Quality of Life Among People Living with HIV/AIDS under Antiretroviral Therapy in Kaski District of Nepal



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นายมิลาน ราช ซิกเดล

วิทยานิพนธ์นี้เป็นส่วนหนึ่งของการศึกษาตามหลักสูตรปริญญาสาธารณสุขศาสตรมหาบัณฑิต สาขาวิชาสาธารณสุขศาสตร์ วิทยาลัยวิทยาศาสตร์สาธารณสุข จุฬาลงกรณ์มหาวิทยาลัย ปีการศึกษา 2558 ลิขสิทธิ์ของจุฬาลงกรณ์มหาวิทยาลัย

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Thesis Advisor	Assistant Professor Usaneya Perngparn, Ph.D.	

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> ......Dean of the College of Public Health Sciences (Professor Sathirakorn Pongpanich, Ph.D.)

THESIS COMMITTEE

มิลาน ราช ซิกเดล : คุณภาพชีวิตของผู้ติดเชื้อเอชไอวี/เอดส์ที่ได้รับยาต้านไวรัสในอำเภอ กัสกี้ ประเทศเนปาล (Quality of Life Among People Living with HIV/AIDS under Antiretroviral Therapy in Kaski District of Nepal) อ.ที่ปรึกษาวิทยานิพนธ์หลัก: ผศ. ดร. อุษณีย์ พึ่งปาน, 98 หน้า.

การศึกษาครั้งนี้มีวัตถุประสงค์เพื่อดูคุณภาพชีวิตของผู้ติดเชื้อเอชไอวี/เอดส์ที่เข้ารับการ บำบัดรักษา ในอำเภอกัสกี้ ประเทศเนปาล เป็นการศึกษาภาคตัดขวาง ศึกษาผู้ติดเชื้อจำนวน 268 คน ที่เข้ารับยา ต้านไวรัสในโรงพยาบาล ในภูมิภาคตะวันตก การประเมินคุณภาพชีวิตได้ใช้แบบสอบถาม ขององค์การ อนามัยโลก (WHO QOL- HIV- BREF ) วิเคราะห์ข้อมูลด้วยโปรแกรม SPSS รุ่น 16 การศึกษาครั้งนี้ พบว่า ผู้ติดเชื้อเอชไอวี/เอดส์ที่เข้ารับการบำบัดรักษา มีคุณภาพชีวิตไม่ดีในเรื่องของ สภาพจิตใจ ส่วนสถานภาพ สมรส (p-value =0.007) การจ้างงาน (p-value =0.002) การดูแล ตนเอง (p-value <0.001) CD4 (p-value =0.040 ) เป็นตัวพยากรณ์ที่บ่งชี้การมีคุณภาพชีวิตที่ดี นอกจากนี้ยังพบว่า ผู้สูงอายุ ว่างงาน และผู้ที่มีค่า CD4 ต่ำ มีความสัมพันธ์กับคุณภาพชีวิตที่ต่ำ ดังนั้น คะแนนที่ต่ำเรื่องของสภาพจิตใจ เป็นเรื่องที่ต้องดำเนินการ แก้ไข แทรกแซง อาทิ ลดความรังเกียจใน กลุ่มผู้ติดเชื้อเอชไอวี/เอดส์

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MILAN RAJ SIGDEL: Quality of Life Among People Living with HIV/AIDS under Antiretroviral Therapy in Kaski District of Nepal. ADVISOR: ASST. PROF. USANEYA PERNGPARN, Ph.D., 98 pp.

The purpose of this study was to determine the association of the HIV/AIDS on the quality of life of the infected individuals in kaski district of Nepal. A cross-sectional study was done among 268 individuals attending antiretroviral therapy in ART center in Western regional hospital. Quality of life was evaluated with the help of World Health Organization Quality of life questionnaire (WHO QOL- HIV-BREF). SPSS version 16 was used for the data analysis. PLWHA in Nepal were having the poor quality of life in psychological domain of QOL. Marital status (p-value 0.007), being employed (p-value 0.002), taking self-care (p-value <0.001), CD4 count (p-value 0.040) were the predictors for having the good QOL in PLWHA. Being old age, unemployed, low CD4 count were associated with the low QOL. Lowest score in the psychological domain suggesting the need of the psychological interventions such as to decrease the discrimination and attitude towards PLWHA.

จุฬาลงกรณ์มหาวิทยาลัย Chulalongkorn University

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Student's Signature	
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"There is nothing impossible in this world for a heart full of desire"Abraham Lincoln

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## **ABBREVIATIONS**

ART Anti-Retroviral Therapy CD4 Cluster of Differentiation 4 HIV/AIDS Human Immunodeficiency Virus/ Acquired Immune Deficiency Syndrome MQOL Multidimensional Quality of Life NCASC National Care for AIDS and STD Control The President Emergency Plans for AIDS Relief PEPFAR **PLWHA** People living with HIV and AIDS Quality of Life QOL UNAIDS Joint United Nations Program on HIV/ Acquired Immune Deficiency Syndrome. UN United Nations VCT Voluntary Counseling and Testing World Health Organization WHO World Health Organization Quality of Life WHOQOL

## **CHAPTER I**

## **INTRODUCTION**

#### 1.1) Global epidemiology of HIV/AIDS

The global pandemic of human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) has caused millions of deaths worldwide and has crippled the lives of many more. The first case of the HIV/AIDS was reported in USA in 1981. It didn't take it a long time for it to be pandemic all over the world. HIV/AIDS is now one of the most concern diseases for all the health providers in the world. It is regarded as a chronic illness as there is still no cure for the HIV, which means that once one is infected with the HIV then he/she will always be infected (Yach, Hawkes, Gould, & Hofman, 2004). Since the beginning of the epidemic of HIV, almost 78 million people were infected with HIV, taking more than 39 million people's life. At the end of 2013 globally about 35 million people are living with HIV, out of which 0.8% of adults aged group 15-49 years worldwide. Saharan Africa remains most severely affected with nearly 1 in every 20 adults, and accounting for nearly 71% of the people living with HIV worldwide, this is only region in the world where there are high number of the female population who were affected with HIV/AIDS then males. (UNAIDS, 2015).

According to the UNAIDS world AIDS day report about 37 million people are living with HIV/AIDS, 2 million people are newly infected, and almost 1.5 million people dying due to the AIDS-related illness in the end of 2014. Although new infections has been decreasing from 35% since 2000, with death rate falling to 42% since 2004 showing that the death rate and the incidence going down, and the effectiveness of the treatment shows that the word is going towards achieving the Millennium development goals 6 (United Nations, 2015). However Sub-Saharan Africa still remains with the highest population living with HIV/AIDS with about 25.8 million accounting about 66% of the total population of PLWHA in the world. Although the prevalence rate of the Asia and Pacific regions is low in compared to the other regions but the PLWHA in them is second largest in the world. In 2014 there were about 5 million PLWHA Asia and pacific regions with the estimated 340,000 new cases. Between the years 2000 to 2014 the number of the deaths due to this deadly virus was decreased to 11% (UNAIDS, 2015).

#### 1.2) Global response to HIV/ AIDS

Since the pandemic of the HIV/ AIDS numerous resources have been done to find the cure for this deadly disease but no definitive treatment have been found till now. In June 2001, United Nations General Assembly Session the global community had cited ART as a key factors for the effectiveness of the HIV/ AIDS programs. They affirmed that prevention, care, support and treatment for those infected and affected by HIV/AIDS are mutually reinforcing elements of an effective response and must be integrated in a comprehensive approach to combat the epidemic ((FHI)). In 2003, USA President George W. Bush with bipartisan support launched The Presidents Emergency Plans for AIDS relief (PEPFAR), to address the AIDS crisis, particularly in Africa where millions of people were dying without access to life saving antiretroviral treatment. The policy is mainly aimed at strengthening efforts to manage and coordinate the response promote HIV/AIDS preventions, provide effective treatment, care and support the PLWHA and to minimize the impact of its epidemic(Services, 2003). According to the report of UNAIDS about 15.8 million PLWHA are receiving the ART which is increased from 13.6 million to about 15.8 million, with which 41% of the adults living with HIV/AIDS are accessed to ART in 2014 up from 23%. In Sub-Saharan Africa being the most PLWHA receiving ART increasing to 41% up from the 10,00,000 people in the year 2002. It is expected that about five out of seven people in this region are on ART (UNAIDS, 2015). ART not only helps in controlling HIV replication but also prevents the PLWHA with the opportunistic infections. With the decreasing the mortality rate and the new cases it can be assumed that ART and the global response for the preventing and the transmission of the HIV/AIDS is effective.

#### **1.3) Investment in HIV/AIDS**

In the low- and middle-income countries, by the end of 2014 USD 20.2 billion was investigated for the AIDS response, with 57% of the total domestic resources for the AIDS. Between 2009 and 2014, 84 out of 121 low- and middle income countries made a sustained increase in the investment in their domestic resources. Out of these countries 46 increased in their investment of more than 50% and 35 reported an increase of more than 100%. Most of the low-middle income countries rely on the international donors for their AIDS investment. It is estimated that about USD 31.1 billion is required by the end of 2020, with 29.3 billion in the year 2030. (UNAIDS, 2015). UNAIDS has been helping to the world for making the HIV/AIDS zero, and also to decrease the stigma and discrimination among the people living with HIV/AIDS. They support the countries with the manpower as well as providing them with the free antiretroviral drugs, free training to provide the counselling for the affected people, working for the gender equality, eliminating new HIV infections especially to the new born child, it also works among the drug users so to prevent the

HIV/AIDS transmission, and targeting to reduce the treatment gap among the people living with HIV/AIDS, They also work for to change the rules among the different countries who have travel restriction to the PLWHA.

#### 1.4) Epidemiology of HIV/AIDS in Nepal and in Kaski district in Nepal

Nepal is a landlocked country with India to its south, east, west and China to its North. The country is divided into 75 districts and 14 Zones. The first case of HIV infection was reported in the year 1988. Prevalence rate among the adult population (15-49) is 0.2% and it has been remained the same during the last years with the range of 0.2% - 0.3%. It is estimated that around 40 thousand people are infected with HIV/AIDS, with deaths of around 1,500 due to HIV/AIDS in 2014 from 1,300 on 2013. About 1,500 new cases was recorded on 2014 as compared to 1,400 in 2013. It is believed that due to the lack of the Public health surveillance system, the actual number of the PLWHA could be much more higher than it is recorded (Government of Nepal Ministry of Health and Population, 2015).

Kaski district is one of the hilly districts of Nepal with an area of 2,017 sq. km that lies in Gandaki zone of western development region. According to preliminary report of census 2011, it had a total population of about 490,429, of which 48% are males and 52% are female. Kaski district falls under the highway district among the Nepal's epidemic zones with HIV prevalence of <1% in general adult population. Kaski district contributed larger number of PLWHA for total estimation of HIV population within the country, reported cases of HIV are 1,178 in which 695 were male and 483 were females. There are 810 patients who are under antiretroviral therapy in the infectious department of western regional hospital, a second largest ART center in Nepal (Tiwari, 2016), with the prevalence rate of the 0.8%

(Government of Nepal Ministry of Health and Population, 2015). Although the number of the people living with HIV/AIDS are high but still less number of the infected participants are under ART as there is still the treatment coverage gap for the ART of 70% (UNAIDS, 2013). Though the exact number of PLWHA in Kaski district is very difficult to trace out due to the mobility of the people from one place to other and many times the true permanent address of HIV clients is unknown, but it is believed that around people are permanent inhabitant of Kaski district in Nepal (Government of Nepal Ministry of Health and Population, 2015).

#### 1.5) Nepal Response to HIV/AIDS

The Ministry of Health and Population started the treatment for HIV/AIDS since 2004 just by providing the free antiretroviral drugs from the Teku Hospital for the limited number of the PLWHA. Nepal has made some substantial progress towards providing ARVs, guided by the Ministry of health and population, National care for AIDS and STD control (NCASC) there are about 64 governmental organizations offering ART, Voluntary counselling with just 13 centers available for the CD4 count. according to National HIV and AIDS strategy, by the December 2014, 39,000 HIV infected people were reported, out of which only 10,407 are receiving antiretroviral therapy (ART), this represent insufficient ART coverage, as 20,000 HIV- infected people were in need of the treatment. Scaling up ART is necessary in Nepal, in order to prolong and improve the lives of PLWHA (Government of Nepal Ministry of Health and Population, 2015). The new clinical recommendation for the guidelines for the effective treatment of HIV/AIDS (e.g. CD4 count of 500cells/mm<sup>3</sup> or less from the last CD4 threshold of 300 cells/mm<sup>3</sup> or less) and its implementation has been done according to the CD4 count.

#### 1.6) Quality of Life and PLWHA under ART therapy

There is an assumption that as long as the antiretroviral drugs are used it helps in improving the life of the PLWHA, it is found that people who are under ART are living a near life then to the people who are not. The ART is also regarded as the "Lazarus Drug" as it helps to bring the people back from the dead, it slows the replication of virus in such a way that the level of the virus in the body is very low or it can even lead to the trace amount. Having ART is not a simple matter, like taking it to some days or for some weeks, once started it should be continued for lifelong in order to live in a near normal life. WHO defines health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, and Quality of life as "individual's perception of their position in their life in the context of the culture and value system in which they are living and in relation to their goals, standards expectations and concerns." (Basavarajaiah. D. M., B. Narasimha murthy, B. Leelavathy, & K., 2012). Physicians, nurses, counselors, PLWHA and all other professionals who directly or indirectly are involved in the care of the PLWHA on ART should know that although ART provides the quantity of life but quality of life should be assessed from PLWHA under ART point of view. Health care is now changing, it is important to know about any medications or interventions on patient's life rather than just on their bodies. This is mostly helpful in the chronic diseases or to those diseases which are life threatening who plays a vital role in the impairment of one's physical, mental as well as mental wellbeing (Julia Addington-Hall & Kalra, 2001). Although these drugs help PLWHA but it also have some side effects like decreasing in appetite, sleeping disorders, disturbed in work schedule with influence in day to day interaction with peoples. Although ART improves the life of

the PLWHA but the challenge arises when the determinants of health like social, psychological, sexual and spiritual aspects of one's life is kept together to sum up as the Quality of Life.

#### 1.7) Significance of the Study

There has been significant efforts by government, but tremendous efforts from the NGOs and INGOs to prevent the new cases of the HIV, improve the quality of care for PLWHA, despite the study of numerous studies on QOL in PLWHA on ART in various other regions, and the availability of the measurements for their comparisons, but those studies cannot represent Nepal's viewpoint. The researchers concern that no research has been done to assess the QOL of PLWHA on ART in Kaski district till now. This study thus will document the QOL of PLWHA on ART using WHO QOL, and thus contribute with the Nepal's prospective. It is hoped that the result will benefit physicians, nurses, counselors, PLWHA and all other professionals who directly or indirectly involved in the care of the PLWHA on ART. The factors which are responsible for the quality of life and during the outpatient or inpatient care to the PLWHA will be known. As a result of which during the treatment and counselling all the care providers will add these factors to the PLWHA. The result can also serve as the important tool to guide health care managers especially in training and hiring the health professionals.

