



UNIVERSITY OF NAIROBI

HEALTH-RELATED QUALITY OF LIFE AMONG HIV/AIDS WOMEN PATIENTS IN
KOROGOCHO SLUMS AND ITS SIGNIFICANCE IN HEALTH CARE
OUTCOMES.

BY

PRISCAH C.N. OTAMBO
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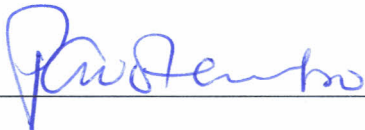
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PRISCAH C.N. OTAMBO

REG NO: C50/70930/2007

This project has been submitted for examination with my approval as a University Supervisor.

Signature:  Date: 18/11/2009

PROFESSOR EDWARD MBURUGU

DEPARTMENT OF SOCIOLOGY AND SOCIAL WORK

UNIVERSITY OF NAIROBI

P.O BOX 30197

NAIROBI, KENYA

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Abbreviations

HRQOL	-	Health Related Quality of Life
HIV	-	Human immunodeficiency Virus
AIDS	-	Acquired immunodeficiency syndrome
NACC	-	National Aids Control Council
WHO	-	World Health Organization
PLHIV	-	People Living with Human immunodeficiency virus
ART	-	Anti Retroviral Therapy
QOL	-	Quality of Life
GOK	-	Government of Kenya
MOH	-	Ministry of Health
UNAIDS	-	Joint United Nations Programme on HIV and Aids
UNIFEM	-	United Nations Development Fund for Women
UNFPA	-	United Nations Population Fund
NIID	-	National Institute of Infectious Diseases
CDC	-	Centres of Disease Control
NACO	-	National Aids Control Organization
MTCT	-	Mother to Child Transmission
STI	-	Sexually Transmitted Infections

KDHS	-	Kenya Demographic Health Survey
SEIQOL	-	Schedule for Evaluation of Individual Quality of Life
TB	-	Tuberculosis
SRPB	-	Religiosity and Personal Beliefs
FGD	-	Focus Group Discussion
CD	-	Compact Disk
SPSS	-	Statistical Package for Social Scientists
KII	-	Key Informant Interviews

ABSTRACT

The concept of quality of life is understood and interpreted differently by people and even professionals. The constitution of the World Health Organization (WHO) defines health as a State of complete physical, mental and social well being and not merely the absence of disease. It follows that the measurement of health and the effects of healthcare must include not only an indication of changes in the frequency and severity of diseases but also an estimation of well being. This can be assessed by measuring the improvement in the quality of life related to health care.

Other researchers have pointed out that a good quality of life can be said to exist when the hopes of an individual are matched and fulfilled by experience. As most chronic diseases often do not disappear in spite of the best biomedical treatments, it might be that the real change patients have for betterment is in understanding and living the noble path of personal development. The hidden potential for improving quality of life really lies in helping the patient to acknowledge that his or her lust for life, his or her needs and his or her wish to contribute, is really deep down in human existence. Quality of life then invariably focuses on the ability of an individual to function in occupational, social, domestic spheres and his/her capacity to involve himself/herself in activities of daily living and self care.

Determining the impact of HIV/AIDS on the quality of life in HIV/AIDS patients is important for estimating the burden of the disease. It is also a gateway to improve understanding of the factors that contribute to HRQOL among HIV/AIDS patients so as to identify targets for improving quality of life for persons with existing HIV/AIDS infections.

This study was a purposive one that examined the determinants of Health Related Quality of Life (HRQOL) among HIV/AIDS women patients in the Korogocho slums of Kenya, aged 18 – 55 years, the significance of HRQOL among

HIV/AIDS patients in the Kenyan healthcare system and whether Spirituality, Religiosity, and Personal Beliefs play any role in the HRQOL in HIV/AIDS women patients. Respondents' participation was on volunteerism basis.

Quality of Life was evaluated using 26 items. Each item used a Likert-type five-point scale. These items were distributed in four domains. The four domains of QOL covered (a) Physical health and level of independence (seven items assessed areas such as presence of pain and discomfort; energy and fatigue, mobility; sleep and rest; activities of daily living: perceived working capacity); (b) Psychological well being (eight items assessed areas such as affect, both positive and negative self concept, higher cognitive functions; body image and spirituality), (c) social relationships (three items assessed areas such as social contacts, family support and ability to look after family, sexual activity and (d) environment (eight items assessed areas such as freedom, quality of home environment; physical safety and security and financial status; involvement in recreational activity; health and social care: quality and accessibility). The domain on environment was considered necessary because it plays a major role in determining health status, mediating disease pathogenesis and limiting or facilitating access to health care. There were two items as well that were examined separately: one which asked about the individual's overall perception of QOL and the other which asked about the individuals overall perception of his or her health. The domain scores were scaled in a positive direction – higher scores denoted higher quality of life. Spirituality, Religiosity and Personal Beliefs (SRPB) were also assessed especially for qualitative research. **Findings:** On the general quality of life the respondents reported experiencing low QOL. 53% reported this. Only 28% reported good quality of life. There is the element of family support and relationships that has been rated very highly by the respondents. On Satisfaction with personal relationships, 67% reported that they are dissatisfied. 70% reported that they do not get enough support from friends. This is in consistent with other researches that affirm on the same (O'Boyle et al. 1992;) (Cattell 2001). There is dissatisfaction on healthcare system that

needs great improvement in this country. On the element of access to health, 54% reported dissatisfaction with the Kenyan health system. Important information gathered from the respondents was that they do not get enough information on HIV and Aids. This puts NACC and those other non-governmental organizations that are supporting PLWHA especially in slum areas on the spot. Limited information on this aspect derails efforts to mitigate the manifestations of HIV and AIDS. 57% reported the lack of information. Education is too low in the slums. Academically 69% of the respondents have only attained primary level of education. This is a huge number going by the disadvantages of low education levels in this country. In itself, this contributes a lot on the prevalence of HIV and Aids in slum areas due to lack of enough information to make major decisions or informed choices. On bodily appearance only 29.5% accept their bodily appearance and 59% do not accept at all. On environment 37% reported that the environment they live in is unhealthy while 34.7% reported that it is healthy. **Conclusions:** Policy makers and clinicians need to consider the implications of this study for health resource allocation, and recognize that small improvements in HRQoL may be of great significance for individuals with HIV manifestations. This will also help in identifying specific intervention programmes that are needed to improve the QOL of HIV patients. This therefore calls for a holistic approach to health and health care. The patient's view, priorities and behaviour on quality of life are thus important for healthcare planning and management systems.

CHAPTER ONE

1.0 Introduction

Since the discovery of HIV and AIDS in Kenya in 1984, the country has been and continues to feel the impact of the disease. In its efforts to mitigate the effects of the disease, the GoK, after acknowledging the impact of the disease that happened to touch on all sectors of the economy, established National Aids Control Council (NACC) a body that was mandated to come up with diverse and immediate programmes to mitigate the epidemic. Although this has been done, people still continues to succumb to the condition of HIV and AIDS. This research appreciates the efforts already put in place but wants to add more value on the already existing dimensions of the mitigation processes by examining the aspect of quality of life of the affected persons and how this may determine health care outcomes. This chapter therefore outlines the problem statement and the justification for the research among other aspects.

1.1 An overview of Aids Epidemic

In 1981, Dr Michael Gottlieb (Hung, 2004) of the University of California at Los Angeles drew the attention of the world of a rare pneumonia occurring in homosexual men. Other reports from about the same time indicated that other homosexual men were developing rare forms of cancer. This new set of symptoms, a syndrome in medical jargon, was eventually called acquired immunodeficiency syndrome because the symptoms were consistent with damage to the immune system in previously healthy individuals.

More over, this disease was not congenital or inherited but appeared to have been acquired. Knowledge now shows that this resulted from infection by a virus. Since then, the acronym AIDS which is used to describe this diseases, has become a prominent and permanent fixture in our language. It evokes a range of responses, including fear, hate and mistrust. Some of these responses e.g. hate and mistrust are related to the association of AIDS with sub cultural groups within our Society such as male homosexuals, who already have experienced discrimination. Other responses like fear are due to the grave nature of the aids disease and the threat it may pose to society. This is because the AIDS epidemic continues to grow, unlike most other major infectious diseases which have been controlled by a combination of clinical treatments and public health measures.

1.2 AIDS in Brief

It is now common knowledge that aids is caused by the human immunodeficiency virus (HIV) but it was originally observed by its effect on the immune system. An important clue was that AIDS patients often developed a lung infection caused by a fungus called pneumocystis carinii (<http://www.cdc.gov/hiv/hap.htm>). This infection is said to be very rare in healthy individuals but patients with cancers of the immune system (lymphomas) were known to be susceptible to this disease. In addition to pneumonia, AIDS is associated with numerous other infections. These secondary infections are caused by various bacteria, protozoa, fungi and viruses (<http://wwwbioscience.jpup.com/aids>). Usually it is these infections known as opportunistic infections that cause death in AIDS patients. HIV on the other hand causes diseases insidiously meaning an individual may look healthy for a long period of time before the manifestations of AIDS.

In the relatively brief period since the beginning of the AIDS epidemic, AIDS has already had a major impact on death and disease in both the developed and developing nations. For example 29 million people in Sub Saharan Africa are infected with HIV. Given the relatively poor medical support available in much

of Africa, the number of infected people continues to increase. World wide AIDS now ranks as the fourth leading cause of death after heart disease, stroke and acute lower respiratory infections. In Africa it is the leading cause of death (<http://www.unaids.org/old>). In the United States there are between 40,000 and 60,000 new cases of HIV infection every year and the number of people dying from AIDS per year is currently approximately 20,000. (<http://www.cdc.gov/hiv/dhap.htm>).

1.3 The Concept of Quality of life

The concept of quality of life is understood and interpreted differently by people and even professionals. The constitution of the World Health Organization (WHO) defines health as a State of complete physical, mental and social well being and not merely the absence of disease (WHO 1948). It follows that the measurement of health and the effects of healthcare must include not only an indication of changes in the frequency and severity of diseases but also an estimation of well being. This can be assessed by measuring the improvement in the quality of life related to health care.

WHO defines quality of life as an individual's perception 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. It is a broad concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationships to salient features of their environment. Jonsen et al (1987) on the other hand refers quality of life to the subjective satisfaction expressed or experienced by an individual in his physical, mental and social situation.

Calman (1984) points out that a good quality of life can be said to exist when the hopes of an individual are matched and fulfilled by experience. On the same dimension, Maslow's concept of self-actualization can play an important role in

modern medicine. As most chronic diseases often do not disappear in spite of the best biomedical treatments, it might be that the real change patients have for betterment is in understanding and living the noble path of personal development. The hidden potential for improving quality of life really lies in helping the patient to acknowledge that his or her lust for life, his or her needs and his or her wish to contribute, is really deep down in human existence. In order to maintain a good quality of life therefore, the priorities and goals of an individual must be realistic. Quality of life then invariably focuses on the ability of an individual to function in occupational, social, domestic spheres and his/her capacity to involve himself/herself in activities of daily living and self care.

Friedland (1996) notes that several researchers have defined quality of life as a fighting spirit associated with longer survival time for individuals. Quality of life then relates to adequacy of material circumstances and to personal feelings about these circumstances. In his input McDowell (1987) conjures that QOL includes overall subjective feelings of well being that are closely related to morale, happiness and satisfaction.

1.4 Problem statement

The manifestation of HIV and AIDS is complex. HIV infected individuals suffer from the chronic symptoms of virus induced immunodeficiency. The prevention and treatment of these complications' lay the foundation of what is now referred to as HIV medicine. The practice of HIV medicine, the management of HIV and AIDS and research has been naturally narrowed down to the cellular/molecular level, and this is not to blame, but to appreciate the fact that HIV and AIDS and its manifestations is contemporary. It has caused panic and no treatment or total eradication is anywhere near the future. Its impact is also overwhelming so to speak especially in the peripheral countries.

Quality of life implies a positive view of the world though a point to note is that it does not neglect the negative features of society like alienation and exclusion, anxieties and fears as well as worries and loneliness. The concept of quality of life is aware of the multiplicity and ambivalence of human life. Besides positive and negative dimensions of life, there is also the future dimension which has to be taken into account additionally. The future perspective in this respect constitutes another dimension of individual and societal well being – what people hope and fear for their future is an essential part of their quality of life.

With respect to the contrasting cases, quality of life can be defined on the one hand for the individual and on the other hand for the global world. In both contexts, however, it is measured differently. In this paper the concept of QOL will be concentrated at the individual level and the sick for that matter.

Determining the impact of HIV and AIDS on the quality of life in HIV and AIDS patients is important for estimating the burden of the disease. It is also a gateway to improve understanding of the factors that contribute to HRQOL among HIV and AIDS patients so as to identify targets for improving quality of life for persons with existing HIV and AIDS infections. This is true because AIDS has a chronic debilitating course and the long term adverse side effects of current treatment modalities are uncertain.

