



THESIS APPROVAL

GRADUATE SCHOOL, KASETSART UNIVERSITY

Master of Nursing Science (Family and Community Health Nursing)

DEGREE

Family and Community Health Nursing

FIELD

Boromarajonani College of Nursing Nopparat Vajira

DEPARTMENT

TITLE: Factors related to quality of life in HIV Infected Women in Medan, North Sumatera, Indonesia

NAME: Miss Siska Evi Martina

THIS THESIS HAS BEEN ACCEPTED BY

THESIS ADVISOR

(Mrs. Sunanta Thongpat, R.N., Ph.D.)

THESIS CO-ADVISOR

(Miss Pornruedee Nitirat, R.N., Ph.D.)

**GRADUATE COMMITTEE
CHAIRMAN**

(Miss Monthana Hemchayat, R.N., Ph.D.)

APPROVED BY THE GRADUATE SCHOOL ON _____

DEAN

(Associate Professor Gunjana Theeragool, D.Agr.)

THESIS

FACTORS RELATED TO QUALITY OF LIFE
IN HIV INFECTED WOMEN IN MEDAN, NORTH SUMATERA,
INDONESIA



SISKA EVI MARTINA

A Thesis Submitted in Partial Fulfillment of
the Requirements for the Degree of
Master of Nursing Science (Family and Community Health Nursing)
Graduate School, Kasetsart University
2014

Siska Evi Martina 2014: Factors related to quality of life in HIV Infected Women in Medan, North Sumatera, Indonesia. Master of Nursing Science (Family and Community Health Nursing), Major Field: Family and Community Health Nursing, Boromarajonani College of Nursing Nopparat Vajira. Thesis Advisor: Mrs. Sunanta Thongpat, R.N., Ph.D. 136 pages.

The prevalence of Human Immunodeficiency Virus (HIV) infected women in Indonesia is increasing dramatically. HIV is a potentially life-threatening condition and impacts the quality of life of patients, particularly women. The purpose of this study was to identify factors related to the quality of life of HIV infected women. The Revised Wilson and Clearly Model for Health Related Quality of Life (HRQOL) was used to guide the study. A cross sectional study was conducted with 111 participants whose ages were 18 to 45 years old from a community HIV clinic in Medan, Indonesia. The questionnaires composed of the demographic characteristics, Fatigue Rating Scale, Inventory Functional Status, General Health Perception, Multidimensional Perceived Social Support Scale, and World Health Organization Quality of Life-BREF (WHOQOL-BREF). Data was analyzed using descriptive statistics, Pearson correlation coefficient and Spearman correlation coefficient.

The study found that functional status, general health perception and social support had a statistically positive relationship with the quality of life in HIV infected women. However, employment status and fatigue had a statistically negative relationship with the quality of life of HIV infected women. There was not statistically significant relationship between age, marital status, educational level, family income to the quality of life of HIV infected women. Based on these findings, social support, general health perception, functional status, and fatigue should be involved in developing nursing assessments and interventions to improve the quality of life of HIV infected women.

Student's signature

Thesis Advisor's signature

___ / ___ / ___

ACKNOWLEDGEMENTS

I would like to acknowledge first and foremost my Lord, Jesus Christ, for His blessings I have been finish this study. My successes are reflection of His overwhelming and through Him I can do all things.

I would like to give my grateful thank to Dr.Sunanta Thongpat, my major advisor for her unending support and thoughtful guidance during this study. I am forever grateful to her for her outstanding mentoring and friendship. Additionally, I thank to my co advisor, Dr.Pornruedee Nitirat. She has provided invaluable support that has challenged my thinking throughout this experience. I would also like to express the deepest appreciation to my committee members, Assist. Prof. Poolsuk Janepanish Visudtibhan and Dr. Monthana Hemchayat for letting my defense be an enjoyable moment, and for brilliant comments and suggestions. A special thanks to Assist. Prof. Boosaba Sanguanprasit who helped me with statistics and data analysis.

In addition, I would especially like to thank to all of the faculties of Master Nursing Program at BCNNV affiliated with Kasetsart University who taught me in the Master program. I grateful acknowledge to STIK Sint Carolus, and Directorate General of Higher Education of Indonesia for funding in part of my study. I would also like to thank to nurses at community HIV clinic of Adam Malik Hospital for their assistance and co-operations. I am appreciate of my participants who provided me with their data and shared their experiences in this study.

Finally, I offers my special thanks to my parents, my family, and my beloved fiancé, Mr. Vetra R.B Sinaga for their endless love, encouragement, and patience during this study. Last but no least, I would like to give special thanks to all of friends in Master program.

Siska Evi Martina

November 2014

TABLE OF CONTENTS

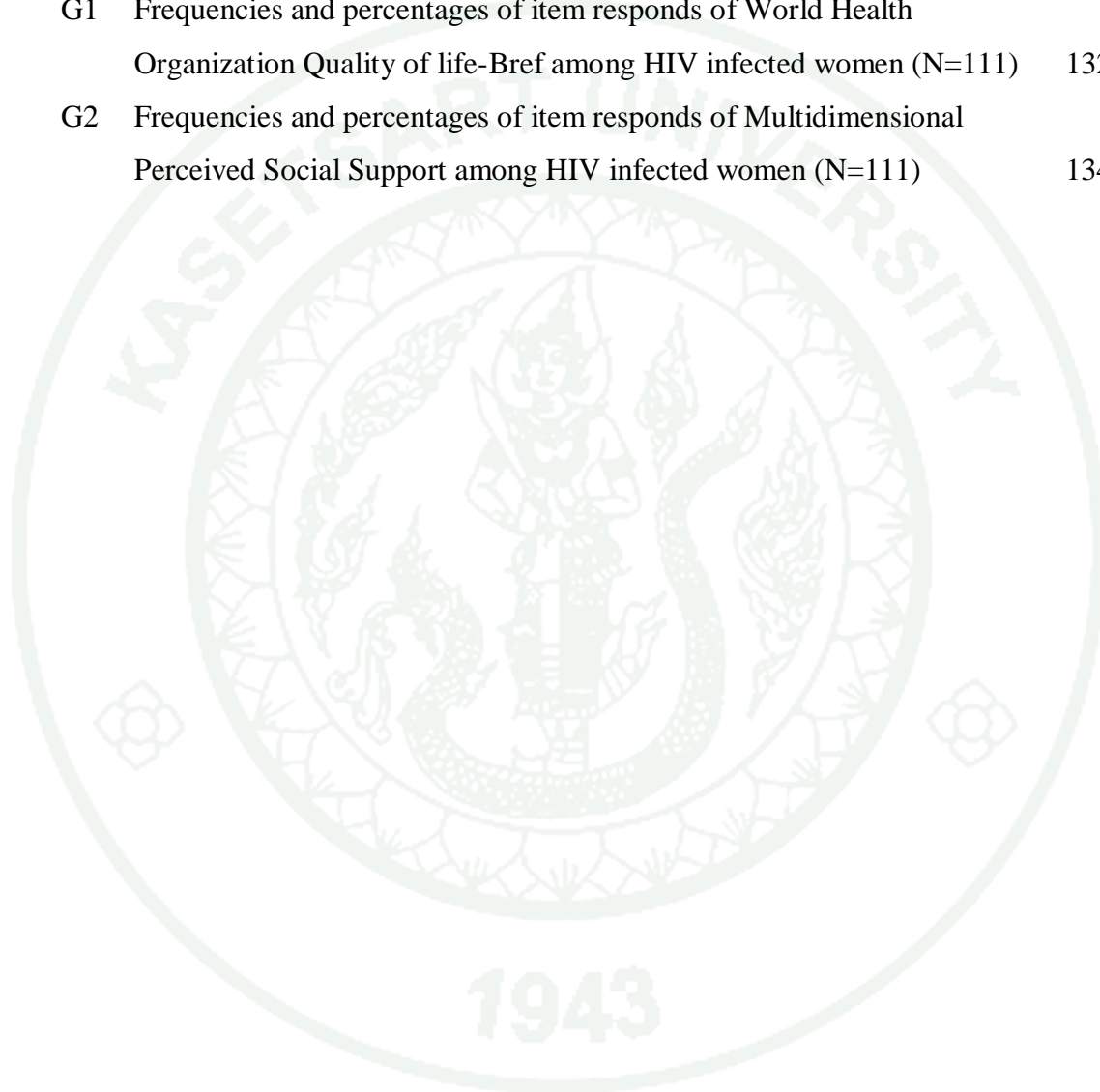
| | Page |
|--|-------------|
| TABLE OF CONTENTS | i |
| LIST OF TABLES | ii |
| LIST OF FIGURES | iv |
| LIST OF ABBREVIATIONS | v |
| INTRODUCTION | 1 |
| OBJECTIVES | 7 |
| LITERATURE REVIEW | 9 |
| MATERIALS AND METHODS | 38 |
| Materials | 38 |
| Methods | 43 |
| RESULTS AND DISCUSSION | 50 |
| Results | 50 |
| Discussion | 60 |
| CONCLUSION AND RECOMMENDATIONS | 70 |
| Conclusion | 70 |
| Recommendations | 71 |
| LITERATURE CITED | 72 |
| APPENDICES | 91 |
| Appendix A Questionnaires | 92 |
| Appendix B Approval Letter | 104 |
| Appendix C Letter of Translation Validation | 108 |
| Appendix D Information Sheet | 110 |
| Appendix E Letters of Expert for Content Validity | 121 |
| Appendix F Permission for Using Picture and Questionnaires | 125 |
| Appendix G Item Responds of Questionnaires | 131 |
| CURRICULUM VITAE | 136 |

LIST OF TABLES

| | Appendix Table | Page |
|----|--|-------------|
| 1 | Internal Reliability of Questionnaires | 43 |
| 2 | Frequencies and percentage of characteristics of individual among HIV infected women (N=111) | 51 |
| 3 | Frequencies and percentages of quality of life among HIV infected women (N=111) | 52 |
| 4 | Frequencies and percentages of fatigue scale among HIV infected women (N=111) | 53 |
| 5 | Frequencies and percentages of functional status among HIV infected women (N=111) | 54 |
| 6 | Frequencies and percentages of general health perception among HIV infected women (N=111) | 54 |
| 7 | Percentages of social support among HIV infected women (N=111) | 55 |
| 8 | Relationships between characteristics of individual and quality of life among HIV infected women (N = 111) | 56 |
| 9 | Relationships between fatigue and quality of life among HIV infected women (N = 111) | 57 |
| 10 | Relationships between functional status and quality of life among HIV infected women (N = 111) | 58 |
| 11 | Relationship between general health perception and quality of life among HIV infected women (N = 111) | 58 |
| 12 | Relationship between social support and quality of life among HIV infected women | 59 |

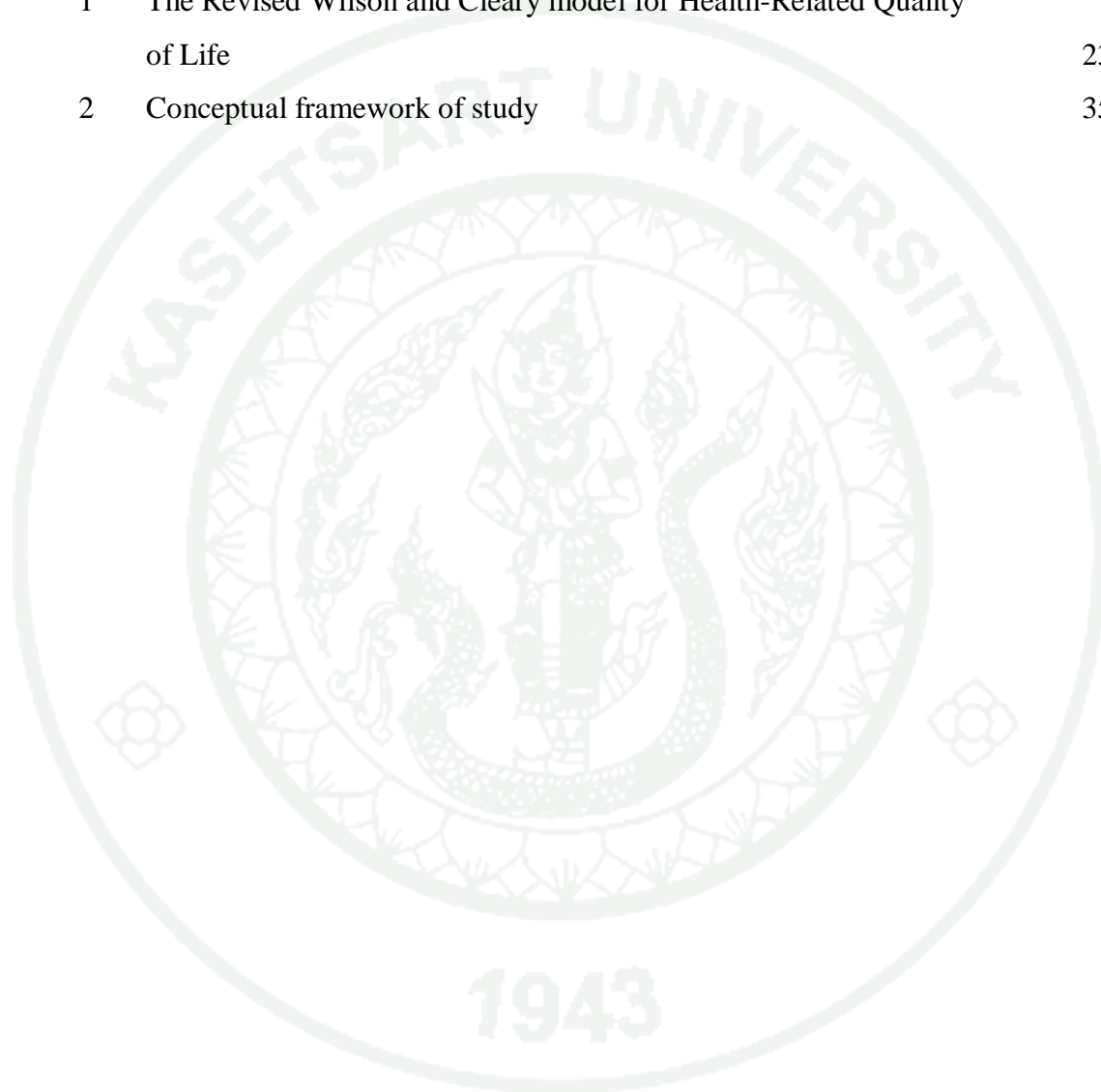
LIST OF TABLES (Continued)

| Appendix Table | Page | |
|-----------------------|---|-----|
| G1 | Frequencies and percentages of item responds of World Health Organization Quality of life-Bref among HIV infected women (N=111) | 132 |
| G2 | Frequencies and percentages of item responds of Multidimensional Perceived Social Support among HIV infected women (N=111) | 134 |



