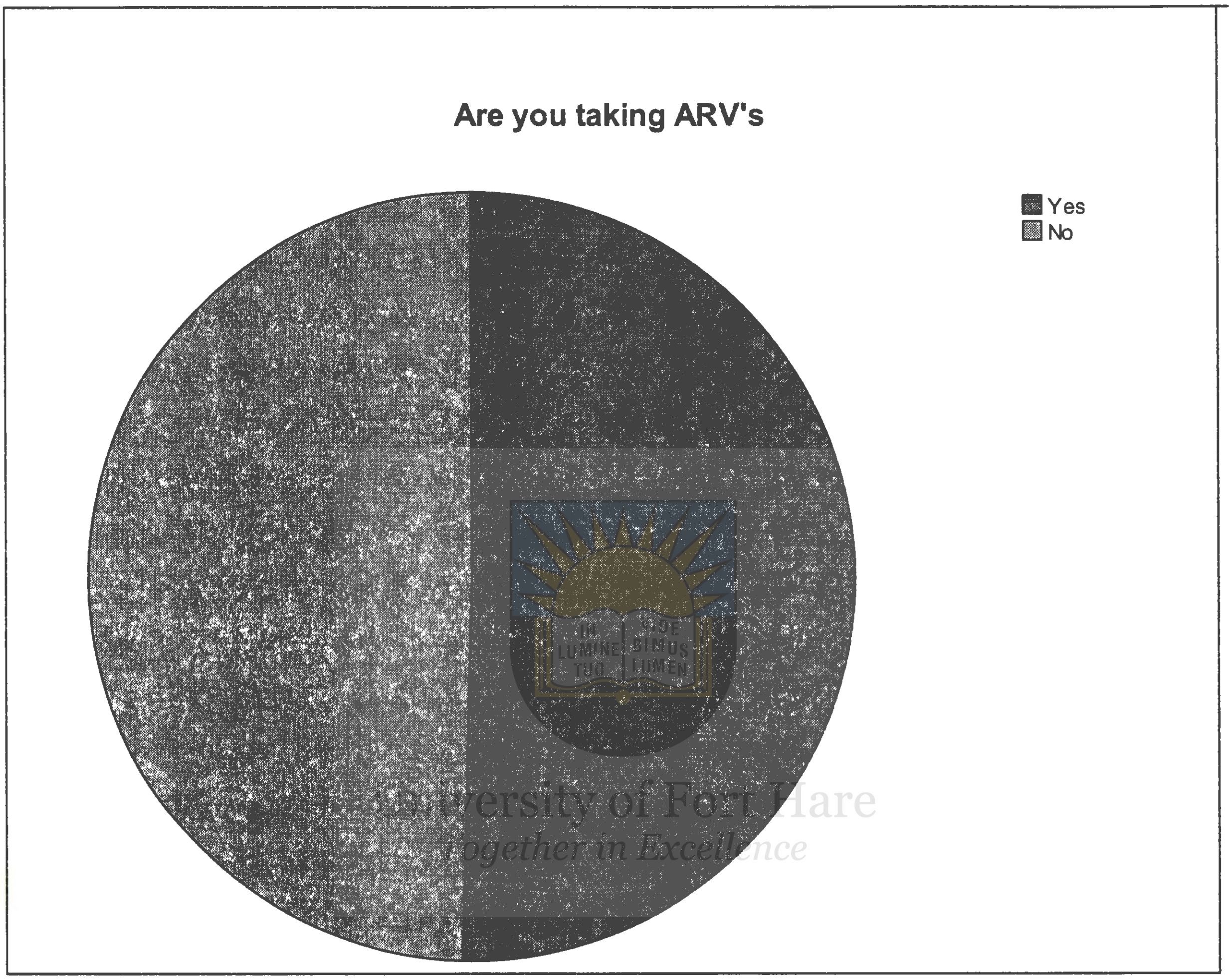

Figure 5. Descriptive statistics for participants' HIV status in this study, (N=115).

Almost half of the participants were on ARVs 50.4% (n=58) and those not on ARVs 49.6% (n=57).