The social stigma attached with the proclamation of HIV sero-positivity may at times force the individual to change jobs or place of living. The insurgent of wars and conflicts, natural disasters like earthquakes, floods that result into internal displacements of people, put further stress on the affected persons. This further leads to progressive deterioration of health, low morale, repeated consultations, abstinence from work and low productivity. The vicious cycle thus goes on. Economic deprivation and social isolation is another dimension that takes its toll on the quality of life of HIV and AIDS patients.

While a lot of research has centered on the clinical manifestations (body gaze) of the condition thus empowering the medical practitioner and the biological research scientists, little emphasis is placed on the patient as a wholesome entity. The medical practitioner has put little emphasis to the fact that HIV and AIDS manifestations goes beyond the individual. It would be good to note that such paradigms as physical, social, emotional and the living environment are bound to affect the infected persons in terms of quality of life whether enhancing or aggravating.

In Kenya there is minimal literature on the aspects of quality of life as no scientific research has been carried out. As a matter of fact National Aids Control Council (NACC) has intended in its 5 year strategic master plan (2005 – 2010) to carry out a scientific research on improvement aspect of HRQOL among HIV and AIDS patients. In a research carried out in South Africa on HRQOL in a sample of HIV infected South Africans it was found out that there was need for better access to psychosocial support and medical services (Karl P., 2008) for PHLIV as well as the need to consider a patient's general health perceptions during the course of ART.

The assessment or determining the QOL in HIV and AIDS patients therefore is critical in understanding their priorities or goals in life and how they impact on health outcomes and health care. And indeed Balint (1967) argued that an adequate diagnosis can only be made through consideration of person's social, psychological and environmental state – this entails examining the patient's emotional, personal and family life which the doctors hardly do. Assessment of QOL in individuals living with HIV and AIDS is therefore crucial to research and evidence based practice in this area. QOL can also be considered an essential element for clinical trials in HIV infection, as commonly used end-points (Indian, 2005).

Having said this, it becomes clear, and especially in Kenya, that there still exists a gap in HIV and AIDS treatment, prevention and intervention efforts if the concept of HRQOL is not aggressively taken into context.

1.5. Research questions

- (a) What are the determinants of Health Related Quality of Life among HIV and AIDS women patients in the Korogocho slums of Kenya?
- (b) What is the significance of Health Related Quality of Life among HIV and AIDS patients in the Kenyan healthcare system?
- (c) Does Spirituality, Religiosity, and Personal Beliefs play any role in the Health Related Quality of Life in HIV and AIDS women patients based in Korogocho Slums?

1.6. Objectives of the study

1.6.1 Overall objective

- (i) To establish the status of quality of life among HIV and AIDS women patients in the Kenyan Korogocho Slums.

1.6.2 Specific Objectives

- (i) To assess the Quality of Life issues in HIV and AIDS women patients in terms of psychological, social relationships and the environment as related to health.
- (ii) To find out whether personal beliefs, spirituality and religiosity (PBSR) play any role in improvement of quality of life among HIV and AIDS women patients in Korogocho slums.

1.7. **Justification for the study**

After the introduction of the Structural Programmes in 1989, the Government of Kenya (GOK) introduced cost-sharing in its health facilities. The main reason for this change in policy was the need to mobilize additional resources for the continued maintenance and improvement of the health care system (Mbatia 1996). However, its use has little impact on revenue generation as less than 3% of the total government recurrent health budget is realized through cost sharing.

Analysis show that about 70% of the resources goes to curative services (mainly hospitals that are allocated 80% of the resources and in fact hospitals in urban centers which merely serve 20% of the urbanites while rural centers that oversee 80% of the population is allocated 20% of health resources) while 11% goes to preventive health care and 80% goes to personnel emoluments.

The GOK spends a higher share of the MOH recurrent expenditure on curative care despite the fact that the major cause of morbidity and mortality are conditions that can be prevented through aggressive primary and preventive health care programmes. The impact of this pattern of funding manifests in poor quality of services and frequent shortages of essential inputs including drugs for health delivery. Further more government health facilities are hardly within easy reach of the patients. This surmounts to inaccessibility for treatment by most patients. And indeed going by The Standard Newspaper report dated 27th May 2009, it was mentioned that of 19 divisions in Turkana North, Central and South the Government has only two medical facilities making patients to walk for 40 Kms to attend to medical care. It is also in the National Aids Council report that inadequate primary health care is to blame for spread of HIV and AIDS especially among the poor (Standard Newspaper, May 27th 2009).

In his study on the impact of HIV and AIDS on the quality of life, a cross sectional study carried out in North India, Naveet (2006) found out that quality of life among HIV patients centered on education, income, occupation and family support. He therefore directed that future studies should encompass the evaluation of more determinants of quality of life in HIV and AIDS female patients particularly as they are the more vulnerable groups and carry out most social burdens.

Donovan et al (1989) also pointed out that adequate quality of life measures should include assessment of the spiritual domain. He added that there was evidence that as the physical condition deteriorates; spiritual issues commonly gain in importance as determinants of quality of life (Gotay, 1984). While this aspect has been relatively less explored in QOL measures and especially in Kenya, it could add vital information for HIV patients. This study heeds to that call. Furthermore, with the modern developments of HIV management through antiretroviral interventions and treatment, it has been noted (Brecht 2001) that people can now live longer lives with the virus and therefore determining the quality of life of HIV and AIDS patients is important for estimating the burden of the disease.

In addition determining the quality of life among HIV and AIDS patients can improve the doctor-patient interaction and in understanding health outcomes in healthcare management. Doctors and patients, even if they come from the same *social and cultural backgrounds, view ill health in very different ways. Their perspectives are based on very different premises, employ a different system of proof and assess the efficacy of treatment in a different way.*

A further point to note is that modern medicine is often very reductionist. Increasingly, its focus is less on the actual patient than on a particular diseased organ, system, group of cells or bodily part. The priorities or perceptions of the

patient in reference to QOL in health related issues offers a better understanding of the treatment outcomes by the doctor.

It is worthy noting that HIV infection is a stressful life event. It is widely accepted that individuals with HIV infection are highly vulnerable to stress (Folkman 1994) and that depression associated with the infection and/or disease significantly impacts the individual's quality of life. Therefore it is important to understand how social support for example impact patient outcomes. Such information would help develop interventions to improve the QOL of individuals with HIV infection. It is now widely recognized that HIV and AIDS is a chronic disease that needs to put more emphasis on self care management that rests solely on those affected (Leatt et al 2000).

In recent years therefore, particularly because of the chronic element of most illnesses, there has been a broadening focus in the measurement of health, beyond traditional health indicators such as mortality and morbidity (WHO, 1993; WHO 1991), to include measures of the impact of disease and impairment on daily activities and behaviours (Bergner, 1989), perceived health measures (Hunt 1989) and disability/functional status measures (Are, 1993). These measures, whilst beginning to provide a measure of the impact of disease, do not assess quality of life per se, which has been aptly described as the missing measurement in health. (Fallowfield, 1990).

Also most measures of health status have been developed and tested in developed countries and little has been done in the developing world. At the same time the increasingly mechanistic model of medicine is purely concerned only with the eradication of disease and symptoms. The introduction of a humanistic element into health care is of paramount importance. By calling for quality of life assessments in healthcare therefore means attention can be focused on this aspect of health and resulting interventions will pay increased attention to this aspect of patients' well being. This creates a holistic approach to health and health care.

The patient's view, priorities and behaviour on quality of life are thus important for healthcare planning and management systems.

Recent estimates by the joint United Nations Programme on HIV and AIDS and the World Health Organization suggest that of the 34.3 million people currently infected with HIV, 95 per cent live in sub Saharan Africa and the developing countries of Asia and Latin America. With nearly 17,000 infections occurring every day, the estimate for the end of the twentieth century is more than 40 million infected people. Unless a cure is found or life-prolonging therapy to be made more widely available, the majority of people living with HIV or AIDS will continue to suffer with the disease, with serious impact on their quality of life.

Therefore assessing QOL is particularly pertinent for those living in developing countries like Kenya where adequate medical care is currently unavailable and social support is at a minimum. Assessment of QOL in individuals living with HIV and AIDS is therefore crucial to research and evidence based practice in this area. QOL can also be considered an essential element for clinical trials in HIV infection, as commonly used end-points (Indian, 2005).

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 INTRODUCTION

This section examined literature on the scope of HIV and AIDS among women globally and Kenya in particular and its impact on the quality of life to the infected women. An overview of the HIV and AIDS among Kenyan women was outlined. A review of literature on QoL was explored followed by some of the theories that were to be applied. At micro level, the theory of symbolic interactionists was explored to explain the vulnerability of women affected by HIV and AIDS.

At societal level the functional theory as exemplified by Talcott Parson's sick role model was explored and this was used to explain the predicament of a sick person and what the society expects of him/her thus examining how this model could fit in the quality of life equation of an HIV and AIDS woman. This model could also be used to expound on the stigma aspects of HIV and AIDS women patients.

2.2. Women and HIV/AIDS

Around the world, women now make up half of all people living with HIV and AIDS. In the USA for example, 25% of new infections are in women. HIV and AIDS is the leading cause of death for African women aged 25 to 34 years (CITE)

While the impact of this epidemic on women has been devastating, many women with HIV and Aids are living longer and stronger lives thanks to new treatments.

While there is no cure yet, HIV treatment has come along way since the first reported cases in the early 1980's. Today there are a number of therapies and medications available. There are also a wide variety of government resources in place to help people cope with HIV.

At the end of 2007, it was estimated that out of the 30.8 million adults worldwide living with HIV and Aids, around half are women (UNAIDS 2008). It is suggested that 98% of these women live in developing countries (UNAIDS/UNIFEM 2004). The AIDS epidemic has had a unique impact on women which has been exacerbated by their role within society and their biological vulnerability to HIV infection.

Generally women are at a greater risk of heterosexual transmission of HIV. Biologically women are twice more likely to become infected with HIV through unprotected heterosexual intercourse than men. (NIID, 2006). In many countries women are less likely to be able to negotiate condom use and are more likely to be subjected to non-sensual sex. Additionally, millions of women have been indirectly affected by the HIV and AIDS epidemic. Women's childbearing role means that they have to contend with issues such as mother-to-child transmission of HIV. The responsibility of caring for aids patients and orphans is also an issue that has a greater effect on women.

2.3. Women and HIV/AIDS – the Global picture

The percentage of women living with HIV and aids varies significantly between different regions of the world. The areas such as Europe, women account for a relatively low percentage of HIV infected people. However, in regions such as sub-Saharan Africa and Caribbean the percentage is significantly higher. In 1985 in Sub-Saharan there were as many HIV infected men as there were women. However, as the infection rate has increased over the years, the number of women living with HIV aids has over taken and remained higher than the number of

infected men. It is noted that in 2007 there were around 12 million women living with HIV aids compared to about 8.3 million men. UNAIDS have estimated that around three quarters of all women with HIV live in sub Saharan Africa. (UNAIDS 2008.)

In the Caribbean, there has been an alarming increase in the number of HIV infected women. Young women for example are approximately 2.5 times more likely to be infected with HIV than young men. (UNAIDS/UNFPA.UNFIEM 2004). The Centres for Disease control (CDC) estimate that in USA, the number of newly HIV infected women is rising. In 2001, there were some 101,398 female adults or adolescents living with HIV and AIDS (CDC 2005). By 2005, this number had increased to 126, 9644.

In Latin America, around 30% of adults living with HIV and aids are women. (UNAIDS/UNFPA/UNFEM 2004). In Asia UNAIDS estimates that around 4.8 million adults are living with HIV and AIDS and approximately 35% are women (UNAIDS 2008). It is estimated that the number of adults living with HIV and AIDS in India is 2.4 million. According to the National Aids Control Organization (NACO 2006), women account for 39.3% of these.

How is the HIV and Aids epidemic affecting women? In areas with a few palliative care facilities, when a person becomes ill from aids, the care is usually a woman's responsibility. In 2004 in Vietnam, for example, 75% of all caregivers for persons living with HIV and AIDS were women. (UNAIDS DEC. 2004). This care-giving is usually in addition to many other tasks that women perform within the household such as cooking, cleaning, fetching water, caring for the children and the elderly.

Caring for ill parents, children's or households is unpaid and can increase a person's workload by up to a third. (UNAIDS/UNFPA/UNIFEM, 2004). Women

often struggle to bring in an income whilst providing care and therefore many families affected by HIV and AIDS suffer from increasing poverty. In some areas of sub Saharan Africa e.g. Kenya where livelihood relies on growing and maintaining crops, the death of farmers can lead to famine (Ibid).