LIST OF FIGURES

| Figure | | Page |
|---------------|--|-------------|
| 1 | The Revised Wilson and Cleary model for Health-Related Quality of Life | 23 |
| 2 | Conceptual framework of study | 35 |



LIST OF ABBREVIATIONS

| | | |
|--------|---|---|
| WHO | = | World Health Organization |
| CDC | = | Centers for Disease Control |
| HIV | = | Human Immune Deficiency Virus |
| AIDS | = | Acquired Immune Deficiency Syndrome |
| STIs | = | Sexually Transmitted Infections |
| MoH | = | Ministry of Health |
| VCT | = | Voluntary Counseling and Testing |
| ART | = | Anti Retroviral Therapy |
| NGOs | = | Non Government Organizations |
| HRQOL | = | Health Related Quality of Life |
| WHOQOL | = | World Health Organization Quality of Life |
| IFS | = | Inventory of Functional Status |
| MPSSS | = | Multidimensional Perceived Social Support Scale |
| SPSS | = | Statistical Package for the Social Sciences |
| M | = | Mean |
| SD | = | Standard Deviation |
| ERB | = | Ethics Review Board |
| UNAIDS | = | United Nation Program on HIV/AIDS |

FACTORS RELATED TO QUALITY OF LIFE IN HIV INFECTED WOMEN IN MEDAN, NORTH SUMATERA, INDONESIA

INTRODUCTION

Human Immunodeficiency Virus (HIV) is known as an infectious disease which is a potentially life-threatening condition. Nowadays, HIV has become an epidemic that affects millions of people particularly in women. The World Health Organization (WHO) reported that the number of people living with HIV in the world has increased from 29.4 million in 2001 to 34 million in 2011. Half of those infected were women (WHO, 2012). Specifically, in South East region there was 5.5 million people living with HIV in 2012 and 36 % were women, which an increase of 35 % from 2011 (WHO, 2012). In Indonesia, even though the total number of people living with HIV has decreased from 21, 591 people in 2010 to 21, 511 people in 2012, the number of HIV infected women tended to increase. In 2010, the Ministry of Health (MoH) of Indonesia reported that the number of HIV infected women has increased from 38.7 % to 43.3 % in 2012. The growing spread of HIV is more apparent in North Sumatera, Indonesia. Ministry of Health (MoH) of North Sumatera Province reported that 75.47 % of people living with HIV are residents of Medan district. The number of HIV infected women in Medan had increased from 25.9 % in 2009 to 32 % in 2012. Therefore, this number indicates women are increasingly vulnerable to HIV. Some of them were infected by sexual transmission with their husband or spouse.

HIV has led to loss of many lives and due to consequences of negative events. People living with HIV are facing with stigma from their society. HIV infected women have perceived higher stigma than men when living with HIV (Subramanian *et al.*, 2009). In particular, HIV infected women were labeled as being sexually promiscuous, prostitutes, or drug users. They were looked down upon with suspicion of morality and have a negative image from society (Subramanian *et al.*, 2009). In Indonesia, HIV infected women were more likely to acquire HIV infection from their

husbands or partners (Haroen *et al.*, 2008). They were often subjected to societal judgment and consider themselves to be living the punishment of their sinful sexual activities (Haroen *et al.*, 2008). This condition leads HIV infected women to a disruption from social interaction with their family, friends, and workplace. Consequently, living with HIV can be a negative factor to quality of life of infected women.

Quality of life is a subjective concept that is associated with various aspects of one's life (Subramanian *et al.*, 2009). Several studies found that the quality of life experienced between women and men living with HIV were different (Nojomi *et al.*, 2008; Chandra *et al.*, 2009; Perez *et al.*, 2009; Pereire and Canavarro, 2011; Figuero *et al.*, 2011; Imam *et al.*, 2011). HIV infected women were more likely to suffer a lower quality of life than men living with HIV (Ichikawa and Natpratan, 2006; Zimpel and Fleck, 2007; Nojomi *et al.*, 2008; Chandra *et al.*, 2009; Pereira and Canavarro, 2011). Previous studies identified HIV infected women had a lower quality of life in psychological and social domains than other domains (Sun *et al.*, 2007; Solomon *et al.*, 2008; Subramanian *et al.*, 2009; Xiaoyan and Sato, 2011). In contrast, previous studies found HIV infected women had better quality of life than men living with HIV (Perez *et al.*, 2009; Imam *et al.*, 2011). Furthermore, several studies reported that there appeared to be no significant differences in quality of life in both those women and men living with HIV (Wig *et al.*, 2006; Abboud *et al.*, 2010; Hasanah *et al.*, 2011; Hosseinian *et al.*, 2011). This inconsistency may be due to a variety of cultural and social environmental factors.

Solomon *et al.* (2008) found that in male-dominated cultures, women were more vulnerable to HIV infection and had lower quality of life. The patriarchal system or male-dominated cultures such as in Medan, Indonesia is more likely to cause in women a sense of powerlessness and inability to refuse sexual relations regarding condom usage from their sexual partner. This social condition leads them to be unable to protect themselves from HIV infection and contribute to the growing number of HIV infected women in Indonesia (Haroen *et al.*, 2008). Women were powerless to

negotiate about safer sexual with their husband or spouse. Therefore, women risky infected and suffer with HIV which is impact to quality of life.

The purpose of the health related quality of life concept is to provide understanding by identifying the factors that related to quality of life based on health problems. Wilson and Clearly's model of Health Related Quality of Life (HRQOL) presented a conceptual model which focuses on the relationship aspect of health. Several studies were applied in the HRQOL model of Wilson and Clearly in the HIV population to identify factors related the quality of life (Clingerman, 2004; Vidirine *et al.*, 2005; Sousa and Kwok, 2006; Tangkawanich *et al.*, 2008). Therefore, this study was provided information to improve understanding of the factors that related the quality of life in HIV infected women.

Many factors related to the quality of life, particularly in people living with HIV. Previous studies found several factors related to quality of life in HIV infected women, including characteristics of the individuals such as age, marital status, education level, employment status and family income. The age of HIV infected women has significant association with the quality of life. A study reported that older women had a lower quality of life (Pereira and Canavarro, 2011). In contrast, several studies found that HIV infected younger women (< 35 years) had a lower quality of life than those who are older than 35 years (Zimpel and Fleck, 2007; Hasanah *et al.*, 2011).

Regarding the marital status factor, previous studies found that there was an inconsistent association of marital status and quality of life in HIV infected women. Stangl *et al.* (2007) showed that there was no differences in quality of life in HIV infected women among married or unmarried status. Whereas, Zimpel and Fleck (2007) found a lower quality of life among HIV infected women with married status. In contrast, several studies found that a higher quality of life among women of married status (Marcelin *et al.*, 2008; Abboud *et al.*, 2010). Furthermore, education level, employment status, and family income are factors that associated with quality

of life in HIV infected women (Subramanian *et al.*, 2009; Reis *et al.*, 2012). Studies found HIV infected women with less education reported significantly lower quality of life than those with higher education (Zimpel and Fleck, 2007; Reis *et al.*, 2012). Study by Khumsaen *et al.* (2012) found that being unemployed or having low family income was associated with lower quality of life. Contrary, to this several studies found that education level, employment status, and family income were not correlated with quality of life of people living with HIV (Figuro *et al.*, 2011; Xiaoyan and Sato, 2011). Thus, despite the characteristics of the individual are relatively unchangeable, however, people have varying personality characteristics. Therefore, this study was to identify the characteristics of individuals in order correlation with quality of life in HIV infected women.

Furthermore, social support is also a factor associated with quality of life in people living with HIV (Li *et al.*, 2006; Khumsaen *et al.*, 2012; Rao *et al.*, 2012). HIV infected women who had a good social relationships had a better quality of life (Imam *et al.*, 2011; Wan Zaidi *et al.*, 2012). Several studies reported in HIV infected women who more likely received support from family than friends or other sources (Li *et al.*, 2006; Ichikawa and Natpratan, 2008). In contrast to the longitudinal study of Burgoyne and Renwick (2004) who found that perceived social support was not a significant factor in determining quality of life of people living with HIV.

People living with HIV were suffered with symptoms and should undergo antiretroviral treatment that lengthen their lifespan (Hudson *et al.*, 2004; Jenkin *et al.*, 2006). Previous studies reported that severity of symptoms was related to lower quality of life among people living with HIV (Nojomi *et al.*, 2008; Abboud *et al.*, 2010). On the other hand, several studies identified the most common symptom of people living with HIV was fatigue (Jenkin *et al.*, 2006; Voss *et al.*, 2007; Bhengu *et al.*, 2009). Plach *et al.* (2006) reported that HIV infected women had severe experience of fatigue than men with HIV. However, study by Voss *et al.* (2007) identified that fatigue of HIV infected women and men were not different. Fatigue led people living with HIV to high levels of unsatisfied with not being able to perform

task that once were easy and impact on their quality of life (Jenkin *et al.*, 2006). Therefore, fatigue as a most symptom of people living with HIV was investigated especially in HIV infected women.

In addition, the functional status of individuals who are living with HIV can related to their quality of life. Several studies found that functional status is one of factors which had relationship with quality of life (Hudson *et al.*, 2004). HIV infected women carry out multiple roles as a wife, mother, and maintaining a household (Hudson *et al.*, 2004; Solomon *et al.*, 2008). Most HIV infected women had social roles such as being a mother, a relative, and a friend. This situation may lead them to confront a higher level of psychosocial stress (Solomon *et al.*, 2008) such as feeling alone as the disease progressed, inability to take care of themselves or family members. Plach *et al.* (2006) found that there was a significant association between functional status and quality of life in HIV infected women.

Living with HIV has many implications in people's lives that relate to their health status including physical and psychological. According to health related quality of life model of Wilson and Clearly (1995), the general health perception is one of the factors in quality of life. General health perceptions represent an integration of all the health concepts and takes into account satisfaction with health as well as how symptoms and functional abilities are valued. This model has been applied in HIV patients. General health perceptions represent an integration of all the health concepts previously (Vidrine *et al.*, 2005; Sousa and Kwok, 2006; Nokes *et al.*, 2011). A study by Eller and Mahat (2007) identified general health perception had relationship with quality of life among people living with HIV. In Indonesia, most people perceive that HIV is a disease that cannot be cured, and need long term medical treatment (Haroen *et al.*, 2008). Therefore, this study was examined whether health perception of HIV infected women related to quality of life.

According to above information, several gaps in quality of life, particularly of HIV infected women were identified. First, gender related to quality of life in people

living with HIV are inconsistent findings followed by characteristics of the individual, social support, fatigue, functional status, and quality of life. Perez *et al.* (2009) suggest gender focused research for further study. Second, most of the studies that focused on quality of life among people living with HIV are conducted in a clinical setting and focus on medical treatment (Eller and Mahat, 2007; Haroen *et al.*, 2008; Chandra *et al.*, 2009; Perez *et al.*, 2009; Patel *et al.*, 2009; Figuero *et al.*, 2011; Hosseinian *et al.*, 2011; Nokes *et al.*, 2011; Pereira and Canavarro, 2011; Handjani *et al.*, 2012). Third, many studies have explored the quality of life of people living with HIV. However, the study of in the patriarchal system as exists in Indonesia is limited. HIV and quality of life. Therefore, the study needs to explore this phenomenon related to quality of life. Fourth, Medan is the capital city of North Sumatera and apparently has an increasing number of HIV infected women (MoH of Medan, 2013). Medan has a unique characteristic: the patriarchal system. Patriarchy is a social system that emphasizes society grouping based on the male lineage. Monika (2009) explained that patriarchal system in Medan puts men in a position higher than women in all aspects social, cultural, and economic. Therefore, women have lower power in their family than men. Women have less power to negotiate for safer sexual intercourse and women risky for HIV infection that will be impacted on their quality of life.

Living with HIV means women are confronted with several personal problems that will impact their quality of life. Therefore, this study aims to identify factors related to quality of life in HIV infected women, particularly in Medan, North Sumatera, Indonesia. The result of this study will provided the information that can be as a references to develop nursing intervention and research for enhancing quality of life in HIV infected women.

OBJECTIVES

1. Overall objective:

The general objective of this study is to identify factors related to quality of life in HIV infected women in Medan, North Sumatera, Indonesia.

2. Specific objectives:

Specific objectives of this study are:

2.1 To identify quality of life in HIV infected women in Medan, North Sumatera, Indonesia.

2.2 To identify characteristics of the individual (age, marital status, educational level, employment status, and family income), fatigue, functional status, general health perception, and social support of HIV infected women in Medan, North Sumatera, Indonesia.