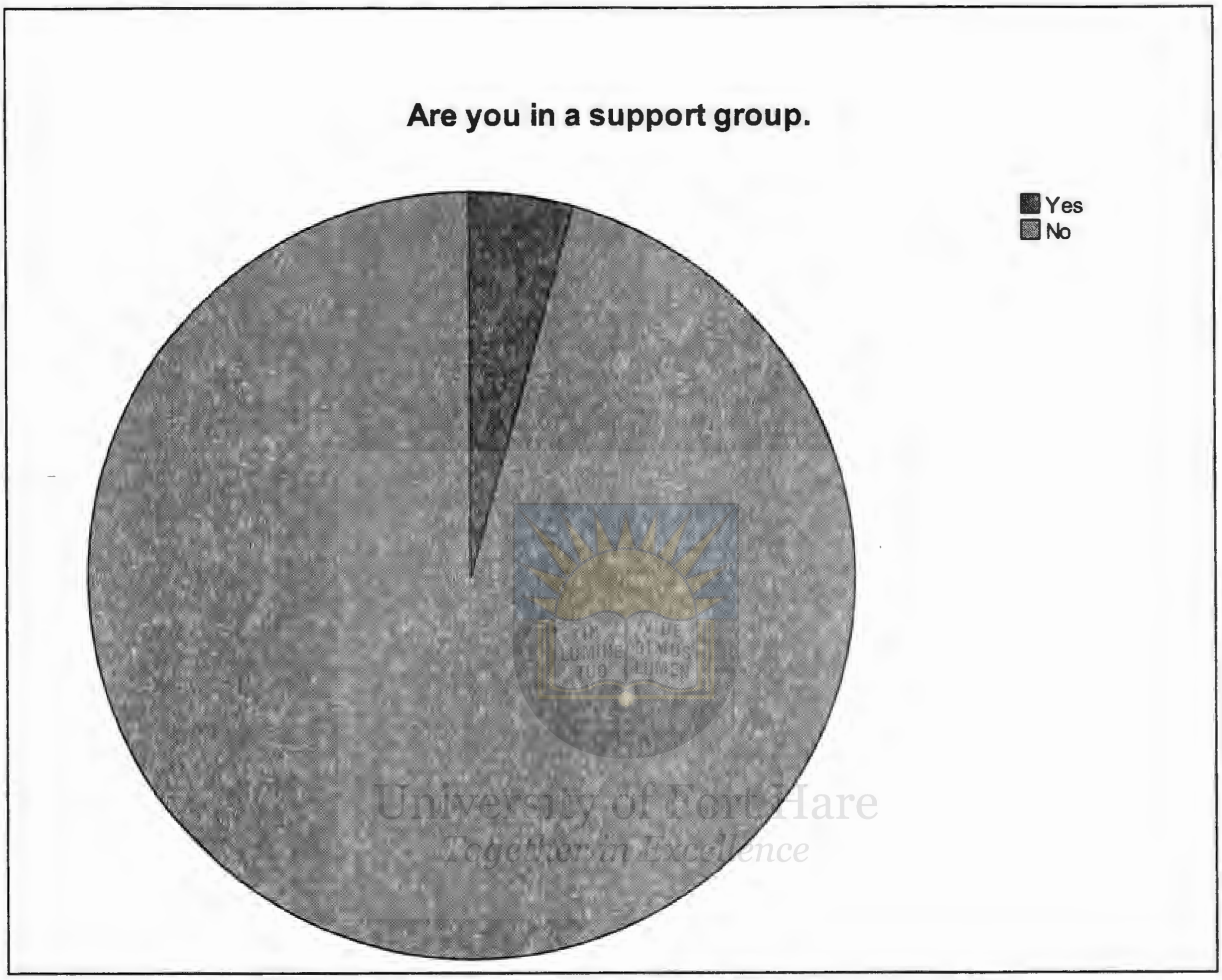

Figure 6. Descriptive statistics for support group membership among participants in this study, (N=115).

The majority of the participants were not in a support group 95.7% (n=110) and the minority were in a support group 4.3% (n=5).

The sample characteristics could be summarized as comprising of 115 participants of which 72 indicated to be HIV positive and 43 indicated that they are HIV negative. The average age for the participants was 33.3 years and ranged from 20 years to 70 years. The average age for the HIV positive group was 37.2 years ranging from 22 to 70 years, while the average age for the HIV negative group was 26.6 years ranging from 20 to 40 years. The HIV positive group was relatively older than the HIV negative group. Of the 115 participants 47 participants indicated to be male and 68 indicated to be female. The HIV positive group indicated to have 24 males and 47 females. The HIV negative group indicated to have 22 males and 21 females. The HIV negative group had a fairly balanced gender composition. The sample had 73 people who indicated to be single, 22 married, 11 divorced, 5 separated and 4 widowed. The HIV positive group had 45 single participants, 14 married, 7 divorced, 3 separated and 3 widowed. The HIV negative group had 28 single participants, 8 married, 4 divorced, 2 separated and 1 widowed. From the HIV positive group 58 participants indicated are on ARVs (80.6%) and 5 indicated to be in a support group (4.3%).

This study used nonprobability purposive snowballing sampling techniques. This was due to the nature of the subject of study which only included those that are HIV+ and in the social settings they are not readily available for participating hence the random snowballing. Purposive sampling can be very useful for situations where you need to reach a targeted sample quickly and where sampling for proportionality is not the primary concern. With a purposive sample, you are likely to get the opinions of your target population, but you are also likely to overweigh subgroups in your population that are more readily accessible. The researcher does not know in advance how many subjects are needed. The use of nonprobability sampling is less desirable if the object of the research is to generalize. It is appropriate for generating theory and a wider understanding of social processes. The major difficulty lies in being unable to determine the sampling error. This disadvantage can be mitigated by working with homogenous populations or enlarging the sample.

3.4. Ethical Considerations

This study involves one of the most sensitive topics in contemporary society and because of the highly personal and sensitive nature of the research in HIV/AIDS participants are to be fully appraised of what participating in the study would entail. The participants voluntarily consented to take part and a written informed consent was obtained thereof. Procedures to protect the right of the participants (informed consent, human rights, and debriefing) were followed. The confidentiality of information disclosed was explained to participants and it was followed as such in its strict sense. In case participants as a result of participating in the study suffer psychological distress provision of counselling services was made.

3.5. Procedure

The Psychology Department of the University of Fort Hare researchers follow the Ethics Committee of the University, these were followed throughout the conduct of the research. On receiving the approval from the Department of Psychology relevant target participants were then identified and their consent was sought to participate. The Buffalo City Health Municipality was approached to conduct research at Moore Street Clinic, Notyatyambo Clinic in Mdatsane Township of East London and Frere Hospital. With support from the supervisor the researcher approached formal structures in East London like clinics, hospitals, support groups and HIV and AIDS organisations such as Light of Hope. Participants were also approached from other structures like support groups, in particular Light of Hope support group in Duncan Village in East London. Meetings with prospective participants were arranged. Full explanation of the nature and purpose of the study, confidentiality and access to research were discussed. The participants signed informed consent forms before participating in the study.

Data was collected using interviewer administered questionnaires. The questionnaires were in English and where the participant did not understand the questionnaire the researcher translated in isiXhosa. The participants were urban based HIV+ male and female participants that were in support groups and those that were not. The target group was culture specific that is Xhosa, and focus on the beliefs about health and sickness of HIV/AIDS individuals in East London.

The control group comprised of HIV negative participants who were University of Fort Hare students from East London campus and local residence in Quigney in October 2009. All the participants filled in questionnaires that were administered to them by the researcher and a translator was used at the hospitals.

3.6. Measures

Two questionnaires the WHOQOL-HIV and the LEE scale were used. The two measures are readily constructed. The WHOQOL_HIV was constructed by the World Health Organisation and the Level of Expressed Emotion scale (LEE) is a questionnaire designed to measure the perception of expressed emotion, an important predictor of the course of several psychiatric disorders.

3.6.1. World Health Organisation Quality of life-HIV (WHOQOL-HIV)

The WHOQOL_HIV is questionnaire specifically designed by the World Health Organisation for people living with HIV/AIDS. Quality of Life was assessed using the scales suggested by the WHO (2002). Different versions of this instrument exist (WHOQOL-HIV, 2002). The scale assumes 24 facets which are pain and discomfort, energy and fatigue, sleep and rest, positive feelings, cognitions, bodily image, negative feelings, mobility, daily living activities, dependence on medication, work capacity, personal relationships, social support, sexual activity, physical safety and security, home environment, financial resources, health and social care, opportunities for new information and skills, leisure, physical environment, transport and spirituality/religion/personal beliefs. These facets are grouped in six domains which are physical, psychological, level of independence, social relationships, environment and spirituality/religion/personal beliefs.

The WHOQOL questionnaires were designed by the World Health Organization to measure the impact that disease and health intervention have on quality of life. There is a 100-item version (WHOQOL-100), and an abbreviated version (WHOQOL-BREF). The abbreviated version which contains 78 items is the one that was used in this research. Both versions categorize quality of life into six domains scores—physical, psychological, social relationships, spirituality, level of independence and environmental health across 24 facets of quality of life (WHO, 2002).

The six domain scores denote an individual's perception of quality of life in the aforesaid domains. Individual items are rated on a 5 point Likert scale where 1 indicates low, negative perceptions and 5 indicate high positive perceptions. Such domains and facet scores are scaled in a positive direction where a higher score denote a higher quality of life. Some facets (pain and discomfort, negative feelings, dependence on medication, death and dying) are not scaled in a positive direction, meaning that for these facets higher scores do not denote higher quality of life. These need to be recoded so that low scores reflect better quality of life. This instrument does not provide an assessment of the individual facets within the domains.