#### 1.8) Research objectives

#### General objective:

 To assess the Quality of life of PLWHA under ART in Kaski district in Nepal.

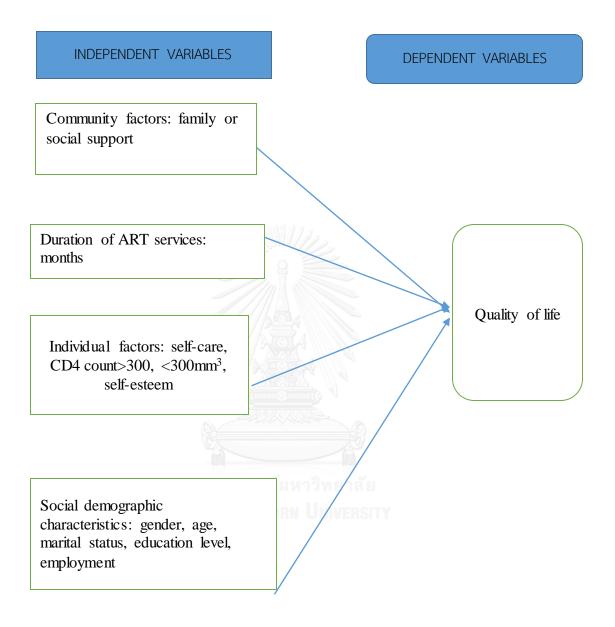
#### **Specific objectives:**

- To determine the relationship of socio-demographic variables like age, sex, education, and marital status, occupation on QOL in PLWHA in Kaski district in Nepal.
- To find the relationship of community factors: social and family support on QOL in PLWHA in Kaski district in Nepal.
- To determine the relationship of individual factors: self-care, CD4 count, selfesteem in the QOL in PLWHA in Kaski district in Nepal.

### 1.9) Research Question

• What is the QOL of the PLWHA in Kaski District in Nepal under ART?

#### **1.10)** Conceptual framework



#### **1.11) Operational Definition**

#### **Independent** variables

#### Individual factors: self-care, CD4 count, self esteem

It measures how the individual is self-aware of his health, taking care of him, minimizing the rate of the hospital visit due to illness, having the good healthy foods, with regularly exercise, and checking the level of his CD4 count regularly, elfesteem reflects a person's overall subjective emotional evaluation of his or her own worth. It is a judgment of oneself as well as an attitude toward the self.

#### **Community factors: social or family support**

It describes how patients relates to other people, the types of support they receive, and the approval they gets from the surroundings.

#### Social demographic characteristics:

Gender into male and female

Age: which is recorded in absolute years e.g. 30 years

**Participant's marital status** was divided into never married, married, divorced and Widowed.

**Education level** which refers to the level of education attained by the respondent, it was classified into: none, primary, secondary and high school and university.

Employment which refers to the unemployed or currently employed.

#### **Dependent** variables

#### Quality of life

Here it refers to the PLWHA perception of their condition in life in the context of the cultural and system in which they live (Kaski district) in relation to their goals, expectations, standards and concerns. It was a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships, and their relationship to salient features of environment. QOL is measured under different domains, for to maintain the QOL, WHO have defined them under six different domains, environmental domain, physical domain, psychological domain, psychological states, personal beliefs, social relationship status, spirituality, and level of the independence domain, these as a whole defines the QOL (O'carroll, Smith, Couston, Cossar, & Hayes, 2000).



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## **CHAPTER II**

## LITERATURE REVIEWS

#### 2.1) Definition of Quality of Life

There are limited amount of the dictionaries that are able to find the actual concept of the QOL. As it when taken together, it's a phrase, and not all the dictionaries include the phrases in them. After breakdown of the phrase, there are words which is well defined that is "Quality" and "Life". Dictionaries provides the definition of those words, after which the definition of the QOL are analyzed. According to WHO, QOL cannot be just explained with one factors, have the different domains, which sum up to assess the QOL of the individuals (Taylor, Myers, Simpson, McPherson, & Weatherall, 2004).

#### Environmental domain

It helps to measure how the environment is playing a key role in the wellbeing of the patient. Five point Likert scale is used, and it measures financial resources of the person, social and health support, physical safety and security, accessibility and quality, and also the chances for them to know about the new skills and information (Saxena, Carlson, Billington, & Orley, 2001).

#### Physical domain

It helps in finding the four sub-dimensions, which is physical pain and discomfort they feel, their feeling of energy and fatigue after certain work, sleep and rest and extend to which patient is disturbed in doing in his day to day activities: physically. It is measured by asking each one of the PLWHA to say his or her feeling for the QOL on five Likert scale. Here 1 represents the lowest positive feeling with 5

representing strong positive feelings. For the pain and discomfort that the patient is experiencing, it is recorded in the opposite directions (Skevington, Lotfy, & O'Connell, 2004).

#### Level of independence domain

It defines to the support the individual needs to do their daily day to day activities. Mobility, daily living activities, medicine or treatment dependence and their work capacity are measured in this domain. For the medicine dependence, score is measured opposite i.e. the higher the score representing the better QOL (Skevington et al., 2004).

#### Social relationship domain

It describes how the individual is relating with the people around him. Their social support, how they are greeted in the society, and their ability to perform the sexual activity are measured by asking each of them in the 5 point Likert score scale. Spirituality, religion domain

It explains how the individuals belief in themselves, how they value their goal of life, it concentrates in the forgiveness and the blame to oneself or to the others, whether they are concern with their future or not, the fear of the death. They are all recorded in the Likert scale chart (Skevington et al., 2004).

#### **Psychological domain**

It is a subjective evaluation of PLWHA towards the stigma and the discrimination they got, their fear towards the society or towards others, anxiety, confusion, their negative feelings they get, anger, whether they feel of losing their dignity or not, how they are able to concentrate in their work. They all are recorded in

the five point Likert scale. Like the medicine dependence, negative feelings are also recorded reversely (Skevington et al., 2004).

Over all these all sum up to make a QOL. It was measured by asking each respondent to rate his or her quality of life on a five point Likert scale with 1 representing lowest and 5 representing highest QOL (Taylor et al., 2004).

Abrams in 1973 defined QOL as the degree is satisfaction or dissatisfaction felt by the people with various aspects of life (Tobiasz-Adamczyk, 2004). However the term quality of life is differs according to the people and the researchers. Till now no definitive meaning of the QOL has been developed, although there has been many theories and their indices has been used for to make it a standard to use in the "Life quality" the Quality of life is regarded only in the positive aspect of the life rather than saying it as "a state" (Farquhar, 1995).

There always has been conflict in defining the concept of QOL, as there are about 100 definitions of QOL, and these definitions only concentrates on the physical condition, social factors and the physical wellbeing of the patients after they have been under treatment. During the late 1960s medical literature presented various philosophy about QOL, addressing the level of professional satisfaction which were experienced by physicians in training and practice. They focused in the patients who have the prevalent and treatable disease condition only. They were mostly concern on how the patient evaluate themselves on their functional status, their feeling of wellness, treatment preferences and their values through standardized patient's surveys (Bowling, 2013).

Quality of life can be defined according to the researcher's research point of view, in order to prove their objectives in their particular research topics. Schrag

(2006) conducted their study in the patients with neurogenic disorders such as Parkinson's disease. They assesses QOL of patients with Parkinson's disease in different stages and compared them with the general population. Three questionnaires combined with the interview and neurological examination was done, the result showed there was the deteriorating QOL of the patient with the progression and worsening of the disease condition (Schrag, 2006). Likewise in the study done by the Neila Paula de Souza and her friends (2015) assessed the HROOL and related factors in patients with chronic liver disease, the findings was the QOL of the patient with low income was worse than to the patient with high income family. It shows that QOL is somewhat related to the family income also (Souza, Villar, Garbin, Rovida, & Garbin, 2015). In 1999 a study done for assessing the QOL of long term breast carcinoma survivors, and for them QOL is especially affected by the socioeconomic and their life burden factors but it wasn't to the ethnicity (Ashing-Giwa, Ganz, & Petersen, 1999). Similarly study done in the QOL and job satisfaction among nurses showed the positive correlation between those variables (Cimete, Gencalp, & Keskin, 2003). Similarly a study done on QOL and social support in cancer patients improved QOL was associated with the social support which he or she got (Courtens, Stevens, Crebolder, & Philipsen, 1996). The QOL therefore can be overlooked to the certain dimension or it can also exclude some of the dimension which were not relevant for the researcher's aim of the study.

#### 2.2) Development for the measurement of the QOL

WHO has been playing a vital role in defining the importance of the quality in life, with two objectives, first objectives deals with the downfall in the relationship of the patient and doctor's relationship. It was believed that by promoting the instruments that measures the QOL will help the physician's aware of their patient's condition and also by talking with them and giving them extra time to share their feelings during the treatment. The second objectives was to assess the medical outcomes due to the medical interventions, a measure of the side effects which that procedure had on patients QOL.

WHO tried to develop the tools that will help to measure the QOL, for that the mental health division of WHO, in 1991, assembled all the expertise from the world like medical sociologist, policy makers, health personals, researchers, and also the clinicians who were expertise in the major diseases. These experts developed the WHOs QOL tools which consists of the more then hundred questions (Power, Bullinger, & Harper, 1999). This instrument was further revised into the short form consisting of thirty-six questions (WHOQOL-SF-36) (WHOQOLgroup, 1995). World Health Organization has contributed in defining and developing the measurement instrument of QOL in HIV AIDS. Till now it has gone through series of conceptualization in many field of studies. It provides some form of the standardization in many different fields and the instruments helps to find for the cross cultural comparison.

#### 2.3) Use of ART and QOL

The use of the ART for the HIV patients means that HIV is now becoming a chronic disease which can be managed but requiring the long term therapy and care. Due to which improvement of the PLWHA quality of life became the primary concern and the treatment strategies(Carpenter et al., 2000). Study done for the QOL in HIV-infected individuals receiving ART by S.B. Mannheimer found that QOL score was 45.4 and 42.9 for the physical and mental health. There was the significant

improvement in the QOL of the PWHA after one to four months which continued till 12 months (p<0.001) (Mannheimer et al., 2005). Yen et al.found in their study that QOL in PLWHA male outpatients who were receiving the ART established that there was the deterioration in their day to day work after they had the HIV infections and also there was the less social support (YEN et al., 2004). A cross-sectional interview survey done by Louwagie in South Africa to find the QOL in PLWHA under ART and to those who were waiting. A combination of three questionnaire was used and from the analysis they reported that PLWHA who were under ART had a better QOL than to the patients who were not (Louwagie et al., 2007). A cross-sectional study done to investigate the association between QOL with ART therapy showed that QOL was closely associated with the ART therapy with poor adherence to ART (OR:2.26:95% CI: 1.39-6.32), in patient taking 14 or more pills/day (OR:2.17: 95% CI: 1.18-4.28), (Carballo et al., 2004)

#### 2.4) Socio-demographic factors on QOL in PLWHA under ART

The effect of the employment status with the QOL in PLWHA was studied by Sergio and his friends in which he found that employment status had a greater impact on physical and mental health of QOL (physical health (B=3.3, 95% CI 0.93 to 5.7)). And mental health QOL 9B=3.3, 95% CI 0.93 to 5.7)) (Rueda et al., 2011). A study done to find the determinants of QOL among PLWHA in Karnataka, India showed that quality of life has been overall rated as poor in their health status with highest in the environmental domain and low in the social relationship domain, with higher in the CD4 count level in body and its association with the better physical domain in QOL (Kumar, Girish, Nawaz, Balu, & Kumar, 2014).

Global self-esteem based on M. Rosenberg's (1965) scale is typically treated as a one-dimensional scale. However, factor analyses suggest separate factors associated with positively and negatively worded items, Self-esteem refers to the how one values themselves it is how one perceive their value to the world and how valuable they think they are to other. Positive self-esteem helps in giving the strength and flexibility to take charge of ones lives and to grow from their mistakes without the fear of rejections (Martín-Albo, Núñez, Navarro, & Grijalvo, 2007). The study done by lee and kochman in 2002 to show the association between the positive attitude towards themselves and the quality of life they showed that those PLWHA who had the positive self-esteem lived in the better quality of life (Lee, Kochman, & Sikkema, 2002) and helps to increase in the spiritual/ Religion/ personal belief domains of life the most (Cotton et al., 2006). People with good self-esteem were likely to have the good quality of life. Study done on the quality of life and its association with the chronic disease showed that Quality of life and the level of selfesteem in long term survivals of childhood cancer is not different from their peers. Although many long tern survivals of the chronic diseases worried not more or even less about health issues than their peers, they often are concerned about some present and future concerns. The investigated factors could explain poor quality of life and worries only to a limited extent (Langeveld, Grootenhuis, Voute, De Haan, & Van Den Bos, 2004). The good self-esteem indicated the good quality of life (Fry, 2001) and in the people with low self-esteem means there the participants are having stress and as a result of which they will be depressed resulting in the low quality of life (Nicolson & Anderson, 2003).

For the social and family support, Coping with HIV Questionnaire, Social Support Appraisals Scale, and Centers for Epidemiological Studies Depression instrument. Path models with strictly ordered relationships were fitted to study the effects of the psychosocial variables on each quality of life subscale they concluded that coping and social support had total effects on some, but not all dimensions of health-related quality of life, whereas depression was associated with all dimensions of health-related quality of life. Furthermore, the effects of both social support and coping were mainly through the intermediate variable, depression leading to the decreased quality of life. Social support can be interpreted as also by the peoples invitation to the community organized program or their acceptance in attending to those programs (Jia et al., 2004). Family support indicated their support to listen or to be listened to when the individual wanted to talk or share their feelings and the study done among the PLWHA to associate with the quality of life it showed that those participants who were being helped by their family members had the better quality of life then to those who were being consoled by their friends or even by their relatives (Friedland, Renwick, & McColl, 1996) (Burgoyne & Renwick, 2004). In this study both the variables social and family support are coated as a single one describing them with the support they get from the society as well as from the family members.

