TAIPEI MEDICAL UNIVERSITY
SCHOOL OF HEALTHCARE ADMINISTRATION

MASTER’S THESIS

# QUALITY OF LIFE OF PEOPLE LIVING WITH HIV/AIDS IN THE GAMBIA

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## Quality of Life of People Living with HIV/AIDS in The Gambia

This thesis is the Master's degree thesis of Ismaila Sanyang at School of Health Care Administration of Taipei Medical University. It has been judged satisfactory by the committee members and the degree candidate has passed an oral examination.

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# Abstract

Title: Quality of Life of People Living with HIV/AIDS in The Gambia

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Objective. Despite increasing use of quality of life assessments for people living with HIV/AIDS in many parts of the world, no such assessment has been conducted in The Gambia. Therefore, objective of this study was to determine the quality of life of people living with HIV/AIDS in the Gambia.

Methods. A face-to-face interview was conducted using the WHO quality of life HIV specific instrument WHOQOL-HIV BREF at the Royal Victoria Teaching Hospital. Data was collected from August to December 2010 with random sample of 208. There were 106 respondents on highly active anti-retroviral therapy. SPSS version 16.0 was used for data analysis and independent-sample *t*-test, *ANOVA* and multiple regression analyses were used to examine hypotheses of the study whilst correlation was assessed by Pearson Correlation analyses. The study was approved by the Gambia Government/ Medical Research Council Joint Ethics Committee.

Results. Independent-sample *t*-test and multiple regression analyses showed that gender is the most important predictor of quality of life ($p<0.024$ and $p<0.043$ respectively) with females exhibiting higher mean quality of life than males ($\mu=3.51$ vs $\mu=3.24$.There were positive correlations between quality of life with physical, psychological, level of independence, social relationship, environment and spirituality/religion domains with quality of life. However, use of highly active anti-retroviral therapy was not a significant determinant of quality of life.

Discussion: The finding of females exhibiting higher quality of life compared to males is not in agreement with many studies. Nonetheless, it gives us another viewpoint of gender difference in quality of life in the research context. Married and living as married statuses improving quality of life underpins the importance of supportive environment in marriage relationships. The findings of this study support the incorporation of quality life assessment into the HIV/AIDS care program at Royal Victoria Teaching Hospital and in The Gambia and expand access to anti-retroviral therapy to all people living with the virus. A follow-up study should be conducted to evaluate the impact of highly active anti-retroviral therapy on quality of life.

Keywords: Quality of Life, People Living with HIV/AIDS, The Gambia

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# CHAPTER ONE

# INTRODUCTION

## 1.1 BACKGROUND

An estimated 31.3 million adults and 2.1 million children were reported to be living with HIV at the end of 2008 (UNAIDS, 2008; 2009). Furthermore, the College of Venereal Disease and Prevention (2010) reported that there are over 6,800 daily new infections and 5,700 deaths from AIDS. Of this global burden, two-thirds are in sub-Saharan Africa. At the end of 2008 an estimated 1.4 million adults and children died as a result of AIDS. Since the outbreak of the epidemic more than 15 million Africans have died (UNAIDS, 2008). There has been a gradual epidemiological transition in the patterns of infection (Curran et al., 1988) from predominantly same sex to heterosexual patterns. Routes of infection have been well documented, including sexual intercourse, contaminated needle sharing by drug abusers, vertical transmission across placenta, labor and delivery, occupational exposure, and contaminated blood transfusion (Brewer et al., 2003; CDC, 2007).

HIV/AIDS has impacted negatively on the world population, especially in developing countries where infection rates have been staggeringly high. The pandemic posed as one of the greatest challenges to mankind in the last two decades of the twentieth century and continue to do so in the first and second decades of the twenty-first century. From the time of its outbreak in the 1980's HIV/AIDS has claimed the lives of over 22 million men, women, and children (Schwartländer et al., 2001) and have cause immense suffering to patients and families and put considerable stress on health care resources.

The socio-economic consequences of HIV/AIDS have been grave with regional variations. Spielberg and colleagues (2005) estimated that in sub-Saharan Africa, the direct medical costs of

AIDS (excluding antiretroviral therapy) is at about US$30 per year for every person infected, occurring at a time when overall public health spending is less than US$10 per year for most African countries. This estimated direct medical cost will increase as the prevalence of the disease increases due to prolong longevity from use of anti-retroviral drugs (Levy et al., 2010). The indirect cost of care by families and forgone economic growth has not been well documented.  The pandemic has wide ranging effects on human societies and has caused disruption in the demographic profiles of many worst affected countries. For instance, in Swaziland, United Nations Joint Program on AIDS Regional Response for Sub-Saharan Africa stated that life expectancy was halved to 37 years between 1990 and 2007. The report further dilated on the plethora of orphanages caused by the outbreak and estimated that over 14.1 million children in the region lost one or both parents by 2008 (UNAIDS, 2007). The outcome of such a situation not only have far reaching social and economic consequences but threaten the fabrics of such societies and raise considerable questions about the psychological and emotional development of   these children.

Although HIV/AIDS is found commonly among the poor in sub-Saharan Africa, it has been reported that the non-poor exhibit lifestyles that put them at risk of the infection and subsequently drive their families into poverty. The relationships of HIV /AIDS and poverty are   complex. The intergenerational consequences of the epidemic are enormous and will create and entrench poverty due to reduce human capacity to produce especially in countries where over 60% of the population relies on farming as their sources of living (Cohen, 2010).

Reduced productivity means that there is a threat to food security. The association of malnutrition and AIDS has been well documented by Van Liere (2002) in a presentation at the 7th annual Economic Community of West African States (ECOWAS) nutrition forum held in Banjul.

The United Nations special session on population and development in 1999, and at the Millennium Summit in 2000 made commitments to intensify the fight against AIDS and specifically to reduce HIV prevalence in young people. These meetings have culminated in ambitious goals for reducing incidence through the expansion of prevention efforts and increasing access to care and support for all people living with HIV/AIDS (UN General Assembly, 2001). Since this declaration, there have been tremendous efforts by governments, nongovernmental organizations, and civil society organizations, donor agencies like the World Bank (WB), World Health Organization (WHO), United Nations Childrens Fund (UNICEF) and the Global Fund to fight AIDS to scale up both prevention activities and improve access to care and antiretroviral drugs. Although the committed resources did not match the projected amounts, there had been a great improvement in access to antiretroviral drugs. At the end of 2008, more than 4 million people in low- and middle-income countries had access to antiretroviral drugs. This figure represented a 36% increase in one year and a ten-fold increase over five years. In a joint WHO, UNICEF and UNAIDS progress report, more than 5 million people living with HIV still do not have access to life-prolonging treatment and care (WHO, 2009).

Despite international and local initiatives to improve access to life prolonging antiretroviral drugs, reduce the incidence of infection, improve care and the availability of measurement instruments, little attention paid to the quality of life of people living with HIV/AIDS in The Gambia. However it can be argued that the primary preoccupations of government, civil societies and other stakeholders in the fight against HIV/AIDS are to improve care, reduce infections and prolong lives. Nonetheless, patients' quality of life of their disease states, treatment or intervention will serve as a practical guide in judging the performance of services, clinical practice and resource allocation and utilization in health care.

## 1.2 STATEMENT OF THE PROBLEM

In The Gambia, HIV/AIDS has not only been recognized as a health problem, but a development challenge. Despite this, efforts to contain the spread of the infection prolong lives by increasing access to antiretroviral drugs and improve clinical care; there has been no focus on patient’s quality of life. The pandemic continues to ravage society and have imposed serious socio-economic burden on individuals, families, communities, government and healthcare system. Although prevalence is relatively low, there are regional variations; some regions show relatively high rates of infection compared to other regions.

Since the diagnosis of the first case of HIV in 1986, there are over 16000 people living with the virus and over 500 people die of AIDS annually. Two earlier population-based sero-prevalence surveys conducted in 1988 and 1991 showed an increase in HIV prevalence in adults from 1.7 percent to 2.2 percent. However, national epidemiological surveillance conducted between 2000 and 2004 demonstrated an increase in the prevalence of HIV-1 from 0.7% to 1.5% and a decrease in HIV-2 from 1.1% to 0.9%. Nonetheless, in 2005 the prevalence of HIV-1 decreased from 1.5% to 1.1% (National AIDS Council, 2007).

The epidemiology of the infection as in many countries in Sub-Saharan Africa shows higher prevalence among females (54%) compared to that of males. Furthermore, The National AIDS Control Program (NACP) and the Medical Research Council (MRC) have established characteristic of the HIV infection in the Gambia (National AIDS Secretariat, 2009).

By 2009, national prevalence was at 1.4% (National AIDS Secretariat, 2009) and as a response; the Government of The Gambia has adopted a multi-sectoral approach. Nonetheless, the initial response was health focused, with the setting up of a National AIDS Control Program (NACP) under the auspices of the Ministry of Health. In addition, policies and guidelines on HIV/AIDS were developed in 1995 with two stated goals and six major components including prevention through sexual intercourse and blood contamination. Further commitment to the combat of the disease was demonstrated through the credit agreement between World Bank worth US$15million under the HIV/AIDS Rapid Response Project (HARRP) in 2000. The establishment of the National AIDS Secretariat followed the formulation of the national strategic framework for 2003 to 2008. In 2004 country secured a grant for its HIV and AIDS response under the Global Fund to fight AIDS. This project enhanced access to antiretroviral drugs of people living with HIV/AIDS including a comprehensive care package as well as drugs for the treatment of opportunistic infections. There was also the revision of the of the policy guidelines that incorporated medium and long term strategies. The response has witnessed the escalation of national sentinel surveillance sites from 4 in 2001 to 9 in 2008 (National AIDS Secretariat, 2008).

In addition, the national response incorporated the reduction of social stigma. Home-based care is also being provided to some people living with HIV/AIDS (PLWHA), as well as emotional support and counseling services by care centers and PLWHA organizations in The Gambia.