The WHOQOL-HIV is a self report measure which assesses individual's perceptions of their position in life in the context of the cultural values and systems in which they live in relation to their gals, expectations, standards and concerns (WHO, 1995).

In the present study only 16 items of the 79 item WHOQOL questionnaire (2002) were used. The reason to use only selected items for the present study was to shorten the answer time for the questionnaires. The 16 items which were used from the 73 item scales are provided in the Appendix. Since only 16 items were used the original multi-dimensional structure of the instrument could not be considered in the present study. Consequently, the 16 items were summarized to an overall measure of quality of life.

The concept of quality of life however is subjective and is deeply embedded in the cultural, social and environmental context. The WHOQOL-HIV questionnaire a copy of which is attached in the appendix was used to assess the participants' quality of life.

3.6.2. Level of Expressed Emotion Scale (LEE)

The Level of Expressed Emotion (LEE) scale was developed by Cole and Kazarian (1988) to provide an index of the perceived emotional climate in a person's influential relationships. Unlike other existing measures, the scale was constructed on the basis of a conceptual framework described by expressed emotion theorists.

The scale underwent extensive psychometric development procedures that include theoretically based item generation, pilot testing with normal psychiatric populations to select the final items and construct validation within a schizophrenic population. The results were quite favourable and indicate that the LEE scale has sound psychometric properties of internal consistency, reliability, independence from sex, age and amount of contacts and construct validity (Cole & Kazarian, 1988). This self report questionnaire measures the perceived EE initially it was used with schizophrenic patients. Cole and Kazarian (1988) selected items based on a study by Vaughn and Leff (1981) that suggested that there were four dimensions that could discriminate between high and low EE. These are intrusiveness, emotional response, negative attitudes towards illness and tolerance and expectations concerning the patient.

Cole and Kazarian (1988) formulated 15 true or false questions for each component of the four dimensions. Scores are calculated for these four scales as is a total score. A participant is classified as high EE when his score lies above the median. The manual of the scale provides an answer pattern based on which the final overall score for the level of expressed emotions as well as the scores for the respective subscales can be calculated (Cole & Kazarian, 1992). Since there is lack of empirical evidence to determine the cut-off points for the LEE scale, that is, to distinguish between high and low scorers, it was decided in accordance with Cole and Kazarian (1992) to use the median split for all four subscales. The respective medians for the four subscales were as follows: the HIV positive group had an intrusiveness median of 7 while the HIV negative group had median of 4. The HIV positive group had a median of 3 for emotional response while the HIV negative group had a median of 2 for the same. The median for attitude towards illness subscale for the HIV positive group was 3.5 while the HIV negative group had a median of 2. The HIV positive group had a median of 4 for tolerance /expectation while the HIV negative group had a median of 2. Participants who scored below the median were classified as low level of expressed emotions, while participants who scored above the median were classified as low level of expressed emotions.

The scales have good internal consistency, good test-retest reliability and temporal stability (Cole & Kazarian, 1988). The LEE scale (Cole & Kazarian, 1992) a copy of which is attached in the appendix was used to assess the participants' level of EE.

3.7 Validity and Reliability

The initial testing sites were in India in 1997. The instruments are currently available in English, Hindi, and Tamil, and are in the process of being translated into other languages (AIDSQuest, 2009). The dimension scores for the longer version exhibited good content validity, discriminate validity, test-retest reliability, and internal consistency, and analyses of the abbreviated version are ongoing. Testing has found that the WHOQOL-Bref correlated highly with a Cronbach alpha

(0.9) with the WHOQOL-100 (AIDSQuest , 2009). The 16 items from the WHOQOL scale used in this present study revealed to have had a good internal consistency with a Cronbach's (.83) for the whole sample. The Cronbach's alpha for the HIV positive group was (.81) and for the HIV negative group (.76).

The predictive validity of the LEE has been tested (Kazarian, Mala, Cole& Barker, 1990; Kazarian, Mazmanian, McDermott, & Olinger, 1991) and the predictive validity was also tested with schizophrenic patients by Cole & Kazarian, 1993. It was found out that the LEE scores are associated with the outcome and that this association is independent of the demographic, social and clinical characteristics examined. It demonstrated a predictive utility among schizophrenic patients who were at risk of rehospitalisation, (Cole & Kazarian, 1993).

3.8 Data Analysis

With data having been collected it was analysed using the Statistical Package for Social Scientists (SSPS) software. The software was used to establish the descriptive statistics, frequencies and correlations that existed among the instruments and the various subscales of the instruments. The SSPS was used to check, recode data and compute domain scores that were observed, (WHO, 2002).

3.9 Chapter Summary and overview

This chapter dealt with the research design of this study, discussed the sample characteristics and the ethical consideration that were guiding the conduct of this research. The procedure that was followed for data collection and the measures that were used were also a part of this chapter. The data analysis method which was used is also part of this chapter. The results would be discussed in the next chapter.

CHAPTER FOUR: RESULTS

4.1 Introduction

This chapter discusses the findings of the research. The various sample characteristics that were identified in this research will be discussed and the data that is specific to the sample characteristic will be discussed. The analysis of the LEE and WHOQOL_HIV scales would be done. The research hypotheses testing will also be presented in this chapter. The data here discussed was analysed using SSPS data software version 17.0.

4.2 Results

It was hypothesized that people who are HIV positive would have high EE compared to HIV negative people. The results of the independent samples t-test of the overall EE score confirm the hypothesis in that HIV positive participants (M = 18.93, SD = 8.75) scored significantly higher on the EE measure than HIV negative participants (M = 12.61, SD = 9.14), t (113) = 3.69, $p < .001$.

It was further hypothesized that HIV positive would score lower on the quality of life measure compare to HIV negative people. The results of the group comparison using independent samples t-test confirmed the assumption since HIV negative participants (M = 3.93, SD = 0.37) scored significantly higher on the quality of life measure than HIV positive participants (M = 3.35, SD = 0.61), t (113) = -5.62, $p < .001$.

The second hypothesis stated that participants who are on ARVs and those who are not on ARVs differ in their EE and Quality of Life. The results indicated that there is no difference in the overall EE score between participants who are on ARVs (M = 19.39, SD = 8.97), (n = 58) and those are not on ARVs (M = 17, SD = 7.74), (n = 14), t (70) = 0.92, $p > .05$. On the use of ARVs results also indicate that participants on ARVs (M = 3.32, SD = 0.61), (n = 58) and participants who are not on ARVs (M = 3.45, SD = 0.63), (n = 14) do not differ in their quality of life scores, t (70) = - 0.67, $p > 0.5$. The reason that no differences were found could be caused by the differences in numbers in the two groups. The sample population for participants was 58 whereas for those not on ARVs was14. The differences in the populations do not give a favourable comparison.