Socio-demographic factors also play a vital role in the QOL in PLWHA, the study done in Northern Ethiopia showed that females have the low score in all the QOL domains then the males, but the perceived stigma was significantly associated with the poor psychological domain over all (Tesfay, Gebremariam, Gerbaba, & Abrha, 2015). Similarly the quality of life was low in the people who were single then to among the person who was married, but most poor in the widowed especially in the psychological domain (Cook et al., 2002) which on the contrary to the study done in the Lebanon study done on the quality of life in PLWHA in only males showed that prevalence of the symptoms due to the HIV/AIDS and the stigma they perceived were the negative predicators of QOL, and being married was the positive predictor of the QOL (Abboud, Noureddine, Huijer, DeJong, & Mokhbat, 2010). (Lubeck & Fries, 1997) In the study done from the multi-site interview project which stress that for the low OOL not only the low CD4 counts acts but also the old age, female, IDU, lower education with low income (Campsmith, Nakashima, & Davidson, 2003) patients who self reportedly accessed to the medical care for the ART had the high levels of the stigma as a result they had a poor access to the health care due to which there was the subsequently decreased in their QOL with the lowest in the psychological domain in QOL (Sayles, Wong, Kinsler, Martins, & Cunningham, 2009). Patient who did care for their health and did the daily exercises, with proper balanced diet showed that they had a better QOL despite of their viral replication state then to those who didn't not (Stringer, Berezovskaya, O'Brien, Beck, & Casaburi, 1998). People who are infected with HIV/AIDS are most likely to be infected with the opportunistic infections or with tuberculosis. Any change in the climate and in the health behavior then there is the high risk of being affected with the common diseases, since they have less immunity power (Kaplan et al., 2000). So individual should visit the hospital or to the health care providers regularly (Crum et al., 2006) so it can be coated as the self-care by the people living with HIV/AIDS to maintain their health, to get the free antiretroviral drugs from the health facilities and also to get the psychological support from the health care providers. Individual factors like CD4 count is also acting a vital role in the patients QOL, people who had the low viral load had a better QOL

especially in the physical domain and in the psychological domain then to those who had the High viral load (Lubeck & Fries, 1997).

There had been many resources in association of quality of life and use of antiretroviral drugs. In which toxic effect of ART have been cited with lower quality of life like hip dystrophy, opportunistic infections. Comparing with males and females, females reporting of having lower quality of life in HIV/AIDS or researches in the different aspect of the domains of the QOL. Although there had been studies in many parts of the world, the QOL of PLWHA in Kaski district in Nepal is unknown. Therefore the researcher will contribute in knowing the QOL of PLWHA and allow for cross cultural comparison.

## **CHAPTER III**

## **RESEARCH METHODOLOGY**

#### 3.1) Research design

This study is a cross-sectional descriptive study to measure the quality of life among the people living with HIV/AIDS under antiretroviral therapy.

#### 3.2) Study site

The research was conducted in the Infectious department of Western Regional Hospital, which is the second largest care service provider for the PLWHA in Nepal, till now they have been providing services for 1,861 HIV/AIDS infected patients out of which just 810 patients follow up regularly, some of the patients are under first line drug therapy and others on second line therapy. Antiretroviral drugs are given for free of costs and for some patients one way transportation costs are also provided. This hospital have a full laboratory facilities as well as the free counselling and peer group support group. This center has also been supporting the patients by providing the few free drugs for the treatment of the opportunistic infections.

#### **3.3) Study population**

For this research patients who regularly follow up to get the care facilities in the Hospital were the study population, majority of the patients were in and around the districts of Kaski district of Nepal. This study was conducted in the month of May till June 2016, the study data was focused on WHO QOL dimensions, sociodemographic characteristics like age, sex, their education, marital and employment status. It also included the family and social support, their current CD4 count, selfesteem, duration of the ART services and self-care done by the participants.

#### 3.4) Sample size determination

The total patients receiving the ART in infectious department in Western Regional Hospital in Kaski district in Nepal were 810 (Tiwari, 2016) with the prevalence rate of HIV/AIDS in Kaski district 0.8%. 95% confidence level was used. The sample size calculation was derived from Yamane formula (1967)

- $N/(1+N(e^2))$
- Total people living with HIV/AIDS (N) = 810
- Confidence level (e) = 95%
- $810/(1+(810x.05^2))$
- 268

#### 3.5) Sample: technique

Patient's record file was the unit of the selection. Simple random sampling method was used to collect data. The serial number of the patients was obtained and used as the sampling frame, all the numbers was printed and was kept in the basket and simple random sampling method was used, there were 810 patients who are currently regularly receiving the ART from the care center.

Individuals who were diagnosed with HIV/AIDS, with age group of 18 years to 60 years seeking ART services for the clinical care or for the follow up, Nepalese citizens, and all the stages on ART therapy were included in this study, those who were not willing to give the consent, individuals who have been diagnosed with the mental disorders were excluded in the study.

#### 3.6) Data collection

Data collection tools:

The WHOQOL HIV BREF questionnaire was used for the study. A face-toface interview was conducted. All the patients attending the ART center and stratified by gender were the participants. It was done on a daily basis interview who turned up to the ART center for care. The WHO QOL-HIV BREF which was derived from the WHO OOL-100, have five more extra specific items and in total it have 31 items. A number of additional questionnaires were included to meet the objectives of the research. Since this Study was first to be done in Nepal to access the Quality of life among PLWHA using WHO QOL HIV BREEF, English version was translated to Nepali language with the help of the bilingual physicians and other research expertise. The translated Nepali questionnaire was reviewed by the monolingual Nepalese. Back translation to English was again done by other bilingual physicians and public health expertise. The similarity and the comfort of the questionnaire was analyzed by the statistician and senior health personal and professors from Community medicine as well as with those who had been working in the HIV/AIDS field. Any error in the translation had to go through the entire process again until maximum similarity was obtained. The final version of the questionnaire was then pretested in 30 individuals LWHA. The pretested PLWHA were excluded from the final data analyzed, for this questionnaire the Cronbach alpha was 0.85. After this this Questionnaire was used as a tool in Nepal.

#### 3.6) Data collection procedures:

Data collection was done in the quiet environment and in a separate room to maintain the participant's privacy. The interviewer introduced himself to the participants. The purpose and objectives and time interval of the interview was clearly explained to them. Before the face to face interview the consent was compulsory. Effort was made to make the participants ensure that the interview was confident, knowledgeable and comfortable. In order to get the natural and comfortable response from the participants. At the end of the interview the interviewer thanked the participants for their valuable information and time.

#### 3.7) Training of research assistances:

Meeting was held after research assistances were recruited and were trained prior to the data collection. It mainly focused on how to administer the proper face to face interview and to develop the nice and comfortable communication with the participants. A posttest was also administered to determine their applicability of the acquired skills for the interview.

#### 3.8) Calculation of domain scores of quality of life:

WHO-HIV QOL BREF had the six different domains, physical, psychological, level of independence, social relationship, spiritual/religious, environmental domains. These domains were summarized with in the different facet defining those domains of QOL. All the individual items were rated in the five point Likert scale, where 1 indicates low, negative perceptions and 5 indicates high, positive perceptions. Each facet contribute equally to the domains for the score. An item in the positive feeling facet asks "How much do you enjoy life?" and the available responses were: 1 (not at all), 2 (a little) 3 (a moderate amount), 4 (very much) and 5 (an extreme amount). For this domain and facet scores were scaled in a positive direction where higher scores denote higher quality of life. Some facets (Pain and Discomfort, Negative Feelings, Dependence on Medication, Death and Dying) were not scaled in a positive direction, meaning that for these facets higher scores do not denote higher quality of life. These need to be recoded so that high scores reflect better QOL. Items were organized by response scale (capacity, frequency, intensity or satisfaction). These domain were calculated after computing the mean of facet within each domain as given in the formula below. Negative items were scored reversed, after which they were summated according to the procedure given below. Finally scores are then multiplied by four in order to get the score between 4 and 20.

Domain1 = (pain + energy + sleep + symptom)/ 4\*4

Domain 2 = (positive feeling + cognitive + self-esteem + body image + negative feeling)/4\* 4

Domain3 = (mobility + daily activities+ medical dependence + work capacity) /4\*4Domain4 = (personal relationship + social support + sexual activity + social inclusion) /4\*4

Domain5 = (physical safety + home environment + financial resources + health and social care + opportunities for acquiring information + participation in and opportunities for recreation/ leisure activities + physical environment + transport)/8\*4 Domain6 = (forgiveness + concern about future + death + spirituality, religion) / 4\*4

All questions of WHOQOL HIV BREF are closed. FIVE-POINT Likert scale will be used, ranging from 4 to 20. The scoring will be done according to the WHOQOL-HIV BREEF, 0- <5 indicates very poor QOL, and 5- <10 indicating poor quality of life, 10-<15 shows that the person is having neither poor nor good QOL, and 15-20 score will be analyzed as very good QOL (Pedroso, Gutierrez, Duarte, Pilatti, & Picinin).

#### 3.9) Data analysis

For descriptive statistics, frequencies, percentage, mean and standard deviation were calculated. T-test and one way ANOVA were used to examine the associations between population characteristics and quality of life. Age group was grouped as 20-24, 24-29, 30- 39, 40-49 and 50- 60 years old. Independent variables were category of population characteristics categorical data and dependent variable was continuous data. One way ANOVA is used to examine the associations between each variables with each subscale of QOL. The information which was given by the patients were sorted, coded and was entered in a data sheet created in SPSS (Statistical Package for Social Sciences) version 16. Double data entry system was recheck in the values of the variables was also done during the data analysis. Socio-demographic factors (age, sex, marital status, education), social and family support, duration of ART in months were presented by frequency, percentage, mean, and standard deviation. The statistical significance was kept as p<.05.

# 3.10) Variables categorization

The categorization of the age group was adopted from Ministry of Health and Population, National center for AIDS and STD control (NCASC, 2016). Since the sample did not have the participants of less than 20 years of age group, age group 20-24 was the reference. Level of the education was categorized as none, primary, secondary, high school and university. CD4 count was categorized as less than 300 mm<sup>3</sup> more than 300 mm<sup>3</sup>, with duration of ART into less than 24 months and greater than 24 months, marital status was coded as never married, married, widowed, divorced. Participant's employment status was coded as unemployed and employed. Self-care by the individual was coded as how often they visit the hospital when they were in trouble, with once in a months, sometimes, when symptoms arises or once in a months as well as when symptoms arises. For the social and family support it was coded as with whom they felt easy to talk, or share their ideas, and with whom they could count when they needed to be consoled, it was recorded as family members, friends, relatives, and others (specify). Invitation and participating to the community was coded as yes or no.

#### **3.11) Ethical approval**

Ethical approval to conduct this study was granted by the Nepal Health Research Council, reference number 2128 on 9<sup>th</sup> June 2016. Participating in this study was optional, they were assured of confidentiality of information provided on the questionnaire. In the questionnaire the participant informant sheet that introduced the purpose of the study and what the result will be used for were well written, in addition participation in the research was voluntary and they could choose to leave the interview at any time, without needing to give any reason.

# 3.12) Expected benefit and application

The study expects to provide following benefits and application of the result and recommendations:

All the health personals, physicians, nurses, counselors, PLWHA VCT, will be aware of thinking of quality is important then the quantity of life.

The NGOS and INGOS who have been working in the HIV field will be caring for to improve the Quality of life.

PLWHA will be concerned about the ART services, and they will be keen to make them think about their quality of life.

All the ART centers in Nepal will make up a policy in developing the secured life style of the PLWHA under ART.



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# **CHAPTER IV**

# RESULT

This study was conducted from 1<sup>st</sup> May to 30<sup>th</sup> May 2016. People living with HIV/AIDS who came for the care in Infectious department of the western regional hospital was included in this study. The main purpose of the study was to assess the Quality of life among the people living with HIV/AIDS and their associated related factors. Quality of life was analyzed after the descriptive statistics of the different variables the Quality of life was analyzed after the descriptive statistics of the different variables the Quality of life was assessed according to the WHO quality of life questionnaire, the scores in the quality of life, with 10 - <15 categorizing as neither poor nor good and 15-20 scores analyzed as good quality of life. In this study there were no participants who had the good quality of life as well as who were living in poor quality of life. To show the association between the different variables with the quality of life one way ANOVA test analysis and t-test was used. The Different hypothesis was developed after analyzing the result. The  $\alpha$  level was kept at 0.05. This chapter presents the result that was analyzed by addressing the hypothesis of this research and also the research questions in this questions.

#### 4.1) Characteristics of the PLWHA

Table 1 shows the general characteristics of the people living with HIV/AIDS. Two hundred and sixty eight people living with HIV/AIDS patients in infectious department in Western regional hospital. From the two hundred and sixty-eight patients it appeared that almost half (51.9%) of them were males. The maximum and minimum age were 21 and 60 years respectively with the average age of 36 years old (SD=8.01) in this research more population of age group was 30-39 consisting of 48.1%. For the marital status of the patients more than half 58.2% of the population were married and more than two third 28.7% were single and living with their family, divorced participants were 5.6% with widowed participants of 7.5%. Less than half of the patients received primary level education with almost one fourth 23.1% of the population not receiving any education at all. From the study none participants were there who had received the university degree. For the employment, 62.7% of the patients were currently unemployed with just 37.3% of them being employed. 78.4% participants have been visiting the hospital for the ART care for more than 24 months and were receiving first line or second line of treatment whereas less than three quarter of the participants were on the first line of treatment visiting the ART care center for less than 24 months. The maximum and minimum level of the CD4 count were 150 and 872mm<sup>3</sup> respectively with 80% of the participants having their CD4 count more than 300mm<sup>3</sup>. (Table 1)

Characteristics	Participants (n=268)	Percentage
Gender		
Male	139	51.9
Female	129	48.1
Age		
20-24	9	3.4
25-29	50	18.7
30-39	129	48.1
40-49	55	20.5
50-60	25	9.3
Mean (SD)	36 (8.01)	

Table 1 General characteristics of the PLWHA

Marital Status		
Single	77	28.7
Married	156	58.2
Divorced	15	5.6
Widowed	20	7.5
Education		
Not at all	62	23.1
Primary	110	41.0
Secondary	83	31.0
Tertiary	13	4.9
Employment		
Employed	100	37.3
Unemplo yed	168	62.7
Current CD4 count		
<299	52	19.4
≥300	216	80.6
Duration of ART	CHANNER (B)	
<24 Months	58	21.6
≥24 Months	210	78.4

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# 4.2) Social and family support

Social and family support are the different variables but in this study they are assessed as the single variables. It is defined as the support they get from the family members, friends to help them to cope with the psychological determinants of health by listening their feelings, consoling them and being there and suggesting them whenever they needed. Inviting and participating in the community organized program was used to describe that there is no discrimination towards the people living with HIV/AIDS. Almost all (86.2%) the participants talked about their feeling or

share their ideas with their family and none of them wanted to talk about their feelings with their relatives. In case when they were in trouble or upset also family members were the first choice to console for 77.6% while 12.7% shared with the doctors in the care provide center while visiting the doctors during the follow up care services, out of which 18.3% consoled every months 12.7% of them consoled with the doctors while visiting to the hospital. More than two third 38.8% of them able to get consoled all the time when they were in need. In which 37.3% of the people living with HIV/AIDS were never been consoled. (Table 2). The question was asked during the past 2 weeks in the community organized programs whether they were invited and whether they participated or not, more than half 51.5% of the patients were invited to attend the program in which just 69% of them did not participated in any community programs (Table 2).