The World Health Organization defines quality of life as ‘individual’s perception of their position in life the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns’ (Skevington, Sartorius, & Amir, 2004). It inclusion in the care of people living with HIV/AIDS in The Gambia will allow the evaluation for patient centered outcomes, that includes their goals, expectations, standards and concerns. More importantly, since HIV/AIDS is a chronic illness with prolong longevity with the advent of antiretroviral drugs, the incorporation quality of life assessment will help physicians, nurses, health counselors and other healthcare workers involved in the care of people living with HIV/AIDS to contribute of helping patient make greater meaning living with the infection and use it as bases for improving care.

## 1.3 SIGNIFICANCE OF THE STUDY

There have been tremendous efforts by government and stakeholders to contain the spread of HIV, prolong longevity and improve quality of care of people living with HIV/ADS in The Gambia. This is reinforced by the formation of patient support groups; which serve as reference groups and provide opportunities for them to engage in gainful economic activities.

Despite the conduct of numerous studies on quality of life of people living with HIV/AIDS across the world and the availability of numerous measurement instruments that allow for cross cultural comparison, such studies cannot represent the Gambia viewpoint. This study will, therefore, document the quality of life of patients living with HIV/AIDS in The Gambia using the World Health Organization Quality of Life, HIV specific instrument (WHOQOL–HIV BREF) and thus contribute a Gambian perspective. It is hoped that the results will help physicians, nurses, counselors and all other professionals who are involved in the care of people living with HIV/AIDS in The Gambia to improve care. The results can as well serve as important tool to guide health care managers in resource allocation, especially in training and hiring health professionals.

## 1.4 OBJECTIVES OF THE STUDY

The general objective of this study is to assess the quality of life of people living with HIV/AIDS in The Gambia. In more specific terms, the study aimed to;

(i) Assess the impact of the physical, psychological, level of dependence, social relationship, environment and spirituality/religion / belief on quality of life of people living with HIV/AIDS in The Gambia.

(ii) Determine the quality of life of people living with HIV/AIDS on highly active antiretroviral therapy in The Gambia.

(iii) Determine the impact of socio-demographic variables; gender, age, educational and marital status on quality of life of people living with HIV/AIDS in the Gambia.

# CHAPTER TWO
# LITERATURE REVIEW

## 2.1 DEFINITION OF QUALITY OF LIFE

Operational definition of quality of life is diverse and such diversity does not only stem from societal or individual perspectives but also by the range of theoretical models and academic orientations. Liu in 1976, (cited in Fleche & Perry, 1995) commented on this diversity, and the associated problems of non agreement that ensued were highlighted by Baxter and Intagliata (1982) (cited in Felche & Perry, 1995).

World Health Organization’s quality of life working group (Skevington, Sartorius, & Amir, 2004) defines quality of life as ‘individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns’(p2).

## *2.2* CONCEPTUALIZATION OF QUALITY OF LIFE

Quantitative strategies for analyzing patients' quality-of-life emerged as part of the medical outcomes and quality assessment. Subsequent work has produced a well-defined set of measurement tools for collecting health related quality-of-life data. During the late 1960s (Galbraith, 1958,1967 cited in Snook, 2000) and early 1970s (Campbell & Rogers, 1976 cited in Snook, 2000) medical literature presented various philosophical discussions about quality-of- life, typically addressing end-of-life contexts or the level of professional satisfaction experienced by physicians in training and practice. Healthcare quality assessment efforts spearheaded by the insightful work of Donabedian (1988) generated new attempts to objectify and enumerate health outcome. Appraisals of patient experiences, obtained through self-reported data, make up a central part of the patient-oriented outcomes section of Donabedian 'structure–process– outcomes'.

Efforts to craft reliable means of measuring patient outcomes accelerated during the late 1980s (Stewart et al., 1989) as a result of the Medical Outcome Study (MOS). This large-scale, multi-year observational survey focused on patients with prevalent and treatable conditions. It laid emphasis on patients' personal evaluation of their functional status, sense of well-being, treatment preferences and values through standardized patient surveys, and correlated these evaluations with conventional clinical measures. The medical outcome study produced a number of survey instruments, the best known of which is the Short Form 36 (SF36).

Health-related quality of life is a framework for examining disease and its impact on a patient's and functional well-being. There are 26–29 symptoms that assess disease and treatment-related concerns. Physical functioning assesses self-care (dressing, bathing) and physical activities (walking, climbing stairs). Psychological functioning assesses depression and anxiety as well as positive subjective experienced feelings. Social functioning relates to disruptions in ability to engage in usual social activities. Functional well-being assesses the ability to conduct normal family and work responsibilities. Patients' evaluation of quality of life has become the preferred and more clinically sensitive method of data gathering.

## *2.3* DEVELOPMENT OF MEASUREMENT INSTRUMENTS BY THE WORLD HEALTH ORGANIZATION

The importance of quality in of life prompted the WHO's response who put forward a program whose objectives were double folded. The first objectives had to deal with the continuous deterioration of the doctor-patient relationship. It was firmly believed that the widespread utilization of an instrument measuring quality of life would make physicians more aware of the need to listen to their patients and to take their feelings into account during treatment. The second objective was to complement the assessment of outcomes of medical interventions by a measure of the effects that interventions had on quality of life.

The Mental Health division at the WHO, in 1991, assembled anthropologists, health psychologists, medical sociologists, psychometricians, policy makers, cross-cultural researchers and clinicians with expertise in the major disease groups. The expert group designed the WHO's Quality of Life Questionnaire (WHOQOL) (WHO, 1997) which is a generic instrument that consists of over hundred item questions. The instrument underwent several revisions and a short form (WHOQOL-SF36) which consists of thirty-six questions items was produced. Subsequently, a shorter brief version was produced. Further revisions of this shorter version were made and various diseases specific instrument have since been developed.

## 2.4 USE OF INSTRUMENTS IN MEASURING QUALITY OF LIFE

A comprehensive review of health-related quality-of-life measures for use in HIV/AIDS in Clinical Trials found out that Functional Assessment of HIV Infection and Medical Outcome Study health survey were deemed the two most appropriate HIV-targeted measures. Each of the measures can be self-administered in less than 10 minutes and there was ample evidence of their excellent psychometric properties (Clayson, et al., 2006). Preau and fellow researchers (2004) investigated health related quality of life of patients on protease inhibitor containing antiretroviral drugs and patient provider relationship. They used the medical outcome study short form as the measurement tool. Male gender was independently associated with high mental scores. Employment, having no children, and self-reported symptoms and satisfaction with the information were independently associated with high physical scores.

## 2.5 USE OF HIGHLY ACTIVE ANTIRETROVIRAL THERAPY AND QUALITY OF LIFE

The availability of highly active antiretroviral therapy means that HIV has become a chronic manageable illness requiring long-term therapy and care (Liu, et al., 2006). As a result, maximizing patient quality of life is now the primary focus of care and treatment strategies for people living with HIV/AIDS (Wu, 2000).

Stangl et al. (2007) conducted a longitudinal study and examined trends and predictors of quality of life among a cohort of 947 HIV-1 infected adults initiating highly active antiretroviral therapy in rural Uganda. The use of HAART by patients improved physical and mental scores and these were reinforced as time of exposure to the drugs increased. In a similar study, Liu et al. (2006) identified the predictors for lower quality of life among patients on HAART. Their study revealed that quality of life before HAART initiation was a strong predictor of quality of life subsequent to initiation of therapy. Older age, lower socioeconomic status, less male sexual partners, no alcohol drinking, and more advanced HIV disease stage were significant predictors for lower physical health summary scores. Greater outpatient visits, depression, amprenavir use, antiretroviral drug interruption, recreational drug use, and less social support were significantly associated with lower mental health summary scores. Yen et al. (2004) in their study of quality of life and its correlates in HIV/AIDS male outpatients receiving highly active antiretroviral therapy in Taiwan established that deterioration of work function after HIV infection and less social support had poorer quality of life in the psychological domain. In addition, Becks Depression Inventory (BDI-21) scores higher than 10 and deterioration of work function after HIV infection were also associated with poorer quality of life in the social relationships domain. Furthermore, deterioration of work function after HIV infection, inconvenience resulting from medication schedules, medical appointments and reduced social support were associated with poorer quality of life in the environmental domain. The findings of the association of medical appointments with lower quality of life corroborate that of Stangl and his colleagues (2007).

In a systematic review of studies of the quality of life of people living with HIV/AIDS on various anti-retroviral drugs combination that evaluated clinical benefits as weighed against the toxicity effect of the drugs, Burgoyne and Tan (2008) employed regression analysis and found out that lipodystropy, anemia and peripheral neuropathy associated with use of antiretroviral drugs are linked with decreased quality of life. Cunningham et al (1998) conducted a study in two public hospitals in Southern California and assessed the severity of constitutional symptoms in persons with HIV infection, and their relationship to health-related quality of life. They administered to consenting subjects battery that included 11 scales measuring various aspects of health-related quality of life and detailed questions about six constitutional symptoms or symptom complexes as well as about other manifestations of HIV disease. The results were that constitutional symptoms except weight loss were all strongly related to all measures of quality of life.

Louwagie and his fellows (2007) conducted a cross-sectional interview survey in South Africa to determine health related quality of life of people living with HIV on antiretroviral therapy and those awaiting treatment. They combined three questionnaires, namely, EuroQol-profile, EuroQol-index and Visual Analogue Scale (VAS) with interview. In their analysis they found out that patients on antiretroviral drugs reported better heath related quality of life compared to those who were waiting to receive treatment.

Jelsma and his colleagues (2005) in their prospective study investigated the efficacy of highly active antiretroviral therapy in improving self-reported health-related quality of life of individuals living with HIV in WHO stage 3 and 4 in a resource poor setting. They ascertained that the rank of the domains of the EQ-5D was significantly greater after one year of use of the drugs.

Determining the long-term quality of life outcomes of patients on different regimens of antiretroviral drugs, Nieuwkerk and his fellows (2001) divided patients into three groups; triple agent highly active antiretroviral therapy protocol, treatment intensification protocol and induction – maintenance protocol. Utilizing the medical outcomes study HIV health instrument, they assessed changes in quality of life from baseline at weeks' intervals. Patients who discontinued medication due to insufficient efficacy, toxicity or at their own request, showed less favorable changes in quality of life compared with patients who continued their regimen.

Manheimer and fellow researchers (2005) assessed the quality of life of HIV infected patients receiving antiretroviral therapy to adherence. The result showed that adherence to therapy was associated with improved quality of life.