The HIV and AIDS epidemic also affects young girls and elderly women often households where both the husband and the wife are ill from AIDS. Girls are usually the main carers even if it means that they have to miss or abandon school. If both parents die then it tends to be the grandmothers, aunts or cousins who then look after the AIDS orphans. Mother to child transmission (MTCT) is another issue that directly affects women and at the same time increases the spread of HIV. UNAIDS contend that at the end of 2007 there were an estimated 2 million children (under 15 years) living with HIV. Most of who were infected by mothers (UNAIDS 2008). It has also been documented that side effects from RV's intake are slightly more common among women (Feinberg et al 2005).

Another challenge to women is the inequalities in society. In some societies, women have few rights within the sexual relationships and the family. Often men make the majority of decisions such as whom they will marry and whether the man will have more than one sexual partner. This power imbalance means that it can be more difficult for women to protect themselves from getting infected with HIV. Marriage does not always protect a woman from becoming infected with HIV. Many new infections occur within marriage or long term relationships as a result of unfaithful partners. In a number of societies, a man having more than one sexual partner is seen as a norm. In a study of 400 women attending an STI clinic in Pune, India, for example, showed that 14% were HIV positive, 93% of these women were married and 91% had not had sex with anyone other than their husbands (UNICEF, UNAIDS, WHO 2002 – young people and HIV and AIDS Opportunity crisis).

Women who are victims of sexual violence are at a higher risk of being exposed to HIV. The lack of condom use and the forced nature of rape mean that women

are immediately more vulnerable to HIV infection. For example one study of 1,366 South African women concluded that those women who were beaten or dominated by their partners were much more likely to become infected with HIV than women who were not. (Dunkle, K.L et al 2004). In many countries around the world women do not have the same property rights as men especially in sub Saharan Africa, property is typically owned by men and even when married, women still do not have as many property rights as their husbands. Inheritance rights are just as discriminatory as when a husband dies, his property often goes to his side of the family and not to his wife. The denial of a woman's inheritance and property rights can increase her vulnerability to HIV. Not being able to own property means that women have limited economic stability. This leads to an increased risk of sexual exploitation and violence, as women may have to endure abuse relationships or resort to informal sex work for economic survival (UNAIDS 2004).

The above literature just shows how a woman bears the burden of HIV and AIDS in society. In the advent of the above though, there is development of drugs that prolong women's life and therefore enabling them to view life differently and the reason why the quality of life is important in this aspect.

Below is an excerpt from an infected HIV and AIDS patient who gave her own ordeal then:

Rebekka Armstrong grew up in a desert town, three hours north of Los Angeles in the USA. At 18, she moved to Los Angeles and got a job modeling swimwear and lingerie. In 1986 she was playboy's Miss September. At 22 after suffering from extreme tiredness, Rebekka had a routine health check within which she had an HIV test. Much to her surprise it came back positive. Rebekka is still not 100% certain how she became infected but suspects that it was a result of unprotected sex at age 16 or a blood transfusion. Rebekka managed to keep her HIV status a secret for five years.

“The secret was eating me alive and all the lies I had told to cover up the secret had gotten out of control. I couldn’t keep up with all of them. This life seemed useless and I certainly didn’t have a place in it. In fact I hated it, hated what I had to live with, hated watching my friends drop like flies, one by one. I hated seeing the pain in my loved ones’ faces. I hated my self. I wished the virus would rear its ugly head high and take its course! When that did not happen I made a decision to take my own life. I thought about my options and that seemed like the only one that would work. (My plan to kill myself before the virus did”: **Armstrong, R. 1999).**

After a suicide attempt, Rebekka went to a seminar for HIV positive women that changed her life. In 1994, she announced in an American Lesbian and Gay magazine that she was living with HIV.

One would ask: what was the quality of life for Rebekka then? It is evident that she wanted to die. Her quality of life had no meaning at all. If research had been carried out on this issue probably clinicians would know how to address her quality of life priorities and offer her an alternative psychological orientation. ~

2.4. Women and HIV and AIDS in Kenya

In Kenya HIV and AIDS prevalence has continued to slow down from 13% in 2001 to 10.2% in 2002 to 7% in 2003 (KDHS 2003). HIV prevalence in women at the age of 15-49 is nearly 9% while for men of 15-54 is under 5%. This female to male ration of 1.9 to 1 is quite high and thus implies that women are particularly vulnerable to HIV and AIDS infections compared to men. Recent estimates even show that prevalence is higher in urban areas (16-17%) than in rural areas (4-12%). Gender differences in HIV infection are most striking in Kenya. In the 15-49 age group 1.4 million women and 0.9 million men in the same category are infected. This is considerably alarming.

It is now widely accepted that HIV and AIDS has major social and economic impact on individuals, families, communities and society as a whole. It has aggravated poverty in Kenya mainly because of those who are dying from the

condition are the productive young people, leaving behind widows and orphans who become dependants on other members of the family. Those who are afflicted with HIV and AIDS consume resources as they require drugs and special diet. Some families are forced to sell their property to cater for these expenses.

All these aspects impact at some level on the quality of life especially on women who are burdened with care and management. It is also notable that those who feel the brunt are those in poor settings especially the slum dwellers. The pandemic has taken a high toll on all sectors in Kenya including the health sector which is really hard hit as health care services face different levels of strain, depending on the number of people who seek services, the nature of their need and the capacity to deliver the care.

2.5. Medicine and Society – An over view

Health and Illness are terms that are culturally and socially defined (Morgan, 1980). Cultures differ in what they consider healthy and normal. All cultures have known concepts of physical health and illness but most of what is recognized as medicine today is a consequence of developments in Western society over the past three centuries. (Giddens 2006). In pre-modern cultures, the family was the main institution coping with sickness or affliction. There have always been individuals who specialized as healers, using a mixture of physical and magical remedies and many of these traditional systems of treatment survive today in non-western cultures throughout the world, a large number of them belonging to the category of alternative medicines.

The understanding of health and illness developed along with the growth of modern societies. Its emergence was closely linked to the triumph of science and reason over traditional or religious based explanations of the world. Historically, traditional societies relied largely on remedies, treatments and healing techniques which were passed down from generation to generation. Illnesses were frequently

regarded in magical or religious terms and were attributed to the presence of evil spirits or sin. Health was a private matter and not a public concern as it is today. For peasants and town dwellers there was no outside authority that was concerned with their health in the way that states and public health systems are today.

The rise of the nation states and industrialization (Marxism) brought about drastic changes in this situation however. The emergence of nation states with defined territories produced a shift in attitudes towards local people who were no longer simply inhabitants of the land but was a population falling under the rule of a central authority. The human population was seen as a resource to be monitored and regulated as part of the process of maximizing national wealth and power. The states began to take a heightened interest in the health of its population, as the well being of its members affected the nation's productivity, level of prosperity, defensive capabilities and rate of growth. The study of demographics – the size, composition and dynamics of human populations – assumed greater importance. The census was introduced in order to record and monitor changes occurring in the population. Statistics of all sorts were collected and calculated: birth rate, mortality rate, average age of marriage and childbearing, suicide rates, life expectancy, diet, common illnesses, causes of death and so on.

The idea of public health took shape in an attempt to eradicate pathologies from the population. The states began to assume responsibility for improving the conditions in which the population lived. Sanitation and water systems were developed to protect against disease. Roads were paved and attention was devoted to housing. Regulations were gradually imposed on slaughterhouses and facilities for food processing. Burial practices including the introduction of morgues were monitored to ensure that they did not pose a health threat to the population. Whole series of institutions such as prisons, asylums, workhouses, schools and hospitals emerged as part of the move towards monitoring, controlling and reforming the people.

But despite all these successive developments, the world is still faced with health problems among its inhabitants. The emergence of HIV and AIDS is the latest challenge in healthcare that is giving countries sleepless nights due to the fact that it is medically uncontrollable, it cannot be vaccinated against and therefore cannot be contained. It is a disease that continues to cause health havoc and curative measures are still a dream globally.

2.6. The Biomedical Model and theories of health and illness

Medical practices were closely intertwined with the social changes described above. There are three assumptions on which the biomedical model of health is predicated. First, disease is viewed as a breakdown within the human body that diverts it from its 'normal' state of being. The germ theory of disease developed in the 1800 century holds that there is a specific identifiable agent behind every disease. In order to restore the body to health, the cause of the disease must be isolated and treated.

Second, the mind and body can be treated separately. The patient represents the sick body pathology – rather than a whole individual. The emphasis is on curing the disease rather than on the individual's well being. The biomedical model holds that the sick body can be manipulated, investigated and treated in isolation without considering other factors. Medical specialists adopt a medical gaze (Foucault, 1973), a detached approach in viewing and treating the sick patient. The treatment is to be carried out in a neutral value free manner with information collected and compiled, in Clinical terms, in a patient's official file.

Third, trained medical specialist is considered the only experts in the treatment of disease. The medical profession, as a body adheres to a recognized code of ethics and is made up of accredited individuals who have successfully completed long term training. They yield so much power towards the patient (J. Osuch 2003). There is no room for self taught healers or non scientific medical practices. The

hospital represents the appropriate environment in which to treat serious illnesses, these treatments often rely on some combination of technology, medication or surgery. But medical specialists and the medical gaze bring scientific training and a dispassionate approach to the treatment of disease, sometimes to the bafflement of the patient.

In spite of the prestige that modern medicine has acquired, improvements in overall health can be attributed for more to social and environmental changes than to medical skill. Effective sanitation, better nutrition and improved sewerage and hygiene were more influential, particularly in reducing the infant mortality (Mckeown, 1979). Drugs, advances in surgery and antibiotics did not significantly decrease death rates. Self care and traditional forms of healing have been discounted. People have become dependent on experts instead of relying on their own skills and knowledge. Modern medicine has also discounted the opinions and experiences of the patients it seeks to treat. Because medicine is supposedly based on objective, scientific understandings of the causes and cures of specific physical ailments, there is little perceived need to listen to the individual interpretations that patients give to their conditions more so in chronic illnesses like HIV and AIDS.

Each patient is a sick body to be treated and cured. However, a patient should be treated as a thinking, capable being with their own valid understanding and interpretations, priorities and concerns. Although there is a realization that medical experts possess knowledge and understanding of health and illnesses, it should also be understood that patients are in a position to interpret and shape their own well being through their own understanding of their bodies and through choices in their everyday lives about diet, exercise, consumption patterns and quality of life orientations. The health transition that now encompasses chronic diseases e.g. HIV and AIDS shows that there is need for new approaches to health care and health management.

Theories about health and illness on the other hand deal with the ideas people use to explain how to maintain a healthy state and why they become ill. Anthropologists often divide theories of illness into two broad categories: *personalistic* and *naturalistic*.

In a personalistic system, illness is believed to be caused by the intervention of a sensate agent who maybe a supernatural being (a deity or dead ancestor) or a human being with special powers (a witch or a sorcerer). The sick person's illness is considered to be a direct result of the malign influence of these agents. In naturalistic causation, illness is explained in impersonal terms. When the body is in balance with the natural environment, a state of health prevails. However, when that balance is disturbed, illness results.

Often, people invoke both types of causation in explaining an episode of illness, and treatment may entail two corresponding types of therapy. According to personalistic theories of illness, illness may be linked to transgressions of a moral and spiritual nature. If someone has violated a social norm or breached a religious taboo, he or she may invoke the wrath of a deity, and sickness—as a form of divine punishment—may result. In Kenya some communities believe HIV and AIDS is as a result of “chira”, a taboo. Possession by evil spirits is also thought to be a cause of illness in many cultures. This may be due to inappropriate behavior on the part of the patient—failure to carry out the proper rituals of respect for a dead ancestor, for example—or it may be simply due to bad luck. Sometimes, one person's envy of another's good fortune is believed to exert a malign influence through the "evil eye," which can result in illness or other calamities.

In Kenya, for example, and in some communities, a severe headache is as a result of “ebikhokho”, a kind of evil spell. It is treated by a traditional specialist who cuts the area of pain with a razor blade and sucks blood using a horn. It is believed the blood comes out with the evil spell and therefore the person is relieved of the pain.

Naturalistic theories of disease causation tend to view health as a state of harmony between a human being and his or her environment; when this balance is upset, illness will result. The humoral system is a naturalistic approach to illness whose roots are over two thousand years old. Humoral concepts of health and illness are widely found in India, Southeast Asia, Africa, China, and, in a somewhat different form, in Latin and South America.

Biomedicine (modern traditional medicine) is founded on a naturalistic set of theories about the body, and these theories are continually evolving. One of the core theories of contemporary biomedicine, the germ theory of disease, is of relatively recent origin. The "body-as-machine" metaphor has been a powerful way of conceptualizing the body within biomedicine, and a core assumption of the value system of biomedicine is that diagnosis and treatment should be based on scientific data.

Alternative therapies (also called complementary therapies) have been rapidly gaining in popularity worldwide. Many alternative therapies have underlying theories of illness causation that are quite different from that of biomedicine.