The third hypothesis stated that female participants will have higher EE and low quality of life compared to their male counterparts. The gender analysis of EE showed that HIV positive male participants have higher scores on EE (M = 24.04, SD = 8.36), (n = 25) whereas their female compatriots scored significantly lower (M = 3.45, SD = 0.63), (n = 47), t (70) = 3.97, $p = .001$. The male participants were also found to have low quality of life (M = 3.06, SD = 0.62), (n = 25) as compared to the female participants (M = 3.49, SD = 0.56), (n = 47), t (70) = - 3.04, $p < .01$.

The age analysis of the participants did not show any significant difference in scores for EE and quality of life, the median split was used to determine between the younger and the older participants and the position was on 35 years. The overall EE <35 years (M = 19.25, SD = 9.89), (n = 36) whereas for >/= 36 (M = 18.61, SD = 7.56), (n = 36), t (70) = 0.31, $p > .05$. There was also no significant difference in the quality of life between the groups <35 years (M = 3.39, SD = 0.57), ($n = 36$) and the >/= (M = 3.31, SD = 0.66), ($n = 36$). t (70) = 0.57, $p > .05$.

The hypothesis on support group membership could not be tested because the number of people who indicated to be in support group was very few (4.3%) as compared to those that were not in support group (95.7%).

In order to conclude that the found gender differences among HIV positive participants are genuine it was decided to conduct a two-way between-group ANOVA which controls for main and interaction effects. A 2 (Gender: male versus female) x 2 (HIV status: HIV positive versus HIV negative) design was used with level of EE and quality of life, respectively. The results revealed a main affect of HIV status (but not of gender) and an interaction effect of gender and HIV status on level of EE. HIV positive participants (M = 18.93, SD = 8.75) scored significantly higher on EE measures than HIV negative participants (M = 12.60, SD = 9.14), F (1,111) = 20.55, $p < .001$. The significant interaction effect, F (1,111) = 10.95, $p < .01$, is illustrated in Figure 7.

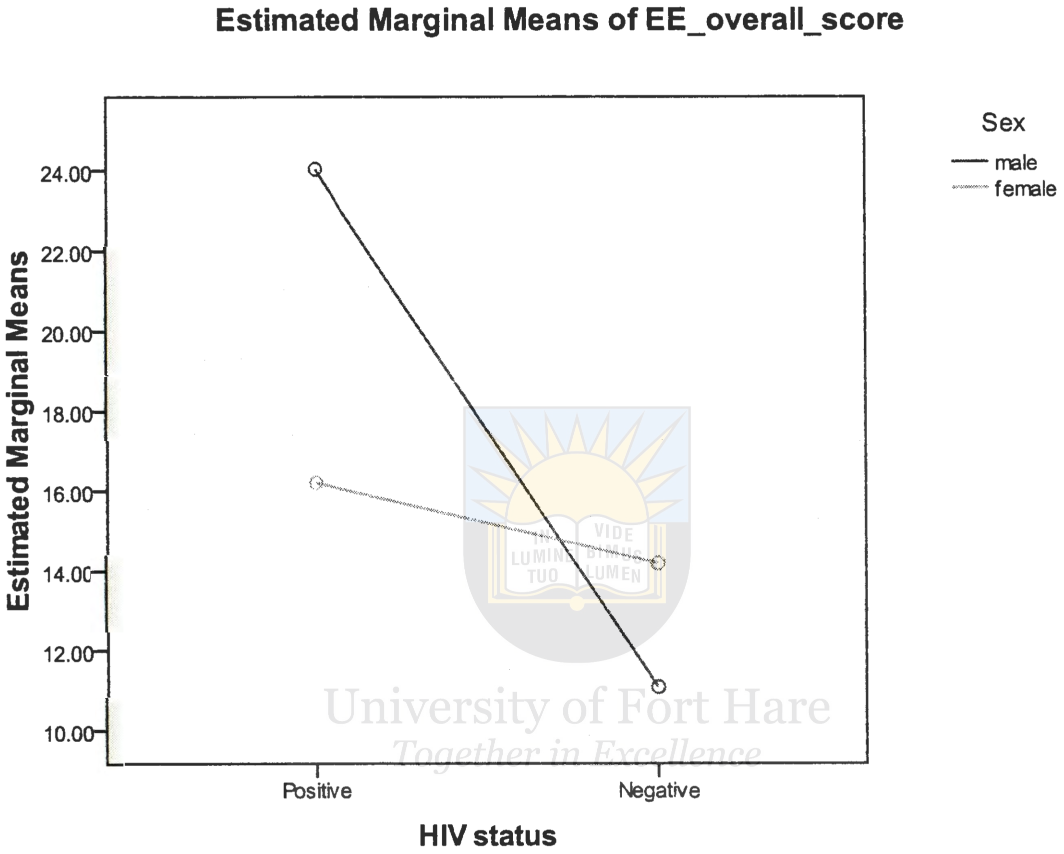

Figure 7: Interaction between Gender and HIV Status on level of EE

As the slope of the two lines (representing males and females) in Figure 1 indicate, the interaction refers to male participants, which means, that the level of EE increases significantly for males who are HIV positive compared to females, whose level of EE seems not to be affected as much by their HIV status.

For the dependent variable quality of life similar results were found. HIV status had a main effect, *F* (1,111) = 41.04, $p < .001$, that is to say, HIV positive participants (M = 3.35, SD = 0.61) scored significantly lower on the quality of life measure than HIV negative participants (M

= 3.93, SD = 0.37). Again, the interaction between gender and HIV status revealed to be significant, F (1,111) = 6.22, $p < .05$. Again, the slope of the two lines (representing males and females) in Figure 2 show that the interaction refers to male participants, that is to say, the level of quality of life decreases particularly for males who are HIV positive compared to females, whose quality of life seems not to be affected as extremely by their HIV status.