## 2.6 GENDER DIFFERENCES IN QUALITY OF LIFE

Using a randomized, double-blinded, placebo-controlled trial, Mrus and colleagues (2005) evaluated gender differences in health related quality of life by comparing antiretroviral regimens and weighed clinical benefits against the toxicity effect. They used the Pearson's correlation coefficient, chi-square test, wilcoxon rank sum test and general estimation equation to estimate association of antiretroviral toxicity effect and quality of life. Baseline data revealed that females reported lower health related quality of life scores than males in all of the domains except social functioning. After repeated measures women continued to report lower quality of life scores than males in except general health. Nonetheless, such differences did not take into account ethnic factors as the majority of females in the study were African Americans. In a separate study, the quality of life of women with symptomatic HIV/AIDS was assessed by Brady et al. (1999) in an exploratory descriptive study. The study revealed that the most prevalent disruptions were in the psycho-social domain, including financial problems, worrying about the family, distress about losing others from HIV, and worrying about disease progression.

In a cross-sectional interview study design conducted in Rakai district in Uganda, Mast et al. (2004) measured quality of life among HIV infected women using a culturally adapted questionnaire. Analysis of variance was used for comparing means of categorical data and t-test was used to determine differences between group means of continuous data. HIV-positive mothers had lower perceived body health, social and physical functioning, pain and role functioning scores than HIV negative mothers. Cederfjall et al. (2001) explored gender differences in perceived health-related quality of life among HIV/AIDS patients using four scales of measurement with high internal consistency among them (cronbach's alpha or coefficient, 0.77, 0.80, 0.76, and 0.82, respectively). The results showed that women scored significantly less positive well-being, weaker sense of coherence, and less social support than the men despite less advanced disease.

## 2.7 DEMOGRAPHIC VARIABLES AND QUALITY OF LIFE

The effect of employment on quality of life and psychological functioning in patients with HIV/AIDS was investigated by Blalock and his group of researchers (2002) in a retrospective longitudinal study. They utilized non-parametric estimates to test for any statistical significant differences. Employed and unemployed participants did not significantly differ in terms of gender, education level, ethnicity, prevalence of diagnosed psychiatric and substance use disorders, or overall level of psychological functioning. However, as the disease progressed employed participants reported significantly higher overall quality of life.

In a study examining the demographic and behavior association health related quality of life among persons with HIV, Campsmith et al. (2003) conducted a survey interview of persons more than18 years. They utilized overall health, pain, physical functioning, role functioning, social functioning, mental health, energy/fatigue, and cognitive functioning and compared them with various demographic and behavioral factors. Multivariate analysis showed that lower CD4 count was the factor most consistently associated with lower health related quality of life. Taking antiretroviral medication was not associated with differences in health-related quality of life regardless of CD4 count. This finding is however not consistent with that of Burgoyne and Tan (2008) because Campsmith and his colleagues did not investigate the toxic effects of antiretroviral drugs as Burgoyne and Tan did.

## 2.8 SPIRITUALITY AND QUALITY OF LIFE

Brady and his co-researchers (1999) measured spirituality in cancer patients by the Functional Assessment of Chronic Illness therapy. Spirituality was associated with quality of life to the same degree as physical well-being. There was a unique association between spirituality and quality of life after controlling for core quality of life domains as well as other possible confounding variables. The study used a sample size large enough with detailed inclusion and non-inclusion criteria. Cotton et al. (2006) examined the spirituality and religion in patients and determine the changes in the levels of spirituality with the disease. The study concluded that most HIV patients belong to one or more organized religious groups and sought solace in their religion to cope with the disease.

## 2.9 QUALITY OF LIFE OF PATIENT WITH CHRONIC DISEASES

In describing the quality of life of long term breast carcinoma survivors, Ashing-Giwa et al. (1999) found out that of quality of life outcomes are attributable to socioeconomic and life-burden factors and not to ethnicity. Crawford et al. (2002) in a community-based trial of epoetin alfa therapy of anemic cancer patients undergoing chemotherapy used the Linear Analog Scale Assessment and the more detailed, disease-specific Functional Assessment of Cancer Therapy-Anemia instrument. Their study demonstrated a nonlinear relationship and significant positive correlation between high hemoglobin levels and high scores using both instruments. It concluded that a direct relationship exists between hemoglobin increases during epoetin alfa therapy and corresponding quality of life improvements in cancer patients receiving chemotherapy. This is finding is consistent with those of Jelsma, et al. (2005), Liu, et al. (2006), Louwagie, et al. (2007) and Stangl, et al. (2007), which showed improved quality of life of patient with HIV/AIDS after initiation of highly active antiretroviral therapy compared to those who are not on the drugs.

In a longitudinal intervention study of quality of life of patients before and after one year liver transplantation for cholestatic liver disease, Gross et al. (1999) utilized a quality of life questionnaire to 157 adult patients with primary biliary cirrhosis or primary sclerosing cholangitis. The questionnaire measured four aspects of quality of life, including symptoms; physical, social, and emotional functioning; health perceptions; and overall quality of life. Multivariate longitudinal regression analysis found that there were no differences in quality of life parameters between patients with primary biliary cirrhosis and primary sclerosing cholangitis. However, quality of life following transplantation was substantially better than that before transplantation. This was observed in all four aspects of quality of life. The finding of this study further demonstrates the value of quality of life in measuring outcome of clinical care interventions in chronic disea

Schrag, Jahanshahi & Qinn (2000) conducted their study on the basis that provision of adequate and appropriate healthcare resources for patients with chronic neurologic disorders such as Parkinson’s disease requires knowledge of the impact of the illness on their lives. They assessed quality of life of patients with Parkinson’s disease in different stages and compared it with the general population. They utilized three questionnaires, and combined it with interview and neurologic examination. The result showed deteriorating quality of life of patients with progressing and worsening disease states irrespective of sex. These findings were comparable to the general population except in the younger age group which showed worse quality of life in comparison with the general population.

## 2.10 SOCIAL SUPPORT AND QUALITY OF LIFE

Social support and health-related quality of life in HIV-infected persons were investigated in Venezuela (Bastardo & Kimberlin, 2000). Multiple regression analysis demonstrated that social support was significantly associated with all health related quality of life except physical functioning and bodily pain. A prospective study by Jia et al. (2004) assessed the total effects of social support and coping as well as the direct and indirect effects of these factors through depression on health-related quality of life. The results showed that coping and social support had total effects on some, but not all dimensions of health-related quality of life. Depression was associated with all dimensions of health-related quality of life.

## 2.11 SUMMARY OF LITERATURE

Quality of life has gone through several generations of conceptualization in many fields of study. Nonetheless, the World Health Organization has contributed immensely to its definition and development of measurement instruments. This definition provides some form of standardization for many researchers in the field and the instruments allow for cross cultural comparison.

Statistical significance and the positive association of quality of life and use of antiretroviral drugs have been established to by numerous studies. However, the toxic effect of antiretroviral like lipodystropy has been linked with lower quality of life. Socio-demographic factors has been found to be a determinant of quality of life in people living with HIV/AIDS with females reporting lower quality of life compared to men. Education level, spirituality and social support are all positively associated with improved quality of life.

Nonetheless, despite all these studies in many parts of the world, the quality of life of people living with HIV/AIDS in The Gambia is unknown. Therefore this study will contribute the Gambia perspective in understanding the quality of life of people living with HIV/AIDS in the Gambia and allow for cross cultural comparison.

# CHAPTER THREE
# METHODS

## 3.1CONCEPTUAL FRAMEWORK

The conceptual framework for the current research is based on the quality of life and the six domain of the WHOQOL-HIV BREF Questionnaire. The six domains are physical, psychological, level of dependence, social relationship, environment, and spirituality/religion/personal belief domains. They quantify individual patient’s quality of life by asking question in each domain that relate to patient’s quality of life and well being.