All theories of health and illness serve to create a context of meaning within which the patient can make sense of his or her bodily experience. Meaningful context for illness usually reflects core cultural values, and allows the patient to bring order to the chaotic world of serious illness and to regain some sense of control in a frightening situation.

The above theories prove that health care cannot be practiced without putting emphasis on culture and value systems. Social networks are equally important to patients who require close attention from the people they are familiar with. This familiarity reinforces appreciation which inevitably creates a positive attitude towards illness. It is this positive attitude that brings out the inner body fighting

strength towards illness. Furthermore love from friends and relatives improve self identity. Patients are likely to view a medical facility as a labeling environment and thus a patient only attends a health facility when he/she is in a critical condition.

Patients usually have a very brief encounter with the doctor, an encounter that is institutional based. Distance to the facility can easily discourage a patient to access professional help which means the patient will instead turn to the nearest lay professional goodwill. This brief encounters also means that 95% of patient space is occupied by the significant others who easily shape their quality of life. It is therefore imperative that healthcare encompasses all aspects that contribute to an individual's well being – both lay and professional.

2.7. Literature on Quality of Life

In this in-depth literature review, quality of life was explored in various dimensions that included views on family support, relationships, emotional status, functionalities and spirituality.

Quality of life (QoL) is a multi-level and amorphous concept, and is popular as an endpoint in the evaluation of public policy (e.g. outcomes of health and social care). It has been defined in macro (societal, objective) and micro (individual, subjective) terms (Rosenberg 1992; Bowling and Windsor 2001). The former includes income, employment, housing, education, other living and environmental circumstances. The latter includes perceptions of overall quality of life, individual experiences and values, and has included related, proxy indicators such as well-being, happiness and life satisfaction. Models of quality of life also ranges from needs based approaches derived from Maslow's (1954; 1968) hierarchy of human needs (deficiency needs: hunger, thirst, loneliness, security; and growth needs: learning, mastery and self-actualization), to classic models based solely on psychological well-being, happiness, morale, life satisfaction (Andrews 1986;)

social expectations (Calman 1983) or the individual's unique perceptions (O'Boyle 1997). Quality of life is thus a complex collection of interacting objective and subjective dimensions (Lawton 1991).

Veenhoven (2000) distinguished between opportunities (chances) for a good life and the good life (outcomes) itself, and postulated four categories of quality of life: i. live-ability of the environment (environmental chances/social capital); ii. Life-ability of the individual (personal capacities/psychological capital); iii. External utility of life (a good life must have an aim other than the life itself, or higher values); iv. Inner appreciation of life (inner outcomes of life/the perceived quality of the life).

Each area of quality of life can also have effects on others. For example, retaining independence and social participation may promote feelings of emotional well being, but the former are partly dependent on retaining health and adequate finances. These can also be influenced by local transport facilities, type of housing, community resources to facilitate social participation and social relationships. Thus, quality of life is multidimensional and its parts affect each other as well as the sum. It is also a dynamic concept, which poses further challenges for measurement. It is made up of both positive and negative experiences and affect, and values and self evaluations of life may change over time in response to life and health events and experiences. For example, consciously or unconsciously people may accommodate, adapt or adjust, to deteriorating circumstances, whether in relation to health, socio-economic or other factors, because they want to feel as good as possible about themselves and hence the perception of quality of life (Sprangers and Schwartz 1999).

Thus when measuring change in quality of life, several variables need to be taken into account, including actual changes in circumstances, including the circumstances of interest (e.g. health), stable or dispositional characteristics of the individual (personality); behavioural, cognitive or affective processes which

might accommodate the changes, such as making social comparisons, reordering of goals and values;. Social desirability bias might also be a personality characteristic, and this might facilitate people when they are adjusting to deteriorating health or circumstances, and lead to an optimistic perception of a higher quality of life (Diener et al. 1991; Sprangers and Schwartz 1999). Past in-depth interviews with people have indicated that consideration of quality of life was dependent upon finding a balance between body, mind and the self (spirit) and on establishing and maintaining harmonious relationships.

In a European study on quality of life in old age, it was discovered that older people nominated family relationships as being an important determinant of quality life in 17 of the studies (O'Boyle et al. 1992; Oleson et al. 1994; Farquhar 1995; Montazeri et al. 1996; Browne et al. (2002) found, using the SEIQoL, that 89% of the older Irish people sampled nominated family as an important aspect of their quality of life. In the UK, Farquhar (1995) found that family (usually meaning children) and social contact (often other family) were very important, with 60% and 34% respectively mentioning these.

On Relationships (other)/contact with others twenty one studies reported relationships (most of the time being distinct from family) as being important to chronically ill people, Waldron et al.1999; Bowling et al. 2003). Social contact was mentioned by 34% of respondents in a survey by Farquhar (1995) and in a similar geographical area the importance of social networks was mentioned (Cattell 2001). Ball et al (2000) found social relationships and interactions to be nominated by cancer people in assisted living facilities. Relationships were important in 45% cancer people in mobile homes in the US studies (Ebersole et al. 1987). General themes such as, connectedness, involving social networks were noted (Oleson et al. 1994; Moore 1997). (O'Boyle et al. 1992; Litwin (2001) also noted that networks involving friends and other social groups increased morale among patients with leukemia.

Emotional well-being or happiness were mentioned in 16 studies, DePaola et al. 1995; Farquhar 1995; Bowling et al. 2003). Confidence, morale and happiness were all mentioned by people in a study by Qureshi et al. (1998). Farquhar (1995) found that older people were concerned about misery or unhappiness which was often accompanied by a loss of hope, whilst general dissatisfaction with life was dreaded by 30% of the men in the UK study by Thomas et al. (1989). Macduff et al. (1998) found that eight of 44 disabled individuals nominated mood as an important component of quality of life.

On religion/spirituality issues, eighteen studies found aspects of religion or spirituality to be important to Cancer people, O'Boyle et al 1992; Bowling 1995b; DePaola et al 1995; In Bowling's survey religion represented the eighth most nominated component for people with HIV and AIDS. (Bowling 1995a; Bowling 1995b). Six per cent of these people had nominated it as one of their most important five components of quality of life. Religion has been found to be particularly important in Ireland. Glass et al. (1997) found that religion was mentioned by US chronically ill patients. DePaola et al. (1995) found that aspects of beliefs were nominated by three per cent and seven per cent of older people in mobile homes and nursing homes respectively, Ebersole et al. (1987). Campbell et al. (1999); Dempster et al. (2002) and Bradley (1997) all found that people with experience of illness mentioned religion. Engle et al. (1998) also found that religion was important to older terminally ill American individuals. Ball et al. (2000) also noted religion/spirituality in a study where individuals were living in assisted living facilities.

Aspects of functionality, mobility or autonomy were mentioned in 25 cases of some other studies (Bertero et al. 1993; Bowling et al. 2003). Bowling found that cancer and HIV and AIDS patients were the most likely of any group to mention the ability to get out and about as being the most important area of life to be affected by illness. Autonomy was again mentioned by leukaemia patients in the study by Bertero et al. (1993) and in the study by Montazeri et al. (1996), ability

to do what one wants to do was the seventh most frequently mentioned component (17% of respondents).

In fifteen studies it was found out that finances or standards of living were important (Spalding et al.1985; Issues of safety and poor transport facilities were highlighted. In a study by Farquhar, material circumstances were found to be important and usually meant finances or a good home (Farquhar 1995). Issues of cleanliness and tidiness of surroundings were raised among people in the study by Qureshi et al. (1998). Two percent of the patients with HIV and AIDS in the study by Burbank mentioned suitability of the home as an important component of the quality of life (Burbank 1992).

This literature shows that quality of life is inherently a dynamic, multi-level and complex concept, reflecting objective, subjective, macro-societal, and micro-individual, positive and negative influences which interact together (Lawton, 1991). There seems to be, though, no overall agreement on definitions which poses inevitable challenges for measurement. However, research has enhanced the body of knowledge on the components and determinants of life quality among all ages. The literature reveals that quality of life can theoretically encompass a wide ranging array of domains, including individual's physical health and functioning, psycho-social well-being, psychological outlook, psychological and social role functioning, social support and resources, independence, autonomy and perceived control over life, material and financial circumstances, community social capital and the external environment, including the political fabric of society. Most importantly, it encompasses the individual's perspective and assesses quality of life through the eye of the experiencer. (Ziller 1974). It is a concept which is likely to be mediated by cognitive factors.

It is clear from the above analysis that quality of life means different aspects for different people in different circumstances but what comes to light is that quality of life is a meaningful consideration during illness and treatment processes.

Something to appreciate here is that the above literature portrays QOL in the developed world, something that may not be generalized in the African context. In the Africa setting and Kenya in particular, there are many aspects that can influence QOL among patients. Culture is one of them. Mazrui (1986) defines culture as a system of interrelated values active enough to influence and condition perception, judgment, communication and behaviour in a given society. The culture of slum dwellers in this country is often inclined to promiscuousness, community support and traditional influences. These areas can affect the QOL in a major diverse manner as compared to traditions in the developing world. Superstitions, beliefs and stereotypes are central in HIV and AIDS prevalence in Africa. These are areas that are not so loud in the developed world where the above literature has been explored. It is also true that the health seeking behaviour in Kenya is remotely based on perceptions, lay professionalism, resources and the influence of the family and friends. In the developed world, it is based on an individual's decision.

Culture plays a vital role in determining the level of health of an individual, the family and the community and determination of health outcomes. In Kenya, culture easily influences health seeking behaviour that can either impact negatively or otherwise to the quality of life of an HIV patient. For example in some communities HIV and AIDS is perceived to be "Chira" (curse) something to be treated by the local medicine man. This aspect can determine the HRQOL in women patients in Kenya.

Another example is wife inheritance where a woman is forced to be inherited when a husband passes on even if he was HIV positive. This scenario can place a lot of stress on the woman diminishing her quality of life in the marriage. Another supporting argument is the values of extended family and community which significantly influence the behaviour of the individual.

A profound area that can affect QOL in Kenya is stigma. Kenya is not immune from HIV and AIDS stigma-related discriminatory practices and human rights abuses particularly in the light of the overwhelming impact of the disease in the African region. Discrimination and abuses take place in families, communities, schools, places of worship and employment and even in healthcare settings. Not forgetting the scarce resources, poverty and inaccessibility of medical care which is common in Kenya that can highly affect the QOL of HIV and AIDS patients.

What comes to light is that a lot of research on QOL seems to have been carried out in the first world; little has been done in the 3rd world countries and therefore the need to contextualize research on HRQOL particularly in Kenya.

2.8.0 Theoretical Frame work

2.8.1 Introduction

In this section the researcher has given an exploration of the sociological perspectives of health and illness as an area that has highlight the deep perceptions of the sick in society. On a minor scale the functionalists and symbolic interactionists' theories are used to explain the predicament of the sick person especially a woman in society.

2.8.2. Sociological perspectives of health and illness

Illness has both personal and public dimensions. When people fall ill, not only do they experience pain, discomfort, confusion and other challenges but others are affected as well. People in close contact with the sick may extent sympathy, care and support. They may struggle to make sense of the fact of the illness or to find ways to incorporate it into the patterns of their own lives. Others who come in contact with the patient may react to illnesses and these reactions in turn help to shape the patient's own interpretations and these can pose challenges to the patient's sense of self.

Two ways of understanding the experience of illness have been particularly influential in sociological thought. The first, associated with the functionalist school, sets forth the norms of behaviour which individuals are thought to adopt when sick. The second view, favored by symbolic interactionists, is a broader attempt to reveal the interpretations which are ascribed to illness and how these meanings influence people's actions and behaviour.

A symbolic Interactionists theory for quality of life for women with HIV and AIDS

Chronic pain caused by opportunistic infections such as TB or Cancer affects many HIV and AIDS women patients in the world over. These conditions are difficult to treat because of both their medical complexity and their ability to impact personal and relationship development far beyond the traditional bio-medical sphere. The lives of many women with HIV and AIDS have been affected both at home and at work. Their relationships with family and friends are substantially changed by the chronic pain they experience. Wide variation in individual's ability to cope with chronic pain and continue to lead satisfying, functional lives weakens the relationship between pain severity or quality and the impact of such pain on daily life and relationships.

The main premise of this theory is that the beliefs and self-perceptions of women with HIV and AIDS may be affected not only by their own experiences and views of the problem, but also by their partners' and friends or family members. The concept that a woman's quality of life may be impacted by both her own view of her pain experience and the ability of spouse or relatives to validate and understand her view is rooted in symbolic interactionists theory.