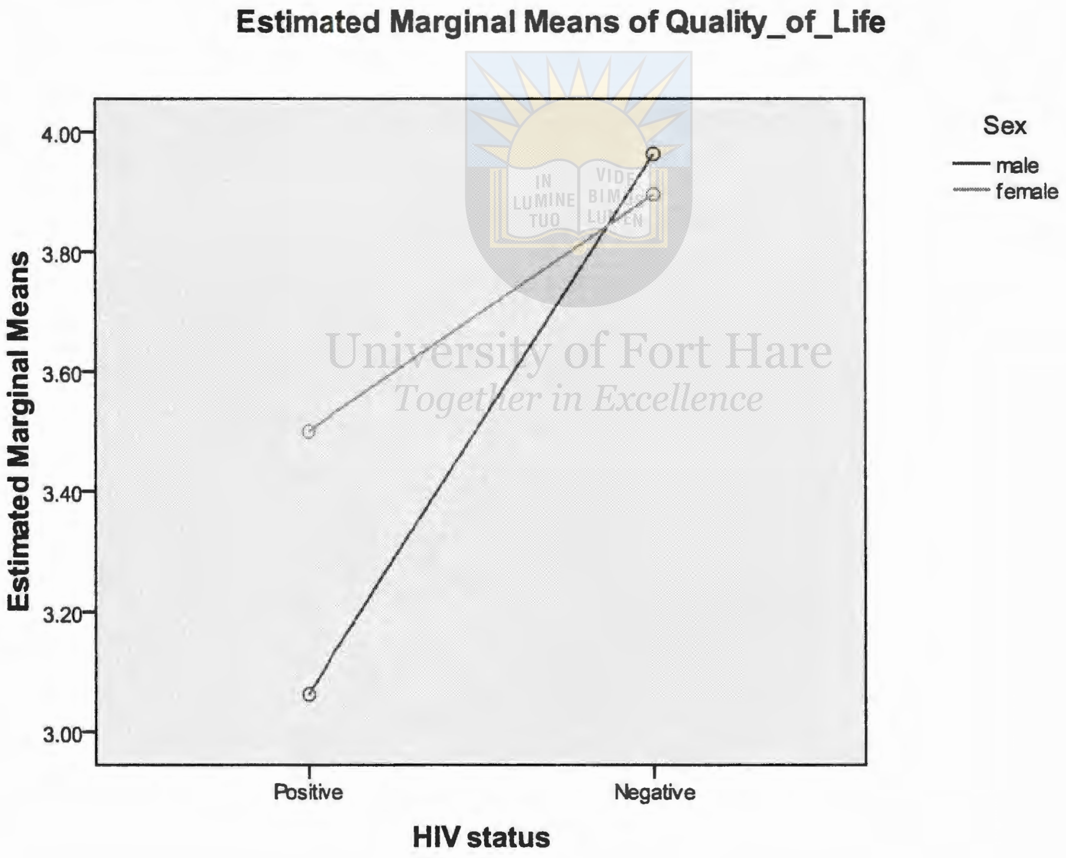

Figure 8: Interaction between Gender and HIV Status on quality of life

4.3 Chapter summary and overview

The chapter attempted to give an overview on the results that were found from the administering of the questionnaire. The scales that were used were analysed for the results that were obtained from the participants. The hypotheses were also tested against the participant's responses.

CHAPTER FIVE: DISCUSSION

5.1 Introduction

This chapter rounds up the study by making an interpretation into the findings of the present research. Explanations to the observed phenomenon would be proffered and findings on the relation between expressed emotion and quality of life would be elucidated. There is so much literature on HIV/AIDS but the concept of expressed emotion has not been much incorporated to the discourse around the study of this subject. The focus of this study had been to establish whether there is a correlation between the expressed emotion in the family of a person who is living with HIV/AIDS and the perceived quality of life.

5.2 The level of expressed emotion

For more than 40 years the influence of the social environment on the course of psychiatrically ill patients has been studied by means of the construct of EE. The LEE scale's subscales of intrusiveness, emotional response, attitude towards illness and tolerance/expectation were very predictive for the relapse rate of patients with schizophrenia and patients with other psychiatric disorders such as mood disorders and eating disorders, (Van Humbeeck, Van Audenhove, De Hert, Pieters & Storms, 2002). Studies such as one by Cole and Kazarian (1993), Rein, Perdereau, Curt, Jeammet, Fermanian and Gordart (2006) and Dennis and Leach (2007) all showed that high EE is associated with negative outcomes for people who have various disorders like anorexia nervosa, schizophrenia and psychosis. The results indicated that LEE scores are associated with outcome and that this association of the demographic, social and clinical characteristics examined (Cole & Kazarian, 1993).

The present study indicated that HIV positive people would have high EE emotion as compared to HIV negative people. This confirmed the hypothesis that HIV positive people would have high expressed emotion. The high expressed emotion was also found to higher in HIV positive male participants than their female counterparts who are also positive. This outcome could also be linked to the sociocultural aspects of gender roles and expectation within the isiXhosa culture. It should be highlighted that although the Xhosa culture is modeled in the collective community of ubuntu men have expected gender roles that places them with overall role of responsibility for the family. The strain of living up to one' expected gender role and the stress induced by a positive diagnosis may be the cause for the high EE. The use of ARVs did not have an effect on people who are HIV positive whether they use them or not, no significant differences were noted in the level of expressed emotion among the groups. The use of ARVs is also dependent on the stage of infection that one is whether asymptomatic or symptomatic. This is also determined by one CD4 cell count and therefore it is not by choice that people were not on ARVs. Most of the people were waiting to be on the medication as soon as their condition determine that they be on the medication. Age also showed not to have an effect on the EE in participants as no significant differences were found in the younger age-group and the older age-group.

The hypothesis on support group membership could not be tested because there were a low number of people who were members of support groups. It can be said that HIV positive people seem not to be keen to join support groups. Earlier on the stigma and discrimination that HIV positive people face has been highlighted and it is possible that because of stigmatization people are reluctant to join support groups. The stigma attached to HIV seriously hinders prevention efforts and makes HIV positive people wary to seek care and support for fear of discrimination. People who are infected may also be reluctant to adopt behavior that might signal their HIV positive status to others. It would be of interest to do some research on the causes of such low support group membership among the HIV positive participants. The differences in the level of expressed emotion were tested to find out if the HIV status is really the cause for the EE out come and there was an interaction effect that was found between HIV status and the participants' gender, and the level of expressed emotion, see Figure 1. This information is important for clinical practice as it gives insight on the participant's functioning and about his or her relationship with significant others.

Previous studies that were carried out with HIV positive participants also indicated the explanatory power of EE in the determining the measure of quality of life that PLWHA perceived. Nxasana (2001) found out that HIV positive Zulu speaking South Africans as having high EE thus participants may perceive their relatives as having more negative attitude towards their illness, lower tolerance and higher expectations of them, as being more intrusive and more emotionally responsive to their illness. However EE is not a simple unidirectional concept and it should not be seen in isolation but I conjunction with factors such as the role of kinship, attitudes of the family to illness and family cultural dynamics (Bhugra & Mckenzie, 2003).

The Xhosa culture is among those culture that have certain cultural norms or practices and expectations that emphasise a culture of silence on sexual matters so that it becomes inappropriate to for men and women to talk about sexuality. This study having been focused on HIV/AIDS which is situated at the core of sexual practices would also mean people would be less expressive about their concerns especially if they are talking to opposite sex people or an elder person.