Characteristics	Participants (n=268)	Percentage
Patients choice to listen	ลงกรณ์มหาวิทยาลัย	
Family members	LONGKOR 231 WERSITY	86.2
Friends	37	13.8
Patients choice to console		
Family members	208	77.6
friends	26	13.8
Others (doctors)	34	12.7
Numbers of times to be con	sole	
All the time when needed	104	38.8
Once a month	49	18.3
Once a week	15	5.6
Never	100	37.3

Table 2 Social	and	family	support	of the	PLWHA

Invited in communit	y program			
	Yes	138	51.5	
	No	130	48.5	
Participated in com	Participated in community program			
Yes		83	31.0	
No		185	69.0	

### 4.3) Self-care

For the self-care by the patient him/her-self, it was assessed by the number of the times they visit the hospital for their care or for follow up. There was the facilities in the hospital that the health personnel calls the patients for the ART services, despite of which there were still few 3.8% people living with HIV/AIDS who visited the hospital sometimes when they wanted to meet or when they were really in need to visit the doctor. There also significant large number 45.5% of the patients who visited the hospital once in every months for their ART care services while one third 38.8% of the people living with HIV/AIDS visited the hospital once in every months as well as when there was any other health related symptoms or HIV/AIDS induced symptoms to the hospital (Table 3).

Characteristics	Participants (n=268)	Percentage
Self-Care		
Once every one month	122	45.5
When symptoms arises	32	11.9
Sometimes	10	3.8
Once Every months and when symptoms arises	104	38.8

#### Table 3 Self-Care by the patient

# 4.4) Self-esteem

Rosenberg self-esteem scale was used to analyze the self-esteem of all the participants living with HIV/AIDS under ART in Kaski district in Nepal. It is the self-respect towards oneself, it reflects the individual's subjective evaluation of his/her own worth's. In our research study none of the participants were the poor or very poor self-esteem scores. From the literature review a hypothesis was developed that there is an association between the self-esteem and quality of life among the people living with HIV/AIDS under ART. All the participants completed the given questionnaires, after analysis in SPSS more than half 53.7% of the patients had the strong positive attitude towards themselves with 46.7% of the participants having the good self-esteem scores (Table 4).

# Table 4 Self-esteem of the patient

Characteristics	Participants (n=268)	Percentage
Self-esteem		
Good	124	46.3
Very good	144	53.7

#### 4.5) Factors related to the Quality of life among PLWHA

#### WHO-HIV QOL BREF in PLWHA

Many advance clinical trials as well as advanced treatment for HIV/AIDS, the survival rate of the people living with HIV/AIDS have increased and their quality of life have been an important concern to all the medical personnel as well as the researchers. This present WHO-HIV QOL BREF module was formed with 6 different domains after the series of edition, the first was questionnaires which contained hundred questions, which was revised to short form to assess the HIV/AIDS QOL.

According to WHO there are six different domains which sum up to form the quality of life as a whole. Different questions were asked in order to know about the Physical, psychological, level of independence, social relationship, environment, spirituality/religion domain which sum up to make a quality if life. All the participants completed all the questionnaire that were in the WHO QOL HIV BREF.

Table 5 highlights about the distribution of the quality of life of all the participants who participated in the research. From the table it indicates that more than two third 75.8% of the participants reported to be living in neither poor nor good quality of life, nor nearly 10% of PLWHA still are having the poor quality of life, out of all less than one fifth of the participants were having good quality of life.

Characteristics	Participants (n=268)	Percentage
Quality of life		
Poor	26	9.7
Neither poor nor good	203	75.8
Good	39	14.5

#### Table 5 Quality of life

#### 4.6) Factors affecting quality of life among PLWHA

1) Socio-demographic factors affects the quality of life among the people living with HIV/AIDS under ART in Kaski district in Nepal.

Association between General characteristics of PLWHA with Quality of life. To find out the association between socio-demographic factors and quality of life ttest and one way ANOVA were used and 95% of Confidence Interval was applied. When a significant association was found by using one way ANOVA, Tukey post hoc test is done to find between which groups of population characteristics there is a significant difference. The results are shown in Table 6 and table 7.

From the t-test (p-value 0.41) there was no association between the gender and the quality of life among people living with HIV/AIDS under ART. There were 51.9% of males in this study, while comparing the quality of life among these two groups 66.7% and 33.3% of males and females respectively were having the good quality of life. There was no significant difference in males and females who were living in neither good nor poor quality of life (Table 6). There were high number of the males 61.5% of them were living in poor quality of life where as just 38.5% of the females were having the poor quality of life.

From the study there was no any association between the ages of the patients with the quality of life of people living with HIV/AIDS under ART, one way ANOVA was used to analyze the result with p-value 0.215. Looking at the quality of life, there were none participants who were having very poor quality of life as well as having very good quality of life. if compared in the different age group for the good quality of life just 2.6% of the participants who were of age group 20-24 were having the good quality of life with 30-39 age group of 51.3% were living in the good quality of life. For poor quality of life age maximum number of participants are age grouped 30-39 were having poor QOL, with none participants with age 50-60 with poor QOL. There were 9.4% of the participants age group 50-60 having neither poor nor good quality of life, with 18.2% of age group 25-30 having the same result (Table 6). Likewise for the association between marital status and quality of life, one way ANOVA was used and from the result there was an association between the marital status and the QOL in PLWHA (p-value 0.007). After using the Tukey post hoc test it

was analyzed that there is the significant difference in quality of life between the married participants to the divorced and from the single participants with divorced (Table7). 19.2% of the participants who were divorced were having the poor quality of life. More than one fourth of the participant who were single were living in neither good nor poor quality of life like-wise if looked only in the neither poor nor good quality of life more than half of the participants were living in the neutral QOL. From the literature review it was found that people who were married would have good quality of life then to the people who were single or divorced. In this study there were more than four fifth of the participants who were single were living in good quality of life with 28.7% of the participants who were single were living in good quality of life (Table 6). From the result it can be conclude that marital status have a positive relationship with the quality of life.

A relationship was between employment and quality of life among people living with HIV/AIDS. To support this t-test analysis was used with p-value 0.009. From the data analysis it showed that people who were employment were having the better quality of life then to those who were unemployed. Participants who were having poor quality of life more than two third 73% of those who were unemployed were having the poor quality of life. more than half of the participants who were employed were having the good quality of life with more than one third of the participants 37% of the participants were having neither good nor poor quality of life and 65.6% of the participants who were unemployed were living with neutral quality of life Table 6.

All the participants who were in this study, there was no any relationship between the education and QOL in people living in HIV/AIDS p-value 0.096. If

looking at scores in the good quality of life, almost half of the participants who had achieved the secondary education were having the good QOL, with 20.5% of those who did not had received any education responded of having good quality of life. Almost 40% of the participants who had no education background responded in having the poor quality of life with more than one quarter of them having poor quality of life. From this result it can be interpreted that greater education had an association of improved quality of life (Table 6).

To show the association between the duration of ART and quality of life t- test was used and it showed that there is an association between the duration of ART and quality of life by using t-test (p-value 0.018). In poor quality of life more than half 53.2% of the participants who were on antiretroviral therapy for more than 24 months responded of having the poor quality of life. If compared in the neutral quality of life, One fifth 19.2% of the patients who were visiting the care center for less than 24 months had the neither poor nor good QOL with more than 80% of the patients receiving ART for more than 24 months had neither good nor poor quality of life. Comparing in the good quality of life among the people receiving the ART for less than or more than twenty four months 17.9% and 82.1% respectively were having the good quality of life (Table 6). From which it can be conclude that longer the duration of ART will decrease the chance of having the poor quality of life.

CD4 count was kept as the cutoff point of 300 mm<sup>3</sup> as in ART care center in Kaski district in Nepal those who had the CD4 count less than 300 were likely to have opportunistic infections and other health related symptoms like loose motions, fever, and even there was the high prevalence of tuberculosis infections so special care were given to them. There was an association between the CD4 count and the quality of life among the people living with HIV/AIDS under ART in Kaski district in Nepal t-test (p-value 0.040). More than 50% of the participants who had more than 300 mm<sup>3</sup> CD4 count were having the poor quality of life. For living in neither good nor poor quality of life more than three quarter of the participants 83.3% of them who had CD4 count more than 300 mm<sup>3</sup> responded, with less than one fifth of the participants responding of having neutral QOL. Likewise in the good quality of life 82.1% and 17.9% of the participants with CD4 count more than 300 mm<sup>3</sup> and less than 300 mm<sup>3</sup> responded of having the good quality of life. From the result it showed that there were significant more number of the people living with HIV/AIDS who had CD4 count more than 300 mm<sup>3</sup> were living in neither good nor bad and good quality of life (Table 6).

Table 6 Association of socio-demographic	characteristic	of PLWHA	and QOL

	1	Qu	ality of Life			
Characteristics	Poor N (%)	Neither poor nor good	Good N (%)	t-value or	e p-value	
		N (%)		f-value		
Gender	<b>0</b>		9 18 9			
Male	16(61.5%)	97 (47.8%)	26(66.7%)	9.472	*0.41	
Female	10(38.5%)	106 (52.2%)	13(33.3%)			
Age						
20-24	1 (3.8%)	7 (3.4%)	1(2.6%)	1.460	**0.215	
25-29	6 (23.1%)	37 (18.2%)	7(17.8%)			
30-39	12(46.2%)	97 (47.8%)	20(51.3%)			
40-49	7(26.9%)	43 (21.2%)	5(12.8%)			
50-60	0 (0)	19 (9.4%)	6(15.4%)			
Marital Status						
Never Married	9 (34.9%)	58(28.6%)	10(25.6%)	4.154	**0.007	
Married	11(42.3%)	117(57.6%)	28(71.8%)			

Divorced	5(19.2%)	10(4.9%)	0(0)		
Widowed	1(3.8%)	18(8.9)	1(2.6%)		
Education					
None	10(38.5%)	44(21.7%)	8(20.5%)	2.13	**0.096
Primary	6(23.1%)	92(45.3%)	12(30.8%)		
Secondary	7(26.9%)	58(28.6%)	18(46.2%)		
Tertiary	3(11.5%)	9(4.9%)	1(2.6%)		
Employment					
Employed	7 (26.9%)	71(35.0%)	22(56.4%)	2.640	*0.002
Unemployed	19(73.1%)	132(65.6%)	17(43.6%)		
CD4 count		SUNI (1)			
0-299	11(42.3%)	34(16.7%)	7(17.9%)	2.064	*0.040
≥300	15(57.7%)	169(83.3%)	32(82.1%)		
Duration of	f ART				
0-24 Months	12(46.2%)	39(19.2%)	7(17.9%)	2.381	*0.018
$\geq$ 24 Months	14(53.8%)	164(80.8%)	32(82.1%)		

\*p-value from t-test analysis \*\* p-value from one way ANOVA analysis

# Table 7 Tukey post hoc test for marital status

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Quality of Life
Tukey HSD

(I) Marital	(J) Marital			95% Confidence Interval		
Status	Status	Std. Error	Sig.	Lower Bound	Upper Bound	
Single	Married	.06720	.483	2697	.0778	
	Divorced	.13618	.056	0058	.6984	
	Widowed	.12110	1.000	3001	.3261	
Married	Single	.06720	.483	0778	.2697	
	Divorced	.13044	.004	.1051	.7796	
	Widowed	.11460	.777	1873	.4053	

# 2) Self-care and quality of life.

One way ANOVA test analysis was used to examine the hypothesis that patient's self-care had an association to their quality of life, and it showed that there is a relationship between the patients taking care of themselves with their quality of life p-value <0.001. Tukey post hoc test showed that there is the significant difference in the quality of life between those participants who visited the hospital once in every months to those who visit hospital only when the symptoms arises (Table 9). More than half of the people who visited the care center once in every months were living in the good quality of life. There were still more than half of the patients who were having poor quality of life since they visited the hospital only when they had the health related problems. Less than 3% of the people living with HIV/AIDS who visited hospital sometimes were having the good quality of life (Table 8).

Table 8 Self-care of the PLWHA and its association with Q	JL
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	43	Q	uality of Life		
Characteristics	Poor N (%)	Neither poor nor good N (%)	Good N (%)	t-value or f-value	p-value
Self-care					
Once every month	3(11.5%)	99(48.7)	20(51.3%)	10.410	**<0.001
When symptoms arises	14(53.8)	16(7.8%)	2(5.2%)		
Sometimes	0(0)	9(4.4%)	1(2.5%)		
Once every months and when symptoms	9(34.6%)	79(38.9%)	16(41.0%)		
arises					

\*\*p-value from one way ANOVA test analysis

#### Table 9 Tukey post hoc test for self-care

Quality of Life

Tukey HSD						
	Mean			95% Confide	ence Interval	
(I) Visit to Hospital	(J) Visit to Hospital	Difference	Std.		Lower	Upper
after ART	after ART	(I-J)	Error	Sig.	Bound	Bound
When Symptoms arises	Once every One Months	51434 <sup>*</sup>	.09274	.000	7541	2746
	Sometimes	47500 <sup>*</sup>	.16916	.027	9124	0376
	Once Every months and when symptoms arrises	44231 <sup>*</sup>	.09439	.000	6864	1983

\* The mean difference is significant at the 0.05 level.

#### 3) Family and social support and Quality of life

From the literature review a hypothesis was developed that there was an association between social and family support to the quality of life in people living with HIV/AIDS under antiretroviral therapy in Kaski district in Nepal. The relationship among the family support was analyzed by the various different questionnaire to the PLWHA. Those questionnaire were mainly focused in the comfort ability of the patients to share their ideas, feelings with whom they were able to share those ideas and feelings, as well as the number of times they were been consoled. The questionnaire which analyzed for the participants choice to share their feelings and being invited in the community organized program as well as participating in those programs were analyzed by the help of t-test. The participant's choice to console with and the number of times they being consoled were analyzed by the help of one way ANOVA.