Symbolic interactionists view an individual's core sense of self as existing in the constructions of realities in views of self and others. All roles are seen to exist in

reciprocals to that in marriage, spouses' views, understandings and expectations of each other, have the potential to impact the core sense of self, and consequently the perceived quality of life that each partner experiences. From this perspective, self identity and quality of life for women is tied not only to their views of themselves as caring and healthy individuals but also to the ways they perceive themselves as viewed by others.

For women with HIV and AIDS changes in role functions and relations issues have considerable potential to result in the perception of self and disabled. In the Kenyan context the "Wanjiku's" roles have been distinctly spelt out. They are expected to fetch water, firewood, milk cows, take care of the children including taking them to hospital whenever the children fall ill. They are expected to take care of ill relatives irrespective of whether the women are ill themselves or not. Gilligan (1982) noted that women's identity and sense of integrity is entwined with their ability to be involved in caring responsibilities and relationships with others. According to Charmaz (1991), chronic illness can become a way of identifying oneself and can lead to an individual's questioning their previous, current and future self-identity. Zadisnky and Boyle (1996) studied women with chronic pelvic pain and noted that the women found it difficult to plan their daily lives and experienced a loss of control, identity and self-esteem. Consequently, the chronic pain and role limitations that can be a part of HIV and AIDS could be expected to have an impact on women's identity and view of self as healthy or disabled individuals. This in turn, tremendously affects their quality of life.

Symbolic interactionists are interested in the way people interpret the social world and the meanings they ascribe to it. This theory is relevant when assessing the QOL in HIV and AIDS patients. This is so because HIV and AIDS is now a chronic disease and with the options of medications to prolong life, people are faced with the prospect of living with the illness over along period of time. This, in its own merit, brings to the fore why quality of life among women patients should be assessed.

The Functionalist Theory

Talcott Parsons was one of the promoters of functionalist thinking. He advanced the notion of the sick role in order to describe the patterns of behaviour which the sick person adopts in order to minimize the disruptive impact of illness (Parsons 1952). Functionalists thought hold that society usually operates in a smooth and consensual manner. Illness is therefore seen as a dysfunction which can disrupt the flow of this normal state of being. A sick individual for example might not be able to perform all of his or her standard responsibilities or might be less reliable and efficient than usual. Because sick people are not able to carry out their normal roles, the lives of people around them are disrupted: work go unfinished and causes stress for coworkers and responsibilities at home are not fulfilled and so forth. In some communities in Kenya, women often meet and gossip when they go to fetch water at a particular water point. It is very easy to identify so and so is missing which then necessitates a visit to the woman's home to find out if she is okay.

According to Parsons, people learn the sick role through socialization and enact it – with the cooperation of others – when they fall ill. There are three assumptions of the sick role. The sick person is not personally responsible for being sick. Illness is seen as the result of physical causes beyond the individual's control. The onset of illness is unrelated to the individual's behaviour or actions. The second assumption is that the sick person is entitled to certain rights and privileges including a withdrawal from normal responsibilities. Since the sick person bears no responsibility for the illness, he/she is exempted from certain duties, roles and behaviors which otherwise apply. For example, the sick person might be 'released' from normal duties around the home. Behaviour that is not as polite or thoughtful as usual might be excused. The sick person gains the right to stay in bed, for example to take time off from work. The third assumption is the sick must work to regain health by consulting a medical expert and agreeing to become a 'patient'.

The sick role is a temporary and 'conditional' one which is contingent on the sick person actively trying to get well. In order to occupy the sick role, the sick person must receive the sanction of a medical professional who legitimates the person's claim of illness. Confirmation of illness via an expert opinion allows those surrounding the sick person to accept the validity of his or her claims. The patient is expected to cooperate in his/her own recovery by following the doctor's orders. In African culture, in the event that the patient repeatedly visits a professional healthcare and does not get well, elicits gossip as there is "a bigger" problem than envisaged by the community. This has resulted into stigmatization when one is HIV positive which is characterized by frequent hospital visits and prolonged body weakness.

Although the sick role model has been an influential theory which reveals clearly how the ill person is an integral part of a larger social context, it fails to capture the experience of the ill person – and his/her priorities. When an illness is seen as uncommonly infectious or is perceived as somehow a mark of shame or dishonor, sufferers may be rejected by the health population. This is true of people affected by HIV and AIDS that has provoked stigmatization (Goffman, 1984). Stigmatization often leads to labeling and when a patient perceives to have been labeled, he/she begins to struggle to be accepted and strains to refocus and to find meaning in his/her life. This is a critical moment for assessment of his/her quality of life.

Critically the realities of life and illness are more complex than the sick role suggest. The increasing emphasis on the lifestyle and health in the modern age means that individuals are seen as bearing ever greater responsibilities for their own well being. Assessment of QOL in HIV and AIDS patient therefore is relevant because of these refocusing of personal priorities, experiences and perceptions. It is then important to know how illness in such cases becomes incorporated in an individual's personal biography.

It follows that it is important to explore how chronically ill individuals learn to cope with the practical and emotional implications of their illness. Illness such as HIV and AIDS demand regular treatments or maintenance which can affect people's daily routines for example taking large numbers of pills demand that individuals adjust their schedules in response to illness. Illness like HIV and AIDS can have unpredictable effects on the body such as sudden loss of body mass affecting self identity (Goffman, 1984) of the patient. Individuals suffering from HIV and AIDS then have to develop strategies for managing the illness in day-to-day life (Kelly M. P. 1992).

At the same time, the experience of illness can pose challenges to and bring about transformations in people's sense of self. These develop both through the actual reactions of others to the illness and through imagined or perceived reactions. For the chronically ill, social interactions which are routine for many people become tinged with risk or uncertainty. The shared understandings that underpin standard everyday interactions are not always present when illness is a factor and interpretations of common situations may differ substantially. The changed context of social interactions can therefore precipitate transformations in self identity.

2.8.3. The HRQOL Model

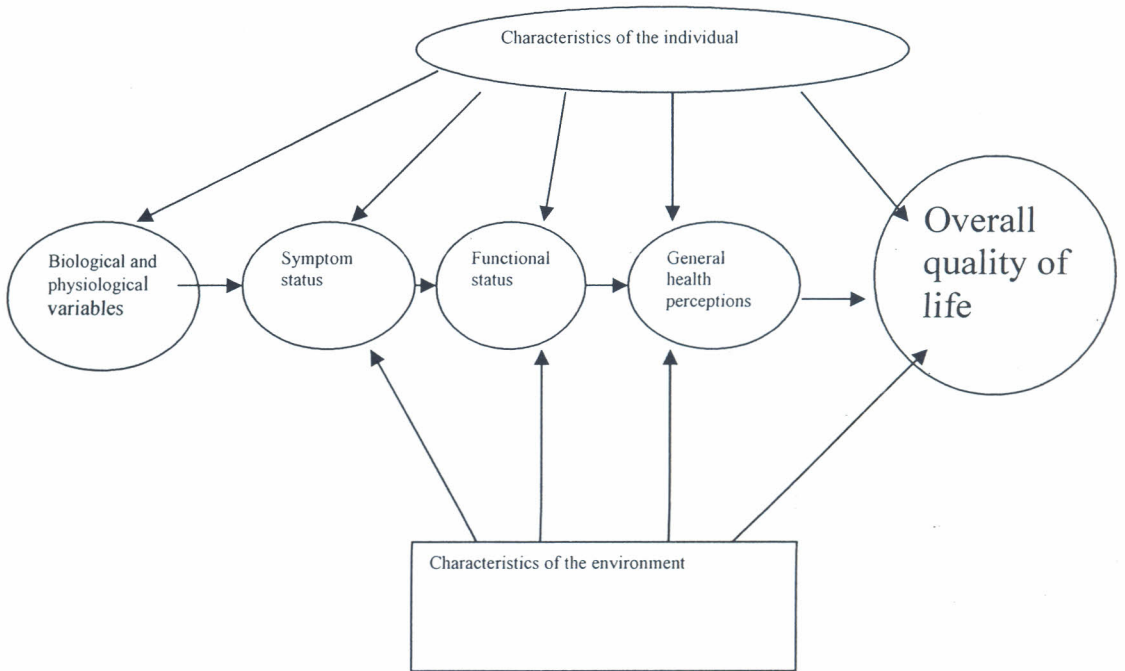
HRQOL is a multidimensional construct with no simple definition. In medical literature HRQOL has been used to describe the quality of changes that occur as a result of medical interventions. A broad conceptualization is used to examine the reciprocal relationships between health and general well being. It has also been used synonymously with health status and functions status. It is a value assigned to duration of life as modified by the impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment or policy.

The principal role of clinical care is improvement of patients' health outcomes. To achieve this goal, they need to craft interventions for their patients that they know are causally related to specific outcomes that patients' value. The model of HRQOL therefore can be used to facilitate better understanding the relationships such as social functioning, physical functioning and general health perceptions may be useful in the formulation of strategies to improve patients' functioning and quality of life. The HRQOL model below shows the relationships of the components of health status. The model classifies types of concepts that can be used to understand HRQOL in HIV and AIDS into 5 levels.

First level, the Biological/physiological factors, focuses on genetic, cellular, organs and organs systems function. The second level is the symptoms level. These are patient's perception of an abnormal physical, emotional or cognitive state. They are subjective by definition, that is, symptoms are self reports of problems. Symptoms prompt persons to seek healthcare and may be influenced by characteristics of the individual e.g. mood and the environment e.g. access to care. Symptom status is a major component of HRQOL and may also affect health services use because people who have symptoms have the potential to seek health services more than people without symptoms. An example of symptoms in HIV and AIDS Patients is diarrhea or swellings on the body. The third level is the functioning aspect which refers to assessments of ability to perform specific tasks or functions. It could be physical, emotional and role functioning. The fourth level captures the general health perception. These are patients' global perceptions about their health and take into account the weights or values that patients attach to different symptoms or functional impairments. It is assessed by self report e.g. "overall how would you rate your health?" It integrates functioning, symptoms and physiological factors. The final level captures the Quality of life. This is described as a person's subjective sense of well being, happiness and satisfaction with life overall. It is also described as the adequacy of people's material circumstances and their feelings about those circumstances.

Characteristics of the individual and the environment potentially influence all levels of the model e.g. a person's coping and problem solving skills, motivation and self efficacy and social support may be related to symptom status, functioning and general health perceptions (Raeburn et al, 1996).

Figure 1: HRQOL Model



This model can be useful to health practitioners and researchers. The model can guide clinicians in conceptualizing and evaluating functioning and HRQOL. Clinicians can also find it helpful in evaluating the effect of interventions on HRQOL outcomes. The model can guide investigators to conceptualize and define domains of HRQOL relevant for specific research questions and provide a framework for data analysis and interpretation.

CHAPTER THREE

3.0 METHODOLOGY

3.1 Introduction

This section describes the process that was used to carry out the study. The research site, the target population, research and sampling design as well as methods of data collection and analysis.

3.2 Research Site

The study was conducted in Korogocho location based in Kariobangi South in Kasarani Division, Nairobi, Province. This represents low- resource- settings in an urban area where HIV and AIDS services are available but at minimal level. Korogocho location has 14,665 households with 24,257 male and 19, 545 female and is a slum settlement. Majority of the population are of low income earners. Korogocho has 7 villages: Grogon, Githaturu, Ngunyumu, Highridge, Ngomongo, Kisumu Ndogo/Nyayo and Korogocho. The area is served by one government health centre, five faith-based health facilities, many individual clinics, a number of chemists, herbalists, and prayer men/churches. The reason for this site was to get a true representation of the phenomenon under study. HIV and AIDS is seen to be more prevalent in slum dwellings than in the up market settlements due to risk behaviours associated with poverty and sometimes illiteracy.

3.3. Target Population

This was a purposive study that targeted women that are infected with HIV and AIDS and therefore a condition specific study. It was carried out at Korogocho slums in Nairobi. The study considered a sample of 83 women aged between 18-

55 years and who are HIV positive. Women are the burden bearers in society and this therefore translates heavily on their many aspects of life including QOL.

3.4. Research design

Research design refers to the scheme, outline or plan that is used to generate answers to research problems. (Combo and Troup 2006). Quality of Life was evaluated using 26 items. Each item used a Likert-type five-point scale. Other data collected included basic demographic information (age, education level, marital status and area of residence). These items were distributed in four domains. The four domains of QOL covered (a) Physical health and level of independence (seven items assessed areas such as presence of pain and discomfort; energy and fatigue, mobility; sleep and rest; activities of daily living: perceived working capacity); (b) Psychological well being (eight items assessed areas such as affect, both positive and negative self concept, higher cognitive functions; and body image; (c) social relationships (three items assessed areas such as social contacts, family support and ability to look after family; sexual activity and (d) environment (eight items assessing areas such as freedom, quality of home environment; physical safety and security and financial status; involvement in recreational activity; health and social care: quality and accessibility). The domain on environment was considered to be necessary because it plays a major role in determining health status, mediating disease pathogenesis and limiting or facilitating access to health care. There were two items that were examined separately: one asked about the individual's overall perception of QOL and the other asked about the individual's overall perception of her health. The domain scores scaled in a positive direction – higher scores denoted higher quality of life. Spirituality, Religiosity and Personal Beliefs (SRPB) were used for qualitative research.