2.3 To identify the relationship between characteristics of the individual, including age, marital status, education level, employment status, family income and quality of life in HIV infected women in Medan, North Sumatera, Indonesia.

2.4 To identify the relationship between fatigue and quality of life in HIV infected women in Medan, North Sumatera, Indonesia.

2.5 To identify the relationship between functional status and quality of life in HIV infected women in Medan, North Sumatera, Indonesia.

2.6 To identify the relationship between general health perception and quality of life in HIV infected women in Medan, North Sumatera, Indonesia.

2.7 To identify the relationship between social support and quality of life in HIV infected women in Medan, North Sumatera, Indonesia.



LITERATURE REVIEW

This part explained the comprehensive concept of HIV/AIDS, HIV services in Indonesia, HIV infected women, the quality of life and the quality of life in HIV infected women. Moreover, theoretical framework of the study and factors that related to the quality of life in HIV infected women also reviewed in this part. Besides, the definitions of terms related to the quality of life in HIV infected women were described as follows.

1. Concepts of HIV

1.1 Definitions of HIV/AIDS

Since the late 19th or early 20th century, many different definitions of HIV/AIDS had been used to report cases or research HIV/AIDS (WHO, 2012). Human Immuno Virus (HIV) is a virus spread through body fluids that affects specific cells of the immune system, called CD4 cells and T cells. HIV can destroy many of CD 4 and T cells in which the body cannot fight off infections and disease (Centers for Disease Control [CDC], 2013). HIV is a type of virus that attacks the human immune system and can cause Acquired Deficiency Syndrome (AIDS) (National AIDS Commission, 2007). The World Health Organization (WHO) stated that the most advanced stage of HIV infection is AIDS. This stage takes place 10-15 years after infection (WHO, 2012). Even though HIV/AIDS treatments had been more effective than palliative care, long term treatment and unpredicted progress of the disease can have adverse affects like psychosocial and spiritual stress of individual and family (Spiritia AIDS Foundation, 2006).

Furthermore, O’Cofaigh and Lewthwaite (2013) described HIV can be transmitted through blood, genital fluids or breast milk that leads to virus-mediated

and immune system destruction (CD4 lymphocyte). Over time, the decline in CD4 lymphocytes leads individual to high risk of opportunistic infection.

In conclusion, HIV is an infectious disease that impaired immune system and can be progressed to AIDS stage in 10-15 years since infected with HIV by body fluids (e.g. blood, genital fluids, and breast milk).

1.2 Sign and symptoms of HIV/AIDS

Symptoms are defined as phenomena that people have experienced which constituted an aberration from normal function, sensation, or appearance (Hudson *et al.*, 2004). Symptoms of HIV/AIDS depended on the stage of disease. WHO explained that after the first few weeks after initial infection, individuals might hardly experienced any of the symptoms or they had mild infections such as the common cold, illness, headache, fever, sore throat, and rash. The progression of HIV infection, could lead to the weakening of the immune system of the person. An individual could show other signs and symptoms such as fever, diarrhea, swollen lymph nodes, cough, and weight loss (WHO, 2012).

WHO revised the clinical staging of HIV/AIDS for adults and how it has been widely used in Asia and also how it has been a useful research tool (WHO, 2012). The clinical staging can be divided into four stages as follows:

1.2.1 Clinical stage I (asymptomatic)

In this stage, people living with HIV may not have symptoms of HIV disease, but usually have lymphadenopathy as a physiological response to bodily infection. Laboratory tests such as viral load level, counting the amount of virus, are used to evaluate the progression of the disease. People who had a higher viral load showed indications that the diseased had progressed more. Though the symptoms seemed to be like a common cold, people in this stage had the possibility to transmit

the disease to other people (WHO, 2012; Bajurniwe *et al.*, 2009; Chen Fan *et al.*, 2011; Patel *et al.*, 2012; Reis *et al.*, 2012).

1.2.2 Clinical stage II

In this stage, unexplained symptoms were common, such as moderate weight loss due to infection (<10% of presumed or measured body weight), fatigue, recurrent respiratory tract infections, sinusitis, tonsillitis, otitis media and pharyngitis, herpes zoster, angular cheilitis, recurrent oral ulceration, papular pruritic eruptions, seborrhoeic dermatitis, and fungal nail infections progression (WHO, 2012; Bajurniwe *et al.*, 2009; Chen Fan *et al.*, 2011; Patel *et al.*, 2012; Reis *et al.*, 2012).

1.2.3 Clinical Stage III

People living with HIV in this stage had experienced more severity of the symptoms than in stage II. The symptoms for this stage such as unexplained severe weight loss (>10% of presumed or measured body weight), chronic diarrhea for longer than one month, persistent fever (above 37.6°C intermittent or constant, or longer than one month), severe fatigue, persistent oral candidiasis, oral hairy leukoplakia, pulmonary tuberculosis (current), severe bacterial infections (such as pneumonia, empyema, pyomyositis, bone or joint infection, meningitis or bacteraemia), acute necrotizing ulcerative stomatitis, gingivitis or periodontitis, unexplained anemia (<8 g/dl), neutropaenia (<0.5 × 10⁹ per litre) or chronic thrombocytopaenia (<50 × 10⁹ per liter) progression. (WHO, 2012; Bajurniwe *et al.*, 2009; Chen Fan *et al.*, 2011; Patel *et al.*, 2012; Reis *et al.*, 2012).

1.2.4 Clinical stage IV (AIDS)

This stage, people living with HIV were more likely to suffer from opportunistic infection such as pneumocystic pneumonia, recurrent severe bacterial pneumonia, chronic herpes simplex infection (orolabial, genital or anorectal of more

than one month's duration or visceral at any site), oesophageal candidiasis (or candidiasis of trachea, bronchi or lungs), Kaposi's sarcoma, cytomegalovirus infection (retinitis or infection of other organs), central nervous system toxoplasmosis, HIV encephalopathy, disseminated non-tuberculous mycobacterial infection, chronic cryptosporidiosis (with diarrhoea), invasive cervical carcinoma. People at this stage can die quickly because of the many opportunities of getting the disease (WHO, 2012; Chen Fan *et al.*, 2011; Patel *et al.*, 2012).

In addition, psychological symptoms related to infection were present in people, including anxiety, fear, and depression, particularly in HIV infected women (Hudson *et al.*, 2004). Psychological problems were often related to the disclosure of one's HIV status to family and friends and uncertainty regarding the course of one's illness. The psychological symptom may have been associated with stigma, limited social support, and perceived powerlessness (Hudson *et al.*, 2004).

1.3 Transmission of HIV

HIV is one of the communicable diseases and the transmission of HIV occurred through body fluids that are contained in blood, semen, and vaginal fluids. Therefore, the HIV transmission occurred through unsafe sexual intercourse, sharing needles in injection through illegal drug use, contaminated blood transfusion, and mother to baby during the prenatal period or the baby delivering process (National AIDS Commission, 2007; WHO, 2012). The study by Oluwagbemiga (2007) explained that the spreading of the HIV virus was different from many other diseases that have occurred in human history. The spreading of HIV infection had occurred by direct contaminated blood or other body fluids. Previous studies found that common HIV transmissions occurred by unsafe sexual behavior, sharing of drug apparatus, transfusion, infected mother to baby during delivery or in the early newborn period (Lashley and Durham, 2010).

2. The effects of HIV/AIDS

The diagnosis of HIV infection is regarded as a traumatic event in a person's life. They may have experienced a threat to survival and psychological distress (Hudson *et al.*, 2010). Living with HIV/AIDS presented unique problems which differed from other chronic illnesses. People living with HIV were not only concerned about HIV related symptoms, but also its complications, the fear of dying, and disruptions in relationships with their family, friends and neighbors. Furthermore, the long term impact of the symptoms of HIV infection on the day to day lives could have led other people who support them to have physical, psychological and social problems (Habib and Rahman, 2010).

2.1 Physical effect of HIV

Accordingly, there are many physical problems that were associated with HIV, it is a progressive disease that continued symptomatically and increased in severity. The most frequent symptoms included fatigue, dizziness, weight loss, lack of appetite, diarrhea, nausea, vomiting, coughing, painful joint, headache, night sweats, fungal infection, and any sexual transmitted disease (Norval, 2004; Phaladze *et al.*, 2005). After the diagnosis of HIV, the inabilities of people increased step by step and the periods of relief tended to be minimal. Therefore, HIV symptoms or physical problems depended on the stage of disease (Habib and Rahman, 2010).

2.2 Psychological effect of HIV

The psychological problem of living with HIV is immense, involving not only the potential burdens of physical deterioration, but also the stress of an accompanying lifestyle and role change (Hudson *et al.*, 2010). HIV diagnosis incurred a stigma associated both with the disease and with the fact that women engaged in high risk behavior. The shock of the news of when people found out they were infected by HIV led most of the people to experience a psychological crisis within the

first week of diagnosis that was associated with the symptoms of depression. Many factors contributed to the symptoms of depression in people living with HIV, including HIV disease and the side effects associated with treatment (Olatunji *et al.*, 2006). Diagnosis and progression of HIV may have elicited a full range of depression symptoms, including lack of motivation, profound sadness and general fear, worries, negative effects, low self-esteem and self confidence (Norval, 2004; Olley, 2006).

2.3 Social effect of HIV

HIV is accorded as punishment of promiscuous sex or illegal drugs used, which was morally disrespectable and social unacceptable (Ko *et al.*, 2007). People living with HIV often disrupted their interpersonal relationships, they would eventually have to confront major social issues that included who to tell about the infection, how to deal with possible disapproval or rejection, how to cope with the infection, how to find the new meaning of life under the threat of a potentially life threatening disease, and whether to pursue life as normally as possible or withdraw from social interactions and relationships (Subramanian *et al.*, 2009).

Previous studies found that most of the people living with HIV disclosed their HIV status to an immediate family member and later to their friends. However, after disclosing their HIV status, they received negative responses such as discrimination, social isolation, rejection by family, friends and relatives which resulted from HIV related stigma (Ko *et al.*, 2007). Fortunately, not all interpersonal consequences of HIV were negative. Some people living with HIV reported that their relationships with lovers, friends and family actually deepened as they show their explicit love and concern for the infected person. In some cases, people treated those with HIV as if they were something special and particularly desirable (Habib and Rahman, 2010).

2.4 Spiritual effect of HIV

HIV can have effects on spiritual practices because of HIV is devastating disease with multiple effect on all aspects of health. Spirituality transcended religious or cultural boundaries that were characterized by faith, search for meaning in life, the life force that led individuals to seek a connection within themselves and to others (Delgado, 2007). Spiritual practices and beliefs acted as a buffer when people were faced with negative life events (Scarinci *et al.*, 2009). Spirituality was used as a resource by HIV infected women to maintain psychological well-being and enhance health related quality of life (Dalmida, 2007). A study by Rivkin *et al.* (2006) about the expressive writing intervention of people living with HIV to examine the effect of living with HIV found that respondents had shown to have a greater appreciation of life, more compassion, and spirituality improvement.

On the other hand, previous studies found that most HIV infected women used practices for committing with their friends and other people. HIV infected women were encouraged to engage in spiritual practices and reflect on how these practices helped them to better understand themselves, their lives, and health and illnesses (Scarinci *et al.*, 2009). Therefore, spirituality played an important role in the lives and care of people living with HIV particularly HIV infected women.

3. HIV/AIDS services in Indonesia

The program for HIV/AIDS in Indonesia has been running for over 20 years since the first case of AIDS was discovered in 1987. Until now, the program had grown rapidly to include such services as prevention, treatment, care, and support. To implement this program, the government collaborated with hospitals and nongovernmental organizations (NGOs). Indonesia has several main hospitals, which provided the services of an HIV center, because not all of the hospitals provided HIV/AIDS services for example private hospitals. Nowadays, the government has tried to develop health care providers and volunteer services for improving capability

in HIV patient cares (MoH, 2009). The details about the services will be explained as follows:

3.1 Voluntary Counseling and Testing (VCT)

The VCT provided the most psychological support for HIV infected people, promoted changes to high risk behaviors, and provided facilities taking Anti Retroviral Therapy (ART) (MoH, 2009). The MoH of Indonesia has established policies to support this program: health care providers had to provide voluntary counseling before and after the HIV test. Previous studies explained that the purpose of VCT was for early detection to determine the status of a person already infected with HIV or have not been through the counseling and testing of HI V/AIDS voluntarily, not forced or obligated (Nasrodin, 2007). Knowing people's early HIV status would lead people living with HIV to utilize many of the services related to prevention, support, and treatment (Febriana, 2013). People living with HIV would understand more why it was important to test for HIV and how to manage self care of HIV infected persons (MoH, 2011). People living with HIV who had higher perceptions about the severity of HIV and the benefit of VCT had more willingness to utilize VCT services than those who had lower perceptions about the severity of HIV and the benefits of VCT (Fibriana, 2013). Therefore, VCT represented an entry point to give treatment, support, and medication for people living with HIV.

3.2 Hospitalized services

The hospital provided the services including VCT, treatment of HIV related symptoms, including opportunistic infections, treatment of Sexually Transmitted Infections (STIs), access to HIV medicines, palliative care ART for prevention of mother to child HIV transmission, nutritional support, and reducing stigma for people living with HIV (MoH, 2011). The MoH of Indonesia collaborated with the AIDS Committee at the central or regional, and the NGOs to support HIV/AIDS service in peripheral areas that were closer to society. These strategies

aimed to reach the society, especially the people those who are high risk for HIV infection. The activities that followed include:

3.2.1 Increasing the awareness of individual, groups, and society in the prevention and treatment of HIV/AIDS, implementing target intervention programs for behavioral change for those who have high risk behavior.