#### Patient's choice to listen

There was an association between the patients choice to be listened when they were really in trouble or when they wanted to share their feelings with the quality of life with P-value <0.001 (Table 10). In poor quality of life 65.5% of the participants who chose their friends to share their ideas had the poor quality of life with just 38.5% of them who chose their family to listen to responded of having the poor QOL. Likewise for those who responded of having neither good nor poor quality of life 93.1% of them share living in neutral quality of life. Even for the good quality of life more than three forth 82.1% the respondents who chose to their family members had the good quality of life (Table 10). From which it can be concluded that people living with HIV/AIDS who consoled with family members had the greater chance of living in good quality of life.

#### Patient's choice to be console:

One way ANOVA was used to find the association between the patients choice to be consoled with the quality of life p-value <0.001. Tukey post hoc test showed that there is an association between those participants who were consoled all the time when they were in need with those who were never been consoled with. In the poor quality of life there were no ay participants who console with doctors with just 11.5% of them having poor quality of live who chose to console with their friends (Table 10). Individuals who responded for having neither good nor poor quality of life, there were much participants 80.3% who responded of having neutral QOL who chose their family members to be consoled with. 30.8% of the participants who chose doctors to be consoled with had the good quality of life with just 12.8% of the participants who consoled with friends had the good quality of life (Table 10).

#### Number of time to be console:

There was an association between number of times to be consoled with the quality of life p-value <0.001. Tukey post hoc test result indicated that there is the significant difference in the quality of life between those participants who were consoled all the time when they were in need to those who were never been consoled (Table 11). With 80.8% of the participants having the poor quality of life who were never been consoled. In good quality of life participants 33.3% and 30.8% who were consoled all the time and once a week were having the good quality of life with just 23.1% of them who were never been consoled (Table 10).

#### Invited and participants in community program:

From the literature review, being invited and participating in the community program is associated with the quality of life among people living with HIV/AIDS. T- test was used to analyze the association between the participants being invited to the community organized program and being participating and there was an association between being invited and participating in those program p-value 0.038 and 0.032 respectively.

For those who were invited in the community program, 73.15 of the participants who were not invited in the community organized program said that they had the poor quality of life with just 26.9% of the respondents who were invited in community program having poor QOL. For the respondents who said of having good quality of life, more than half 56.4% of the participants who were being invited in the community organized program were having the better quality of life then compared to those who have not been invited. For to participate in the program, those who were having poor quality of life, just 7.7% of the individuals who participated in those

program had the poor quality with 92.3% of them who didn't having the poor quality of life. Likewise for those responding the good quality of life 35.95 of them were having the good quality of life who participated in the community organized program (Table 10). It can be concluded that family and social support had an association with the good quality of life, it may be due to the psychological support thy get from the family and from the society.

	Quality of Life						
Chamatariation	Poor	Neither poor	Good	t-value	p-value		
Characteristics	N (%)	nor good	N (%)	or			
		N (%)		f-value			
Patients choice t	o listen		1				
Family member	10(38.5%)	189(93.1%)	32(82.1%)	4.001	*<0.001		
Friends	16(61.5%)	14(6.9%)	7(17.9%)				
Patients choice	to console		10				
Family member	23(11.1%)	163(80.3%)	22(56.4%)	8.228	**<0.001		
Friends	3(11.50%)	18(8.9%)	5(12.8%)				
Others(doctors)	0(0)	22(10.8%)	12(30.8%)				
Number of time	to be consol	e					
Al the time	5(19.2%)	86(42.4%)	13(33.3%)	19.212	**<0.001		
when							
Once a month	0(0)	44(21.7%)	5(12.8%)				
Once a week	0(0)	3(1.5%)	12(30.8%)				
Never	21(80.8%)	70(34.5%)	9(9.23%)				
Invited to comm	unity progra	m					
Yes	7(26.9%)	109(53.7%)	22(56.4%)	2.080	*0.038		
No	19(73.1%)	94(46.3%)	17(43.6%)				

Table 10 Association between social and family support and QOL

Participated in c	community p	rogram			
Yes	2(7.7%)	67(33.3%)	14(35.9%)	2.16	*0.032
No	4(92.3%)	136(66.7%)	25(64.1%)		

\*p-value from t-test analysis \*\* p-value from one way ANOVA analysis

#### Table 11 Tukey post hoc test for patients choice to console

Quality of Life

Tukey HSD	
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(I) Patients	(J) Patients				95% Confidence Interval	
Choice to	Choice to	Mean Difference				
Console	Console	(I-J)	Std. Error	Sig.	Lower Bound	Upper Bound
Family Members	Friends	08173	.09948	.690	3162	.1527
	Others(doctors)	35775 <sup>*</sup>	.08847	.000	5663	1492

\*. The mean difference is significant at the 0.05 level.

#### 4) Self-esteem and quality of life

T-test analysis test was used to examine the relationship between the selfesteem and quality of life, there was no relationship was established between the selfesteem and quality of life among the people living with HIV/AIDS p-value 0.038. The result was interpreted as the Rosenberg self-esteem scale, all the participants completed the questionnaires. There were no participants living with HIV/AIDS who were having poor or very poor self-esteem score. The result indicates that poor quality of life was associated with good self-esteem as 69.2% of them were having good esteem had a poor quality of life, and half of them who were having very good selfesteem were having poor quality of life. There was not much significant difference in the people who were having good or very good quality of life for having the good quality of life. To address the objective a hypothesis was developed that there is an association between quality of life and self-esteem (Table 12).

	Quality of Life					
	Poor	Neither poor	Good	t-value	p-value	
Characteristics	N (%)	nor good	N (%)	or		
		N (%)		f-value		
Self-esteem						
Good	1869.2%	87(42.9%)	19(48.7%)	1.757	*0.080	
Very good	8(30.8%)	116(57.1%)	20(51.3%)			

Table 12 Association between Self-esteem and QOL

\*p-value from t-test analysis

#### Quality of life and the domains of the quality of life

WHO QOL HIV BREF consisted with the 31 questions and these all the questions were described by the physical, psychological, level of independence, social relationship, environment, spirituality/religion domains which sum up to make the quality of life as a whole. Table 14 shows the relationship between the domains of the quality life with the self-care, marital status, self-esteem, age, gender, education, employment, duration of ART and CD4 count. To show the relationship between gender, employment, duration of ART, CD4 count and self-esteem t-test analysis was used. For the education, marital status, education and self-care one way ANOVA was used to show the relationship between the each domain of the quality of life.

### Physical domain of quality of life

Physical domain of the quality of life was calculated by physical pain and discomfort that the participants felt, their feeling of energy and fatigue after certain

work, sleep and rest and extend to which patient is disturbed in doing in his day to day activities. Questions 3, 4, 14, 21 were asked to analyze the physical domain of quality of life. All the participants completed the question. The transformed score of the physical domain of life of PLWHA in Kaski district in Nepal was 10.62, which was analyzed as neither good nor poor quality of life in physical domain (table 13). From the table 14, one way ANOVA test was used to show the association between the physical domain of quality of life and the marital status and education status of the participants, p-value 0.04 and 0.023. There was also association between the gender and the physical domain of the quality of life, t-test was used for the association between the gender, employment status with physical domain of quality of life p-value 0.030 and 0.042 respectively. From the analysis there was no any association in between the physical domain of the quality of life with the self-care, self-esteem and current CD4 count of the participants.

#### Psychological domain of quality of life

Psychological domain was calculated with five different subjective feelings of **Characteristic** the participants towards the stigma or the discrimination they felt, whether they had negative feelings or not, their fear towards other in the society or in the family members, after their infections if they are feeling loss of dignity or not, with how they were able to concentrate in their work. It was analyzed by the questions 6, 11,15,24,31. All the patient completed the questionnaire to assess the psychological domain of quality of life. From the result it was found that the participants were having the least score if compared with all other domains for their psychological domain of quality of life with transformed score of 9.42 indicating the poor quality of life. (Table 13).

One way ANOVA was used to show the association between the

psychological domain of the quality of life with education, age, marital status, and self-care of the participants, and t-test was used to analyze the association between the duration of ART, gender, current CD4 count, employment and self-esteem of the patients with the psychological domain of the QOL. There was an association between the gender (p-value 0.010) and CD4 count (p-value 0.049) with the psychological domain of the quality of life but no association between the employment, age, education, duration of ART, self-esteem and marital status with the psychological domain of the QOL (Table 14).

#### Level of independence domain of the quality of life

The support that the patient need to do their daily day to day activities. Their mobility, daily living activities, medicine or treatment dependence and the participants work capacity were the factors which describes the level of independence of the individual in WHO-HIV/QOL BREF. From the result analysis it was found that level of independence was neither good nor poor with the transformed score of 11.63 (SD 11.309) suggesting the neither good nor poor quality of life (Table 13).

There was an association between employment (p-value 0.032), education (0.048), duration of ART (p-value 0.023) and CD4 count (0.013) with the level of independence domain of the quality of life. No association was found between the gender, age, self-care and self-esteem with the level of independence domain of QOL (Table 14).

#### Social relationship domain of quality of life

There were four different questionnaires which was used to develop the social relationship of the people living with HIV/AIDS. From the tool to assess their quality of life questions 5,20,22,23 was used to describe this domain. Social relationship domain was assessed by how they relate themselves with the people around them, their greeting or the support they got, and their ability to perform the sexual activities. The transformed score of all the participants after calculating from the WHO QOL guidelines was 10.72 (S.D 1.49) indicating they were too having neither poor nor good quality of life (Table 13).

From table 14, it showed that there is an association between the self-esteem (p-value 0.042), employment (p-value 0.032) and education (p-value 0.025) to the social relationship domain of the quality of life. There was no association between gender, age, self-esteem, self-care, marital status and current CD4 count with the social relationship domain of quality of life.

# Environmental domain of quality of life

For to have the quality of life environmental factors also plays a role. It was analyzed as how the environment was playing a key role in the well-being of the participants, it was measured by the financial resources that the patients had, their social and health support with their subjective feelings of the physical safety and security, with their chance to get the new skills and information. For this domain questions 12, 13,16,18,19,28,29,30 from the tools described the environmental domain as a whole. None of the participants missed a single questions for this

questionnaire. The transformed score of this domain 11.64 (SD 1.49) indicating neither good nor poor quality of life. (Table 13).

There was an association between the self-care (p-value <0.001, marital status (p-value <0.001), duration of ART (p-value 0.027), education (p-value 0.014), age (p-value 0.019), employment (p-value 0.031) with the environmental domain of the QOL. No association was between the gender, CD4 count, self-care and self-esteem to the environmental domain of quality of life (Table 14).

#### Spirituality/religion domain of quality of life

Spirituality/religion domain describes how the individuals living with HIV/AIDS belief in themselves and also how they value their goal of life, it mainly focuses in the forgiveness and the blame to oneself or to the others, and whether they are concern with their future or not on death. Different questions 7, 8,9,10 were used to sum up this spirituality/religious domain of quality of life in the tools. All the participants who participated in the research had neither good nor poor quality of life with transformed score from the raw score showing neither good nor poor quality of life 11.29 (Table 13).

From table 14, there was a relationship between age, education and CD4 count with spiritual religion and personal belief domain of the QOL, p-value 0.037, 0.019, 0.021 respectively. There was no any relationship between the self-esteem, gender, employment, duration of ART and self-care with the spiritual religion and personal belief domain of QOL (Table 14).

Domains	Transformed score	
Physical	10.62	
Psychological	9.42	
Level of independence	11.63	
Social relationship	10.73	
Environment	11.64	
Spiritual religion/personal belief	11.29	

# Table 13 Transformed scores of each domains of QOL

Table 14 Association between the domains of QOL with general characteristics

Domain	**Self-care		**Marital Status		*Self-esteem	
	t-value/ f-value	p-value	t-value/ f-value	p-value	t-value/ f-value	p-value
Physical	0.187	0.901	2.68	0.04	1.398	0.582
Psychological	1.03	0.333	2.90	0.43	1.520	0.129
Level of	2.26	0.081	5.95	< 0.001	3.796	0.052
independence						
Social	1.78	0.40	1.45	0.71	2.452	0.042
relationship						
Environmental	9.66	< 0.001	9.66	< 0.001	1.851	0.320
Spiritual religion	2.15	0.094	1.58	0.20	1.240	0.231
and personal belief						

\*t-test analysis used \*\* one way ANOVA analysis used

Table 14. cont.

Domain	*Gender		*Employment		**Age	
	t-value/ f-value	p-value	t-value/ f-value	p-value	t-value/ f-value	p-value
Physical	1.72	0.030	3.320	0.042	2.774	0.043
Psychological	2.690	0.017	0.170	0.363	1.698	0.151
Levelof	1.208	0.648	2.083	0.032	1.517	0.97
independence						
Social	1.018	0.895	1.148	0.025	1.689	0.530
relationship						
Environmental	1.170	0.681	1.524	0.031	1.538	0.019
Spiritual	1.080	0.778	1.353	0.246	2.760	0.037
religion and			12			
personal belief	ų.					

\*t-test analysis used \*\* one way ANOVA analysis used

Table	14.	cont.
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Domain	**Education		*Duration of ART		*CD4 count	
	t-value/ f-value	p-value	t-value/ f-value	p-value	t-value/ f-value	p-value
Physical	1.115	0.023	1.602	0.048	2.431	0.051
Psychological	0.411	0.745	1.47	0.328	2.994	0.049
Levelof	2.242	0.048	1.412	0.023	2.693	0.013
independence						
Social	1.359	0.025	1.709	0.381	1.520	0.021
relationship						
Environmental		0.0146	1.090	0.029	1.034	0.855
Spiritual	1.840	0.019	1.128	0.721	1.078	0.087
religion and						
personal belief	stasta		7 4 1 1			

\*t-test analysis used \*\* one way ANOVA analysis used

# **CHAPTER V**

# DISCUSSION, CONCLUSION, LIMITATION AND RECOMMENDATION

This is the first study done among the People Living with HIV/AIDS under Antiretroviral Therapy to assess their quality of life in Kaski District in Nepal using WHO QOL HIV BREF questionnaire. The preliminary concern of this chapter was to discuss about the findings and the factors which have the association with the quality of life among the people living with HIV/AIDS as well as relate our result with the other research results.