5.3 Quality of life

Quality of life is an important component in the evaluation of the well-being of HIV-infected people. Wong and Ussher (2008) say the reification and quantification of quality of life devalues the complexity of the concept by privileging aspects of lived experiences that are measurable and quantifiable. The quality of life does not necessarily mean that poorer participants would have low quality of life than richer participants because it is a subjective report that can enable even disadvantaged groups to fully report their quality of life as satisfactory. The highly valued community themes such as social status and connections, relations with community and family life would be better measures of quality of life than material things in some communities. For example Wolf and Ussher (2008) report that in Culcutta positive and enhancing aspects of quality of life connected to the social domain were found as opposed to the conventional assumption that QOL is poorer in poverty. The quality of life of the people was assessed using the WHOQOL-HIV of which 16 items were used to assess the quality of life as they were the only ones that were answered by all participants. The reliability of the items used was found out to acceptable Cronbach's alpha (.80). The 16 items could not be analysed according to the six domains of physical, psychological, level of independence, social relationships, environment and spirituality/religion/personal beliefs but only an overall quality of life score of the 16 items was used. The 16 items were few to form the relevant facets that make the domains and it was prudent that an overall quality of life score from the 16 items be used. It was hypothesized that quality of life would be low for HIV positive participants compared to HIV negative participants. The findings confirmed the hypothesis because HIV positive participants were found to have a lower quality of life compared to HIV negative participants.

The use of ARVs was found no to have any significant difference on the quality of life among participants who were on ARVs and those not on ARVs. This result could possibly be because of the fact that people who were not on ARVs were so not because of choice but because their CD4 count level was still fine and as soon as it goes down they would also be on ARVs. The hypothesis that male participants would have higher quality of life than female participants was disconfirmed as it is the female participants that were found to have higher quality of life than male participants. Again this can be possibly because of the gender differences in terms of the patriarchal nature of the Xhosa community and the learned helplessness in anticipation of illness or HIV mortality. This flies in the face of male dominance and is a challenge to masculinity hence the perceived low quality of life. Lindegger and Durrheim (2001) argue that intervention programmes should be directed at men because of the social cultural and historical construction of masculinity. They further argue that in the face of HIV/AIDS masculinity faces a crisis because of the challenge to its dominance which is characterized by the discourse of the male sex drive, the notion of conquest, masculinity as penetration, males as risk takers and the idealized male body. All these characteristics of masculinity are at a crisis when a man is infected with the HIV/AIDS virus.

The HRSC (2004) conceded that the most harmful sexual practices have their origin in patriarchal societies that promote male superiority. HIV positive men are more devastated than female HIV positive people because of the challenge of maintaining the superior status. Females are usually accorded the subordinate role in the family and in public life and they easily acknowledge their vulnerability than men hence they are likely to seek emotional support and advice in the face of a crisis than men who are socialized to be strong and solve their own problems. The interaction effect between genders shows that level of quality of life of males decrease sharply as compared to the female participants. Age findings revealed that age did not have any significant effect on the quality of life of either younger or older participants.

5.4 The correlation between EE and quality of life.

It was found out that as the level of expression is high the quality of life decreases as demonstrated by figure 7 and 8. The level of expressed emotion was particularly found to be high for men than it is for women whilst the quality of life was high for females than for males. It was found that it was HIV status that is associated with the changes in the level of expressed emotion and subsequently on the quality of life. It is generally regarded in the Xhosa culture that women are more emotionally expressive than men who tend to bottle up emotion because of their gender expectations in terms of their norms and value (Lindergger & Durrheim, 2001). The findings of this contradicts earlier findings by Nxasana (2003) where it was found out that male participants had generally better quality of life than their female counterparts. The differences in the quality of life in that study attributed to the difference in treatment that males and females receive in society. Females in that study scored lowly on the environment domain which included facets such as: physical safety and security, health and social care accessibility and quality, home environment and financial resources. Women were described as possibly feeling more vulnerable than their male counterparts due to lack of financial resources, unemployment and ill-health.

5.5 Critique and recommendations for future research

This study is envisaged to contribute to the discussion about HIV/AIDS emotional support and the quality of life of people infected or affected by HIV/AIDS. In the absence of a cure for HIV/AIDS, the correct attitudes and emotional involvement by family members and relatives will go a long way in prolonging the lives of those living with the virus.

There were no material rewards that were being given to the participants but it is believed that this study helped them to have the appropriate emotional atmosphere within the family which would benefit those that are living with HIV/AIDS and those who are significant in their lives.

The questionnaire available for both EE and quality of life are very long and they are tedious to complete as reported by most of the participants that took part in the study. It is recommended that the 31 item WHOQOL scale be used as it is user friendly than the longer versions. In this study the 79 item questionnaire was used in an attempt to get detailed information on participants' quality of life but it tended to put off respondents who were leaving some of the questions unanswered.

In terms of interventions, it is the recommendation of this researcher that future interventions in HIV/AIDS focus on male subjects as it is this research's finding that male HIV positive participants experience high EE and the quality of life sharply decreases. These findings are also in concurrence with Lindegger and Durrheim's (2001) findings that intervention programmes should be aimed at South African men where traditional and hegemonic form of masculinity are alive and well, contributing to the HIV crisis.

5.6 Limitations

It is envisaged that generalisability would be very difficult to apply to other groups because of the sampling method which was purposive and targeted isiXhosa speaking HIV positive participants. This research method may not be representative of the HIV/AIDS population of South Africa but it is the researcher's desire that this piece of work would provide some valuable insights and perspectives on developing additional theories on the quality of life in HIV positive individuals especially in view of the no cure as yet period. However, it is my hope that other groups outside the setting and cultural orientation would find useful ways of solving their own problems.

The instruments that were used were self reporting and there is a possibility of participants would be affected by social desirability effect rather than objective reporting. The results would be possibly different if other techniques such as direct observation methods had been used.

5.7 Conclusion

In summary this study was an exploration of the relationship between EE and quality of life in HIV positive people in the isiXhosa speaking community. It was found out that there is an inverse relationship between EE and quality of life. In addition to that it was found out that male individuals experience high EE as compared to females in turn the quality of life would decrease sharply for male HIV positive individuals than for female.

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APPENDIX A: INFORMED CONSENT FORM

UNIVERSITY OF FORT HARE
MASTERS IN COUNSELLING PSYCHOLOGY PROJECT 2009
RESEARCHER STUDENT: PENWELL MUTIZE

Title of project: People Living With HIV/ AIDS (PLWHA) and Expressed Emotion (EE) in Xhosa speaking South Africans in the East London town.

This study recognizes that HIV/AIDS impacts on individuals and their families, and aims to explore the relationship between PLWHA and their families.

It is hoped that the results of this will be of benefit to PLWHA and their families, though no material benefits are offered through participation in the study.

I hereby agree to participate in the research project outlined above. I acknowledge that I have been informed of the purpose of the study, and wish to proceed as a participant. I understand that my contribution to the research will be used by the researcher to fulfil the requirements of his Masters in Counselling Psychology degree. I have in no way been coerced into this decision.

I understand that it will not be possible to identify me from the questionnaire and that my participation will be anonymous.