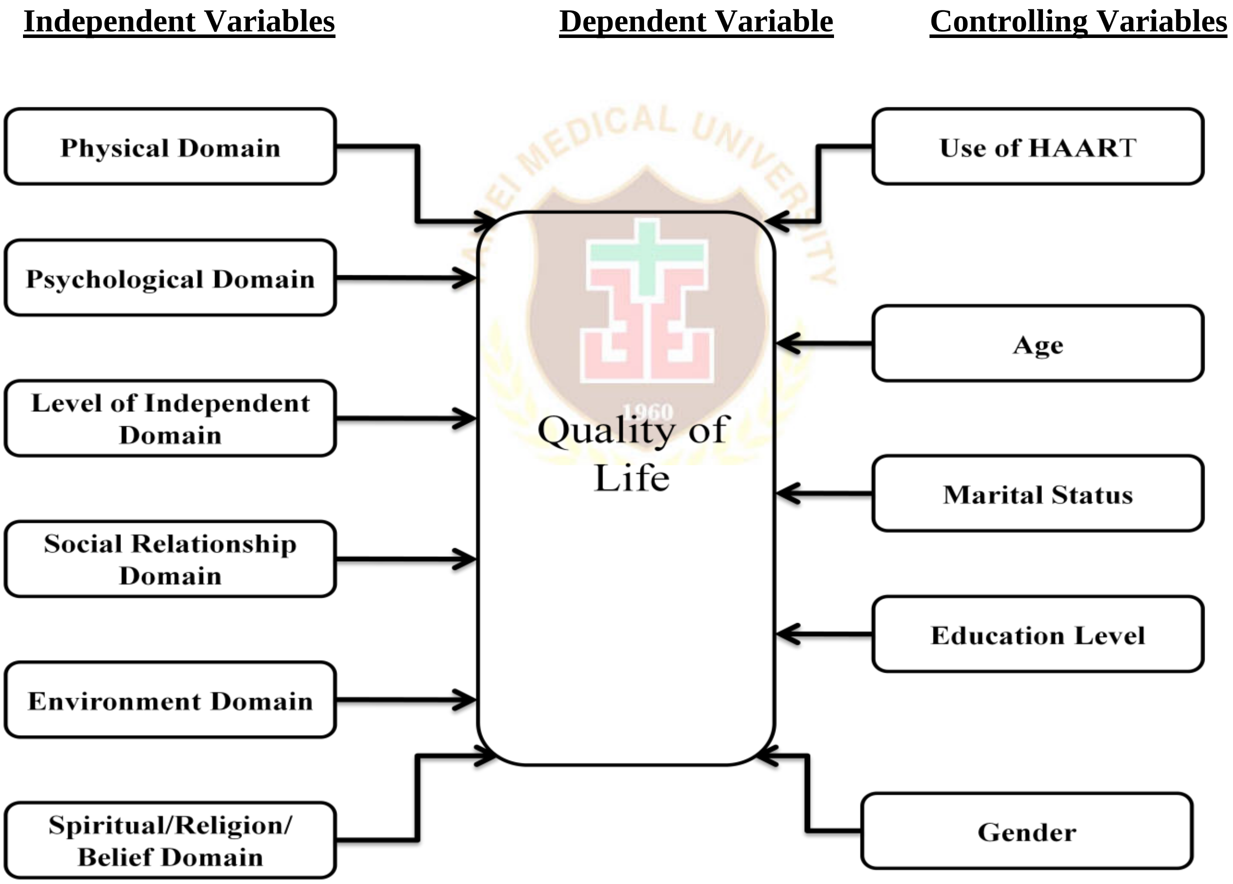

**Figure 1. Conceptual frame work of quality of life of people living with HIV/AIDS in The Gambia.**

## 3.2 OPERATIONAL DEFINITIONS OF VARIABLES

### 3.2.1 Dependent Variable

Quality of life is the dependent variable in this study. It is relates to HIV/AIDS perception of their position in life the context of the culture and value systems in which they live (The Gambia) and in relation to their goals, expectations, standards and concerns. It is a measure of patients' evaluation of their quality of life. It was measured by asking each respondent to rate his or her quality of life on a five point Likert scale with 1 representing lowest quality of life and 5 representing highest quality of life.

### 3.2.2 Independent Variables

1. Physical domain variable refers to the aggregate measure four sub-dimensions. These are physical pain and discomfort, energy and fatigue, sleep and rest and, and extent to which patient is bothered physically by HIV infection. They are measured by asking each participant to state his or her evaluation each item on a five point Likert scale with 1 representing low positive feeling and 5 representing highest positive feelings. Negatively worded feelings like pain and discomfort when rated are re-coded in the reverse direction. This means that higher score (e.g. 5) were re-coded to represent higher quality of life.

2. Psychological domain is the measure of the patient's subjective evaluation of his or her feelings, thinking, and learning, ability to retain and recall information, concentration level, self-esteem, body image and negative feelings. These facets were measured on a five-point Likert scale. Negative feelings were reversely re-coded as in the physical domain.

3. Level of independence domain refers to the extent of support the respondent needs in the performance of their daily activities. The variable was measured on the following sub dimension or facets; mobility, activities of daily living, dependence on medication or treatments and work

capacity on a five-point Likert scale. Dependence on medication was reversely recoded so that higher score denoted better quality of life.

4. Social relationship domain describes how patients relates to other people, the type of support they receives, their ability of perform sexual function and the approval they gets from the surroundings. The sub-dimensions were measured by asking patients to state each item on a five-point likert scale.

5. Environmental domain measures how environment contributes to well being of the patient. It was measured on a five point Likert scale. The facets measured are physical safety and security, home environment, financial resources, health and social care; accessibility and quality, opportunities for acquiring new information and skills, participation in and opportunities for recreation/leisure activities and physical environment (pollution/noise/traffic).

6. Spirituality, Religion or Personal Beliefs domain defines patients' beliefs and their valuation of purpose of life. It focuses on forgiveness and blame, concerns about the future, death and dying. It was rated on a five point Likert scale (see appendix for tables of domains and sub dimension or facets and how they were coded and how other sub-dimension were re-coded in the data set).

### 3.2.3 Controlling Variables

The control variables of this study are use of highly active antiretroviral therapy by respondents. This data was obtained from the respondents' records. Age was recorded in absolute years e.g. 34 years. Patients were asked to provide their actual age and when they provide the year of birth their actual age was estimated from it. Marital status was classified into the following categories; single, married, living as married, separated, divorced and widowed. The education level refers to the highest level of education attained by the respondent. This was categorized into; none at all, primary, secondary and tertiary. Gender was referred to male and female respondents.

## 3.3 HYPOTHESES

There are twelve hypotheses for this study as listed below.

Hypothesis1: Physical domain affects the quality life of people living with HIV/AIDS in The Gambia.

Hypothesis 2: Psychological domain affects quality life of people living with HIV/AIDS in The Gambia.

Hypothesis 3: Level of dependent domain affects quality life of people living with HIV/AIDS in The Gambia.

Hypothesis 4: Social relationship domain affects the quality life of people living with HIV/AIDS in The Gambia.

Hypothesis 5: Environmental domain affects the quality life of people living with HIV/AIDS in The Gambia.

Hypothesis 6: Spirituality/religion/belief affects the quality life of people living with HIV/AIDS in The Gambia.

Hypothesis 7: There are differences in the quality of life of people living with HIV/AIDS in The Gambia on HAART and those not on HAART care.

Hypothesis 8: Age affects quality of life of people living with HIV/AIDS in The Gambia.

Hypothesis 9: Marital status affects quality of life of people living with HIV/AIDS in The Gambia.

Hypothesis 10: Educational Level affects quality of life of people living with HIV/AIDS in The Gambia.

Hypothesis Eleven 11: There are gender differences in the quality of life of people living with HIV/AIDS in The Gambia.

Hypothesis 12: Independent and controlling variables affect the affect quality of life of people living with HIV/AIDS in The Gambia.

## 3. 4 STUDY DESIGN

A cross-sectional survey study was conducted. Data was collected from August to December 2010. The data collected was used to examine the hypotheses above.

## 3.5 DATA COLLECTION TOOLS AND TECHNIQUES

The WHOQOL_HIV BREF questionnaire was used for the study. A face-to- face interview was conducted with all respondents irrespective of educational status. The data on the use of HAART by respondent were included in the questionnaire by the code HT.

The two registered nurses collected data from August to December 2010. They are familiar with the use of instrument as the nursing profession uses similar scales to evaluate care, for instance the pain scale. They collected the list of all patients attending the clinic and stratified it by gender. On a daily basis they interviewed respondents who turned up to the clinic for care.

## 3.6 STUDY SAMPLE

### 3.6.1 Inclusion and non-inclusion criteria

People living with HIV/AIDS in The Gambia are the subject of this study. The inclusion criteria involve being diagnosed of HIV, participants more than 18 years of age, attending Royal Victoria Teaching Hospital for clinical care and follow up. The criteria are because adult people living with HIV/AIDS are the subject of study and the Royal Victoria Teaching Hospital is the study site.

The non-inclusion criteria include participants not consenting to the study, for those on HAART if the duration of use is less than three months, patient with a diagnosis of mental disorder. The first non inclusion criterion respect individual autonomy and right to decline to participate in the study while second non-inclusion criterion is based on the assumption that quality of life score for chronic disease patients on drugs changes after three months (Kosinski et al., 2005). Mental disorders will confound quality of life scores of respondents.

### 3.6.2 Sampling

Patient records file was the unit of selection. The serial number of patient records file was obtained from the clinic and used as the sampling frame. Stratification by gender was employed and allocated proportionate number of males and females.

### 3.6.3 Sample Size

G-Power statistical software version 3.10 was used to calculate sample size. An initial sample of 200 was used with significant level set at α=0.05, power of the study at 0.8 and effect size at 0.07. The software produced a final sample size of 202 that satisfied the above conditions and a final sample size 208 was used. The sample estimations were based on the studies of Tiwari et al.

(2009) and Mayo (2002). They utilized samples sizes of 60 and 292 respectively in conducting quality of life studies on HIV infected persons.

## 3.7 DATA ANALYSES

SPSS version 16.0 was used for the analysis. Statistical methods are as follows:

1. Frequency tables were used to summarize categorical data, like educational level, marital status, use of HAART and gender.
2. Means and standard deviation were used to summarize age, six independent variables, health status and satisfaction with health.
3. Hypothesis 1: Physical domain variable affects the quality life of people living with HIV/AIDS in the Gambia.

   (i) Pearson correlation assessed correlation between physical domain variable and quality of life.
4. Hypothesis 2: Psychological domain variable affects the quality life of people living with HIV/AIDS in the Gambia.

   (i) Pearson correlation assessed correlation between psychological domain variable and quality of life.
5. Hypothesis 3: Level of independent domain variable affects the quality life of people living with HIV/AIDS in the Gambia.

   (i) Pearson correlation assessed correlation between level of independence domain variable and quality of life.
6. Hypothesis 4: Social relationship domain variable affects the quality life of people living with HIV/AIDS in the Gambia.

   (i) Pearson correlation assessed correlation between social relationship domain variable and quality of life.

7. Hypothesis 5: Environment domain affects the quality life of people living with HIV/AIDS in the Gambia.

   (i) Pearson correlation assessed correlation between environment domain variable and quality of life.

8. Hypothesis 6: Spirituality/religion/belief domain affects the quality life of people living with HIV/AIDS in the Gambia.

   (i) Pearson correlation assessed correlation between spirituality/religion/belief domain variable and quality of life.

9. Hypothesis 7: There are differences in the quality of people living with HIV/AIDS in

   The Gambia on HAART and those not on HAART care.

   (i) *ANOVA* examined gender difference in the quality of life of people living with HIV/AIDS in The Gambia.

10. Hypothesis 8: Age affects quality of life of people living with HIV/AIDS in The Gambia.

    (i) Pearson correlation assessed the relationship of age and quality of life of people living with HIV/AIDS in The Gambia.

11. Hypothesis 9: Marital status affects quality of life of people living with HIV/AIDS in The Gambia.

    (i) *ANOVA* examined the impact of marital status on quality of life of people living with HIV/AIDS in The Gambia.

12. Hypothesis 10: Educational status affects quality of life of people living with HIV/AIDS in The Gambia.

(i) *ANOVA* examined the impact of educational status on quality of life of people living with HIV/AIDS in The Gambia.

13. Hypothesis 11: There are gender differences in the quality of life of people living with HIV/AIDS in The Gambia.

    (i) *ANOVA* examined gender differences on quality of life of people living with HIV/AIDS in The Gambia.