3.2.2 Advocating human rights, eliminating discrimination against people living with HIV, and providing social and family support.

Consequently, the HIV services in Indonesia has tried to improve the utilization of the HIV program to reach or cover the HIV infected women. The less awareness of the community, disempowered health care volunteers, and lack of knowledge of HIV infected women due to limitation of information sources and accessibility to the health care services were the main reasons that prohibiting the optimum HIV service utilization. Those reasons are also impacting the quality of life in HIV infected women. Thus, the study related to the predicting factors of quality of life in HIV infected women is needed to perform.

4. HIV infected women

People living with HIV were commonly discriminated against and rejected by their families, friends, and community (Cao *et al.*, 2010). Women were an increasingly vulnerable group for HIV infection, even though for more than two decades the HIV prevention had been widely promoted (UNAIDS, 2008). HIV infected women were labeled as being sexually promiscuous or drug users (Subramanian *et al.*, 2009). They were often subjected to societal judgment and were stigmatized because of the disease. Therefore, HIV infected women tended to have many negative impacts such as unemployment and less accessibility to health care services (Plach *et al.*, 2006).

HIV infected women were more likely to acquire HIV infection from their husbands or partners. Married women had been shown to be at a high risk for infection with HIV (Subramanian *et al.*, 2009). In some culture, women had a lack of power to negotiate or decide for safer sexual behaviors with their husbands or partners.

The gender of people living with HIV was found to have had a different variety of aspects including health care access, employment, and social settings (Chandra *et al.*, 2009). Barriers of care were due to the lack of knowledge about HIV, family responsibilities, and the burden or fear of disclosure. There were suggestions of empowerment that could be used as a strategy for attaining health and improving the quality of life in HIV infected women as required. Therefore, this study was to explore the factors related to quality of life in a specific gender, in this case the HIV infected women.

In conclusion, HIV infected women were faced with many problems. Fear and prejudice that are experienced by HIV infected women was from socially related discrimination (Subramanian *et al.*, 2009). They were challenged with economic, cultural, and social disadvantages, including inequitable health care services and lack of empowerment in the society (Reis *et al.*, 2012). A gender sensitive approach should be highly focused on women, particularly in access to health care services. Therefore, this study was identified the quality of life in HIV infected women and factors that related to quality of life to provide fully understanding for this phenomenon.

5. Concepts of quality of life

Quality of life is a concept that has been used since the time of Aristotle (384-322 BC) to the current day (Mandzuk and McMillan, 2005). Quality of life has become an important issue in philosophy, Biometry, social science, clinical medicine, health services and outcomes research (Ferrans *et al.*, 2005). Based on literature

review, there are two concepts regarded to the quality of life in the health literature: quality of life and health-related quality of life.

5.1 Definitions of Quality of Life

In 1997, the WHO defined quality of life as individuals' perception of their position in life in the context of the culture and value systems in which they lived and in relation to their goals, expectations, standards and concerns. This was the most widely accepted definition, since many scholars had different definitions. Similarly, Khumsaen *et al.* (2012) defined quality of life of people living with HIV referred to an individuals' perception about the degree of satisfaction with and ability to perform in life. Ferrans and Power (1992) defined quality of life as a sense of a person's well-being that stemmed from satisfaction or dissatisfaction with the areas of life that were important to him/her.

5.2 Health Related Quality of Life

In relation between health and quality of life of an individual, quality of life was affected by health conditions either physical or psychological. Therefore, the term health related quality of life (HRQOL) was introduced to focus on the effects of health, disease, or treatment on quality of life (Ferrans *et al.*, 2005). Patrick and Erickson (1993) defined HRQOL as the value assigned to the duration of life as modified by the impairments, functional states, perceptions, and social opportunities that were influenced by disease and health care delivery. Smith *et al.* (1999) stated that health related quality of life was defined as a multidimensional construct for the patients' perceived well-being, which centered on physical, mental, and social functioning. HRQOL concept is possible to demonstrate scientifically the impact of health on quality of life.

5.3 Domain of quality of life

According to the definition of quality of life, there were many used to describe the various domains that examined the quality of life. WHOQOL-HIV Group (2004) mentioned four domains of quality of life: physical domain, psychological domain, social domain, and environmental domain. Previous studies used this domain to describe the quality of life of people living with HIV ((Nojomi *et al.*, 2008; Subramanian *et al.*, 2009; Abboud *et al.*, 2010; Handjani *et al.*, 2012; Khumsaen *et al.*, 2012; Bello *et al.*, 2013).

Based on several definitions of quality of life, the individual was the common source of information to measure the quality of life. Nevertheless, a study conducted by Wisawatapnimit (2009) explained that significant others such as relatives or families as caregivers and health care professionals could provide information related to the patient's quality of life. Moreover, several definitions of quality of life were studied with several population groups, the quality of life of people living with HIV was a concept that had received increasing attention, as it was recognized that HIV can impact all aspects of their lives. Quality of life had become an essential outcome to consider in the overall health and well-being of people living with HIV (Tam *et al.*, 2012) and an increasingly relevant outcome measured in medical practice and research. Therefore, the quality of life was a very important focus of research in people living with HIV, particularly in women who were more affected than men with the same disease. This problem deserved further investigation.

6. Quality of life in HIV infected women

The quality of life was related to an individual's health or disease status. The HIV status of women had influenced their quality of life. Previous studies had explored the quality of life among people living with HIV (Chandra *et al.*, 2009; Figuero *et al.*, 2011; Imam *et al.*, 2011; Khumsaen *et al.*, 2012; Wan Zaidi *et al.*, 2012), and focused on the HIV infected women (Eller and Mahat, 2007; Hosseinian *et*

al., 2011; Reis *et al.*, 2012). The quality of life for HIV infected women was an interesting topic to explore for many reasons. First, the quality of life among women and men those who living with HIV were different (Nojomi *et al.*, 2008; Perez *et al.*, 2009; Pereire and Canavarro, 2011). Second, several studies found that HIV infected women had lower quality of life than men who lived with HIV (Ichikawa and Natpratan, 2006; Zimple and Fleck, 2007). Third, most of the HIV infected women had lower quality of life in the psychological domain (Sun *et al.*, 2007; Solomon *et al.*, 2008), and social domain (Subramanian *et al.*, 2009; Xiaoyan and Sato, 2011). Fourth, contradictory findings showed that HIV infected women had better quality of life than men who lived with HIV (Perez *et al.*, 2009; Imam *et al.*, 2011). Additionally, many factors had influenced the quality of life of people living with HIV.

Various quality of life instruments had been used in people living with HIV such as the Medical Outcomes Study (MOS), the Health Survey HIV (Wu *et al.*, 1997), the Functional Assessment of HIV Infection (FAHI) (Peterman *et al.*, 1997), the Multidimensional Quality of Life Questionnaire for HIV/AIDS (MQOL-HIV) (Smith *et al.*, 1997), the McGill Quality of Life Questionnaire (MQOL) (Cohen *et al.*, 1995), the HIV QOL Questionnaire (HIV-QL31) (Leplege *et al.*, 1997), and the HIV Overview Problems Evaluation System (HOPES) (De Boer *et al.*, 1996). These instruments were developed in a single culture, particularly the western culture. Even though translated, they may have been insensitive materials or they did not apply to people from another culture. Several questionnaires were very long because they consisted of many items such as the HOPES questionnaire which had 142 items for 33 sub-scales and the Multidimensional Quality of life Questionnaire-HIV had 40 items on 10 dimensions. Robinson *et al.* (2004) identified that MOS-HIV had limited use in HIV infected women.

The WHO collaborated with 15 centers around the world which had developed an instrument to measure quality of life that called the WHOQOL-Bref, which can be used in varied cultures (WHOQOL Group, 1998). WHOQOL-Bref had proven cross

culture validity also and was available in more than 40 languages included Bahasa Indonesia. WHOQOL-Bref consisted of four domains; 1) physical domain, 2) psychological domain, 3) social domain, and 4) environment domain. On the other hand the WHOQOL-Bref was a short instrument that had high reliability (Cronbach's alpha 0.93) and each domain had a good reliability score that was about 0.75-0.86, which was easy to understand and easy to score (Hsiung *et al.*, 2005). Thus, the WHOQOL-Bref in Bahasa Indonesia version was used to achieve the aims of the study.

7. Theoretical Framework of the study

Research in quality of life areas needed theoretical framework that appropriates with the purposes of the study. Most studies were focused on the quality of life and how it related to the domains for people living with HIV (Astoro, 2007; Chandra *et al.*, 2009; Perez *et al.*, 2009; Imam *et al.*, 2011; Pereira and Canavarro, 2011; Tran *et al.*, 2011; Reis *et al.*, 2012; Oktavia, 2012; Wan Zaidi., 2012). The health related quality of life was increasingly used as an outcome in clinical trials and research on quality of life. Wilson and Clearly (1995) introduced the Health Related Quality of Life (HRQOL) model that composed of five subsections a) biological and physiological factors, b) symptoms, c) functioning, d) general health perceptions, and e) overall quality of life. Each of the variables described causal relationships that linked to the measures of health related quality of life (Wilson and Clearly, 1995).

Later on, the health related quality of life model was revised by Ferrans *et al.* (2005) based on the ecological model of Eyer *et al.* (2002). The ecological model explained about individual characteristics (intrapersonal factors) and environmental characteristics (interpersonal factors). Ferrans *et al.* (2005) believed both of the individual and environment factors had influenced the health outcomes. Therefore, the revised Wilson and Clearly model for HRQOL was used to guide the study (see Figure 1).

In the revised Wilson and Cleary model for HRQOL, it explained how the characteristics of the individual would have influenced the overall quality of life. There were six variables such as a biological function, symptoms, functional status, and general health perception, characteristics of the individual and characteristics of the environment which influenced the quality of life (Ferrans *et al.*, 2005).

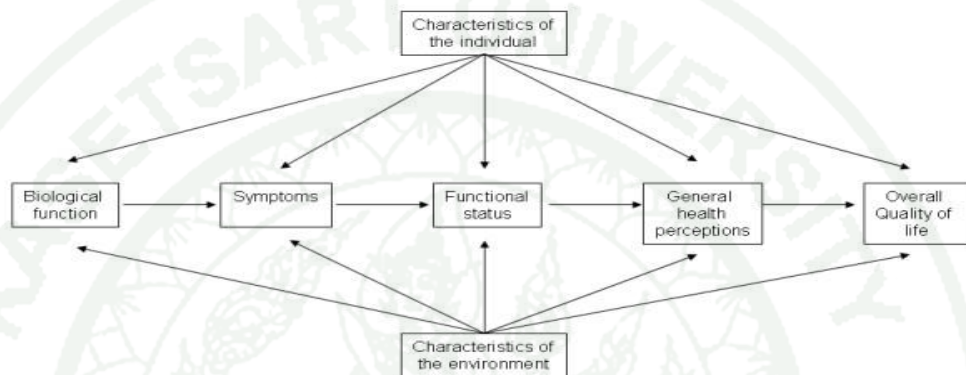


Figure 1 Revised version Wilson and Cleary Model for Health Related Quality of Life (Ferrans *et al.*, 2005)

Source: Ferrans *et al.* (2005)

7.1 Characteristics of the individual

The characteristics of the individual are categorized as factors that determined the health issue which included demographic, biological, developmental, and psychological factors (Ferrans *et al.*, 2005). Biological factors included body mass index, and family stories that related to genetically related disease and disease risk. Demographic factors in this model were identified as age, gender, marital status, and ethnicity. These features were difficult to modify, but useful for specific groups in the intervention and gave guidance to health care providers in targeting whom to screen for health problems to reduce the risk. Psychological factors were dynamic, modifiable, and response to interventions. These dynamic psychological factors could have influenced one and another (Ferrans *et al.*, 2005).

7.2 Characteristics of the environment

Beside characteristics of the individual, quality of life was determined by characteristics of the environment. Characteristics of the environment were an additional factor in the revised model. This factor was developed from an ecological model by Eyer *et al.* (2002). Characteristics of the environment were categorized as either social or physical (Eyer *et al.*, 2002). Moreover, social environmental characteristics were the interpersonal or social influences on health outcomes, including the influence of family, friends, and health care providers (McLeroy *et al.*, 1988). The effects of the social environment were significantly influenced by an individual's cultural heritage that could affect participation in care and treatment. Social support was considered to represent an aspect of the social environment. Furthermore, physical environmental characteristics were the home, neighborhood, and workplace that influenced the health outcomes either positively or negatively (Ferrans *et al.*, 2005). Both of the characteristics of the individual and the characteristics of the environment had influenced the quality of life.

7.3 Biological function

In the revised Wilson and Clearly model for HRQOL, the indirect pathway started from biological function. This meant that it was an important predicting factor. Biological function included the whole organ level processes that supported life. The revised Wilson and Clearly model for HRQOL showed the effects of individual and environmental characteristics on biological functions (Ferrans *et al.*, 2005). Biological functions consisted of cell function and the whole organ system. It was commonly measured by laboratory testing and physical examination. The interaction of individual and environmental characteristics influenced biological functions (Ferrans *et al.*, 2005). Based on this model, biological function is related to the symptoms.

7.4 Symptom

Wilson and Clearly (1995) had indicated that moving attention from biological and physiological variables to symptoms required a shift in focus from the cellular and organism level to the person level. Symptoms were a patient's perception of an abnormal physical, emotional, or cognitive state, which can be categorized as physical, psychological, or psychophysical (Wilson and Clearly, 1995). The symptoms are influenced by complex interactions between individual and environment characteristics (Ferrans *et al.*, 2005).