I expect the researcher to treat me with respect.
I will try to answer all questions put to me as honestly as possible.
I understand that I can withdraw at anytime.

…………………………………………… ……………………..
Participant's Signature Date

Research Supervisor: Hlonelwa Ngqangweni, Psychology Department, University of Fort Hare.
Cel (0825109488)
Researcher: Penwell Mutize. Cel (0791132688)

APPENDIX B

LEVEL OF EXPRESSED EMOTION (LEE)

SCALE

Client Version

John D. Cole, Ph.D

Shahe S. Kazarian, Ph.D

Instructions:

The following are a number of statements that describe the way in which someone may act towards you. Please identify the person who has been most influential in your life during the past three months.

Examples of influential persons could be: Mother/Father
Brother/Sister
Husband/Wife
Relative (e.g. aunt/uncle
Grandmother/grandfather)
Friend

Read each statement and indicate whether this person has acted in these ways towards you over the past three months.

Mark your answer on a separate answer sheet provided.

Circle the (T) box if you feel the answer is TRUE.

Circle the (F) box if you feel the answer is FALSE.

It is important to make sure that the statement number agrees with the number of your response on the answer sheet.

1. Understands if I sometimes don’t want to talk.
2. Calms me down when I’m upset.
3. Says I lack self control.
4. Is tolerant with me even when I’m not meeting his/her expectations.
5. Doesn’t butt into my conversations
6. Doesn’t make me nervous.
7. Says I just want attention when I say I’m not well.
8. Makes me feel guilty for not meeting his/her expectations.
9. Isn’t overprotective with me.
10. Loses his/her temper when I’m not feeling well.
11. Is sympathetic to me when I’m ill or upset.
12. Can see my point of view.
13. Is always interfering.
14. Doesn’t panic when things start going wrong.
15. Encourages me to seek outside help when Im not feeling well.
16. Doesn’t feel that I’m causing him/her a lot of trouble.
17. Doesn’t insist on doings for me.
18. Can’t think straight when things go wrong.
19. Doesn’t help me when I’m upset or feeling unwell.
20. Put me down if I don’t live up to his/her expectations.
21. Doesn’t insist on being with me all the time.
22. Blames me for things not going well.
23. Makes me fell valuable as a person.
24. Can’t stand it when I’m upset.
25. Leaves me feeling overwhelmed.
26. Doesn’t know how to handle my feelings when I’m not feeling well.
27. Says I cause my troubles to occur in order to get back to him/her.
28. Understands my limitations.
29. Often checks up on me to see what I’m doing.
30. Is able to be in control in stressful
31. Tries to make me feel better when I’m upset or ill.
32. Is realistic about what I can and cannot do.
33. Is always nosing into my business.
34. Hears me out.
35. Says it’s OK to seek professional help.
36. Gets angry with me when things don’t

go right.

37. Always has to know everything about me.

38. Makes me feel relaxed when he/she is around me.

39. Accuses me of exaggerating when I say I'm unwell.

40. Will take it easy with me, even if things aren't going right.

41. Insists on knowing where I'm going.

42. Gets angry when with me for no reason.

43. Is considerate when I'm ill or upset.

44.Supports me when I need it.

45. Butts into my private matters.

46. Can cope well with stress.

47. Is willing to gain more information to understands my condition, when I'm not feeling well.

48. Is understanding when I make mistakes.

49. Doesn't pry into my life.

50. Is impatient with me when I'm not well.

51. Doesn't blame me when I'm feeling unwell.

52. Expects too much from me.

53. Doesn't ask a lot of personal questions.

54. Makes me worse when things aren't going well.

55. Often accuses me of making things up when I'm not feeling well.

56. 'Flies off the handle' when I don't do something well.

57. Gets upset when I don't check in with him/her.

58. Gets irritated when things don't go right.

59. Tries to reassure me when things don't go right.

60. Expects the same level of effort from me, even if I don't feel well.

THE LEE SCALE (Client version):

Answer Sheet

Your Name:_______________ Age______ Date:

Sex: Male/Female (circle one)

Marital status: single married/common-law separated divorced widow/er (circle one)

Indicate who has been the most influential person in your life over the past 3 months: (circle one)

Mother Father Brother Sister Spouse Friend

Other relative (e.g. aunt, grandfather/mother) Other (please specify.............................)

1. Have you been living with your influential person during the past 3 months?

(circle one) Yes No

2. How many hours on a typical weekday have you been spending with your influential person during the past 3 months?_________Hours per day

3. How many hours on a typical weekend have you been spending with your influential person during the past 3 months?_________Hours per weekend

Instructions: Circle “T” if you feel the item is TRUE

Circle “F” if you feel the answer is FALSE

1 T – F
2 T – F
3 T – F
4 T – F
5 T – F
6 T – F
7 T – F
8 T – F
9 T – F
10 T – F

11 T – F
12 T – F
13 T – F
14 T – F
15 T – F
16 T – F
17 T – F
18 T – F
19 T – F
20 T – F

21 T – F
22 T – F
23 T – F
24 T – F
25 T – F
26 T – F
27 T – F
28 T – F
29 T – F
30 T – F

31 T – F
32 T – F
33 T – F
34 T – F
35 T – F
36 T – F
37 T – F
38 T – F
39 T – F
40 T – F

41 T – F
42 T – F
43 T – F
44 T – F
45 T – F
46 T – F
47 T – F
48 T – F
49 T – F
50 T – F

51 T - F
52 T - F
53 T - F
54 T - F
55 T - F
56 T - F
57 T - F
58 T - F
59 T - F
60 T – F

APPENDIX C

WHO (World Health Organisation)-

QUALITY of LIFE SCALE (WHOQOL-HIV)

The world Health Organisation created the WHOQOL-HIV instrument to analyse HIV/AIDS pilot data.

Instructions

Questions cover:

- Pain and discomfort
- Symptoms of PLWHA
- Positive images
- Body image and appearance
- Personal relationships
- Sexual activity
- Forgiveness
- Spiritual connection

Please answer all questions. If you are unsure about which response to give a question, please answer the one that appears most appropriate. **You do not need to spend a lot of time on any questions: initial responses are usually the best.**

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks.

For example, thinking about the last two weeks, a question might ask:
How much do you worry about your health?
1 - Not at all
2 - A little
3 - Often
4 - Very often

You should circle the number that best fits how you often you have worried about your health over the last two weeks.

Please read each question, assess your feelings, and circle the number on the scale for each question that best fits for you.

World Health Organisation- WHOQOL- HIV scale

F1.2 Do you worry about your pain and discomfort?

Not at all	A little	A moderate amount	Very much	An Extreme amount
1	2	3	4	5

F1.3 How difficult is it for you to handle any pain or discomfort?

Not at all	Slightly	moderately	very much	Extremely
1	2	3	4	5

F1.4 To what extent do you feel that (physical) pain prevents you from doing what you need to do?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F2.2 How easily do you get tired?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F2.4 How much are you bothered by fatigue?