14. Hypothesis 12: Independent and controlling variables affects quality of life of people living with HIV/AIDS in The Gambia.

    (i) Multiple regression analyses examined the impact of independent and controlling variables on quality of life of people living with HIV/AIDS in The Gambia.

## 3.8 ETHICAL APPROVAL

Ethical approval to conduct the study was granted by The Gambia Government/ Medical Research Council joint Ethics Committee. Respondents' willingness to participate in the study was sought and they were assured of confidentiality of information that they provided on the questionnaire. The questionnaire contained the participant information sheet that introduced the purpose of the study and what the results will be used for. In addition, participants were given the choice to withdraw from when the study or fail to answer questions that they are not comfortable with. The participant information sheet contained a portion the data collector marked to indicate respondent's willingness to participate in the study after having understood the purpose of the study.

# CHAPTER FOUR
# RESULTS

## 4.1 Descriptive Statistics Results

### 4.1.1 Demographic Distributions of Respondents

Two hundred and eight respondents completed the questionnaire and of these, 53.8% (N=112) were females. The typical respondent was 38 years old (SD=10.63), was married (64.9%) and half had no education at all (50%).

### 4.1.2 Distributions of Respondents by Use of HAART

Approximately half (N=106) of respondents were on HAART and them 59.4% (N=63) were females. Of all males respondents 44.8 % (N= 43) were on HAART.

### 4.1.3 Descriptive Statistics of Independent Variables Scores

The six domain or independent variables had varying mean scores. Spirituality domain had the highest score. Level of independent and environment domains had the lowest scores (Table 2).

**Table 1. Basic characteristics of respondents (N=208)**

| Variables | | N (%) | Mean (SD) | Range |
|---|---|---|---|---|
| Gender | Male | 96 (46.2) | | |
| | Female | 112 (53.8) | | |
| Age | | | 38 (10.63) | 18-70 |
| Use of HAART | Use | 106 (51) | | |
| | No Use | 102 (49) | | |
| Marital Status | Single | 24 (11.5) | | |
| | Married | 133 (63.9) | | |
| | Living as Married | 2 (1) | | |
| | Separated | 3 (1.4) | | |
| | Divorced | 17 (8.2) | | |
| | Widowed | 29 (14.2) | | |
| Educational Level | None at all | 102 (50) | | |
| | Primary | 29 (14.2) | | |
| | Secondary | 55 (27) | | |
| | Tertiary | 18 (8.8) | | |

**Table 2. Descriptive statistics of independent variables and quality of life**

| Variables | Mean (SD) | Range |
|---|---|---|
| Physical Domain | 3.54 ((1.16) | 1-5 |
| Psychological Domain | 3.44 (0.72) | 1.2-4.6 |
| Level of independent Domain | 3.13 (1.07) | 1.25 -5 |
| Social Relationship Domain | 3.42 (0.62) | 2-4.6 |
| Environment Domain | 3.33 (0.45) | 1-5 |
| Spirituality/Religion Domain | 3.80 (0.78) | 1-5 |
| Quality of Life | 3.24[a] | |
| | 3.51[b] | |

*NOTE*: [a] -males; [b] -females

## 4.2 Inferential Statistics Results

### 4.2.1 Analytical Results for Hypothesis 1: Physical domain variable affect quality of life of people living with HIV/AIDS in The Gambia

In accordance with hypothesis 1, Pearson correlation determined the relationship between physical domain and quality of life. There was positive correlation between physical domain and quality of life (Table 3).

### 4.2.2 Analytical Results for Hypothesis 2: Psychological domain variable affect quality of life of people living with HIV/AIDS in The Gambia

Pearson correlation examined this hypothesis. There was positive correlation between psychological domain and quality of life (Tables 3).

### 4.2.3 Analytical Results for Hypothesis 3: Level of independent domain variable affects quality of life of people living with HIV/AIDs in The Gambia

This hypothesis was examined by Pearson correlation analyses. There was positive correlation between level of independent domain and quality of life (Table 3).

### 4.2.4 Analytical Results for Hypothesis 4: Social relationship domain variable affects quality of life of people living with HIV/AIDS in The Gambia

This hypothesis was examined by Pearson correlation analyses. There was positive correlation between social relationship domain and quality of life (Table 3).

### 4.2.5 Analytical Results for Hypothesis 5: Environment domain variable affects quality of life of people living with HIV/AIDS in The Gambia

This hypothesis was examined by Pearson correlation analyses. There was positive correlation between environment domain and quality of life (Tables 3).

### 4.2.6 Analytical Results for Hypothesis for Hypothesis 6: Spirituality /religion domain affects quality of life of people living with HIV/AIDS in The Gambia

Pearson correlation analyses examined this hypothesis. There was positive correlation between spirituality/religion domain and quality of life (Tables 3).

**Table 3. Pearson correlation analyses results of independent variable, age and quality of life**

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
|---|---|---|---|---|---|---|---|---|
| 1.Quality of Life | | | | | | | | |
| 2. Physical Domain | 0.610*** | | | | | | | |
| 3.Psychological Domain | 0.540*** | 0.514*** | | | | | | |
| 4.Level of Independence Domain | 0.203*** | 0.307*** | 0.251*** | | | | | |
| 5.Social Relationship Domain | 0.146* | 0.106 | 0.171* | 0.268*** | | | | |
| 6.Environment Domain | 0.498*** | 0.535*** | 0.451*** | 0.220** | 0.125 | | | |
| 7.Spirituality/ Religion Domain | 0.406*** | 0.333*** | 0.433*** | -0.077 | 0.074 | 0.386*** | | |
| 8. Age | -0.016 | -0.165* | -0.067 | -0.021** | -0.009 | -0.121 | 0.008 | |

*p<0.05, **p<0.01, ***p<0.001

**Table 4. Independent-sample *t*-test and *ANOVA* of the relationship among quality of life and predictor variables**

| Predictor Variables | | N | Mean | SD | *t*/F | p |
|---|---|---|---|---|---|---|
| Use of HAART | | | | | | 0.611 |
| | Use | 106 | 3.36 | 0.886 | -0.51 | |
| | No Use | 100 | 3.42 | 0.843 | | |
| Gender | | | | | | 0.024 |
| | Male | 95 | 3.24 | 0.896 | -2.271 | |
| | Female | 111 | 3.51 | 0.819 | | |
| Educational Level | | | | | 0.482 | 0.695 |
| | (1) none at all | 100 | 3.41 | 0.78 | | |
| | (2) primary | 29 | 3.38 | 0.175 | | |
| | (3) secondary | 55 | 3.44 | 0.115 | | |
| | (4) tertiary | 18 | 3.17 | 0.259 | | |
| Marital Status | | | | | 2.185 | 0.057 |
| | (1) single | 24 | 3 | 0.978 | | |
| | (2) married | 131 | 3.48 | 0.826 | | |
| | (3) living as married | 2 | 4 | 0 | | |
| | (4) separated | 3 | 2.67 | 1.155 | | |
| | (5) divorced | 17 | 3.18 | 0.809 | | |
| | (6) widowed | 29 | 3.45 | 0.87 | | |

Table 5. Multiple regression results of the relationships among quality of life and predictor variables

| Predictor Variable | | B | S.E | β | p |
|---|---|---|---|---|---|
| Constant | | 0.87 | 0.545 | | 0.873 |
| Physical Domain | | 0.038 | 0.087 | 0.050 | 0.664 |
| Psychological Domain | | 0.186 | 0.125 | 0.153 | 0.142 |
| Level of independence Domain | | 0.076 | 0.086 | 0.093 | 0.381 |
| Social Relationship Domain | | 0.045 | 0.095 | 0.033 | 0.635 |
| Environment Domain | | 0.256 | 0.144 | 0.131 | 0.078 |
| Spirituality/Religion Domain | | 0.077 | 0.075 | 0.069 | 0.306 |
| Females | | 0.204 | 0.100 | 0.120 | 0.043 |
| Use of HAART (Use) | | 0.077 | 0.089 | 0.045 | 0.392 |
| Age | | 0.003 | 0.005 | 0.034 | 0.590 |
| Educational Status | None at all (reference group) | | | | |
| | Primary | 0.184 | 0.135 | 0.075 | 0.174 |
| | Secondary | 0.079 | 0.110 | 0.041 | 0.478 |
| | Tertiary | -0.303 | 0.168 | -0.100 | 0.073 |

Table 5 (cont'd)

| Predictor Variable | | B | S.E | β | p |
|---|---|---|---|---|---|
| Marital Status | Single (reference group) | | | | |
| | Married | 0.280 | 0.151 | 0.158 | 0.066 |
| | Living as married | 0.194 | 0.593 | 0.017 | 0.745 |
| | Separated | -0.277 | 0.357 | -0.041 | 0.438 |
| | Divorced | -0.030 | 0.271 | -0.01 | 0.880 |
| | Widowed | 0.225 | 0.194 | 0.089 | 0.248 |

### 4.2.7 Analytical Results for Hypothesis 7: There are differences in the quality of life of people living with HIV/AIDS in The Gambia on HAART and those not on HAART care

This hypothesis was examined by independent-sample *t*-test. There were no significant differences in the quality of life of people living with people on HAART and those not on HAART (Table 4).

### 4.2.8 Analytical Results for Hypothesis 8: Age affects quality of life of people living with HIV/AIDS in The Gambia.

Pearson correlation assessed correlation between age and quality of life of people living with HIV/AIDS in The Gambia. There was negative correlation between age and quality of life of people living with HIV/AIDS in The Gambia (Table 3).

### 4.2.9 Analytical Results for Hypothesis 9: Marital status affects quality of life of people living with HIV/AIDS in The Gambia.

*ANOVA* examined the impact of marital status on quality of life of people living with HIV/AIDS in The Gambia. There was no significant impact of marital status on quality of life of people living with HIV/AIDS in The Gambia (Table 4)

### 4.2.10 Analytical Results for Hypothesis 10: educational level affects quality of life of people living with HIV/AIDS in The Gambia

*ANOVA* examined the impact of educational level on quality of life of people living with HIV/AIDS in The Gambia. Educational level had no significant impact on quality of life of people living with HIV/AIDS in the Gambia (Table 4).