The study therefore explored issues of HRQOL. This is because HRQOL can be contextual and therefore a multidimensional approach is deemed to be ideal. Both primary and secondary data was used to give an in depth understanding of

priorities of HRQOL in sickness and disease burdens like HIV and AIDS. Primary data was obtained using questionnaires, Focus Group Discussions (FGD) and interviews. Secondary data was obtained from books, journals and internet sources for further enrichment of the research.

3.5. Sampling design

Due to the nature of the research, i.e. research on HIV and AIDS women patients and because of the stigmatization process involved, non probability sampling was used. Specifically the researcher adopted purposive sampling and snowballing. Therefore only HIV positive women were included in the study. To make the process a success the researcher employed the services of social workers who are HIV positive as well and who were familiar with positive women respondents in the above mentioned villages. It would be good to mention here that it was not necessary to allocate equal representation from the 7 villages since all of them probably have near similar environmental experiences but everything possible was done to ensure that every village got a representation of some kind.

3.6.0 Methods of data collection

The researcher collected primary data by carrying out interviews. The following set of interviews were carried out.

3.6.1 Structured interview

One-on-one interviews were carried out with the respondents purposively sampled. A questionnaire with closed questions was administered. The Researcher was on the ground and was assisted by two assistants who are HIV positive. Several dimensions of the questions were put into consideration to cover issues that determine HRQOL as mentioned above. Since the research was dealing with human subjects and those who have HIV and AIDS for that matter, the question of ethical considerations was mandatory. The subjects were

therefore informed that the research was voluntary and confidentiality would be adhered to.

3.6.2 Focus Group Discussions

Focus Group Discussion (FGD) is a widely used method in qualitative/behavioural research (Murphy et al., 1992; Hardon et al., 2001b). This method is open and flexible, allowing more probing/exploration of opinions, feelings, attitudes, previous experiences and other behaviours that may not be possible to obtain through quantitative methods. Two FGDs of 10 people each were administered. A moderator's/facilitator's guide was developed and used to provide direction for the group discussion. This ensured that all related issues were covered in the study.

The 3 categories of questions in the guide for FGDs included:

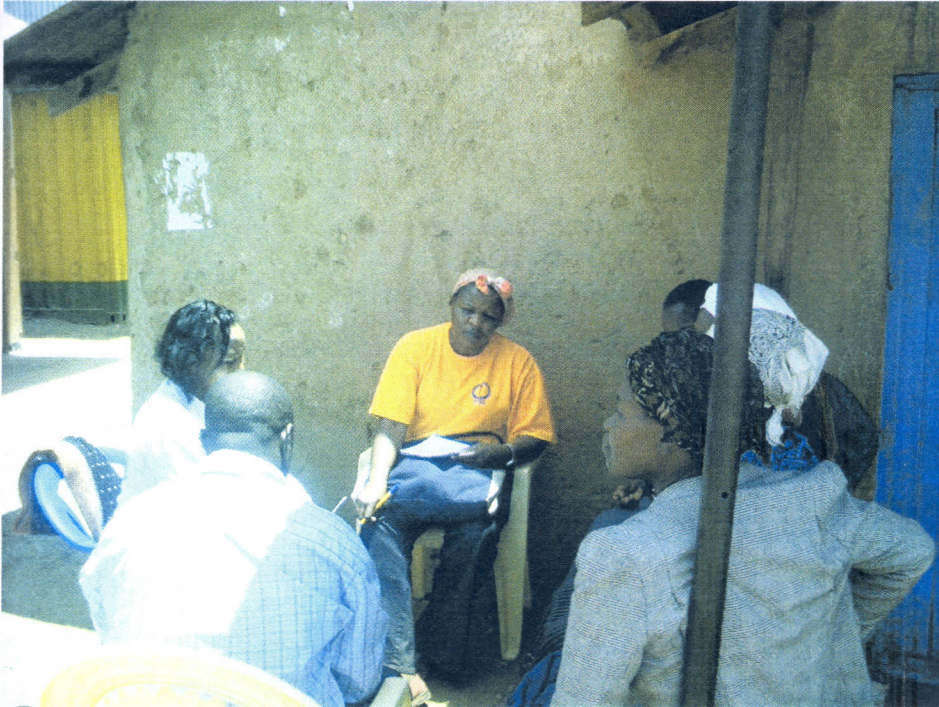
- General questions that were designed to open the discussion and to allow respondents to reveal common perceptions and attitudes.
- Specific questions that revealed key information and showed the feelings and attitudes of the participants
- Probed questions that revealed more in-depth information or clarified previous statements or responses.

The FGDs began with a warm up i.e. self-introductions by the facilitators and provision of information about the study and clarification of any inquiries. This was followed by discussions using the facilitator's guide and finally wrap-ups and summary so as to recap the identified themes in the group. An observer was trained on taking field notes. The content of the observer's notes included: group, date, time (group began and ended), meeting place, participants (including number and personal characteristics), group dynamics (general description, level of participation), interruptions, seating diagram of the group (preferably circular), and notes on discussion of various topics. FGDs were tape-recorded for purposes of accuracy, as it is difficult to capture the entire discussion by note taking. The tape recordings were subsequently transcribed for analysis. Each session lasted close to one hour to one hour and 30 minutes. Again

exclusivity was employed as much as possible as only positive women were interviewed.

3.6.3 Key Informant Interviews

Key informant interviews were included in the study. It targeted social workers (HIV positive as well and counselors), guardians who often interact with the patients from time to time, leaders of support groups, the area chief and church leaders.



Picture 1: The researcher (in orange T-Shirt) conducting Key informant Interviews at the Korogocho Chiefs Camp.

3.6.4 Data management, Storage, and analysis

Qualitative data collected was tape-recorded. The data was also stored on a flash disk, hard disk and CD for back up purposes to safeguard against losses. Data was transcribed. Quantitative data was analyzed using statistical package for Social Scientist (SPSS). Frequency and cross tabulations were used to show HRQOL dimensions. For

qualitative data, content analysis was undertaken to reduce the data to more manageable data set which was categorized, coded accordingly and interpreted.

3.6.5 Ethical Considerations

Participants were asked to respond to a series of oral questions, by an interviewer fluent in a language they understood well, requiring up to an hour of their time.

Such questionnaires are unlikely to have adverse effects on both participants and respondents. They were, however, not obliged to answer any question. It was clearly explained to them that they had the freedom of choosing not to respond to or to leave the interview at any time. Participation in the study did not involve undergoing any medical procedures.

3.6.6 Protection of Research Participant Confidentiality

The participants' responses to questions were strictly confidential. In particular it was emphasized that no individual data, anonymous or otherwise, would be shown to non authorized persons and therefore data analysts on the project accessed to anonymous individual data. Only field workers who were in direct contact with the respondent knew their name. The following strategy was used to ensure anonymity:

1. Names of focus group participants were not recorded
2. All data sheets in other in-depth interviews were identified using a unique numerical code.
3. A list matching participants names to numerical code were only available to the study team.
4. Respondents were interviewed by the same interviewer as far as possible.

3.6.7 Informed Consent

Informed consent was sought from all respondents. The study was explained to them that they participated on a voluntary basis and that they could withdraw at anytime without loss of benefit or negative implication on staff.

3.6.8 Pre-interview counseling and post interview training aspects

Those who participated in the FGDs had to undergo some form of counseling due to the dilapidating nature of the research. Prayers were said and messages of hope disseminated after the interviews. This was important to minimize emotional harm to the participants.

3.6.9.. Difficulties encountered:

The following difficulties were encountered:

- The FGDs comprised of participants from different ethnic groups meaning that only Kiswahili was allowed as a medium of communication. Some participants however could not express themselves very well in Kiswahili and therefore mentioned some issues in their mother tongue. Whereas this enabled the participants to express their views better, it had to be translated for others to understand.
- It was a delicate discussion as emotions were clearly displayed.
- There were delays in assembling especially in the Key Informant Interviews and so those who came earlier had to wait for others and this created an atmosphere of impatience.

CHAPTER FOUR

4.0 DATA PRESENTATION, ANALYSIS AND INTERPRETATION

4.1 Introduction

This chapter provides information on the study findings. The section is divided into two sections. Section A includes the presentation of the data in form of tables, charts and graphs. The presentation of this information sheds light on the feelings of the respondents on the dimensions of their quality of life as people living with the condition of HIV and AIDS. Section B reflects the analysis and interpretation of the findings in accordance with the objectives of the study. This particular section attempts to bring out the feelings of participants as obtained from the Focus Group Discussions and the Key Informant Interviews. It will be noted that there is a lot of verbatim presentation. This is seen as important to reflect true feelings of the participants.

The objectives of the study were as follows:

- (i) To assess the Quality of Life issues in HIV and AIDS women patients in terms of psychological, social relationships and the environment as related to health.
- (ii) To find out whether personal beliefs, spirituality and religiosity (PBSR) play any role in improvement of quality of life among HIV and AIDS women patients in Korogocho slums.

4.2. Descriptive Presentation And Analysis

4.2.1 Distribution of respondents according to residential areas

Information displayed by Table 1 below shows the representation of the respondents in all the 6 villages although this does not add much meaning to our evaluation since all the villages share near similar experiences because they belong to the same slum, no village is superior to the other in any way.

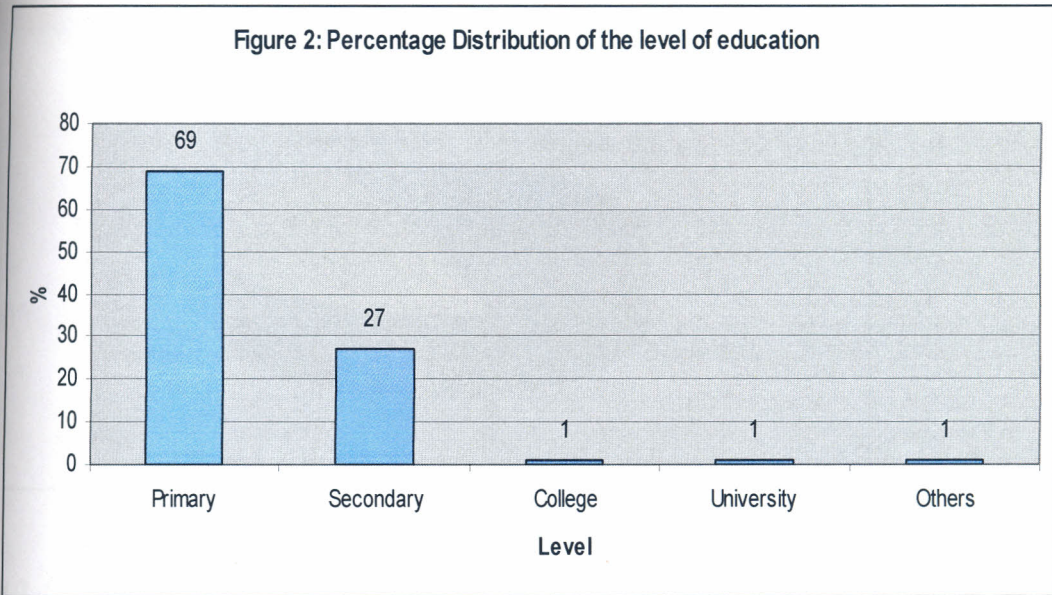
Table 1: Distribution of respondents according to residential areas

Area	N	Percentage
Gitathuro	19	23
Grogan A	19	23
Highridge	22	26
Kisumu Ndogo	12	14
Korogocho	3	4
Nyayo	8	10
TOTAL	83	100

4.2.2. Education level of the women

It is noted from Figure 2 below that academically 69% of the respondents have only attained primary level of education. This is a huge number going by the disadvantages of low education levels in this country. In itself, this contributes a lot on the prevalence of HIV and Aids in slum areas due to lack of enough information to make major decisions or informed choices.

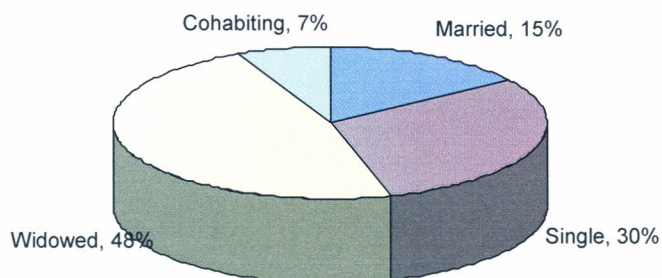
Figure 2: Percentage Distribution of the level of education



4.2.3. Marital status of women

As seen from figure 3 below, the majority of women are single and widowed. This factor poses a lot of challenges both economically and socially. Stigmatization due to HIV negates social network capital in any community. Sustaining intimate relationships becomes near impossible because of the burden of the condition and its associated risks. On the next level the burden of taking care of children both academically and feeding complicates the meaning of existence. The woman then becomes vulnerable to seemingly comfort zones like sex bartering thereby increasing the chances of re-infections. These factors pose a lot of challenges to caregivers both at micro level and macro level.