None at all	little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F2.1 Do you have enough energy for everyday life?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F7.1 Are you able to accept your bodily appearance?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F10.1 To what extent are you able to carry out your daily activities?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F11.1 How dependent are you on your medications?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F1.1 How often do you suffer (physical) pain?

Never	Seldom	Quite often	Very often	Always
1	2	3	4	5

F9.1 How well are you able to get around?

Never	Seldom	Quite often	Very often	Always
1	2	3	4	5

F9.3 How much do any difficulties in mobility bother you?

Not at all	A little	A moderate amount	Very much	Extremely
1	2	3	4	5

F9.4 To what extent do any difficulties in movement affect your way of life?

Not at all	A little	A moderate amount	Very much	Extremely
1	2	3	4	5

F9.2 How satisfied are you with your ability to move around?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F1.2 How much do you worry about you health?

Not at all	A little	A moderate amount	Very much	Extremely
1	2	3	4	5

F4.1 How much do you enjoy life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F4.3 How positive do you feel about the future?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F4.4 How much do you experience positive feelings in your life?

Not at all	A little	A moderate amount	Very much	Extremely
1	2	3	4	5

F5.3 How well are you able to concentrate?

Not at all	A little	A moderate amount	Very much	Extremely
1	2	3	4	5

F6.1 How do you value yourself?

Not at all	A little	A moderate amount	Very much	Extremely
1	2	3	4	5

F6.2 How much confidence do you have in yourself?

Not at all	A little	A moderate amount	Very much	Extremely
1	2	3	4	5

F7.2 Do you feel inhibited by your looks?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F7.3 Is there any part of your appearance which makes you feel uncomfortable?

Not at all	A little	A moderate amount	Very much	Extremely
1	2	3	4	5

F8.2 How worried do you feel?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F8.3 How much do any feelings of sadness or depression interfere in your everyday functioning?

Not at all	A little	A moderate amount	Very much	Extremely
1	2	3	4	5

F8.4 How much do feelings of depression bother you?

Not at all	A little	A moderate amount	Very much	Extremely
1	2	3	4	5

F10.4 How much are you bothered by any limitations in performing everyday living activities?

Not at all	A little	A moderate amount	Very much	Extremely
1	2	3	4	5

F13.1 How lonely do you feel in your life?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F15.2 How well are your sexual needs fulfilled?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F15.4 Are you bothered by any difficulties in your sex life?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F16.1 How safe do you feel in your daily life?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F16.2 Do you feel you are living in a safe and secure environment?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F16.3 How much do you worry about your safety and security?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

The following questions ask you how **satisfied, happy or good** you have felt about various aspects of your life over the last two weeks. Circle the number that best fits how you feel about this.

G2 How satisfied are you with your quality of life?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

G3 In general, how satisfied are you with your life?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

G4 How satisfied are you with your health?

Very satisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F2 How satisfied are you with the energy that you have?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F3 How satisfied are you with your sleep?

Very satisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F4 How satisfied are you with your ability to make decisions?

Very satisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F5 How satisfied are you with yourself?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F6 How satisfied are you with your abilities?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F7 How satisfied are you with your personal relationships?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F8 How satisfied are you with your sex life?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F9 How satisfied are you with the support you get from your family?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F10 How satisfied are you with the support you get from your friends?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F11 How satisfied are you with the support you get from your sexual partner?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F12 How satisfied are you with your ability to provide for or support others?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F13 How satisfied are you with your physical safety and security?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F14 How satisfied are you with the conditions of your living place?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F15 How satisfied are you with your financial situation?

Very dissatisfied	Dissatisfied	Neither dissatisfied nor satisfied	Satisfied	Very satisfied
1	2	3	4	5

F16 How satisfied are you with your access to health services?

Very dissatisfied	Dissatisfied	Neither dissatisfied nor satisfied	Satisfied	Very satisfied
1	2	3	4	5

F17 How satisfied are you with the social care services?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F18 How satisfied are you with opportunities for acquiring new skills?

Very dissatisfied	Dissatisfied	Neither dissatisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F19 How satisfied are you with your opportunities to learn new information?

Very dissatisfied	Dissatisfied	Neither dissatisfied nor satisfied	Satisfied	Very satisfied
1	2	3	4	5

F20 How satisfied are you with the way you spend your spare time?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F21 How satisfied are you with your physical environment (e.g. pollution, climate, noise, attractiveness)?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F22 How satisfied are with the climate of the place where you live?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F23 How satisfied are you with your transport?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F24 Do you feel happy with your relationship with your family members?

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very happy
1	2	3	4	5

G1 How would you rate your quality of life?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

G2 How would you rate your sex life?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

G3 How well do you sleep?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

G4 How would you rate your memory?

Very poor	Poor	Neither poor nor good	Good	Very good

1 2 3 4 5

S1 To what extent do you fear possible future pain?
Never Seldom Quite often Vey often Always
1 2 3 4 5

S2 How much are you bothered by unpleasant physical symptoms that you may have?
Never Seldom Quite often Very often Always
1 2 3 4 5

S3 To what extent do you feel any of these unpleasant physical symptoms prevent you from doing things that are important to you?
Not at all A little A moderate amount Very much
An extreme amount
1 2 3 4 5

S4 To what extent do you feel inner peace harmony?
Not at all A little A moderate amount Very much Extremely
1 2 3 4 5

S5 How often do you have negative feelings such as despair, anxiety, depression?
Never Seldom Quite often Very often Always
1 2 3 4 5

S6 Do you feel that life has been unfair to you?
Not at all Slightly Moderately Very Extremely
1 2 3 4 5

S7 How often do you feel that you are discriminated against because of your health condition?
Never Seldom Quite often Very often Always
1 2 3 4 5

S8 How much do you worry about death?
Never Seldom Quite often Very often Always
1 2 3 4 5

S9 How concerned are you about how and where you will die?
Not at all A little A moderate amount Very much Extremely
1 2 3 4 5

S10 How preoccupied are you about suffering before dying?
Not at all A little A moderate amount Very much Extremely
1 2 3 4 5

S11 To what extent are you concerned about your HIV status breaking your family line and future generations?
Not at all A little A moderate amount Very much Extremely
1 2 3 4 5

S12 To what extent are you concerned about how people will remember you when you are dead?

Not at all	A little	A moderate amount	Very much	Extremely
1	2	3	4	5

S13 How much do you blame yourself for your HIV infection?

Not at all	A little	A moderate amount	Very much	Extremely
1	2	3	4	5

S14 How much has your sex life worsened?

Not at all	A little	A moderate amount	Very much	Extremely
1	2	3	4	5

S15 Are you bothered by people blaming you for your HIV status?

Not at all	A little	A moderate amount	Very much	Extremely

amount

1	2	3	4	5

S16 How guilty do you feel about being HIV+?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5