### 4.2.11 There are gender difference in the quality of life of people living with HIV/AIDS in The Gambia.

Independent-sample t-test examined gender differences in the quality of life of people living with HIV/AIDS in The Gambia. The mean of quality of life for females was higher than for males (µ=3.51 vs µ=3.24). The results demonstrated that gender is a significant predictor of life and females have a higher quality of life compared to males (Table 4)

### 4.2.12 Independent and controlling variables affect quality of life of people living with HIV/AIDS in The Gambia

Multiple regression analysis examined the impact of independent and controlling variables on the quality of life of people living with HIV/AIDS in The Gambia. Gender was the only determinant of quality of life with females exhibiting higher quality of life compared to male counterparts. Married also showed positive improvement in quality (β=0.158) compared to negative changes in quality of life of separated and widowed (β=-0.041 and β=-0.01) (Table 5)

# CHAPTER FIVE
# DISCUSSION

## 5.1 Association of Marital Status and HIV infection

In this study, 64.9% of respondent are married. This figure leaves us wondering the effects of HIV spread in marriages in The Gambia where polygyny is commonly practiced. There are numerous studies have studied the association of concurrency in marriages and or multiple partners and the spread of HIV in sub-Saharan Africa. Many of them have established and supported that multiple concurrent partnerships significantly increase exposure to HIV infection (Helleringer et al., 2009; Epstein & Morris, 2010; Mah, 2010; Mah & Halperin, 2010; Goodreau, 2010). This position has been used with effect among other strategies by the Joint United Nation Program on HIV/AIDS and the Southern African Development Community to curb the spread of the infection. However their work was subject to much criticism by Sawers and Stillwaggon (2010) and Murray and Burnham (2009). Sawers and Stillwaggon conducted systematic review of published literature and asserted that concurrent sexual partnership do not explain the spread of HIV in Africa. Lagarde and his co-researchers (2001) studied ‘concurrent sexual partnerships and HIV prevalence in five urban communities of sub-Saharan Africa’ and found no evidence to support that concurrency is the driving force for African HIV epidemic. Ecological studies by Reiners and Watkins (2010) failed to provide evidence to support that concurrent sexual partnership is linked to the spread of HIV in Africa. They studied polygyny the type of concurrent sexual partnership found in The Gambia and concluded that it may have some beneficial effects.

Although both positions used methods and data available to them and both are have been subject of so much critique, it is important to look at the evidence presented in the context of Gambia. Most of the studies that support the position that concurrent partner is linked with the spread of HIV were conducted in Eastern and Southern Africa where there HIV infection prevalence was highest. Secondly there are cultural differences between the studied areas and The Gambia, as culture influence human sexual behavior. Reiners and Watkins also found out that HIV prevalence was lowest in region where the practice of polygyny is common between countries and within country. Therefore the role of polygny should be carefully studies to determine its contribution to the spread or control of HIV in The Gambia.

In the multiple regressions married and living as married had positive effect on the changes on quality of life (β=0.158 and β=0.017) respectively as compared to the negative changes of separated and divorced (β= -0.041 and β= -0.01) respectively. Subramanian, et al. (2009) in their study of 'psycho-social impact and quality of life of people living with HIV/AIDS in South India' showed that marital status had significant association with quality of life. Nojomi, Anbary, & Ranjbar, (2008) yielded similar results. However Tiwari et al. (2009) conducted another study of HIV infected patient in India using the WHOQOL-26 BREF Hindi version found no association between marital status and quality of life.

Although standardized beta coefficient in the multiple point to a beneficial effect of being married and living with HIV/AIDS in The Gambia, it is not conclusive and therefore , a study need to be conducted to explore the role of marriage in the quality of life of people living with HIV/AIDS in The Gambia.

### 5.2 Gender and its association with Quality of life

From the one way ANOVA results (Table 4), females demonstrated higher quality of life than males. The significance of this result was further highlighted by the multiple regression output (Table 5).This findings in however not in agreement with the earlier findings of Mrus et al. (2005) Mast et al. (2004) and Cederfjall et al. (2001). These studies reported that women HIV had lower quality of life compared to men. However the study by Chandra et al. (2009) in southern India showed that women had higher score in some facets of the WHO Quality of Life Instrument for HIV (WHOQOL-HIV120) and in spirituality and personal beliefs domain.

Nonetheless, Mayo (2002) in her study found no gender difference in quality of life of people living with HIV in the US. The gender differences in quality of life do not only reflects disease status, but also the prevailing socio-economic condition of the given society. For instance in the studies of Mast et al in Uganda, attention need to be paid to the prevalence of the disease, the plethora of orphanages that wrecked those societies and those who are left with the burden of care of orphans.

A study in Malawi, Zambia and Zimbabwe (SADC/FA, 2003, cited in de Wagt & Connolly, 2005) reported that 20 percent of household are caring for orphans and it is often the female-headed households that care for orphans. Gilborn et al. (2001) in their study found out that 40 percent of adults looking after orphans were HIV positive. Therefore it is necessary to put the result of this study in its context. In the Gambia, HIV has not reached the above devastation and therefore women would not have been subjected to such situations. The strong social solidarity may also help explain why females with HIV have better quality of life compare to males.

### 5.3 Association of Quality of life and use of HAART

The independent sample *t*-test showed no significant differences in the quality of life of respondents on HAART and those not on HAART (Table 4). This result is however not consistent with numerous other studies (Stangl et al., 2007; Louwagie, et al., 2007; Jelsma et al., 2005; Manheimer et al., 2005; Yen et al., 2004). These studies established the value of HAART in improving quality of life of recipients. The result is likely due two factors. The first factor is emanates from the time of starting patients on HAART therapy. In the Gambia, HIV patients are started on HAART when they are in WHO stage III and IV of the disease (MOH, 2009). This is due to the fact that there is no universal coverage of HAART for all persons living with HIV. Therefore potential gains of starting on HAART therapy at this stage of the disease when compared with those on stage I and II of the disease would diminish. Therefore the need for universal coverage for HAART for people living with the HIV/AIDS in The Gambia is important not only to improve quality of life but to reduce transmission to the virus to sexual partners. In a study by the National Institute of Health in the United States published by UNIADS (2011) press release, 'adhering to effective antiretroviral treatment reduces the risk of transmitting the virus to an uninfected sexual partner by 96%'.

The second factor relates to the study design. To properly evaluate the potential benefits of HAART for this group of recipients, it will be appropriate to collect data at two (Jelsma, et al., 2005) points in time or more. Therefore, a prospective study design would be appropriate. Hence, it would be inappropriate to state that HAART therapy has no value in improving the quality of life of people living with HIV/AIDS.

### 5.4 Association of quality of life with the six independent variables

Table 3 shows that physical, psychological, level of independence; social relationship environment and spirituality/religious domains had varying strengths of association with quality. Hasanah, Zaliha & Mahiran (2010) assessed factors influencing the quality of life in patients with HIV in Malaysia. They showed that patient functioned satisfactorily in the physical domain and were impaired in the social domain. However, other studies have shown that in the social relationship domain, social support for patients with HIV/AIDS has shown a strong potential to influence health related quality of life (Badia et al., 1999; Anderson et al., 1998, Wu et al., 1998). In the domain of spirituality, creating meaning and purpose to life was found to correlate with psychological well-being in a large sample of African American men and women with HIV/AIDS (Coleman & Holzemer, 1999). Adewuya et al. (2008) in their study showed that poor social support correlated with poor quality of life scores on the domain of physical health and social relationship.

Although correlation of the domains with quality of life is not significance in the multiple regression output, it would be appropriate to put this result in the context of the clinic setting. Physicians, nurses, health counselors and other professionals caring for people living with HIV/AIDS need to pay attention to patients' physical, psychological and emotional health, their need for independence from use of medication, the environment in which they live and their spiritual needs. The social relationship and level of independence domains show less strong correlation with improved quality of life. Therefore, awareness of the concerns of people living with HIV/AIDS have for being accepted, sexual functional ability and support they get from those around them will be a crucial in improving their quality of life. In the level of independence and spirituality domains, it will imperative to improves patients' capacity to work, and their satisfaction with the performance of the activities of daily living, to probe into the meaning they attach to purpose of life, concerns for stigma attached to living with the virus, their fears about the future and worries about death.

### 5.5 Conclusion

The findings of this study support the incorporation of quality life assessment into the HIV/AIDS care program at Royal Victoria Teaching Hospital and in The Gambia and the need to expand access to anti-retroviral therapy to all people living with the virus.. In this effect, assessing patient health status and satisfaction with their health can constitute important yardsticks to measure the response to care. Since HIV is a chronic illness, attention needs to be paid to the spiritual needs of patients, their concerns and fears for stigma and the environments in which they live.

## 5.6 Recommendations

Care Giver**.** Physicians, nurses, health counselors caring for people living with HIV/AIDS should pay greater attention the social relationship and level of independence domain that show less strong positive correlation with quality of life. It will be important to periodically evaluate their patient's health status and satisfaction with health as these influences patients' quality of life.

Policy makers. The weak correlation in the level of independent domain and social relationship domain with quality of life means that additional resources are needed to tackle stigma and discrimination, improve patient work capacity and performance of the activities of daily living. The need for patients to be free from medication should be supported by proper nutrition program. There is need for universal coverage with HAART to improve quality of life and reduce transmission of the virus to uninfected sexual partners.

Future study directions. A prospective study design should to be conducted to evaluate the potential benefit use of HAART in people living on HIV/AIDS in the Gambia.

## 5.7 Limitations of the study

As noted by Sey-Sawo et al. (2011), there were problems of interpreting some terms in the questionnaire, and therefore data collectors used approximation to describe the terms. Similar difficulties in the interpretation of English term related to the concept of health were noted by Kenyan field workers (Allen et al., 1997). Although, the instrument has been validated in multicultural settings (WHO, 1997), this difficulty requires the tool to be validated if future studies using the instrument are to be free from this problem.

Furthermore, ten respondents failed to answer the question on satisfaction with sex. Therefore in the future it will be important to conduct a study to evaluate the appropriateness of inclusion of this statement in the questionnaire for use in The Gambia.

Moreover, adults patients with HIV/AIDS are the subjects of study, and thus the results cannot be applied to population of other HIV/AIDS patients less than 18 years.