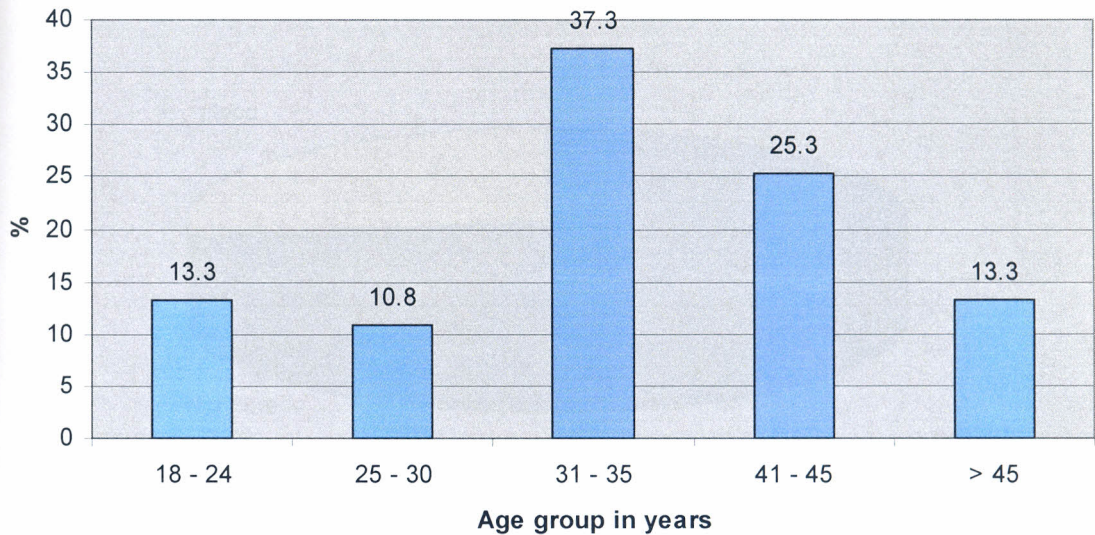
Figure 3: Percentage distribution of the marital status of the respondents



4.2.4. Average age of respondents

As seen from figure 4 below the majority of respondents average 33 years of age. These are young women with many aspirations and hopes of life but already burdened with this roaring lion called HIV/AIDS. The same group is disadvantaged due to the fact that they also lie in the majority group with primary education. Due to this they are limited in choice making of many issues for lack of appropriate knowledge. Being mothers, they are caregivers in all spheres of life. The fact that they may want to engage in fulfilling relationships but hampered with stigmatization may make them engage in risk behaviours that continue to reduce their life cycle. These factors may actually lower their QOL perceptions.

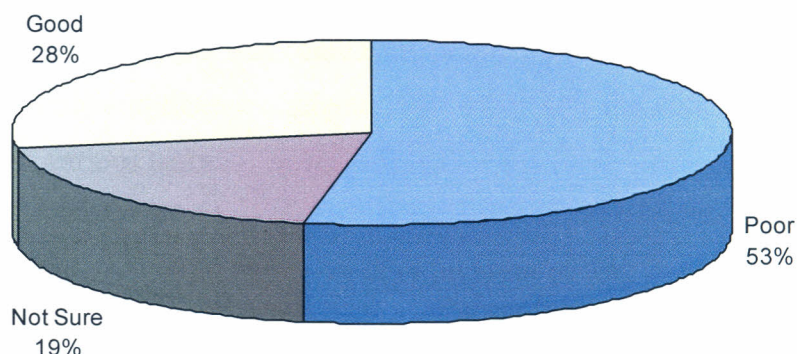
Figure 4: Percentage Distribution of the age group of the respondents



4.2.5 How respondents rated their quality of life

On the general quality of life the respondents reported experiencing low QOL. Fifty three percent reported this. Only 28% reported good quality of life. This can be attributed to the fact that HIV and Aids issues are myriad and comes with a lot of discomforts in all spheres of patient's life. Most women contended that life is difficult especially in the state they are in. They feel weak most of the time and this limits their efforts to carter for their children. Most of them are single mothers with an average of 5 children. This places a huge burden on how to feed them, take them to school and take care of their health aspects as some of the children are positive.

Figure 5: Percentge distribution of how the respondents rated their quality of life



4.2.6 Extent of physical Pain

Apparently only 31% reported that they are hampered by physical pain to go about their business. This is probably due to the fact that HIV and Aids is not a disease but a condition. Pain only sets in when opportunistic diseases like malaria or TB strikes.

On medical care, 46.2% reported that medical care was crucial. This is to keep the opportunistic diseases at bay. However, only 3.8% reported that they did not need medical care. There could be an explanation for this, however low the figure. People have been known to be carriers of HIV virus without any symptoms or diseases and therefore continue to enjoy a disease-free life.

Table 2: Distribution of respondents according to the extent to which the physical pain prevents them from doing what they need.

Response	N	Percentage
Not at all	6	7.3
A little	37	45.1
Moderately	13	15.9
Mostly	17	20.0
Completely	9	11.0
TOTAL	83	100.0

On enjoyment of life, which is actually relative, 31.5% reported that they enjoy life. The aspect of life enjoyment is individually centered; it could also be linked to the environment, the circumstance and the condition of the body system. People with HIV condition face a lot of challenges that could hamper one's enjoyment of life. Included are the persistent opportunistic diseases, stigma associated with the condition and limited strength to perform various tasks.

Table 3: Distribution according to degree of enjoyment of life.

Response	N	Percentage
Not at all	6	8.2
A little	20	27.4
Moderately	24	32.9
Mostly	10	13.7
Completely	13	17.8
TOTAL	83	100.0

4.2.7 Meaningfulness of life

Almost 50% of the respondents reported that life is meaningful as seen from table 4 below. As found out in the qualitative data, most respondents believe in a higher being where they draw strength and hope from. *"I belief Allah is taking care and my faith in him keeps me going"; " knowing there is a God and he loves me the way I am helps me go through hard times better than I used to before"; " spiritual strength makes me enjoy life knowing that there is better life after death"; " the bible tells me to ask for food for each day. It also says Godliness and contentment is great gain"; "Without faith I would not know where to go, it is all that I have"; "Life is only enjoyable because of Allah and it is only worth living because of him"; "Sundays are good when I go to church and meet with other believers I feel strong again"; "I believe my ancestors are watching me and this gives me inner strength".* This affirms what other researchers found out on spiritual matters for people with chronic illness (O'Boyle et al. 1992;) (Cattell 2001). Therefore on spirituality and personal beliefs, it was confirmed that spiritual nourishment indeed play a distinctive role in enhancing the women's strengths and hopes to move on. Spiritual motivation makes them accept their status and feel accepted in society. It was noted that spiritual uptake has led to behavioural changes hence enhancing responsibility. Some have stopped drinking and now look at their status

positively. More than often they go to pastors to pray for them when they feel challenged. Coupled with relationships and support from close friends this could enable them enjoy life. However on emotional issues 44% reported that they hardly concentrated on issues.

Table 4: Distribution of extend to which respondents feel life is meaningful

Response	N	Percentage
Not at all	3	4.1
A little	17	23.0
Moderately	18	24.3
Mostly	22	29.7
Completely	14	18.9
TOTAL	83	100.0

However on the component of environment 37% reported that the environment they live in is unhealthy while 34.7% reported that it is healthy. This could be explained due to the fact that living in a slum, especially in Kenya, where there is usually no sewerage system, or a large household putting up in one single room, or due to overpopulation, garbage is strewn all over the place, makes the environment not conducive enough for human habitation. On the other hand people tend to get used to after staying in such a place for a while and so do not attribute much attention to the health of the environment because to them it is not an issue.

On energy levels, only 3% reported high energy levels while 71% reported low energy levels most of the time. This could be due to many factors e.g. if one has gone without food for a while, if one is sick or just emotionally tired. On bodily appearance only 29.5% accept their bodily appearance and 59% do not accept at all. Again this could be due to many factors e.g. lean body mass caused by the wearing down of body muscles due to the periodic attacks of opportunistic diseases, or if any form of beautification regimens proves impossible. As much as 70% reported that they are in dire need of finances; of course this is understandable although even the rich do not get satisfied with their finances.

4.2.8 Availability of information on HIV and AIDS

Important information gathered from the respondents was that they do not get enough information on HIV and Aids. This puts NACC and those other non-governmental organizations that are supporting PLWHA especially in slum areas on the spot. Limited information on this aspect derails efforts to mitigate the manifestations of HIV and AIDS. Fifty seven percent reported the lack of information.

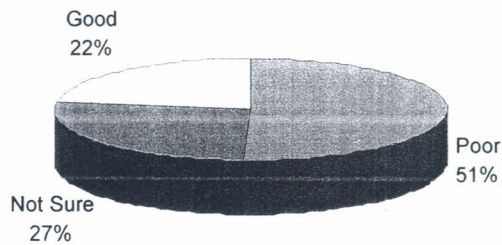
Table 5: Response to the extend to which information on HIV and AIDS is available

Response	N	Percentage
Not at all	46	57.5
A little	22	27.5
Moderately	9	11.3
Mostly	1	1.3
Completely	2	2.5
TOTAL	83	100.0

4.2.9. Capacity to work or get around

On the element of capacity to work, 70% reported they were unable to work or carry on with their normal daily activities most of the time while 51% reported that they are not able to comfortably get around most of the time. This again depends on many factors e.g. if one is sick, emotionally stressed or just feeling strengthless due to some reasons that the body knows better. The manifestations of HIV and Aids are myriad sometimes due to the opportunistic diseases that affects the patients thus limiting their functionality options especially if nutrition is poor.

Figure 6: Percentage distribution of how well the respondents reported they are able to get around



4.2.10. Satisfaction with personal relationships

On Satisfaction with personal relationships, 67% reported that they are dissatisfied. Generally people fear rejection at all levels. HIV has stigma, both self perceived or real profoundly attached to it. Body appearance is another factor, yet risk involved is another aspect. In the qualitative interviews it was mentioned that in intimate relationships, women do not disclose their status because when they do, the male partner takes off. Although it was also noted that group therapies plays a distinctive role. *“I get inspired when I meet with other PLWH”*.

Table 6: Distribution of respondents’ satisfaction with personal relationships

Response	N	Percentage
Very dissatisfied	26	31.7
Dissatisfied	29	35.4
Neither nor dissatisfied	18	22.0
Satisfied	4	4.9
Very satisfied	5	6.1
TOTAL	82	100.0

4.2.11. Satisfaction with sex life

Another negative report is the sex life where 80% reported that they are not satisfied with their sex life. It should be noted that a large percentage of respondents involved in this

study is widowed and single. This creates a lot of challenges to get sex satisfaction because they hardly engage in permanent relationships, why, because the intimate partners take off on realization that the women are positive. Some of the mothers still practice unprotected commercial sex because it pays higher than the protected sex. It was reported that most male partners do not disclose their HIV status and they demand unprotected sex. This can only lead to re-infections most of the time. Some of the women engage in alcoholism because they believe that alcohol makes them forget their problems. This of course means that children are likely to be neglected. This is dangerous because then they become vulnerable to circumstances surrounding them. Commercial sex is highly practiced to supplement their income and of course it comes with all fears and concerns. *“My husband died and left me with HIV and 7 children. I struggle to feed them. Sometimes I am forced to leave them in the house alone as I go to do sex business at night. But now I discovered that my girl of 15 years is pregnant and I feel so sad because I do not know whether she is positive. I am depressed about this”.*

Table 7: Distribution of respondents’ satisfaction with sex life

Response	N	Percentage
Very dissatisfied	44	54.3
Dissatisfied	21	25.9
Neither nor dissatisfied	10	12.3
Satisfied	1	1.2
Very satisfied	5	6.2
TOTAL	81	100.0

4.2.12. Satisfaction with support from friends.

As high as 70% of the respondents reported that they do not get enough support from friends. There was an element of lack of family support. It was noted that most mothers are single, they settled in the slums several years ago and because of the condition they are in, their families abandoned them. *“My neighbour got very sick and was quickly transported to western province after a small harambee was conducted to raise her fare to go and die since the community feared costs of transporting a corpse”.* Most of them succumb to loneliness as they do not get enough support from their friends and families. They easily fall into depression as a result. Falling in love inspires them

although the relationships do not ordinarily last. This is why they do not wish to state their status because the men take off on revelation that they are positive. Well, friends can only help you up to a certain point. The burden of assisting an HIV person may also be perceived as a continuum hence no beginning or no ending points. No human being is ready to carry burdens forever and therefore may be available only occasionally.