7.5 Functional status

The following factor is functional status. Wilson and Clearly (1995) defined functional status as the ability to perform tasks in multiple domains such as physical function, social function, role function, and psychological function. In this model, multiple factors could have affected functional status, such as a biological function, symptoms, individual and environmental characteristics (Ferrans *et al.*, 2005). Nevertheless, symptoms alone did not fully relate to the decrease in functional status. This depended on the severity of symptoms, it might have disrupted the day to day level of activity which could have impacted a patient to experience a decline in functional status. Yet, the decline also could have been influenced by individual characteristics and social environment factors such as social support (Ferrans *et al.*, 2005).

7.6 General health perception

The next factor in this model is the general health perception that directly related to the functional status and indirectly related to symptoms and biological function. This model also explained that the general health perception was also influenced by the characteristics of the individual and the environment. Wilson and Clearly (1995) had explained that the general health perception was an individual

overall evaluation of various aspects of health. The perception was mostly measured by a single global question about their health perceptions on a scale that ranged from poor to excellent (Ferrans *et al.*, 2005).

7.7 Overall quality of life

The final version of this model is the overall quality of life. Wilson and Cleary (1995) defined overall quality of life as subjective well-being that related to how happy or satisfied someone was with life as a whole. The number of life domains varied among authors, depending on the desired level of generality. The domains had been characterized as a healthy and functioning, psychological and spiritual, family, social, and economic. This characterization was consistent with the existing views of the domains of quality of life (Ferrans *et al.*, 2005).

The Health Related Quality of Life conceptual model had been widely applied for chronic illnesses such as end stage renal disease on hemodialysis (Kring and Crane, 2009), type 2 diabetes melitus (Agustini, 2013), for the elderly with hypertension (Kamaryati, 2013), and HIV (Tangkawanich *et al.*, 2008; Nokes *et al.*, 2011). The model was modified and showed some concern for cancer patients and was able to be applied for use in chronic illness (Ferrans *et al.*, 2005). Previous studies used this model to identify the relationship between variables and the quality of life of people living with HIV (Vidrine *et al.*, 2005; Sousa and Kwok, 2006; Saban *et al.*, 2007; Kring, 2008; Nokes *et al.*, 2011).

HIV is a chronic disease that is a life-threatening condition (Tangkawanich *et al.*, 2008), by using this model it would help the researcher understand the relationship among concepts that related to the quality of life. Vidrine *et al.* (2005) assessed a health related quality of life model to that of the Wilson and Cleary model (1995) in an HIV/AIDS population. They suggested that the variables of this model related to the overall quality of life in people living with HIV. On the other hand, they explained that the biological variables related to the symptom status,

which further related to functional status, forward related to general health perceptions, and then the last related to the quality of life people living with HIV. Therefore, this model was helped the researcher to achieve the purpose of the study.

8. Factors related to quality of life in HIV infected women

Various factors that related to the quality of life in HIV infected women were identified by previous studies (Eller and Mahat, 2007; Andrinopoulus *et al.*, 2011; Reis *et al.*, 2012). However, there were still inconsistent findings in the characteristics of the individuals, fatigue, functional status, and social support. The explanations were provided as followed.

8.1 Age

Various characteristics of the individual that related to the quality of life in HIV infected women, included age, marital status, education level, employment status, and family income. Age as one of the demographic factors that related to the quality of life was explained by previous studies (Chandra *et al.*, 2009; Hasanah *et al.*, 2011; Nokes *et al.*, 2011; Pereira and Canavarro, 2011). Reis *et al.* (2012) conducted quality of life surveys among HIV infected women, in subjects that ranged in age from 20 to ≥ 50 years old found that age range was associated with the quality of life. Khumsaen *et al.* (2012) conducted studies on factors that influenced the quality of life among people living with HIV with ages that ranged from 18 to 65 years old. They found age to be a statistically significant association with quality of life. Previous studies identified that older (≥ 35 years) HIV infected women had lower quality of life scores (Chandra *et al.*, 2009; Pereira and Canavarro, 2011). In contrast, several studies found that younger HIV infected women had lower quality of life scores (Zimpel and Fleck, 2007; Hasanah *et al.*, 2011; Khumsaen *et al.*, 2012). Although age was an unchangeable factor, it was important to recognize how it influenced the population. Therefore, in this study was identified age as a factor related to the quality of life among HIV infected women.

8.2 Marital status

Marital status is one of characteristics of the individuals that are associated with quality of life in HIV (Nojomi *et al.*, 2008; Chandra *et al.*, 2009; Abboud *et al.*, 2010). Several studies observed the inconsistent association of marital status and quality of life of HIV. Previous studies showed that HIV infected women who were married had a higher quality of life (Marcelin *et al.*, 2008; Abboud *et al.*, 2010; Bello *et al.*, 2013). It can be reflected that married women have better support from their spouse to encounter their problem, hence enhanced their quality of life. In contrast, several studies found that HIV infected women who were married had lower quality of life than those that were unmarried (Zimpel and Fleck, 2007; Nojomi *et al.*, 2008). Being married had been shown to be risky for women to acquire the HIV infection from their husband. Married women diagnosed with HIV were looked down upon and felt worried that their husbands and families would leave them alone. The inconsistent findings indicated that there were many factors that could have influenced the lives of married women with HIV. Therefore, this study was identified relationship between marital status and quality of life in HIV infected women.

8.3 Education level

Another factor of characteristics of the individual is educational level. Previous studies reported that educational level had a significant association with the quality of life in people living with HIV (Nojomi *et al.*, 2008; Khumsaen *et al.*, 2012; Bello *et al.*, 2013). The study found people living with HIV who had a higher education level had higher quality of life (Nojomi *et al.*, 2008). People who were more educated could better understand the disease and the instructions on disease management such as ART usage. They were able to conceptualize on how to deal with HIV related symptoms and had higher quality of life than the lower educated people (Zimpel and Fleck, 2007; Khumsaen *et al.*, 2012). However, Abboud *et al.* (2010) identified the that people living with HIV who had lower education levels had higher quality of life. Educated people may have been more aware of the disease, its

complications and the alterations in lifestyle needed to prevent its transmission to others, which may have caused them to worry and get depressed, and in effect caused them to have lower quality of life. Therefore, this study was included educational level as a factors related to quality of life in HIV infected women.

8.4 Employment status

On the other hand, the employment status was identified as one of the factors that were significantly associated with the quality of life (Nojomi *et al.*, 2008; Imam *et al.*, 2011; Khumsaen *et al.*, 2012; Reis *et al.*, 2012). Several studies showed that being unemployed (or not currently working) was associated with lower quality of life among people living with HIV (Nojomi *et al.*, 2008; Pereira and Canavarro, 2011; Khumsaen *et al.*, 2012). The chronic complications of the HIV virus brought new challenges such as employment status related issues, as employment not only provided financial benefits but might also have been a source of social support. HIV infected women faced difficulties for accessibility to economic and social resources, and it often led them to be have a lower quality of life.

8.5 Family Income

Income was viewed as the socioeconomic status of individuals and was typically divided into three categories, high socio-economic status, middle socio-economic status, and low socio-economic status. Previous studies found that family income was a significant relationship with the quality of life of people living with HIV (Hasanah *et al.*, 2011; Khumsaen *et al.*, 2012). They identified that people with higher monthly incomes had a higher quality of life than those without any incomes or those with lower incomes. On the other hand, a study by Imam *et al.* (2011) determined the financial sufficiency was significantly associated with the quality of life of people living with HIV. They found that people living with HIV with good financial sufficiency had better quality of life.

Since people that were diagnosed with HIV, there had been an effect on the economic status or those of people who had lost their jobs. Particularly those that were HIV infected women who were most often economically disadvantaged (Subramanian *et al.*, 2009). This ultimately resulted in additional burden to their families. Contradictory, several studies found that family income had no significant relationship with the quality of life of people living with HIV (Figuro *et al.*, 2011; Xiaoyan and Sato, 2012). This could have occurred due to the diversity of the sample nature. For these reasons family income played an important factor in the quality of life and interestingly income status need to be explored more in this study. Furthermore, there had been limited investigations in the association between income status and the quality of life in HIV infected women in Medan, North Sumatera, Indonesia. Thus, this study was identified the relationship between family income and quality of life in HIV infected women.

8.6 Fatigue

Fatigue is a highly prevalent symptom among people living with HIV especially in develop countries (Voss *et al.*, 2007). Symptoms is a patient's perception of an abnormal physical, emotional, or cognitive state (Wilson and Clearly, 1995). Therefore, HIV related fatigue has been describes as extended perception of tiredness and exhaustion which is unrelieved by a full night sleep or rest. Previous study found that fatigue has significant association with quality of life in HIV infected women (Nokes *et al.*, 2009; Hudson *et al.*, 2010). Plach *et al.* (2006) reported that HIV infected women had severe experience of fatigue than men with HIV. However, study by Voss *et al.* (2007) identified that fatigue of HIV infected women and men were not different. Therefore, this study was investigated whether the fatigue related to quality of life in HIV infected women.

To identify fatigue of people living with HIV, previous studies used several measurement such as SSC-HIV rev by Holzemer *et al.* (1999) which is checklist of HIV/AIDS-specific symptoms. Yet, this questionnaire consisted 72 item

that inconvenient for people living with HIV. Moreover, HIV-Related Fatigue Scale (HRFS) by Barroso and Lynn. (2002) is specific questionnaire to measure fatigue of people living with HIV, however this questionnaire consisted 56 items. The participants take more time to complete the question, especially if study consists of several questionnaires. Another questionnaire is fatigue rating scale by Waltz *et al.* (2010) that measured by Visual Analog Scale (VAS). This scale was a common approach to measure the intensity of symptom (e.g. pain, fatigue, etc.). The questionnaire asked participants to rate the fatigue that are currently perceived (Waltz *et al.*, 2010). This questionnaire have been used in chronic illness such as hypertension of Indonesian population (Kamaryati, 2013). This questionnaire more convenient for participants to identify the symptom. Therefore, in this study was employed Fatigue Rating Scale by Waltz *et al.* (2010) to measure fatigue scale of HIV infected women.

8.7 Functional status

Functional status was defined as the ability of an individual to perform and adapt to one's environment, measured both objectively and subjectively over a given period (Sousa and Kwok, 2006). The functional variables included physical functioning, social functioning, emotional functioning, and role functioning. Solomon *et al.* (2008) found that HIV infected women carried out multiple roles as a wife and maintaining a household. HIV infected women were particularly difficult beings when they suffered from HIV symptoms. These situations may have led those people who had HIV to confront higher psychosocial distress (Kumarasamy *et al.*, 2008) such as feeling alone as the disease progressed and the inability to take care of themselves.

Plach *et al.* (2006) identified that most the HIV infected women had social role functions like being a mother, a relative and a friend. Then, functional status had a significant correlation with the symptoms. A study of Hudson *et al.* (2010) on functional status among HIV infected women found that specifically self

care activities rather than household activities were the components of functional status and quality of life.

To measure functional status a few studies used specific instruments, most of the studies were identified by an instrument that included a quality of life instrument such as FAHI. However, a study by Hudson *et al.* (2010) used the Inventory of Functional Status by Tulman *et al.* (1991) to measure functional status in HIV infected women. This questionnaire was specifically used to measure the functional status of women. Therefore, this questionnaire was applied to HIV infected women.

8.8 General health perception

Wilson and Clearly (1995) defined the general health perception as an individual's perception of various aspects of health. General health perception was affected by functional status, symptom, biological function, and the characteristic of individual and environment. However, each factor had different components. Therefore, using measurements of other components, including symptom, functional status to evaluate general health perceptions was not appropriate (Ferrans *et al.*, 2005).

Furthermore, general health perception had significant association with the individual's quality of life (Ferrans *et al.*, 2005). A study by Eller and Mahat (2007) identified general health perception was has significant relationship with the quality of life of people living with HIV. On the other hand, a study by Figuero *et al.* (2011) showed that HIV infected women, those who lived alone and those without children had higher scores of general health perception, and this led them to have a higher quality of life. In Indonesia, particularly Medan, the study about general health perception that related to the quality of life had not been found yet. Therefore, this is an interesting challenge to explore this phenomena regarding the general health perception could be a factor that related to quality of life in HIV infected women.

Based on recommendation of Ferrans *et al.* (2005) , general health perception are often measured by single question that asks people to rate their health on a scale ranging from poor to excellent although it can also be measured by battery of items.

8.9 Social support

Social support had been interesting in previous studies because of its potential to influence health outcomes, including the quality of life in a variety of situations (Khumsaen *et al.*, 2012). Then social support had been a widely used concept in studies that related to psychological distress and health. Generally, increased social support served to decrease psychological problems and increase greater satisfaction with social support which was seen an important factor that was associated with the quality of life in people living with HIV (Sun *et al.*, 2007).

Several studies found that perceived social support for people living with HIV had better quality of life (Bajurniwe *et al.*, 2009; Imam *et al.*, 2011; Rao *et al.*, 2012; Wan Zaidi *et al.*, 2012). Then, Khumsaen *et al.* (2012) also identified that social support was one of the predictors of the quality of life among people living with HIV. Contradictory, a study by Eller and Mahat (2007) of HIV infected women found that family support was not related to the quality of life. Family was the primary source of social support for those who experienced serious illnesses such as people living with HIV (Bor *et al.*, 2004). However, a study by Gordillo *et al.* (2009) identified that HIV infected women had more difficulties in receiving support from their partners and families.