#### 5.1) Discussion

Association of General characteristic of PLWHA with QOL

#### 1) Gender and Quality of life of PLWHA under ART

In this research, almost half of the participants were females 48.1%. From the study it was found that there was no association between the gender and Quality of life, but there was an association between the physical and psychological domain of the QOL. From one way ANOVA result it showed that females demonstrated the better quality of life than males. There were less number of the females who were having the poor quality of life and more of them were having neither good nor poor quality of life in compared to the males. It may be due to the fact that females do the daily house hold works and they don't practice the health enhancing behaviors like alcohol, smoking. For the psychological domain of quality of life females are most likely to be affected due to the fact that females are stigmatized more than men for

having HIV/AIDS, lack family and social support, and still in a low income country like Nepal females are regarded as a passive partner from social and economic point of view. Previous studies have shown that women with HIV/AIDS report poorer QOL than men (Nirmal, Divya, Dorairaj, & Venkateswaran, 2008) Men and women are often not dealt with in the same way when infected or believed to be infected by HIV: a woman is more likely to be blamed even when the source of her infection is her husband, and are mostly affected infected women may be less likely to be accepted by their communities similar to the study done in the South India (Chandra, Satyanarayana, Satishchandra, Satish, & Kumar, 2009) and (Pereira & Canavarro, 2011). These studies highlighted that females living with HIV/AIDS had the low Quality of life than males.

However the study done in India (Kohli, Sane, Kumar, Paranjape, & Mehendale, 2005) showed the same findings despite of having less advance disease state. A study showed that better mental health and quality of life was found among the females who had the strong social and family support then to those who didn't (Gielen, McDonnell, Wu, O'campo, & Faden, 2001). By looking in the study contest there are lots of Nepal woman whose problems stem directly from inequality and underdevelopment (Aguirre & Pietropaoli, 2008). Even in the high income countries there are still internal stigma towards the HIV/AIDS, and more experienced by the females (Aguirre & Pietropaoli, 2008), In the low income countries like Nepal although there had been tremendous effects from the NGOS and INGOS to minimize the stigmatization but also due to the cultural aspect and less adequate knowledge to the HIV/AIDS (Mahat & Scoloveno, 2006) still there is discrimination towards the people living with HIV/AIDS (P. Poudel & Carryer, 2000), and the case is wore worse in the female population. This strong social contest of Nepal also helps to explain why females with HIV/AIDS under ART in Kaski district are having the poor quality of life than males.

#### 2) Marital status and Quality of life of PLWHA under ART

More than half of the participants in this study were married. This figure makes us concentrate in the effect of the marital status with spread of HIV/AIDS in Nepal where polygamy is usually practiced, there are many male population who are migrant worker abroad. Most of the female participants were infected with HIV/AIDS by having the sexual relationship with the males, leading to the increase in the prevalence in the HIV/AIDS.

Marital status plays a role in improving the quality of life. From the table 6 it showed that those participants who were divorced were living in the poor quality of life, and there was a significant difference in the quality of life among the single and divorced as well as in between married and divorced. It can be that single and divorced people who are infected with HIV/AIDS had to do all their works by themselves, and they are more likely to be depressed then those who are married and more over in a low income countries like Nepal there is still discrimination and stigma towards the HIV/AIDS, more common in those people who were single or widowed. Similar on the other studies done among HIV infected participants, they all highlighted that marital status had a significant association with their Quality of life (Fan, Kuo, Kao, Morisky, & Chen, 2011), (Subramanian, Gupte, Dorairaj, Periannan, & Mathai, 2009) (Zimpel & Fleck, 2007). There was an association between the physical, level of independence, environmental domain of the QOL. The

environment, accessibility to health and social care, freedom, security, participation, and opportunities for leisure activities on the QOL. Those participants who were married had the better social relationship and environmental domain of QOL. It may be that they may enjoy better social support, and additional stability and support, and they can only disclose their serostatus to one person i.e. their partner, thus alleviating some of the anxiety felt while revealing HIV-positive status. Likewise for low scores for single, divorced, widowed participants might be explained by having the stigma and discrimination towards them. There have been few studies done in Nepal to show the association of the marriage, the multiple sex partners, migrant population to the spread of the HIV/AIDS in Nepal, and they all have supported that multiple sex partners significantly increased the incidence of the HIV/AIDS, also highlights that migrant population engage in the risky sexual behavior (K. C. Poudel et al., 2003; Puri & Cleland, 2006), (Puri & Cleland, 2006), (K. C. Poudel, Jimba, Okumura, Joshi, & Wakai, 2004). There was an association

#### 3) Education and Quality of life among PLWHA

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From the study it showed that there was no any association between the education and quality of life. More individuals who had the better education were living in the good quality of life. There was an association between the education with the physical, level of independence, social relationship, environmental and spiritual religion and personal belief domain of QOL. Education helps the individual to know about the risk factors, and some knowledge about their disease state too, educated people are more likely to be employed as a result of which they are dependent upon themselves. They try to make themselves fit by doing regularly exercise, as well as by taking proper balanced diet and they have a less chance of practicing the risky health

seeking behavior. They knows about the disease better leading to the between coping attitude. They are also likely to interact with in the society which will help them to cope with the stigma. With the better education improves the people's standard of living. Other studies done to assess the quality of life also showed that there was a positive relationship between these two variables. They all highlighted that education had the positive impact in the quality of life and with the increased education, there is decreased in stigma and discrimination as a result of which there is the increased access to the health care facilities ultimately improving the quality of life. (Yang, Thai, & Choi, 2016), (Kumar, Girish, Nawaz, Balu, & Kumar, 2014), (Nojomi, Anbary, & Ranjbar, 2008) and (Monteiro, Canavarro, & Pereira, 2016).

# 4) Employment and Quality of life among PLWHA under ART

Although more participants were unemployed in this study. From this study there was an association between physical, psychological, level of independence, level of independence, and environmental domain of quality of life. Employed participants were living in the better quality of life then the unemployed participants, it may be due to individuals who were employed had the better financial support with which they can get the proper balance diet as well as get the proper health facilities, also they don't want to be unemployed so they try to make themselves fit for the work by doing regular exercise, proper diet, not only that they get the social support from the environment they work, employed people may act as the role model among the PLWHA as a result of which they have a better self-esteem, may be cause of this employment have a positive relationship with the better quality of life (Rueda et al., 2011) It can be explained that employed On the contrary to which unemployment may lead to the depression, anxiety and low self-esteem as well as less social support as a result of which poor quality in their way of living. Monteirro et al as well as other studies highlighted that employment participants received the greater social acceptance and as a result of which helping them with their increase in quality of life (Blalock, Mcdaniel, & Farber, 2002), (Mafirakureva, Dzingirai, Postma, van Hulst, & Khoza, 2016) (Monteiro et al., 2016).

#### 5) Duration of ART, CD4 Count and Quality of life among PLWHA

In general ART is capable of improving the survival, reducing the occurrence of the HIV - related opportunistic infection and reducing the viral load in the body of the PLWHA. There was an association of the current cd4 count with the physical, psychological, level of independence and social relationship domain of quality of life. From our study those participants who were having CD4 count more than 300 mm<sup>3</sup> had the better quality of life. Those participants who were having CD4 count less than 300mm<sup>3</sup> were living in the poor quality of life. The reason may be cause they have the low viral load in their body as a result of which the chance of getting the opportunistic infection is decreased, increase in CD4 count mean living in a near normal life people, as a result of which their immune power is increased ultimately decreasing in getting infected by common disease problems, these findings were similar to the study in Uganda and other studies which showed that there is an association in the CD4 count more than 300 mm<sup>3</sup> and the mental health and ultimately to the better quality of life (Bajunirwe et al., 2009) (Bing et al., 2000) (Weinfurt, Willke, Glick, Freimuth, & Schulman, 2000). It may be because CD4 count are the better predictor of the disease progression compared to the other causes, and it has the differential impact on the progression of the disease and the QOL of the individual at the various stages of the diseases. From the study all the participants were under ART and were enrolled in

different categories according to the duration of ART, the cutoff point was 24 months. Those participants who had been receiving the ART services for more than 24 months had the better physical, social relationship, environmental domains of QOL then to those who were under ART less than 24 months, and these findings were also almost similar to the other studies done (Mannheimer et al., 2005), (Chandra et al., 2006) it may be due to the better understanding of the disease, decrease in the stigma towards the disease and by the long term effect of the ART helping them to decrease the viral load in their body with the progression of the time.

#### 6) Social and family support and Quality of life among PLWHA.

Support from the family and community members is absolute it could be a fact that PLWHA may be socialized to expect support from their family members and their friends, in our research family members were giving them the support and willing to listen to them when needed. HIV/AIDS is a disease which affects physical, psychological factor the most. Studies showed that people having social and family support have increased the CD4 count, motivating the people to change their risky health behavior, and ultimately increasing their quality of life. To participate in the community based program were invited to more than half of the participants but less than two third of the participants only attended to these program (Table 2), it may be due to the stigma and fear of discrimination. Those who participated in the community program had the overall better QOL than those who didn't not (Table 7). It may be due to the psychological support they get and help in achieving change in the poor health risk factors like cessation in smoking, drinking. They may also facilitate the physical activity and improving the depressive symptoms. These findings were also supported by other studies where they all highlighted that social and family support helps in improving the domains of the quality of life except for the physical domain of WHO –QOL (Smith & Rapkin, 1996), (McDowell & Serovich, 2007), (Kabore et al., 2010), (Power et al., 2003).

#### 7) Self-esteem and Quality of life among PLWHA

Self-esteem refers to the how one values themselves it is how one perceive their value to the world and how valuable they think they are to other. Positive selfesteem helps in giving the strength and flexibility to take charge of ones lives and to grow from their mistakes without the fear of rejections. From our research all the participants had the positive self-esteem with good and very good scores according to the mean they score. More than fifty percent of the participants were having the very good score of self-esteem (Table 4). Many studies supported that those PLWHA who had the positive self-esteem lived in the better quality of life (Lee, Kochman, & Sikkema, 2002), (Schönnesson, 2002) and helps to increase in the spiritual/ Religion/ personal belief domains of life the most (Cotton et al., 2006). In this study too those participants who had the very good score in self-esteem score had the better mean scores in all the domains of the QOL and the most in the level of independence. Improvement of the way of living may be due to the positive thinking among themselves, their social support they get, despite of their illness they might be able to recognize their personal strength and their abilities within themselves to cope with the disease, and also to change their depressive symptoms with time.

#### 8) Self-care and quality of life among PLWHA

In this research self-care was described as the number of times the patients visited the hospital, either for the follow up or when they were in need. It was analyzed by asking the questions to the participants the number of times they visit the hospital and at what conditions they visited. From the survey it was found that those participants who visited hospitals once in every months with when they got the health related symptoms had the better scores in all the domains of the quality of life then to those who visited hospital sometimes or only when symptoms arises. It may be because they were on regular under guidelines of the medical personal, they knew what was going on to on their body, and their disease conditions, suggestions might be given to the participants if they had any disease complications or to improve their way of living. This was also suggested in the other studies done among the chronic disease that those participants who were under the influence of the medical personal had the good prognosis of the disease as well as had the better quality of life as the people with chronic diseases were under the influence of the medical personnel, they helped them to cope with the disease, prevent them from getting the secondary infections, letting them know about their disease condition regularly, (Au, Udris, Fihn, McDonell, & Curtis, 2006; Spitzer et al., 1981).

#### Quality of life

Quality of life when defined it had a different domains to sum up as a whole. The transformed score of each domains of QOL is shown in table 13, from which it can be analyze that there is the poor quality of life in the psychological domain of the quality of life. In Nepal still the literacy rate is high and there is still discrimination and stigma towards the HIV/AIDS. Due to the stigma, PLWHA are most likely to be indoor and their social interaction is decreased. The people who are infected with HIV/AIDS are most likely to be discriminated among the friends, family or in the society due to which they might have the negative feelings they might not care for themselves ultimately decreasing in the quality of life. There is still less actual education about this disease in the society of Nepal due to which it is regarded as the communicable disease and people tend to discriminate the PLWHA. Due to the lack of the proper consoling to the PLWHA they regard it as a chronic disease and due to which they are most likely to be depressed ultimately decreasing in the quality of life (Holzemer et al., 2009). Even for those who were infected with HV/AIDS Table 14 showed the association between those domains physical, psychological, level of independence, environmental and spirituality/religion domain with the characteristics of the participants like age, gender, education, self-esteem, and self-care. These relationship will be appropriate when it is implemented in the clinics. Physicians, nurses, health personal, counselors and their professions who are directly or indirectly involved in taking care for the PLWHA need to pay attention to the physical, psychological and emotional aspect of patients health. Discuss with them about their independence from the use of medications, their health problems, their environment in which they are living and the spiritual aspect of health. Although social relationship domain showed the less association with QOL but also awareness should be done in the family, society and from the hospital set up. Sexual functioning ability and the support they get from the family members, friends, and society will play a vital role in improving their quality. It will ultimately help them to improve their work capacity and their satisfaction they get from their work capacity, their performance. They may

develop the positive aspect in their purpose of life leading to decrease in stigma, fear about future and death.

## 5.2) Conclusion

This study used the quantitative, descriptive study design to assess the QOL among people living with HIV/AIDS under ART in Kaski district in Nepal. Quantitative design was more suitable to approach this study design as there was the suitable tools developed by WHO for PLWHA. The study was unique as it was the first of its kind to be done in Nepal among PLWHA with WHO QOL HIV BREF questionnaire containing six domains of quality of life. This study provides the understanding that ART improves the quantity of life but their quality remains the main concern since it didn't show any improvement. Since HIV/AIDS is a chronic disease, attention need to paid to the various factors by the health personal and other professionals who are linked to provide care to PLWHA. From the study it was conclude that WHO-HIV BREF tool is reliable, valid and is suitable to measure the quality of life among PLWHA in Nepal. Low level of education, unemployment, marital status, patient visiting hospitals only when symptoms arises or sometimes, patient having low level of CD4 count were associated with the low level of quality of life which were consistent with the findings from the literature and have a vital role in treating the PLWHA to develop their way of living. Findings suggests that improving the family and social support, improving the self-esteem, and their CD4 count will help to improve their quality of life.

#### 5.3) Limitations

• There are some problems in interpreting some terms in the questionnaire, questionnaires like question 15, 16, 25 and question 26

of WHO QOL HIV BREF so the researcher used those question according to the cultural aspect in Nepal's context to describe these terms.

- Adults patients with HIV/AIDS were subjects of this study, thus results cannot be applied to populations of other HIV/AIDS patient's less than 18 years.
- Only Kaski district population with HIV/AIDS under ART is taken, it can be that similar research at the other center could come up with different results.

## 5.4) Recommendation

- 1) Care providers:
- Physicians, nurses, health counselors or other professionals who take care of PLWHA should give greater attention to the social relationship, psychological support and CD4 count by making sure that they are having antiretroviral drugs regularly, suggesting them with healthy diet and making sure that they are practicing the good health behavior to improve the patient's way of living.
  - Health care giver are encouraged to measure the quality of life among HIV infected adults on the interval of six months in their routine HIV care. This would facilitate them to provide holistic care and improves the quality of services provided by physicians.
- All of the care provider should encourage their patients to engage in income generating activities.