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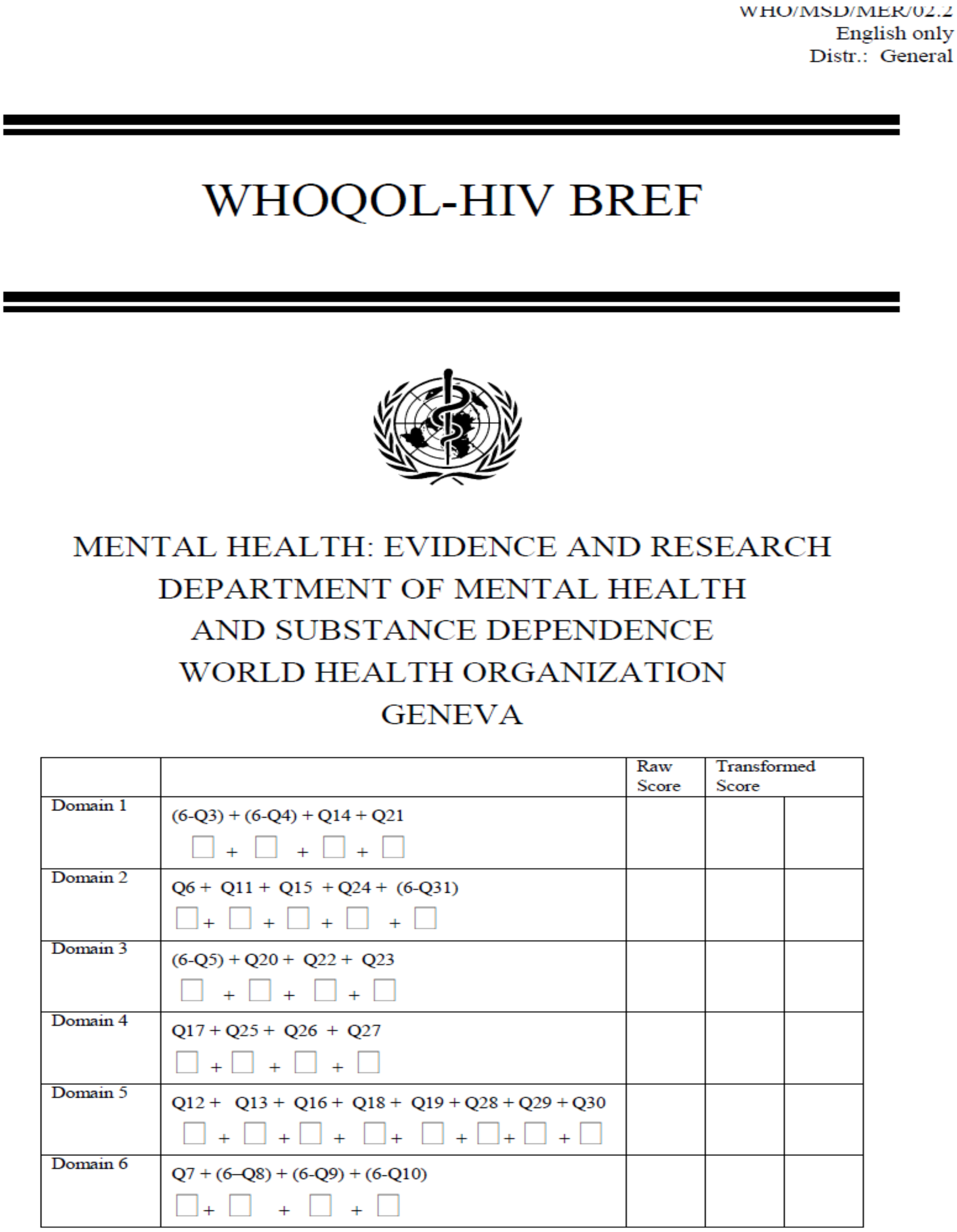
## Appendix 1. Research Questionnaire



WHO/MSD/MER/02.2
English only
Distr.: General

# WHOQOL-HIV BREF

MENTAL HEALTH: EVIDENCE AND RESEARCH
DEPARTMENT OF MENTAL HEALTH
AND SUBSTANCE DEPENDENCE
WORLD HEALTH ORGANIZATION
GENEVA

| | | Raw Score | Transformed Score | |
|---|---|---|---|---|
| Domain 1 | (6-Q3) + (6-Q4) + Q14 + Q21<br>☐ + ☐ + ☐ + ☐ | | | |
| Domain 2 | Q6 + Q11 + Q15 + Q24 + (6-Q31)<br>☐ + ☐ + ☐ + ☐ + ☐ | | | |
| Domain 3 | (6-Q5) + Q20 + Q22 + Q23<br>☐ + ☐ + ☐ + ☐ | | | |
| Domain 4 | Q17 + Q25 + Q26 + Q27<br>☐ + ☐ + ☐ + ☐ | | | |
| Domain 5 | Q12 + Q13 + Q16 + Q18 + Q19 + Q28 + Q29 + Q30<br>☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐ | | | |
| Domain 6 | Q7 + (6–Q8) + (6-Q9) + (6-Q10)<br>☐ + ☐ + ☐ + ☐ | | | |

## ABOUT YOU

Before you begin we would like to ask you to answer a few general questions about yourself: by circling the correct answer or by filling in the space provided.

| | |
|---|---|
| What is your **gender**? | Male / Female |
| How old are you? | ____________ (age in years) |
| What is the highest **education** you received? | None at all / Primary / Secondary / Tertiary |
| What is your **marital status**? | Single / Married/ Living as married / Separated / Divorced / Widowed |
| How is your **health**? | Very Poor / Poor / Neither Poor nor Good / Good / Very Good |
| Do you consider yourself currently ill? | Yes / No |

If there is something wrong with you, what do you think it is? ________________________

*Please respond to the following questions if they are applicable to you:*

What is your **HIV serostatus**? Asymptomatic / Symptomatic / AIDS converted

In what year did you first **test positive** for HIV? ________________________________

In what year do you think you were infected? ____________________________________

How do you believe you were **infected with HIV**? (circle one only):
Sex with a man / Sex with a woman / Injecting drugs / Blood products / Other (specify)________________

### *Instructions*

This assessment asks how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response. 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:

| | | Not at all | A little | A moderate amount | Very much | Extremely |
|---|---|---|---|---|---|---|
| 11 (F5.3) | How well are you able to concentrate? | 1 | 2 | 3 | 4 | 5 |

You should circle the number that best fits how well are you able to concentrate over the last two weeks. So you would circle the number 4 if you were able to concentrate very much. You would circle number 1 if you were not able to concentrate at all in the last two weeks.

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

| | | Very poor | Poor | Neither poor nor good | Good | Very good |
|---|---|---|---|---|---|---|
| 1(G1) | How would you rate your quality of life? | 1 | 2 | 3 | 4 | 5 |

| | | Very dissatisfied | Dissatisfied | Neither satisfied nor dissatisfied | Satisfied | Very satisfied |
|---|---|---|---|---|---|---|
| 2 (G4) | How satisfied are you with your health? | 1 | 2 | 3 | 4 | 5 |

The following questions ask about **how much** you have experienced certain things in the last two weeks.

| | | Not at all | A little | A moderate amount | Very much | An extreme amount |
|---|---|---|---|---|---|---|
| 3 (F1.4) | To what extent do you feel that physical pain prevents you from doing what you need to do? | 1 | 2 | 3 | 4 | 5 |
| 4 (F50.1) | How much are you bothered by any physical problems related to your HIV infection? | 1 | 2 | 3 | 4 | 5 |
| 5 (F11.3) | How much do you need any medical treatment to function in your daily life? | 1 | 2 | 3 | 4 | 5 |
| 6 (F4.1) | How much do you enjoy life? | 1 | 2 | 3 | 4 | 5 |
| 7 (F24.2) | To what extent do you feel your life to be meaningful? | 1 | 2 | 3 | 4 | 5 |
| 8 (F52.2) | To what extent are you bothered by people blaming you for your HIV status | 1 | 2 | 3 | 4 | 5 |
| 9 (F53.4) | How much do you fear the future? | 1 | 2 | 3 | 4 | 5 |
| 10 (F54.1) | How much do you worry about death? | 1 | 2 | 3 | 4 | 5 |

| | | Not at all | A little | A moderate amount | Very much | Extremely |
|---|---|---|---|---|---|---|
| 11 (F5.3) | How well are you able to concentrate? | 1 | 2 | 3 | 4 | 5 |
| 12 (F16.1) | How safe do you feel in your daily life? | 1 | 2 | 3 | 4 | 5 |
| 13 (F22.1) | How healthy is your physical environment? | 1 | 2 | 3 | 4 | 5 |

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

| | | Not at all | A little | Moderately | Mostly | Completely |
|---|---|---|---|---|---|---|
| 14 (F2.1) | Do you have enough energy for everyday life? | 1 | 2 | 3 | 4 | 5 |
| 15 (F7.1) | Are you able to accept your bodily appearance? | 1 | 2 | 3 | 4 | 5 |
| 16 (F18.1) | Have you enough money to meet your needs? | 1 | 2 | 3 | 4 | 5 |
| 17 (F51.1) | To what extent do you feel accepted by the people you know? | 1 | 2 | 3 | 4 | 5 |
| 18 (F20.1) | How available to you is the information that you need in your day-to-day life? | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|---|---|---|---|---|---|---|
| 19 (F21.1) | To what extent do you have the opportunity for leisure activities? | 1 | 2 | 3 | 4 | 5 |

| | | Very poor | Poor | Neither poor nor good | Good | Very good |
|---|---|---|---|---|---|---|
| 20 (F9.1) | How well are you able to get around? | 1 | 2 | 3 | 4 | 5 |

The following questions ask you how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

| | | Very dissatisfied | Dissatisfied | Neither satisfied nor dissatisfied | Satisfied | Very satisfied |
|---|---|---|---|---|---|---|
| 21 (F3.3) | How satisfied are you with your sleep? | 1 | 2 | 3 | 4 | 5 |
| 22 (F10.3) | How satisfied are you with your ability to perform your daily living activities? | 1 | 2 | 3 | 4 | 5 |
| 23 (F12.4) | How satisfied are you with your capacity for work? | 1 | 2 | 3 | 4 | 5 |
| 24 (F6.3) | How satisfied are you with yourself? | 1 | 2 | 3 | 4 | 5 |
| 25 (F13.3) | How satisfied are you with your personal relationships? | 1 | 2 | 3 | 4 | 5 |
| 26 (F15.3) | How satisfied are you with your sex life? | 1 | 2 | 3 | 4 | 5 |
| 27 (F14.4) | How satisfied are you with the support you get from your friends? | 1 | 2 | 3 | 4 | 5 |
| 28 (F17.3) | How satisfied are you with the conditions of your living place? | 1 | 2 | 3 | 4 | 5 |
| 29 (F19.3) | How satisfied are you with your access to health services? | 1 | 2 | 3 | 4 | 5 |
| 30 (F23.3) | How satisfied are you with your transport? | 1 | 2 | 3 | 4 | 5 |

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

| | | Never | Seldom | Quite often | Very often | Always |
|---|---|---|---|---|---|---|
| 31 (F8.1) | How often do you have negative feelings such as blue mood, despair, anxiety, depression? | 1 | 2 | 3 | 4 | 5 |

Did someone help you to fill out this form? ____________________

How long did it take to fill this form out? ____________________

Do you have any comments about the assessment? ____________________

____________________

____________________

____________________

## THANK YOU FOR YOUR HELP

## Appendix 2. Participant Information Sheet

Preamble

I am coming from university of the Gambia. Currently I am undertaking master degree studies at Taipei Medical University in Taiwan.