Previous studies showed that among people living with HIV there was perceived social support, especially family support (Sun *et al.*, 2007; Khumsaen *et al.*, 2012), and greater family support was found to be a predictor for a better quality of life among people living with HIV (Jia *et al.*, 2007). Other studies were investigated among people living with HIV perceived support from their friends (Imam *et al.*,

2011; Wan Zaidi *et al.*, 2012), when their friends who knew about the HIV status, they were more likely to have had a positive effect on the quality of life.

HIV is a disease often characterized by social stigma and people living with HIV interact with and view various people as their family because of the support, commitment, and significant roles. Then, they are satisfied with the family support which may include anyone, such as immediate relatives, spouse, co-workers, and friends (Prachakul *et al.*, 2009). For these reasons, social support was an interesting factor in the quality of life, there has been limited investigations of the social support of the association between HIV infected women on the quality of life. Therefore, it has become a challenge in this study to identify social support as a factor related to quality of life of HIV infected women.

Based on literature review, several studies used various social support questionnaires in their studies such as the Medical Outcome Study (MOS) Social Support Survey (SSS) developed by Sherbourne and Stewart (1991) that consisted of four dimensions; 1) emotional-informational, 2) affectionate, 3) tangible, and 4) positive social interaction to represent the types of support available from unspecific sources. The MOS-SSS was applied in people living with HIV with a reliability of 0.86 (Lyons, 2010). Another questionnaire that was used to measure availability was the Multidimensional Perceived Social Support Survey (MSPSS) which was developed by Zimet *et al.* (1988) that consisted of 12 items.

The MPSS questionnaire was the easiest to use in people living with HIV, self explanatory time effective scale distinguished perceived social support from three sources include family, friends, and a significant other, and a good reliability score was 0.89 (Sun, 2007; Xiaoyan and Sato, 2011). Previous studies determined that HIV infected women had more perceived family support than friends or other social support which were an important measure for other types of support that were available (Li *et al.*, 2006; Ichikawa and Natpratan, 2008). This study was identified the source of support of HIV infected women. Therefore, MSPSS was employed and

appropriated questionnaire in this study to identify social support in HIV infected women.

9. Conceptual framework of the study

This study was utilized the revised Wilson and Cleary's (1995) model for health-related quality of life (Ferrans *et al.*, 2005) as a conceptual framework. The independent variables were characteristics of the individual (age, marital status, education, employment status, and family income), fatigue, functional status, general health perception, and social support. As a result, the quality of life is a health outcome. This model can be used in HIV infected women. Therefore, the model was used to describe whether characteristics of the individual, functional status, general health perception, and social support can predict the quality of life in HIV infected women in Medan, North Sumatera, Indonesia.

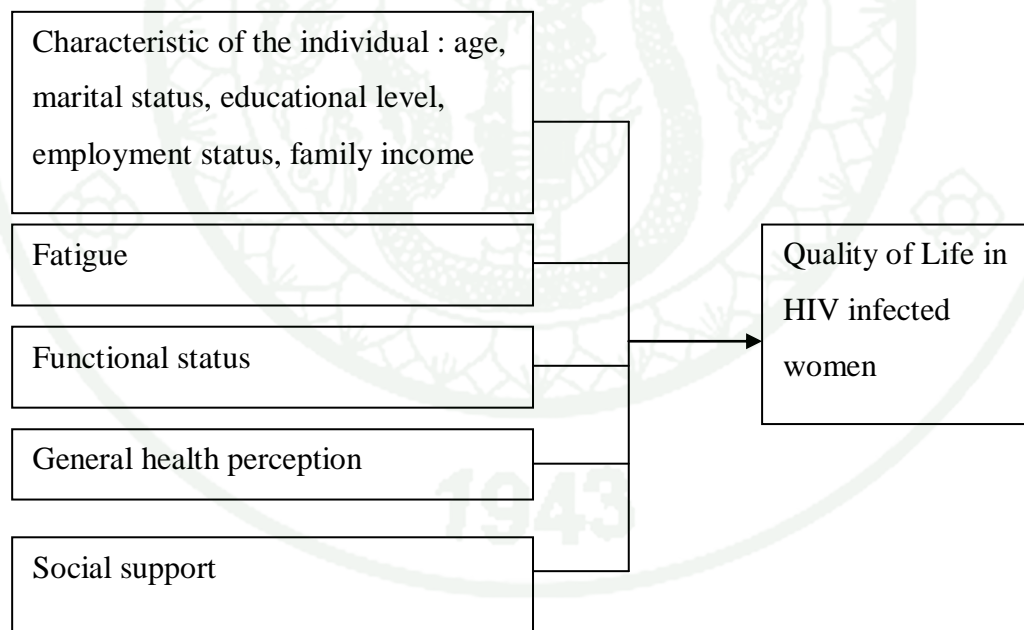


Figure 2 Conceptual framework of the study

10. Definition of terms

The general objective of this study was to identify the factors that related to quality of life in HIV infected women, including characteristics of the individual (age, marital status, education level, employment status, family income), fatigue, functional status, general health perception, and social support of quality of life in HIV infected women in Medan, Indonesia. This part described about operational definitions variables. The operational definitions of this study were as follows.

10.1 Age refers to HIV infected women aged 18-45 years old calculated from birth until last birthday that was determined by Demographic Information Questionnaire.

10.2 Marital status defines a legal condition of HIV infected women in Medan, North Sumatera, Indonesia from family card divided by single, married, divorced, and widowed determined as reported on the Demographic Information Questionnaire. It is categorized married and unmarried. Married is HIV infected women who has legal certificate. Unmarried is HIV infected women who did not have legal certificate those who were divorced and widowed.

10.3 Educational level distinct as HIV infected womens' degree of school attendance that measured by year of the school stage with categorized by Indonesian basic year education program; elementary (grade 1-6), junior high school (grade 7-9), senior high school (grade 10-12), and college (grade 13-18) level determined as reported on Demographic Information Questionnaire. According Ministry of Education of Indonesia, the level of education divided to three categories based on to 9th years compulsory education. There are low education (elementary and junior high school), moderate education (senior high school), and high education (college/university).

10.4 Employment status means the present work of HIV infected women was categorized by two types: employed refers to HIV infected women who could obtain the money, unemployed refer to HIV infected women who could not earn the money was identified by using the Demographic Information Questionnaire.

10.5 Family income is defined as the total amount of money that obtained by the household members. This data was identified by the minimum monthly income of Medan district and categorized into three types; high, moderate, and low income were used the Demographic Information Questionnaire.

10.6 Fatigue is a symptom of HIV that HIV infected women feel. It was measured by fatigue rating scale from 0 (no fatigue) to 10 (extreme fatigue) by Waltz *et al.* (2010).

10.7 Functional status defined the ability of HIV infected women to perform household activities, social and community activities, self care activities, and employment status activities that was measured by the Inventory of Functional Status (IFS) by Tulman *et al.* (1991).

10.8 General health perception refers to the perception of HIV infected women on their health status that was measured by single question general health perception (Ferrans *et al.*, 2005).

10.9 Social support is perceived availability of support that HIV infected women received from family, friend, and others. It was measured by the Multidimensional Perceived Social Support Scale (MPSSS) questionnaire developed by Zimet *et al.* (1988).

10.10 Quality of life determined as an HIV infected women's perception about how satisfy their life as a whole that measured by WHOQOL-Bref (2004). It consisted of physical, psychological, social, and environment domain.

MATERIALS AND METHODS

Materials

This part aimed to describe the materials and methods of the study such as the research instrument that were used and the explanation of the procedure in conducting this study.

The instruments used for data collection comprised of demographic information questionnaire, Fatigue Rating Scale, Inventory of Functional Status (IFS), General Health Perception, Multidimensional Perceived Social Support Scale, and WHOQOL-Bref. These entire research instruments were appropriately modified to the Indonesian women population and have been translated into Bahasa Indonesia by expert and bilingual speakers using back translation techniques before applying in the current study. Firstly, the questionnaires were translated from English into Bahasa Indonesia. Secondly, the questionnaires were translated back into English. The English translation was compared with the original and if any discrepancies were discussed to get the correct translation. However the WHOQOL-Bref had been provided in Bahasa Indonesia version. Each questionnaires were permit from the authors to be used in this study, except demographic information questionnaire, which developed by researcher (see appendix F).

The validity test of instruments was employed by three experts. The experts are nursing educator and researcher on HIV, medical doctor who was specialized in HIV, and social scientist who had responsibility in HIV infected women program. The experts were asked to rate the clarity and relevancy of the instrument by using Content Validity Index (CVI) which developed by Waltz and Bousel (1981, cited in Burn and Grove, 2009). The expert rated each item clarity and relevancy using 4-point starting scale: 1 = irrelevant, 2 = cannot be assessed without revising the item in questionnaire, 3 = relevant, it takes a bit revision, and 4 = very relevant. The experts

also provided suggestions in a few items of questionnaires. If 80 % of experts rated items as 3 to 4, the question of questionnaires were clear and relevant for target samples (Burn and Grove, 2009). The validity test revealed that clarity of all questionnaire in this study was ranged from 91% to 100 % and 95% to 100 % for relevancy. Based on suggestions or comments from experts, a few items of questionnaires were revised. The research instruments are described as follows:

1. Demographic information questionnaire

The demographic information questionnaire was developed by the researcher to collect information from the participants. This questionnaire consisted of age, marital status, education level, employment status, and family income. Other questions included in the demographic information questionnaire are the year were infected with HIV, and the perception of transmitted to HIV. Content validity was examined, the relevant and clarity of demographic information questionnaire were 100 %.

2. Fatigue Rating Scale

Fatigue was measured by single numeric rating scale that common approach to measure the intensity of symptom (e.g. pain, fatigue, etc.) (Waltz *et al.*, 2010). Participants were asked to rate the fatigue symptom that currently perceived from 0= no fatigue to 10= extreme fatigue. Based on Waltz *et al.* (2010), fatigue scale was divided into three categorized; no fatigue (0 – 3), intermediate fatigue (4 – 7), and worst fatigue (8-10). The researcher was revised and improved the questionnaire based on their suggestion and comments. The relevant and clarity of the fatigue rating scale questionnaire was 100 %.

3. Inventory of Functional Status (IFS)

The Inventory of Functional Status (IFS) is a brief self-administrated questionnaire developed by Tulman *et al.* (1991). The IFS questionnaire was originally developed to measure functional status in women with chronic illness such as cancer and HIV (Hudson *et al.*, 2004). The IFS questionnaire is composed of four sub-scale with 39 items comprising four sub-scale activities: a) household and family activities (14 items), b) social and community activities (7 items), c) self care activities (10 items), and d) occupation activities (8 items). Items were measured by using a 4 Likert-scale from 1 (not at all), 2 (just beginning), 3 (partially) and 4 (all the time). There were eight items that were negative questions (23, 24, 28, 30, 31, 33, 34, and 36) which were reversed backwardly when analyzed. Participants who were unemployed, they were not filled the items of occupation activities and the scores were divided by 31 as a total items of household and family activities, social and community activities, and self care activities. Interpretation by using mean score, mean score ≥ 3 indicated independently performing function and mean score < 3 indicated dependently performing function (Tulman and Fawcett., 2007). In this study, the relevant of this instrument was 95% and clarity of instrument was 97 %. The reliability test of IFS was employed by pilot study with 22 HIV infected women who had the same inclusion criteria in this study. The internal consistency of Inventory Functional Status showed a good reliability with Chronbach's alpha 0.83 (see table 1).

4. General Health Perception Questionnaire

General health perception was often measured by a single question. The question was asked people to scale their health from 1 = poor health to 10 = excellent health by Ferrans *et al.* (2005). In this study the general health perception was divided into two categories according to the range of the score. The score from 1 to 5 was representative of a poor perception of their general health. The score from 6-10 was representative of a good perception of general health (Ferrans *et al.*, 2005). In this

study, content validity was examined by three expert who have experiences working with HIV infected women. Three expert examined the instrument to ensure the content validity and language appropriateness (Burns and Groves, 2009). The researcher revised and improved the questionnaire based on their suggestion and comments. The relevant and clarity of this question were 100%.

5. Multidimensional Perceived Social Support Scale (MPSS)

The Multidimensional Perceived Social Support Scale (MPSS) questionnaire (Zimet *et al.*, 1988) was used to measure social support of HIV infected women in this study. Previous studies used MPSS questionnaire in people living with HIV (Xiaoyan and Sato, 2011; Sun *et al.*, 2007). The MPSS questionnaire consisted of 12 items, divided into 3 subscales such as perceived social support from family (4 items), friends (4 items), and significant others (4 items). All items were in positive questions. The MPSS measured by the 7 Likert-type scale from very strongly disagree = 1 to very agree = 7. Interpretation by using the mean scale score ranging from 1 to 2.9 considered low support; a score of 3 to 5 considered moderate support; a score from 5.1 to 7 considered high support (Zimet *et al.*, 1988). In this study, the instruments had demonstrated for its validity and reliability. The researcher was revised and improved the questionnaire base on comments and suggestions from experts. The relevant of the instrument was 100 % and clarity of the instrument was 91 %. This instrument was examined with 22 HIV infected women who had the same inclusion criteria with the sample. This internal consistency was a good reliability, with Chronbach's alpha 0.87.