## 2) Policy makers:

• Less score in the psychological domain of the health, and the social relationship domain of quality of life means additional laws and resources

are required to tackle stigma and discrimination. Not only policy for the free of medication but there be nutritional program. There should be decrease in treatment gap by implementing the universal coverage of ART to improve the quality of life as well as to decrease the transmission of the virus to the uninfected partners.



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## **Informed Consent Form**

Interviewee ID:

## **Background and Purpose of the study**

Dr. Milan Raj Sigdel, inhabitant of Pokhara, Nepal, student at College of Public Health in Chulalongkorn University in Bangkok, Thailand is undertaking a research as thesis of his Masters of Public Health (MPH) program. The research (thesis) topic -

# Quality of life among People living with HIV/AIDS under Antiretroviral Therapy in Kaski district in Nepal.

Approved by the university is in the phase of data collection in the proposed study area. As the topic clearly illuminates, the purpose of this study is to access the Quality of life among the people living with HIV/AIDS under Antiretroviral therapy, and the related factors which plays a role for the Quality of life among PLWHA.

#### Participation

Your participation is required for a face to face interview for about 10 to 15 minutes at maximum. The interview is based on a semi-structured checklist that objects to help you express your personal/professional experiences and learning in order to aid the study with valuable information. Since, the study can contribute as recommendations for health personable as well as the organizations who are working in HIV/AIDS field to improve their quality of living, your honest expression/sharing is requested. Participating in this interview will not effect on either of your personal and professional life. Your participation is voluntary and you can choose to leave the interview at any time, without needing to give any reason.

#### **Benefits to interviewee**

#### **Risk in participation**

Though the questions are geared towards collecting information on the law enforcement and its implications on harm reduction programs and PWIDs, you may reflect upon tough personal experiences that might trigger your stress or emotions.

Sufficient time and effort has been invested in devising the IDI questions in order to avoid any leading or biased questions that might challenge the opinion of the interviewee. You are free to express your own opinion on every question.

#### Confidentiality and consent

All the information collected during the interview will be solely used for the analysis and development of the thesis report. Any critical information disclosed relating your personal life, not relevant to the development of this document will be destroyed as soon as the information is analyzed.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study and use the information for the development of the study report.

Signature of interviewee: .....

Date:.....

Please sign below to verify that you have received the aforementioned amount of NRs............/- as your remuneration to your valuable contribution.

Signature of interviewee:

Date:.....

Please sign below to authorize us to mention your name in the acknowledgement of the final report and publications.

Full Name:	
Designation:	
Organization:	
Signature of interv	iewee:
Date:	

## Questionnaire: WHO/MSD/MER/Rev.2012.02

English only



WHOQOL-HIV BREF

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

		Raw	Transformed	b
		Score	Score	
Domain 1				
	Q3 + Q4 + Q14 + Q21			
Domain 2				
	จุฬาลงกรณ์มหาวิทยาลัย			
	Q6 + Q11 + Q15 + Q24 + Q31			
Domain 3				
	Q5 + Q20 + Q22 + Q23			
Domain 4				
	Q17 + Q25 + Q26 + Q27			
Domain 5				
	Q12 + Q13 + Q16 + Q18 + Q19 + Q28 + Q29 + Q30			
Domain 6				
	Q7 + Q8 + Q9 + Q10			

#### **ABOUT YOU**

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

- a) What is your **gender**? Male / Female
- b) How old are you? (Age in years)
- c) What is the highest education you received? None at all / Primary / Secondary / High school/ university
- d) What is your marital status? Single / married/ Divorced / Widowed
- e) Are you currently employed? Employed/ unemployed

#### SOCIAL AND FAMILY SUPPORT:

- a) Whom can you really count to listen when you need to talk? Family members/friends/ relatives/ others (specify)
- b) Whom can you count on to console you when you are really upset?
  Family members/ Friends/ Relatives/ others (specify)
- c) How often you console with your relatives when you are in need? All the time when you are in need/ Once a month/ never
- d) During the last 2 weeks have you ever been invited in the community organized program? Yes/No
- e) During the last 2 weeks have participated in the community organized program?
  Yes/No

## Self-care

a) How often do you visit the hospitals after you were in ART?

Once every 1 months/ when symptoms arises (symptoms of loose motion/ dizziness/ loss of appetite)/ sometimes.

## **Duration of ART**

a) How long have you been visiting this ART center for ART?

.....months

## CD4 count

a) What is your current CD4 count?

..... mmm

GHULALONGKORN UNIVERS

## Self-esteem.

Statement	Strongly agree	Agree	Disagree	Strongly disagree
1. On the whole, I am satisfied with myself.				
2. I am able to do things as well as most other people do.				
3. I feel that I have a number of good Qualities.				

4. At the times I am no good at all.			
5. I feel that I do have much to be proud of.			
6. I feel that I do have much to be proud of.			
7. I certainly feel useless at times			
8. I feel I am the person of worth at least on equal basis on others.	Mer.		
9. I wish I have more respect for myself.			
10. All in all I am inclined to find myself as a failure			
11. I take positive attitude towards myself			

จุฬาลงกรณ์มหาวิทยาลัย Chulalongkorn University

#### Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last two weeks.** For example, thinking about the last two weeks, a question might ask:

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

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

Please read each question, assess your feelings, and circle the number on

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

the scale for each question that gives the best answer for you.

		Very dissatisfie	Dissatisfie	Neither satisfied	Satisfied	Very satisfied
2	How satisfied are you	1	2	3	4	5
(G4)	with your health?					

The following questions ask about how much you have experienced certain

things in the last two weeks.

ſ						
	จุหาลงกรณ์มหาวี Chulalongkorn U	Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4 (F50.1)	How much are you bothered by any physical problems related to your HIV infection?	1	2	3	4	5

5	How much do you need any	1	2	3	4	5
(F11.3)	medical treatment to function					
	in your daily life?					
6 (F4.1)	How much do you enjoy life?	1	2	3	4	5
7	To what extent do you feel	1	2	3	4	5
(F24.2)	your life to be meaningful?					
8	To what extent are you	1	2	3	4	5
(F52.2)	bothered by people blaming	2				
	you for your HIV status					
9	How much do you fear the	1	2	3	4	5
(F53.4)	future?		2			
10	How much do you worry	1	2	3	4	5
(F54.1)	about death?		2			
	จุหาลงกรณ์มหาวิ Chulalongkorn U	Not at all	A little	A moderate amount	Very much	Extremely
11	How well are you able to	1	2	3	4	5
(F5.3)	concentrate?					
12	How safe do you feel in your	1	2	3	4	5
(F16.1)	daily life?					
13	How healthy is your physical	1	2	3	4	5
(F22.1)	environment?					

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

		Not at all	A little	Moderately	Mostly	Completely
14 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
15 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
16 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
17 (F51.1)	To what extent do you feel accepted by the people you know?	1	2	3	4	5
18 (F20.1)	How available to you is the information that you need in your day-to-day life?	า ทยาส์ NIVER	2 SITY	3	4	5
19 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
20 (F9.1)	How well are you able to get around?	1	2	3	4	5

## The following questions ask you how good or satisfied you have felt

about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
21	How satisfied are you with	1	2	3	4	5
(F3.3)	your sleep?					
22	How satisfied are you with	1	2	3	4	5
(F10.3)	your ability to perform your	2				
	daily living activities?					
23	How satisfied are you with	1	2	3	4	5
(F12.4)	your capacity for work?					
24	How satisfied are you with	1	2	3	4	5
(F6.3)	yourself?	-33				
25	How satisfied are you with	เวิทปาลั	2	3	4	5
(F13.3)	your personal relationships?	Univers	ITY			
26	How satisfied are you with	1	2	3	4	5
(F15.3)	your sex life?					
27	How satisfied are you with	1	2	3	4	5
(F14.4)	the support you get from					
	your friends?					

28	How satisfied are you with	1	2	3	4	5
(F17.3)	the conditions of your living					
	place?					
29	How satisfied are you with	1	2	3	4	5
(F19.3)	your access to health					
	services?					
30	How satisfied are you with	1	2	3	4	5
(F23.3)	your transport?					

The following question refers to how often you have felt or experienced

certain things in the last two weeks.

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

THANK YOU FOR YOUR HELP

## मानिसक स्वास्थ्यः मानसिक स्वास्थ्य र दुर्व्यसनको प्रभाव प्रमाण तथा अनुसन्धान विभाग विश्व स्वास्थ्य संठगन, जेनेभा

## तपाईँका बारेमा

हामीले तपाईंका बारेमा केही सामान्य प्रश्नवली तयार गरेका छौं। ती प्रश्नहरूको सही उत्तर छान्नुहोस् र खालि ठाउँमा उपर्युत जवाफ लेख्नुहोस् ।

- क. तपाइँको पहिचान के हो ? महिला/ पुरुष
- ख. तपाईं कति वर्षको हुनुभयो ? .....
- ग. तपाईंको वैवाहिक स्थिति के हो ? एकल/विवाहित/वैवाहिक जीवन/अलग/सम्बन्ध विच्छेद/विदुर/विधवा
- घ. तपाईँ हाल रोजगारी हुनुहुन्छ ? .....

## सामाजिक पारिवारिक सहयोग

- क. तपाईं आफ्ना कुरा सबैभन्दा बढी कोसँग व्यक्त गर्नुहुन्छ ? परिवारको सदस्य/साथी/नातेदार/ अन्य (विशेष)
- ख. तपाईं साँच्चिकै विचलित भएको अवस्था कसैले बढी सान्त्वना दिन्छ ? परिवारको सदस्य/साथी/नातेदार/ अन्य (विशेष)
- ग. तपाईंले आफ्ना नातेदारबाट कति धेरै सान्त्वना पाउनुभएको छ ? तपाईंलाई आवश्यक पुरै समय /महिनाको एकपटक/कहिल्यै पनि
- घ. पछिल्लो एक वर्षमा सामुदायले आयोजना गरेको कुनै कार्यक्रममा तपाई सहभागी हुन्भयो ? **भएँ / भइन**
- ड. पछिल्लो एक वर्षमा सामुदायिक कार्यक्रममा सहभागिताका लागि तपाईँलाई आमन्त्रण गरियो? गरियो / गरिएन

Chulalongkorn University

## स्वहेरविचार

क. एन्टिरिट्रोभाइरल उपचार (एआरटी) गराएपछि तपाई कतिपल्ट अस्पताल जानुभयो ?
 प्रत्येक महिनाको एकपटक/लक्षण देखिएपछि/(गतिछाडा लक्षण/रिंगटा लागेमा/भोक हराउँदा वा खान मन नलाग्दा)/ कहिलेकाँही

## एआरटी को अवधि

- क. तपाई कति समयसम्म अस्पतालको ए आर टी केन्द्रमा जानुभयो? ..... महिना/... वर्ष
- सी डी ४
- क. हाल तपाईको सी डी ४ मात्रा (CD4) कति छ ? <CD4२००/>२०० सीयुएमएम

## आत्मबल

क. म समग्रमा आफूप्रति सन्तुष्ट छु, पूर्ण सहमत/सहमत/असहमत/पूर्ण असहमत

- ख. म अरू मानिसहरू जस्तै काम गर्न सक्षम छु, पूर्ण सहमत/सहमत/असहमत/पूर्ण असहमत
- ग. म असल गुणले युक्त छु भन्ने महशुस हुन्छ, पूर्ण सहमत/सहमत/असहमत/पूर्ण असहमत
- घ. कहिलेकाँही म केहीमा पनि राम्रो छैन जस्तो लाग्छ, **पूर्ण** सहमत/सहमत/असहमत/पूर्ण असहमत
- ड. म गर्व गर्न लायक छैन भन्ने महशुस हुन्छ, पूर्ण सहमत/सहमत/असहमत/पूर्ण असहमत
- च. कहिलेकाँही म आफैंलाई अनुपयोगी ठान्छु, पूर्ण सहमत/सहमत/असहमत/पूर्ण असहमत
- छ. म कम्तिमा पनि आफुलाई अरू मानिस सरह मुल्यवान सोच्छु, **पूर्ण** सहमत/सहमत/असहमत/पूर्ण असहमत
- ज. म मेरै लागि उच्च सम्मान गर्न चाहन्छु, पूर्ण सहमत/सहमत/असहमत/पूर्ण असहमत
- भः. समग्रमा म कहिलेकाँही असफल भएँकी भन्ने लाग्छ, **पूर्ण** सहमत/सहमत/असहमत/पूर्ण असहमत
- ञ. म आफुप्रति सकारात्मक धारणा राख्छु, पूर्ण सहमत / सहमत / असहमत / पूर्ण असहमत
- कृपाय, यदि तपाईँले एचआइभी परीक्षण गर्नु भएको छ भने निम्न प्रश्नहरूको सही जवाफ दिनुहोस् ।
- क. तपाईको एच.आई.भी सिरोस्टाटस के हो? संक्रमित/लक्षण/एड्स परिवर्तित
- ख. कति वर्षको हुँदा तपाईँले पहिलो पटक एचआइभी परीक्षण गर्नुभयो? .....
- ग. कति वर्षमा तपाई संक्रमित भएको हुनु भएको थियो? .....
- घ. एचआईभी संक्रमित भएको कुरा तपाईंले कसरी विश्वास गर्नुभयो ? (कुनै एउटामा चिन्ह लगाउनुहोस्) पुरुषसँगको यौनसम्बन्ध/महिलासँगको यौन सम्बन्ध/लागुपदार्थ इन्जेकसन/रगतबाट/अन्य (विशेष)

## निर्देशन

तपाईले आफ्नो जीवन र गुणस्तरीय स्वास्थ्यका बारेमा कस्तो महशुस गर्नुभएको छ भन्नेबारेमा यो अध्ययन केन्द्रित रहेको छ । यहाँ सोधिएका सबै प्रश्नहरूको उत्तर दिनुहोस् । यदि तपाई यी प्रश्नबारे अस्पष्ट हुनुहुन्छ भने यहाँ दिइएका मध्येबाट सबैभन्दा सही लागेको उत्तर छनौट गर्नुहोस् । सम्भवत् यो नै तपाईँको पहिलो जवाफ हुनसक्छ । तपाईँ आफ्नो सरोकार, खुसी, आशा एवम् भरोसा र स्तरबारे गहिरो चिन्तनमनन गर्नुहोस् । हामी पछिल्लो दुई हप्तामा तपाईँले आफ्नो जीवनका बारेमा के सोच्नु भएको छ भनेर प्रश्न गर्दछौं । उदाहरणका लागि दुई सातामा तपाईले गरेका चिन्तनमननबारे एक महत्वपूर्ण प्रश्न सोधिन्छ

		कत्ति छैन	थोरै मात्र	मध्यम	धेरै	अत्यन्तै
99	तपाईं आफ्नो ध्यान					
(	केन्द्रित गर्न कत्तिको	٩	२	२	४	X
एफ४.३)	सक्षम हुनुहुन्छ ?					