Table 8: Distribution of respondents' satisfaction with support from friends

Response	N	Percentage
Very dissatisfied	34	42.5
Dissatisfied	22	27.5
Neither nor dissatisfied	15	18.8
Satisfied	7	8.8
Very satisfied	2	2.5
TOTAL	80	100.0

4.2.13. Satisfaction with access to health facilities

On the element of access to health, 54% reported dissatisfaction with the Kenyan health system. In the qualitative interviews, it was noted that there is only one GOK health facility in Kocho (Korogocho), in fact recently instituted and therefore it is not fully operational. There are no ARVs and doctor's visits are scheduled. The faith based clinic available is restrictive because for a patient to be attended to, she must be a bonafide member of the church. On another level, transport system is still wanting due to lack of proper infrastructure in the area. But there is light in the tunnel if there will be political goodwill and sustained good leadership for completion of slum upgrading programmes.

Table 9: Distribution of respondents' satisfaction with access to health facilities

Response	N	Percentage
Very dissatisfied	14	18.2
Dissatisfied	28	36.4
Neither nor dissatisfied	18	23.4
Satisfied	11	14.3
Very satisfied	6	7.8
TOTAL	77	100.0

4.3. Issues and plights of women living with HIV and AIDS, aspirations and hopes as brought out in the discussions.

The issues and fears that women with HIV and AIDS face are myriad. There were incredible revelations from the participants that outlay their fears, aspirations and hopes. One crucial fear that crowds the mothers is that of leaving orphans behind when they eventually die. *"I know that even if I take drugs I will eventually die anyway and this freaks me out"* said one participant. Another aspect that was discovered was the non-adherence to medication. *"When I feel a little better I do not take medicine and sometimes we share medication especially if one is too weak to visit a health facility"*, put in one participant.

There were those women who fell in the category of age 18-24 and are positive. *"I got infected as a child through mother to child transmission. Am still a virgin but I wish to get married and have my own children and live a normal life like everybody else. I still do not know how to deal with the fact that am a virgin yet am positive"*

Yet another aspect learned was that mothers are still delivering at home for fear of finding out their status. This of course means that efforts to prevent mother to child transmission are being hampered.

The participants also outlined their concern towards most Non governmental organizations and support groups. *"Most of them have been carrying out research using us as guinea pigs and yet we do not see or benefit from these researches. Infact we are tired of people using us to collect data. Some go as far as exposing our status"*, one participant contented.

On cultural issues most women said that they are the ones who pay the price for cultural practices. In one community when a husband dies the woman is supposed to be inherited regardless whether her husband was positive or not or whether the incoming husband is positive or not. This disorients them leading to diminished quality of life. The rituals take a lot of money and leave the bereaved family in dire need. Travelling to the village interferes with their health most of the time. Sometimes they forget to carry medication and they easily succumb to sickness while in the village. *“I wish the government could do something about these cultures. I hear now that the government is encouraging some communities to stop circumcision rites. I wish it could also discourage burial rites as well”*, wished one participant.

CHAPTER FIVE

5.0 Summary, Discussion and recommendations

5.1 Summary

The study has revealed and indeed affirmed that QOL should be taken into context to better health care outcomes. Issues like sharing of drugs has been revealed which of course impede intervention efforts. The issue of education in the poor settings has also come out strongly. There is the element of family support and relationships that has been rated very highly by the respondents. This is in consistent with other researches that affirm on the same (O'Boyle et al. 1992;) (Cattell 2001).

The perception that families or friends will always be there for you is misplaced and can only be countered by information on responsible behaviour and accountability. There is dissatisfaction on healthcare system that needs great improvement in this country. Primary health care is paramount and more so accessibility to all regardless of economical status. As a matter of fact it is high time HIV programmes are scaled down to the woman since she is the reason why a society exists in the first place. Education is too low in the slums and this will continue negating vision 2030 aspirations. There is need for continuous commitment in efforts to compact the manifestations of HIV and AIDS.

Policy makers and clinicians need to consider the implications of this study for health resource allocation, and recognize that small improvements in HRQoL may be of great significance for individuals with HIV manifestations. This will also

help in identifying specific intervention programmes that are needed to improve the QOL of HIV patients. This creates a holistic approach to health and health care. The patient's view, priorities and behaviour on quality of life are thus *important for healthcare planning and management systems.*

5.2. Discussion

Behind these dry statistics are women from traditional families caught in the terrible bind of pressure to produce children, and unable to admit that they have contracted HIV from a husband who is unfaithful. There are teenage girls from very poor homes whose only way of staying on at school is to barter sex with teachers or "sugar daddies" that will pay for books, uniforms and fees. And there are babies born healthy to HIV-positive mothers and who acquired the infection from breast milk because their mothers had no real choice: they were unaware of the risks of breastfeeding, or there was no safe and affordable alternative.

Many will have been too afraid of drawing attention to their HIV status by not breastfeeding, and suffered the silent agony of putting their babies at risk because of the cruel stigma of AIDS. HIV does not strike at random, and over the years there is great knowledge about what makes people vulnerable. Where once the focus was solely on personal risk behaviour, today there is knowledge that there are factors way beyond the control of the individual that encourage risk behaviour and make it hard for people to protect themselves. These factors include poverty, discrimination, lack of education and opportunity, and, crucially, the subordination of women which puts young females at even greater risk than males. The disproportionate risk for women has enormous social implications, since they are the principal guardians of future generations, the carers and nurturers of society. Yet women's health and wellbeing have always had low priority. The case for righting these wrongs has never been more pressing.

On this AIDS front, HIV and AIDS programmes must be a continuous process. The policy makers must expand and intensify HIV prevention measures, because knowledge has shown that prevention works. This should be done at two levels, at the level of the individual to increase knowledge and skills and encourage safe personal behaviour, and at the level of society, its institutions and attitudes, to create an environment supportive of safe behaviour.

Furthermore, the prevention campaigns must give higher priority to the most vulnerable groups. They must actively involve their target populations to ensure they are relevant. And they must strive for equity so that women all over this country and from all walks of life are able to benefit from the advances in science and technology that only a tiny minority enjoys at present. For example the educated HIV positive woman from the affluent zone is likely to give birth in the most appropriate private hospital where there is technology like cleansing of birth canal during the delivery process or simply taking the Cesarean section option to prevent Mother to children transmission of the HIV. What option does a mother from a slum have when in the first place the hospital will demand down payment of a huge amount of money before any admission is made? She would rather quietly give birth at home.

5.3 Recommendations

Specific HIV and AIDS programmes should be tailored to suit slum environment so as to enhance the quality of life of HIV and AIDS women patients.

Clinicians and health practitioners in their interaction with women with HIV to consider involving them in decision making since they are the owners of their bodies who continuously listen to its manifestation in order to improve health care outcomes.

The Clinicians and medical practitioners in their efforts to treat symptoms or ailments that drives the patients to health facilities need also to conceptualize and evaluate Physical health and level of independence of the patients, Psychological well being, social relationships and environment to improve patient-doctor relation outcomes. It is not just enough to limit the interaction to “how are you, what is your problem, go to room so and so for examination or to take your drugs” as is usually the case. This scenario leaves the patient wanting more and no wonder they turn to the significant others who usually are very keen to listen and even make follow ups to the patient.

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ANNEX 1 RESEARCH CONSENT FORM

Title: Health-related Quality of life among HIV/AIDS women patients.

Introduce yourself

INFORMATION TO BE READ TO RESPONDENTS

These questions are not part of an exam. We would like you to try and answer the questions honestly and to think carefully about them. However, if you prefer not to answer some questions that is OK. You do not have to. We will not tell anyone the answers you give to our questions.

Your questions answered:

Why am I needed for this study?

We would like to speak to HIV/AIDS women patients to give us an overview of their experiences in terms of physical health, psychological well being, social relationships, environment and your spiritual life and how these facts affect your well being.

What will I be asked to do?

We will ask you some questions lasting for about one hour. That is all!

What is the purpose of this study?

Illness such as HIV/AIDS demand regular treatments or maintenance which can affect people's daily routines. We are doing this study to find out your experiences with the condition and the same can be communicated to the health practitioners and government policy makers for effective intervention programmes.

Who will read the answers I give?

When we record the answers you give to the questions, we will not write down your name on the same sheet. This way you will feel free to discuss any issue without worrying that other people will discover what you have said. The interviewer will not discuss the interview with anyone else, including supervisors and other health workers. These questions are not a test or exam. We just want to know what your experiences are for people living with the condition.

Are there any risks?

This study has no risks. Participation in this study will not involve undergoing any medical procedures.

How will I benefit from the study?

The study will give in depth results of your experiences and this will add value in formulation of effective and practical solutions to mitigate the pandemic.

What if I have more questions?

If you have questions about this study, you should contact Mrs. Prisca Otambo (telephone 020 2722541 Ext 3420;

Your Rights to Participate, Not Participate, or to Withdraw from the Study

We would like you to answer all questions but participation in this study is entirely voluntary. You have the right to refuse to take part in this study. You do not have to answer every question if you do not wish. You are free to leave the interview at any point without repercussions.

By signing below, you confirm that you have been informed about the study and agree to participate. If there is any part of this explanation that you do not understand, you should ask the investigator before signing.

You will be given a copy of this signed consent form.

I, have read the above information/ the above information has been explained to me by, and I have fully understood the information. I have had opportunity to ask questions, and all my questions have been answered to my satisfaction. I consent that I be enrolled into the study.

Signature.....Date.....
(Investigator)

Signature.....Date.....
(Participant)

ANNEX 2 (a) structured questionnaire (English version)

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

A. General Background of respondent

1. How old are you?

1. 18-24 years ()
2. 25-30 years ()
3. 31-35 years; ()
4. 41-45 year; ()
5. Over 45 ()

2. Highest level of education attained

1. Primary ()
2. Secondary ()
3. College ()
4. University ()
5. Other ()

3. Marital status

1. Married ()

- 2. Single ()
- 3. Widowed ()
- 4. Cohabiting ()
- 5. No. of children.....

4. **Area of Residence**

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 or good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2	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 ONE MONTH.

		Not at all	A little	A moderate amount	Very Much	An extreme amount
3	To what extent do you feel that physical pain prevents you from doing what you need to do	1	2	3	4	5
4	How much do you need for medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life	1	2	3	4	5
6	To what extent do you feel your life to be meaningful	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	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 ONE MONTH.

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for every day life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	Have you enough money to meet your needs?	1	2	3	4	5

13	How available to you is the information about HIV/AIDS that you need in your day-to-day?	1	2	3	4	5
14	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
15	How well are you able to get around	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last ONE MONTH.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep	1	2	3	4	5
17	How satisfied are you with your ability to perform your daily living activities	1	2	3	4	5
18	How satisfied are you with your capacity for work	1	2	3	4	5
19	How satisfied are you with yourself	1	2	3	4	5
20	How satisfied are you with your personal relationships	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends	1	2	3	4	5
23	How satisfied are you with the conditions of your living place	1	2	3	4	5
24	How satisfied are you with your access to health services	1	2	3	4	5
25	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 ONE MONTH.

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

ANNEX 3

FOCUS GROUP INTERVIEW GUIDE

The following questions ask about your spiritual, religious or personal beliefs and how these beliefs have affected your quality of life. If you follow a particular religion such as Judaism, Christianity, Islam or Buddhism you will probably answer the following questions with your religious beliefs in mind. If you do not follow a particular religion but you still believe that something higher and more powerful exists beyond the physical and material world, you may answer the following questions from that perspective. While some of these questions will use words such as spirituality please answer them in terms of your own personal belief system whether it be religious, spiritual or personal.

1. To what extent does any connection to a spiritual being help you to get through hard times?
2. To what extent does any connection to a spiritual being help you to tolerate stress?
3. To what extent does any connection to a spiritual being provide you with comfort?
4. To what extent do you feel inner spiritual strength?
5. To what extent does faith contribute to your well being?
6. To what extent do you have feelings of inspiration/excitement in your life?
7. To what extent are you hopeful with your life?
8. How much does spiritual strength help you to live better?
9. To what extent does faith help you to enjoy life

These questions will allow you to give us more information about your general quality of life.

1. Does culture affect you in any way as a person living positively? If yes how – probe
2. Do you value family support and if so to what extent.
3. How would you rate our healthcare system? Are policy makers doing enough to support HIV/Aids patients

ANNEX 4

KEY INFORMANT INTERVIEW GUIDE

1. What is the general quality of life for women HIV/AIDS patients?
2. What are their major concerns?
3. Do they ever fail to attend their scheduled clinic appointments? If so what reasons do they give?
4. Do you think matters of spiritual life are important in their lives?
5. Do the patients ever show signs of depression?