I am conducting this study to determine the quality of life of people living with HIV/AIDS in The Gambia. This has not yet been studied in The Gambia despite the high priority given to HIV/AIDS care. This study will therefore attempt to determine this by with the use of a questionnaire. The answers you provide will be used for analysis and a report will be produced as part of my research for the program. The results will be shared with policy makers in the Gambia and I intend to have it published.

However the answers you provide are strictly confidential and your name or the names of any other persons will not be mentioned in any report. You are free to participate and you have the exclusive right to with draw from the study. I encourage you to fill all items of the questionnaire as this will help in writing a comprehensive report. If there is a section of the questionnaire that you don’t want to fill or you are not comfortable with, you can decide not so fill it.

Thank you for accepting for participate in this study

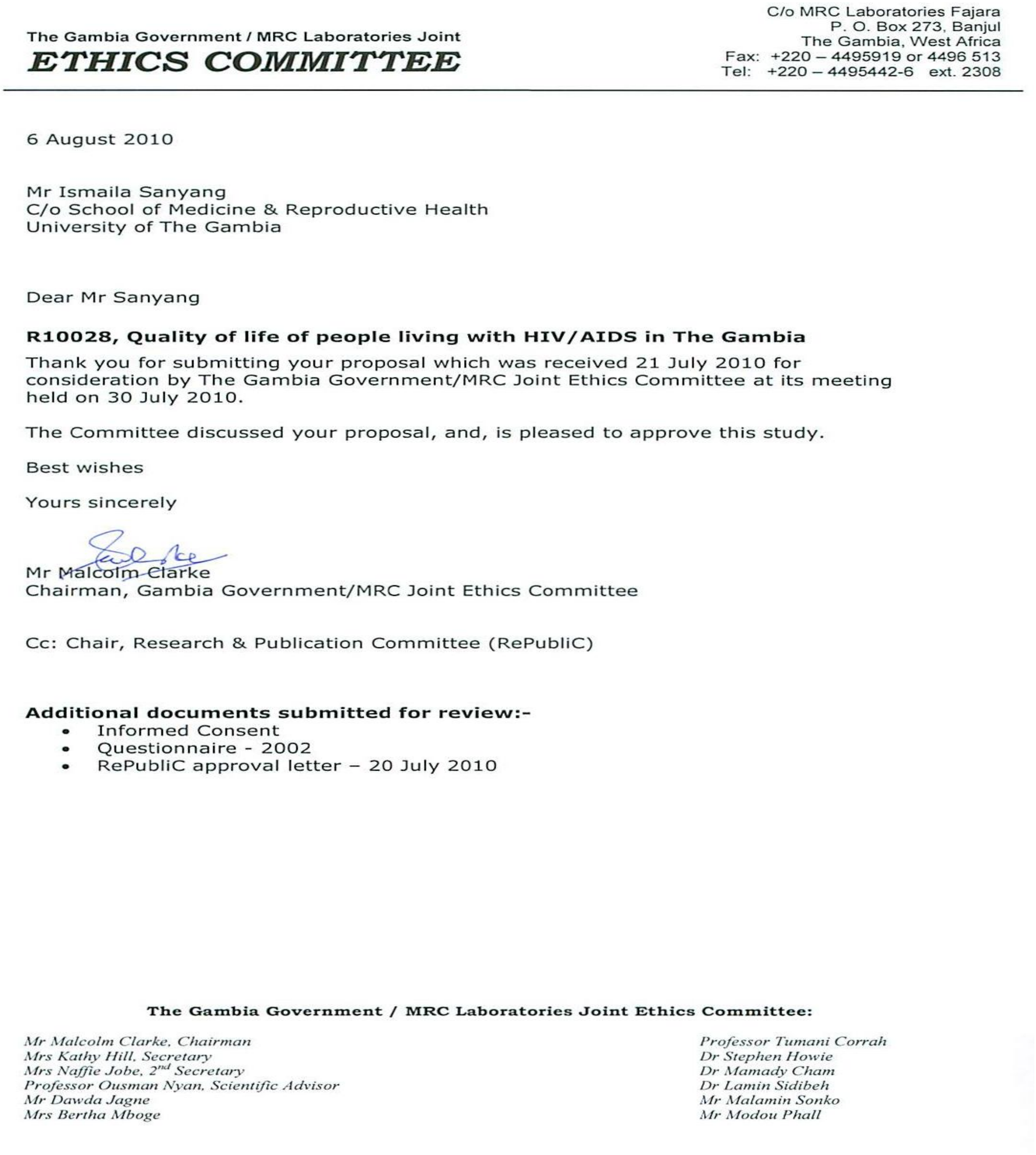
Please sign the consent form below

Consent to form

Mark X in the box provided below this statement to indicate your voluntary participation in this study.

I have read the preamble and the objectives of the study have been explained to me. I therefore consent to participate in this study and complete this questionnaire.

## Appendix 3. Ethical Approval Letter



The Gambia Government / MRC Laboratories Joint
**ETHICS COMMITTEE**

C/o MRC Laboratories Fajara
P. O. Box 273, Banjul
The Gambia, West Africa
Fax: +220 – 4495919 or 4496 513
Tel: +220 – 4495442-6 ext. 2308

6 August 2010

Mr Ismaila Sanyang
C/o School of Medicine & Reproductive Health
University of The Gambia

Dear Mr Sanyang

**R10028, Quality of life of people living with HIV/AIDS in The Gambia**

Thank you for submitting your proposal which was received 21 July 2010 for consideration by The Gambia Government/MRC Joint Ethics Committee at its meeting held on 30 July 2010.

The Committee discussed your proposal, and, is pleased to approve this study.

Best wishes

Yours sincerely

Mr Malcolm Clarke
Chairman, Gambia Government/MRC Joint Ethics Committee

Cc: Chair, Research & Publication Committee (RePubliC)

**Additional documents submitted for review:-**
- Informed Consent
- Questionnaire - 2002
- RePubliC approval letter – 20 July 2010

**Appendix 4. Table showing sub-dimension or facets of the independent variables, how they are rated, how they are coded and how they some of the items were re-coded in the data analysis sheet.**

| ID | Domain | Facets or sub -dimensions | | | | | | | | Coding | Comment |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | | |
| 1 | Physical Domain | Bothered by Physical pain | Physical problems related to HIV | energy | sleep | | | | | (a)1,2 and 3 rated on a five point likert scale; not at all=1; a little=2; a moderate amount=3; very much=4; an extreme amount=5. (b)Sleep rated as very dissatisfied=1;dissatisfied=2; neither satisfied no dissatisfied=3; satisfied=4; very satisfied=5 | 1 and 2 were reversely re-coded in the data set: 1=5, 2=4, 3=3,4=2, 5=1 |
| 2 | Psychological domain | Enjoy life | Ability to concentrate | Body appearance | Satisfaction with one self | Negative feelings | | | | 1 rated as (a). (c) 2 rated as not at all=1, a little=2, a moderate amount=3, very much=4, extremely=5. (d) 3 rated as not at all=1, a little=2, moderately=3 mostly=4, completely =5. Rated as (b). | 5. was reversely re-coded in the data set as above |

|  |  |  |  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 3 | Level of independent domain | Need for medication | Ability to get round | Satisfaction with ability to perform daily activites | Satisfaction with capacity to work |  |  |  |  | Rated as not at all=1, a little=2, a moderate amount= 3, very much = 4 an extreme amount =5.<br>2,3 and 4. Rated as very dissatisfied=1, dissatisfied=2, neither satisfied nor dissatisfied=3, satisfied=4, very satisfied=5 | 1.was reversely re-coded in the data set |
| 4 | Social relationship p domain | Feeling of acceptance by people you know | Satisfaction with personal relationship-p | Satisfaction with sexual life | Satisfaction with support from friends |  |  |  |  | 1.rated as, not at all=1, a little=2, moderately=3, very much=4, completely=5. Very dissatisfied=1,dissatisfied=2, neither satisfied nor dissatisfied=3, satisfied=4, very satisfied=5 |  |
| 5 | Environment domain | Personal relationship in daily life | Health of physical environment | Money to meet daily needs | Availability of information needs | Extent of opportunity for leisure | Satisfaction with conditions of living | Satisfaction with access to health service-es | Satisfaction with transport | 1 2 rated as not at all=1, a little=2, a moderate amount=3, very much=4 extremely=5.<br>3,4,5. Rated as not at all=1, a little=2, moderately=3, mostly=4, completely=5.<br>6,7,8. Rated as very |  |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | dissatisfied=1, dissatisfied=2, neither satisfied nor dissatisfied=3, satisfied=4 very satisfied=5 | |
| 6 | Spirituality/Religion domain | Feeling of life to be meaningful | Bothered by people blaming for HIV status | Fear for future | Worry about death | | | | | | |