तपाई दुई हप्ताको अवधिमा आफ्नो ध्यान केन्द्रित गर्न कत्तिको सक्षम हुनुहुन्छ भन्ने बारेमा दिइएका विकल्पमध्ये एउटा सही विकल्प छनौट गर्नुहोस् । यदि तपाईंले ४ नम्बरको विकल्प छनौट गर्नु भयो भने तपाई आफूप्रति ध्यान केन्द्रित गर्न धेरै सक्षम हुन्छ । यद्यपि पहिलो विकल्प छनौट गर्नुभयो भने तपाईं आफूप्रति ध्यान केन्द्रित गर्न पछिल्लो दुई हप्तासम्म पनि सक्षम हुनु भएन ।

कृपाय, प्रत्येक प्रश्नको अध्ययन गर्नुहोस् र आफ्ना भावनामाथि आफैं मूल्याङ्कन पनि गर्नुहोस् । हरेक प्रश्नको विकल्पमध्ये बाट सही जवाफ छान्नुहोस् ।

		धेरै नराम्रो	नराम्रो	न राम्रो नत नराम्रो	राम्रो	धेरै राम्रो
9 (जी9)	तपाईँको आफ्नै जीवनको गुणस्तरीयता मापन कस्तो छ?	٩	२	<b>ર</b>	ሄ	X

Contraction (2)

	จุฬ Chul	धेरै असन्तुष्ट	असन्तुष्ट	न सन्तुष्ट नत असन्तुष्ट	सन्तुष्ट	धेरै सन्तुष्ट
२ ( जी४)	तपाईं आफ्नो स्वास्थ्यप्रति कत्तिको सन्तुष्ट हुन्छ?	٩	२	<b>ર</b>	ጽ	X

दुई हप्ताको अवधिमा तपाईंले के कति विषयवस्तुमा कति धेरै अनुभव हासिल गर्नुभयो भन्नेबारेमा तलका प्रश्नहरू केन्द्रित रहेका छन् ।

		कत्ति छैन	थोरै मात्र	मध्यम	धेरै	अत्यन्तै
३ (एफ१.४)	तपाईँलाई शारीरिक पीडा हुँदा तपाईँका कार्य योजनामा कत्तिको वाधा उत्पन्न भएको छ?	٩	R	m	8	X

8	गच भार भी					
	एचआइभी		5	5		U.
(एफ४०.१)	संक्रमणबाट सम्बन्धित	۲	२	<b>२</b>	8	x
	शारीरिक समस्याले					
	तपाईँ कति प्रभावित					
	हुनुहुन्छ?					
x	तपाईँको दैनिकीमा					
(एफ ११.३)	चिकित्सा उपचारको	٩	२	३	४	X
	आवश्यकता कति छ?					
દ્	तपाईंले जीवनमा कति					
<b>एफ४.१</b> )	धेरै आनन्द अनुभूति	٩	२	३	४	X
	गर्नु हुन्छ?					
७	तपाईँ आफ्नो					
(एफ२४.२)	जीवनलाई कत्तिको	9	२	३	४	X
	अर्थपूर्ण ठान्नुहुन्छ?					
5	तपाईंको एचआइभी					
(एफ ४२.२)	सम्बन्धी मान्छेले गर्ने	9	२	३	8	X
	नकरात्मक टिप्पणीले					
	तपाईको जीवनका					
	कति असर परेको छ?					
	अवस्था		4			
९	तपाईं भविष्यप्रति	THE REAL PROPERTY OF				
, (एफ४३.४)	कत्तिको चिन्तित	٩	ર	२	8	x
· · · · · · · /	हुनुहुन्छ?			N N		
90	तपाईंलाई मृत्युसँग					
(एफ४४.१)	कत्तिको डर लाग्छ?	٩	าลย จ	ર	8	X
<u>() () () () () () () () () () () () () (</u>		ा कत्ति	थोरै	र मध्यम	ु धेरै	्र अत्यन्तै
		कात छैन	पार मात्र	יושיי	4\	जरजरा
99	तपाईं आफ्नो ध्यान	<u></u>	117			
(एफ <b>५</b> .३)	केन्द्रित गर्न कत्तिको	9	२	२	8	X
(5,714, 4)			1	۲		<b>^</b>
१२	सक्षम हुनुहुन्छ ? तपाईंको दैनिक					
		<u>م</u>	2	а	8	U
(एफ१६.१)	जीवनमा आफूलाई	1	२	ર	0	X
	कत्तिको सुरक्षित					
03	ठान्नुभएको छ?					
9३	तपाईँको वरिपरिको			_		
(एफ२२.१)	वातवारण कत्तिको	٩	२	ર	8	x
	स्वस्थकर छ?					

दुईहप्ताको अवधिमा तपाईले कुन कुन विषयवस्तुमा के कसरी पूर्ण अनुभव हासिल गर्नुभयो भन्नेबारेमा तलका प्रश्नहरू सम्बन्धित छन् ।

		कत्ति छैन		मध्यम	धेरै	अत्यन्तै
			मात्र			
१४	तपाईँको दैनिक					
(एफ२.१)	जीवनका लागि	٩	२	३	४	X
	आवश्यक उर्जा					
	पर्याप्त छ?					
ঀৼ	तपाईं आफ्नो					
	शारीरिक	٩	२	३	४	X
(एफ७.१)	उपस्थितलाई	s de la de se				
	स्वीकारर्नु हुन्छ? 💦					
१६	आफ्ना 🔄					
(एफ१८.१)	आवश्यकता पूरा	9	२	३	४	X
	गर्न तपाईँसँग					
	पर्याप्त सम्पत्ति छ?					
ঀ७	तपाईँका परिचत					
एफ (४१.१)	मान्छेले तपाईँलाई	٩	२	३	४	x
	कति हदसम्म	Keese Doord	<b>A</b>			
	स्वीकारेका छन्?	THE SERVICE				
१८	तपाईंको दैनिकीमा		X			
(एफ२०.१)	आवश्यक पर्ने	٩	2	३	४	x
	सूचनाहरू कत्तिको	รณ์มหาวิ	ายาลัย			
	उपलब्ध छन?	CKORN III	IVERCITY			
१९	फुर्सदिला गतिविधि					
(एफ२१.१)	गर्न तपाईँलाई	٩	२	३	४	X
	कत्तिको अवसर					
	दिइएको छ?					
		धेरै	नराम्रो	न राम्रो	राम्रो	धेरै राम्रो
		नराम्रो		नत		
				नराम्रो		
२०	तपाईँ आफ्नो	٩	२	२	ጽ	x
(एफ९.१)	वरिपरिको					
	वातावरणमा					
	घुलमिल हुन कत्ति					
	सक्षम हुनुहुन्छ?					

		धेरै असन्तुष्ट	असन्तुष्ट	न सन्तुष्ट नत असन्तुष्ट	सन्तुष्ट	धेरै सन्तुष्ट
२१ (एफ३.३)	तपाईं आफ्नो सुताइप्रति कत्तिको सन्तुष्ट हुनुहुन्छ?	٩	२	<b>ə</b>	8	X
२२ (एफ१०.३)	तपाईं आफ्ना दैनिक जीवनका कियाकलाप सम्बन्धी प्रस्तुती र क्षमतासँग सन्तुष्ट हुनुहुन्छ?	9	२	n r	8	X
२३ (एफ१२.४)	तपाईं आफ्नै कार्यशैली र तत्सम्बन्धी क्षमतामा सन्तुष्ट हुनुहुन्छ?	٩	२	n <del>a</del>	8	X
२४ (एफइ.३)	तपाईं स्वयम् आफूप्रति कत्तिको सन्तुष्ट हुनुहुन्छ?		2	nr	ጽ	x
२५ (एफ१३.३)	तपाईं वैयक्तिक सम्बन्धप्रति कत्तिको सन्तुष्ट हुनुहुन्छ?	ngkorn l 9	REAL	ñ	8	X
२६ (एफ१४.३)	तपाईं आफ्नो यौनजीवनप्रति कत्तिको सन्तुष्ट हुनुहुन्छ?	٩	२	n	Y	X
२७ (एफ१४.४)	तपाईं आफ्ना साथीसंगीबाट पाएको सहयोगले कत्तिको सन्तुष्ट हुनुहुन्छ?	٩	२	R.	8	X
२८ (एफ१७.३)	तपाईँ आफ्नो बासस्थानप्रति	٩	२	n	8	X

दुई हप्ताको अविधिमा तपाइँले आफ्नो जीवनका विविध पक्षसँग सबन्धित विषयवस्तुमाथि उचित सन्तुष्टि प्राप्त गर्नु भयो वा भएन भन्नेबारेमा तलका प्रश्नहरू केन्द्रित छन् ।

	कत्तिको सन्तुष्ट हुनुहुन्छ?					
२९	तपाईंले पाउँदै					
(एफ१९.३)	आएको स्वास्थ्य सेवाको पहुँचप्रति	٩	२	3	8	x
	कत्तिको सन्तुष्ट					
३०	हुनुहुन्छ? तपाईँ					
(एफ२३.३)	यातायातको सुविधाप्रति	٩	२	ર	४	X
	कत्तिको सन्तुष्ट हुनुहुन्छ?					

पछिल्ला दुई हप्ताको अविधिमा तपाईँले महशुस गरेका आफ्नै जीवनका केही पक्षहरूबारे बुभ्त्ने शिलशिला अन्तर्गत निम्न प्रश्नहरू सोधिएको छ ।

		छैन	विरलै	एकदम थोरै	एकदम धेरै	हरेक क्षण
३१ (एफ <b>न्द.१</b> )	तपाईँसँग नकरात्मक धारणा छन्? जस्तैः निराशा, चिन्ता, हरेश आदि ।	٩	R	३	Y	X

तपाईंलाई यो फारम भर्न कसैले सहयोग गऱ्यो ? ..... तपाईलाई यो फारम भर्न कति समय लाग्यो?..... यो मूल्याङ्कन फारमका बारेमा तपाईंको सुभाव वा प्रतिक्रिया के छ ?

## सहयोगका लागि धन्यवाद !



Sovernment of Nepal Nepal Health Research Council (NHRC



Ref. No.: 2 12-8 09 June 2016

> Dr. Milan Raj Sigdel Principal Investigator College of Public Health Sciences (CPHS) Chulalongkorn University, Thailand

#### Ref: Approval of Research Proposal entitled People living with HIV/AIDS under Antiretroviral Therapy in Kaski District of Nepal: Quality of life and Related Pactors

#### Dear Dr. Sigdel,

It is my pleasure to inform you that the above-mentioned proposal submitted on 06 May 2016 (Reg.no.118/2016 please use this Reg. No. during further correspondence) has been approved by NHRC Ethical Review Board on 08 June 2016.

As per NHRC rules and regulations, the investigator has to strictly follow the protocol stipulated in the proposal. Any change in objective(s), problem statement, research question or hypothesis, methodology, implementation procedure, data management and budget that may be necessary in course of the implementation of the research proposal can only be made so and implemented after prior approval from this council. Thus, it is compulsory to submit the detail of such changes intended or desired with justification prior to actual change in the protocol.

If the researcher requires transfer of the bio samples to other countries, the investigator should apply to the NHRC for the permission. The researchers will not be allowed to ship any raw/crude human biomaterial outside the country; only extracted and amplified samples can be taken to labs outside of Nepal for further study, as per the protocol submitted and approved by the NHRC. The remaining samples of the lab should be destroyed as per standard operating procedure, the process documented, and the NHRC informed.

Further, the researchers are directed to strictly abide by the National Ethical Guidelines published by NHRC during the implementation of their research proposal and submit progress report and full or summary report upon completion.

As per your research proposal, the total research amount is Self-funded and accordingly the processing fee amount to NRs. 10,670.00. It is acknowledged that the above-mentioned processing fee has been received at NHRC.

If you have any questions, please contact the Ethical Review M & E section of NHRC.

Thanking you,

Dr. Khem Bahadur Karki Member-Secretary



Dr. Milan Raj Sigdel

MBBS,

MPH, Chulalongkorn University

Ref: Approval for Research Proposal

Dear Dr. Milan Raj Sigdel,

Thank you for the submission of your thesis proposal topic "Quality of life among People Living with HIV/AIDS in Kaski district of Nepal under Antiretroviral Therapy" to National Center for AIDS and STD control (NCASC)

I appreciate for your effort in choosing the above mentioned topic and wish you all the best for your thesis work and future endurance. You are requested to follow the ethical principles for Health and Public Health research. After completion of your study you must submit a copy of final thesis to the NCASC.

If you have any further queries please do not hesitate to contact us.

M Dr. Tarun Poudel

Director



Government of Nepal Ministry of Health and Population Western Regional Hospital Phone No.: 061-520461 061-533500 E-mail: wrhpkr@fewanet.com

Development Committe Ramghat, Pokhara

Ref. 2380

Date: 17th April 17, 2016

Dr. Milan Raj Sigdel

MBBS

MPH, Chulalongkorn University

Ref: Approval for Research Proposal

Dear Dr. Milan Raj Sigdel

Thank you for submission of your Thesis Proposal Topic "Quality of Life among People Living with HIV/AIDS in Kaski District of Nepal under Antiretroviral Therapy" to "Western Regional Hospital"

I appreciate for your effort in choosing the above mentioned topic thesis and wish you all the best for your thesis work and future endurance. Any change in the Objectives, Variables, Data analysis, Questionnaire should be informed to the hospital committee. You are requested to follow ethical principles for Health and Public Health Research. After completion of your study you must submit a copy of final thesis to the Western Regional Hospital.

If you have any further queries please do not hesitate to contact us

Dr. Shree Krishna Shrestha

MBBS, MD

Chief Medical Superintendent

Western Regional Hospital

#### VITA

Dr. Milan Raj Sigdel

Permanent address: Pokhara Sub-metro city 13, kaski Nepal

Current Address: 55/46 So Kolit, Phayathai- Bangkok

Mobile number: Nepal 9779856035951

: Thailand 0959075080

Email: millanderaj14@gmail.com

Summary of Expertise:

Chief Medical Officer Kaski Sewa Hospital and Research center from September 29 2014 to February 28 2015

Medical Officer Charak Memorial Hospital PVT Ltd. 15th July 2014 to 20th July 2015.

Academic qualification

Masters of Public Health 2015

Chulalongkorn University, Bangkok, Thailand

Major in Health Behavior

Bachelor in Medicine Bachelor in Surgery (MBBS)

Manipal College of Medical Sciences, Pokhara Nepal

Batch: August 2008- 2014