6. World Health Organization Quality of Life Bref (WHOQOL- Bref)

WHOQOL- Bref was used to measure people's perceptions on their own quality of life in the context of their culture and their personal standards and purposes. Several studies were used WHOQOL-Bref questionnaire to examine the quality of life in people living with HIV, including the Indonesian population (Nojomi *et al.*, 2008;

Subramanian *et al.*, 2009; Abboud *et al.*, 2010; Handjani *et al.*, 2012; Khumsaen *et al.*, 2012; Bello *et al.*, 2013). The WHOQOL-Bref consisted of overall 26-item self-administered generic questionnaire on four domains; 1) physical (7 items), 2) psychological (6 items), 3) social (3 items), and 4) environment (8 items), and 2 items which measure overall quality of life and individual's health satisfaction. There are 23 positive items and 3 negative items (number 3, 4, and 26). The participants were asked to rate on a 5 Likert-type scale according to their health in the last 4 weeks, ranging from very bad (extremely unsatisfied) = 1, bad (not satisfied)= 2, moderate good (moderate satisfied) = 3, good (satisfied)= 4, and very good (very satisfied)= 5. For 3 negative items were reversed negatively phrased, 1=very good, 2= good, 3 = moderate, 4= bad, 5= very bad. The score of each domain were calculated according to the WHOQOL administration of scoring (WHOQOL-Bref Group, 2004). The mean scores of each domain were multiplied by 4 to make domain scores comparable with the scores in the manual instrument of WHOQOL, therefore the scores range between 4-20. The mean scores which more than 12 indicated a good quality of life. WHOQOL- Bref was developed to be used as a cross-cultural instrument and validated across 15 field centers worldwide (O' Connell and Skevington, 2012).

The WHOQOL-Bref have been validated and extensively used in the study of people living with HIV in Indonesia. Therefore, the questionnaire was not modified by the researcher. Previous reliability was tested with Cronbach's alpha 0.93 for whole scale and also each domain was examined, resulting in a) physical domain has Cronbach's alpha 0.79, b) psychological domain had Cronbach's alpha 0.85, c) social had Cronbach's alpha 0.75, and e) environment domain had Cronbach's alpha 0.86, (Hsiung *et al.*, 2005). The study in Indonesia that was used WHOQOL- Bref in people living with HIV obtained Cronbach's alpha 0.89 (Handjani *et al.*, 2012). In this study, test of reliability was also examined with 22 HIV infected women. Then internal consistency revealed that WHOQOL-Bref was a good reliability, with Cronbach's alpha for overall quality of life were 0.85 and for the four domains ranged from 0.79 to 0.90 (see table 1).

Table 1 Internal Reliability of Questionnaires ($n = 22$)

| Instrument | No of items | Cronbach's alpha |
|---|--------------------|-----------------------------|
| Quality of life (QOL) | | |
| Overall quality of life | 2 | 0.85 |
| Physical domain | 7 | 0.89 |
| Psychological domain | 6 | 0.90 |
| Social domain | 3 | 0.79 |
| Environment domain | 8 | 0.83 |
| Inventory Functional Status | | 0.83 |
| Household and family activities | 14 | 0.79 |
| Social and Community activities | 7 | 0.81 |
| Personal care activities | 10 | 0.71 |
| Employment status activities | 8 | 0.71 |
| Multidimensional Perceived Social Support Scale (MPSS) | 12 | 0.87 |

Methods

In this part, the study described about the research methodology which is consisted of hypotheses, study design, population, and sample, data collection, data analysis, ethical consideration, place and duration, and benefits.

1. Hypotheses

Hypotheses were set according to the specific objectives of the study. The hypotheses are as follows:

1.1 There is a relationship between characteristics of the individual including age, marital status, education level, employment status, family income and quality of life in HIV infected women in Medan, North Sumatera, Indonesia.

1.2 There is a negative relationship between fatigue and quality of life in HIV infected women in Medan, North Sumatera, Indonesia.

1.3 There is a positive relationship between functional status and quality of life in HIV infected women in Medan, North Sumatera, Indonesia.

1.4 There is a positive relationship between general health perception and quality of life in HIV infected women in Medan, North Sumatera, Indonesia.

1.5 There is a positive relationship between social support and quality of life in HIV infected women in Medan, North Sumatera, Indonesia.

2. Research design

The descriptive cross sectional design was used to describe the relationship among factors with quality of life in HIV infected women at one point in time.

3. Population and sample

3.1 Population

The population of this study were 155 HIV infected women in Medan, North Sumatera, Indonesia (MoH of Medan district, 2012).

3.2 Sample

The sample size was determined by using Slovin's formula:

$$n = \frac{N}{1 + Ne^2}$$

n = sample size

N = Population (155)

e = Confidence level (0.05) based on confidence level of 95 %

Based on the formula above, the sample size in the study was 101 HIV infected women and the researcher consider 10 % (Reis *et al.*, 2012) from the sample for anticipation drop out. Therefore, for this study was required 111 HIV infected women in Medan, North Sumatera, Indonesia.

The sampling method in this study was employed purposive sampling method. The researcher was decided purposely to select people who are judged to be similar characteristics of a population (Polit and Beck, 2012). For judgment people to be a representative sample through inclusion and exclusion criteria (Burns and Grove, 2009). Therefore, researcher was set up the inclusion and exclusion in this study. The inclusion criteria were a) an adult HIV infected women aged 18 to 45 years old, b) diagnosed with HIV at least three months (Hasanah *et al.*, 2011), c) HIV infected women attending routine clinical care visit such as the regular appointment with a doctor, to get treatment, to meet peer group at a community HIV clinic, Adam Malik Hospital, Medan, North Sumatera, Indonesia, d) able to speak, write and read in Bahasa Indonesia, and e) willing to participate in this study. Exclusion criteria was HIV infected women who should be hospitalized after meeting physicians.

4. Data collection

The study was approved by Committee and Ethics Review Board (ERB) Committee for Research Involving Human Research Subjects, Boromarajonani College of Nopparat Vajira, Bangkok, Thailand with number approval ERB No. 47/2014 (see Appendix B). This study was also approved from Adam Malik Hospital,

Medan, Indonesia and the head of community HIV clinic, Adam Malik Hospital, Medan, Indonesia. After gaining the permission from the head of community HIV clinic, Adam Malik Hospital, researcher was introduced and explained the detail about research topic, purposes, benefits, and procedure to the nurses who were responsible for the HIV program in the community HIV clinic of Adam Malik Hospital, Medan, Indonesia.

Data collection was conducted through blind collecting data method at the community HIV clinic of Adam Malik Hospital, Medan from July to September 2014. The researcher did not meet with each participants who were participate in this study. Therefore, researcher was putted the participant information sheet and questionnaires on the table in the room B at community HIV clinic of Adam Malik Hospital, Medan, Indonesia. All participants were fully informed regarding to the study by using information sheet. The nurses were asked the participants for taking the provided information sheet on the table to read carefully. Then participants took the questionnaires and answers the questionnaire at their convenience time such as before or after meet physician or during waiting the medicine. Participants took 45-60 minutes to complete the all questionnaires. After the participants have finished completing the questionnaires, they were put questionnaires on the table. The Nurses were help researcher to collect questionnaires. After that, the participants took a small gift from the box for their time and willingness to participate in this study.

5. Data analysis

The data analysis was performed by using Statistical Package for the Social Sciences for Windows provided by Kasetsart University. Data was checked for missing data before analyzed data begins and found a few missing data. The missing data were replaced by the correct value. Finally, no missing data in all variables of this study.

The data were also examined to determine the normality of the continuous data including age, fatigue, functional status, general health perception, social support, and quality of life. Based on Kolmogorov-Smirnov criterion by Pallant (2010), the normality distribution assumption was $p > .05$. In this study only quality of life, functional status, general health perception, and fatigue were normal distribution. Therefore, histogram, scatter diagram, and outliers were examined for age and social support. The results indicated those variables approximated normal distribution, and found no outliers. Data analysis were divided into two parts: descriptive statistics and relationship analysis.

5.1 Descriptive statistics

Descriptive statistics was used to identify the characteristics each variable. Characteristics of individual including a) age, b) marital status, c) marital status, d) educational level, e) employment status, f) family income was calculated by percentage and frequency. Whereas, another independent variables of this study such as a) fatigue, b) functional status, c) general health perception, d) social support were analyzed using percentage and frequency. Furthermore, to give picture about quality of life (overall quality of life, physical, psychological, social, environment) of HIV infected women in this study were also analyzed using percentage and frequency, however mean (M), standard deviation (SD), and range still employed.

5.2 Relationship analysis

The relationships between the independent variables and the dependent variable were used three methods of statistical analysis. First, relationship between independent and dependent variables which are interval/ratio measurement scale, such as age, fatigue, functional status, general health perception, social support and quality of life in HIV infected women were analyzed using Pearson's correlation coefficient r (Heavey, 2011). Second, to analyze the relationship between two variables and at least one is the ordinal measurement scale: educational level, family income and

quality of life in HIV infected women were analyzed using the Spearman correlation coefficient (ρ) (Heavey, 2011). Third, to examine the relationship between dichotomous as an independent variable and continues as a dependent variable was analyzed using Point Biserial correlation coefficient (Heavy, 2011). In this study the relationship between marital status and employment status as a dichotomous and quality of life in HIV infected women were analyzed using Point Biserial correlation coefficient.

The relationships under analysis were determined as a positive or a negative relationship. The positive relationship is when one variable increases will be followed by an increase in another variable. In the opposite direction, a negative relationship is when one variable increases and other variable decreases. Accordingly, the strength of the relationship described as mild ($r < .3$), moderate ($r = .3$ to $.5$), and strong ($r > .5$). Then, a significant level was set a prior at $p < .01$ (Grove, 2007).

6. Ethical Consideration

The study was approved by Kasetsart University and granted from the Ethical Review Committee for Research Involving Human Research Subjects, Boromarajonani College of Nursing Nopparat Vajira (ERB No. 47/ 2014) and Director of Adam Malik Hospital, Medan, Indonesia (see Appendix B). Then the letter permission was sent to Head of community HIV clinic of Adam Malik Hospital, Medan. The researcher was introduced herself and explain about the objectives, benefits, and procedures of the study to the nurses who have responsibility in HIV program of community HIV clinic of Adam Malik Hospital, Medan.

HIV is a sensitive issue and HIV infected women are a vulnerable group. The blind collecting method was applied in this study. The researcher was not meet participants directly and did not know who are participate in this study. The nurses were asked the participants to take and read provided information sheet which has been provided on the table in the room B at community HIV clinic carefully. In this

study, all participants were willing to participate in this study, they took and answered the questionnaires which has been provided on the table. Then, participants were putted the questionnaire on the table when they finished completing the questionnaires.

The participant's Information sheet and questionnaires were translated into Bahasa Indonesia by an accurate translation before given to the participants. All of the original questionnaires were getting permissions from author, This was taken about 45 – 60 minutes for completing questionnaires. This process was continued until an appropriate sample size (111 participants) was recruited. The participants have rights to reject or decline to answer questions without any reasons and negative effect on the community HIV clinic of Adam Malik Hospital. Similarly, participants were guaranteed by the protection of their rights and the confidential nature of the research process.

Confidentiality was maintained on all data collection forms by assigning a code number. Therefore, participants did not need to write their name to protect the participant's identity. All participants' data were put in the electronic program. The data were kept in the program with limited access. Only the researcher and the advisor could access to the data by using password. Hard copies of questionnaires were kept in a safely locked and private place. All questionnaires would be kept for 3 years after the thesis defense, and the they will be destroyed. The findings of the study were reported as total picture, and will be explained in aggregate not specific explain for each participants. The final study was distributed to the institutions who give permission to the researcher.

RESULTS AND DISCUSSION

Results

The study aimed to identify factors related to quality of life in HIV infected women. The related factors included in this study were individual characteristics (age, marital status, educational level, employment status, and family income), fatigue scale, functional status, general health perception, and social support. This chapter presents the result of the statistical analysis. The results of the study are divided into three sections consisting of individual characteristics, description of variables, and relationship among variables.

1. Characteristics of individual

A total of 111 HIV infected women completed the self administered questionnaires and were analyzed. In the following Table 2, the individual characteristics can be clearly seen. The majority of participants were in an age 26-35 years old with an average age 31.41 years old, minimum age was 20 years old and maximum age was 44 years old. Most of participants were married, unemployed, and had monthly family income Rp. 1,000,000 – Rp. 2,999,900. Based on North Sumatera Province Central Bureau of Statistics in 2011, this family income was classified to moderate level of income. According to Ministry of Education of Indonesia, the level of education in Indonesia divided into three categories based on 9th year compulsory education, including low education (elementary-junior high school), moderate education (senior high school), and high education (college/university). In this study the majority of participants were graduated from a high school. Furthermore, more than half of participants had time of HIV infection less than 2 years.

Table 2 Frequencies and percentage of characteristics of individual among HIV infected women (N=111)

| Individual characteristics | Frequency (N) | Percent (%) |
|--|--------------------------|------------------------|
| Age | | |
| 18 – 25 years | 14 | 12.60 |
| 26 – 35 years | 71 | 64.00 |
| 36 – 45 years | 26 | 23.40 |
| Range 20-44 (M = 31.41,SD = 5.38) | | |
| Education level | | |
| Junior high school | 20 | 18.00 |
| Senior high school | 68 | 61.30 |
| College | 23 | 20.70 |
| Marital status | | |
| Married | 73 | 65.80 |
| Unmarried (Single, Divorced, Widowed) | 38 | 34.20 |
| Employment status | | |
| Employed | 39 | 35.10 |
| Unemployed | 72 | 64.90 |
| Family income | | |
| Low (< Rp. 1,000,000) | 12 | 10.80 |
| Moderate (Rp. 1,000,000 – Rp. 2,999,900) | 73 | 65.80 |
| High (≥ Rp. 3,000,000) | 26 | 23.40 |
| Time since HIV diagnosis | | |
| < 2 years | 60 | 54.00 |
| 2-5 years | 42 | 37.90 |
| >5 years | 9 | 8.10 |

2. Description of variables

Descriptive analyses of variables including quality of life, fatigue, functional status, general health perception, and social support were presented in the following. Firstly, the overall quality of life and four domains of quality of life were presented to a good and poor quality. Secondly, the frequency and percentage of factors related to quality of life such as fatigue scale, functional status, general health perception, and social support are presented.

2.1 Quality of life

The quality of life of HIV infected women consisted of overall quality of life and its four domains. Quality of life was presented as a good and poor level based on cut of point at a midrange of mean score. Those HIV infected women who reported mean score more than 12 were categorized to a good quality of life, while those who had score less than and thru 12 were categorized to poor quality of life.

Table 3 Frequencies and percentages of quality of life (QoL) among HIV infected women (N = 111)

| Quality of Life (QoL) | Poor | | Good | | M | SD |
|-----------------------|------|-------|------|-------|-------|------|
| | N | % | N | % | | |
| Overall QoL | 50 | 45.00 | 61 | 55.00 | 12.25 | 3.45 |
| Physical domain | 27 | 24.30 | 84 | 75.70 | 14.12 | 2.40 |
| Psychological domain | 38 | 34.20 | 73 | 65.80 | 13.16 | 2.55 |
| Social domain | 61 | 55.00 | 50 | 45.00 | 11.50 | 2.51 |
| Environmental domain | 35 | 31.50 | 76 | 68.50 | 13.57 | 1.87 |

Note: M = Mean, SD = Standard deviation

The level of quality of life of participants can be clearly seen. In regards to the four domain of quality of life, mostly participants reported a good quality of life except in social domain. The highest mean score of quality of life was in physical domain (14.12) with 75.70 % of participants reported a good quality of life, followed by environmental domain (13.57) with 68.50 % of participants reported a good quality of life. The lowest mean score was in social domain (11.50) with more than half of participants (55 %) reported a poor quality of life (see Table 3).

2.2 Factors related to quality of life

Factors related to quality of life in HIV infected women consisted of fatigue scale, functional status, general health status, and social support. The results of data analysis were presented in table 4 to 7.

Table 4 Frequencies and percentages of fatigue scale among HIV infected women (N = 111)

| Fatigue scale | Frequency (N) | Percent (%) |
|--|------------------|----------------|
| No fatigue (0 - 3) | 52 | 46.80 |
| Intermediate fatigue (4 - 7) | 50 | 45.10 |
| Worst fatigue (8 -10) | 9 | 8.10 |
| Mean (SD) = 3.74 (2.35), Range = 0 - 9 | | |

The fatigue scale was divided to three categorized; no fatigue, intermediate fatigue, and worst fatigue with score range from 0 to 9. The higher score indicated worst fatigue. The results of this study found that 52 participants (46.80 %) rated they did not perceived fatigue in the last four weeks when data collected. The average score of the fatigue scale of participants was 3.74 (see Table 4).

Table 5 Frequencies and percentages of functional status among HIV infected women (N = 111)

| Functional status | Frequency (N) | Percent (%) |
|--|---------------|-------------|
| Dependently performing function (< 3) | 31 | 27.90 |
| Independently performing function (≥ 3) | 80 | 72.10 |
| Mean = 2.83, SD = 0.59, Range = 1 – 4 | | |

Functional status identifies how HIV infected women able to perform their function since they diagnosed with HIV. This variable was classified into dependently performing function with mean scores < 3 and independently performing function with mean scores ≥ 3 . The data showed that majority of participants (72.10%) were performed their function independently even though their life were threaten with HIV. The average score of functional status was 2.83 from mean score with range from 1 to 4 (see Table 5).

Table 6 Frequencies and percentages of general health among HIV infected women (N = 111)

| General health perception | Frequency (N) | Percent (%) |
|--|---------------|-------------|
| Poor health perception (1 – 5) | 53 | 47.70 |
| Good health perception (6 – 10) | 58 | 52.30 |
| Mean = 6.00, SD = 1.97, Range = 2 – 10 | | |

The general health perception was divided into two categorized according to the range of the score. The score from 1 to 5 were representative of a poor health perception and those from 6 to 10 were representative of a good health perception. The data showed more than half of participants (52.30 %) had a good perception of their health, with mean score 6.00 (SD = 1.97) and with the range from 2 to 10 (see Table 6).

Table 7 Percentages of level of social support among HIV infected women (N = 111)

| Perceived social support | Low | Moderate | High | M | SD |
|--------------------------|-------|----------|-------|------|------|
| | % | % | % | | |
| Overall social support | 3.60 | 59.50 | 36.90 | 4.80 | 0.93 |
| From family | 6.30 | 27.90 | 65.80 | 5.31 | 1.13 |
| From friends | 36.10 | 38.70 | 25.20 | 3.63 | 1.51 |
| From significant others | 3.60 | 27.00 | 69.40 | 5.49 | 1.02 |

Social support was classified into three level of perceived support. There are low support, moderate, and higher support. Besides of the overall social support, this study considering the resources of the social support which is divided into three categorized; support from family, friends, and significant others. This study revealed that more than half (59.50 %) of the participants perceived moderate level of overall social support. The highest of participants was perceived higher support from significant other (69.40 %) with average score was 5.49 (SD= 1.02), followed by perceived support from family (65.80 %). This indicated that the HIV infected women received more support from significant other than family or friends (see Table 7).

3. Relationship analysis

This part presents the relationship between characteristics of individual, fatigue, functional status, general health perception, social support and quality of life. The results were presented in table 8 to 12.

3.1 Relationship between characteristics of individual and quality of life in HIV infected women

This study identified characteristics of individual including age, marital status, educational level, employment status, and family income were analyzed for the association of quality of life. This study revealed that age, marital status, educational level, and family income were not statistically relationship with four domains of quality of life including physical domain, psychological domain, social domain, and environment domain. However, there was statistically negative relationship between employment status and four domains of quality of quality of life, especially in environment domain ($r = -0.30, p < .01$). This indicated that those HIV infected women who were employed had poorer quality of life in environment domain than HIV infected women who an unemployed (see Table 8).

Table 8 Relationships between characteristics of individual and quality of life among HIV infected women (N=111)

| Variables | Physical domain | Psychological domain | Social domain | Environment domain |
|--------------------------------|-----------------|----------------------|---------------|--------------------|
| | r | r | r | r |
| Age ^a | 0.15 | 0.15 | 0.01 | 0.21 |
| Marital status ^b | 0.03 | -0.07 | -0.14 | -0.08 |
| Employment status ^b | -0.20* | -0.23* | -0.20* | -0.30* |
| Educational level ^c | 0.04 | 0.11 | 0.05 | 0.15 |
| Family income ^c | 0.14 | 0.16 | 0.01 | 0.27 |

Note : (^a) = Person-Product Moment correlation coefficient; (^b) = Point Biserial correlation coefficient; (^c) = Spearman correlation coefficient, * $p < .01$

3.2 Relationship between fatigue and quality of life in HIV infected women

The relationship between fatigue and quality of life in HIV infected women was examined in this study. The fatigue was statistically negative relationship with four domains of quality of life at moderate level, particularly in physical domain ($r = -0.49, p < .01$), followed by psychological domain of quality of life ($r = -0.45, p < .01$). This meant that HIV infected women who were reported worse fatigue had a poor quality of life, particularly in physical and psychological domain (see Table 9).

Table 9 Relationship between fatigue and quality of life among HIV infected women (N=111)

| Variables | Physical domain | Psychological domain | Social domain | Environment domain |
|---------------|-----------------|----------------------|---------------|--------------------|
| | r | r | r | r |
| Fatigue scale | -0.49* | -0.45* | -0.26* | -0.36* |

Note : Person-Product Moment correlation coefficient test, * $p < .01$

3.3 Relationship between functional status and quality of life in HIV infected women

There was statistically positive relationship between functional status and four domains of quality of life at a high level, particularly in physical domain ($r=0.63, p < .01$) followed by psychological and environment domain of quality of life. This meant that when HIV infected women were able to practice their roles and function more likely to have better quality of life (see Table 10).

Table 10 Relationship between functional status and quality of life among HIV infected women (N=111)

| Variables | Physical domain | Psychological domain | Social domain | Environment domain |
|-------------------|-----------------|----------------------|---------------|--------------------|
| | r | r | r | r |
| Functional status | 0.63* | 0.61* | 0.46* | 0.61* |

Note : Person-Product Moment correlation coefficient test, * $p < .01$

3.4 Relationship between general health perception and quality of life in HIV infected women

General health perception was statistically positive relationship with four quality especially in physiological domain at a high level ($r = 0.67, p < .01$). This indicated that the HIV infected women who were reported a good perception of their health more likely to have a good quality of life, particularly for psychological domain (see Table 11).

Table 11 Relationship between general health perception and quality of life among HIV infected women (N=111)

| Variables | Physical domain | Psychological domain | Social domain | Environment domain |
|---------------------------|-----------------|----------------------|---------------|--------------------|
| | r | r | r | r |
| General health perception | 0.58* | 0.67* | 0.55* | 0.48* |

Note : Person-Product Moment correlation coefficient test, * $p < .01$

3.5 Relationship between social support and quality of life in HIV infected women

Social support of HIV infected women was statistically positive relationship with four domains of quality of life, particularly in social domain of quality of life at high level ($r = 0.67, p < .01$) followed by psychological domain ($r = 0.58, p < .01$). This indicated that HIV infected women who were perceived higher social support more likely reported a better quality of life, especially social and psychological domain of quality of life (see Table 12).

Table 12 Relationship between social support and quality of life among HIV infected women (N=111)

| Variables | Physical domain | Psychological domain | Social domain | Environment domain |
|----------------|-----------------|----------------------|---------------|--------------------|
| | r | r | r | r |
| Social support | 0.50* | 0.58* | 0.67* | 0.53* |

Note : Person-Product Moment correlation coefficient test, * $p < .01$

In conclusion, this study revealed that the majority of HIV infected women whose aged 26 to 35years old (64 %), married (65.8 %), unemployed (64.9 %), had a moderate level of education (61.3 %) and family income (65.8%), and were diagnosed with HIV less than 2 years prior (54 %). The study identified the factors related to quality of life in HIV infected women consisted of employment status, fatigue, functional status, general health perception, and social support. However, age, marital status, educational level, and family income were not associated to quality of life in HIV infected women.

Discussions

The purpose of this study was to identify factors related to quality of life in HIV infected women. The variables consisted of individual characteristics (age, marital status, educational level, employment status, and family income), fatigue scale, functional status, general health perception, and social support. The variables were chosen based on finding from previous studies and gaps of knowledge according to quality of life in HIV infected women. This part provides a discussion of results, strength, and limitation of the study.

1. Quality of life in HIV infected women in Medan, Indonesia

This study was to identify the quality of life in HIV infected women in Medan, Indonesia. The findings showed that 55 % of HIV infected women in Medan, Indonesia were reported a good quality of life, especially in the physical domain. This finding was consistent with previous studies that HIV infected women reported a high level of quality of life (Perez *et al.*, 2009; Imam *et al.*, 2011). This can be explained that the majority of HIV infected women in this study were diagnosed with HIV less than 2 year and 46.8 % of those HIV infected women were not perceived fatigue. Considering to duration of infection, the women in this study were in asymptomatic stage of HIV symptom (WHO, 2007). Their life not much effect by the invasive infection of HIV. They were able to perform their activities as normal. Therefore, they reported physical domain of quality of life is at a good level. Similarly, study by Hasanah *et al.* (2011) found that HIV infected who had HIV for less than 2 years had a better physical quality of life. Therefore, the period of diagnose with HIV can be the variable to determine quality of life in long term.

Social domain was the poorest quality of life in HIV infected women in this study. This result was congruent with previous studies which found that people living with HIV, particularly in women had lower quality of life in social domain than other domains (Chandra *et al.*, 2009; Xiaoyan and Sato, 2011). This situation can be

explained by stigmatization and discrimination which common against people living with HIV. Subramanian *et al.* (2009) found that HIV infected women were perceived with a higher stigma than men when living with HIV (Subramanian *et al.*, 2009). In Indonesia, HIV infected women were commonly stigmatized by their community. They were rejected from social interaction, for instance, friends or family tended to avoid contact with them (Haroen *et al.*, 2008). Another possible reason is people were misunderstanding related to routes of HIV transmission. Some people understand that HIV could be transmitted by social contact. Therefore, people avoid to involve in social activity with people living with HIV and devalue people living with HIV are being left behind. Nurses could promote and provide clear information that HIV is transmitted through body fluids including blood, genital fluids or breast milk that leads to virus-mediated (CDC, 2013), not through social interaction.

2. Relationship between characteristics of individual (age, marital status, educational level, employment status, and family income) and quality of life in HIV infected women in Medan, Indonesia

Based on the correlation analysis, the findings showed that characteristics of individual including age, marital status, educational level, and family income were not significant relationship with four domains of quality of life, including physical domain, psychological domain, social domain, and environment domain. However, employment status was statistically negative relationship with four domains of quality of life.

In this study, age was not significant relationship with quality of life. This finding was not consistent with previous studies which found a relationship between age and quality of life in HIV infected women, the younger HIV infected women more likely to have poorer quality of life than the older women (Chandra *et al.*, 2009; Hasanah *et al.*, 2011; Nokes *et al.*, 2011; Pereira and Canavarro, 2011). In this study, the majority of HIV infected women in the age range of 26 to 35 years old. This finding was similar to Ministry of Health of Indonesia (2013) reported that most HIV

infected women in the age range between 25 to 45 years old. This age group recognized as a productive age (MoH, 2013). However, age in this study could not indicate whether HIV infected women have a poor or good quality of life. The contrasting findings of this study could be explained by the impacts of HIV. HIV has devastating physical, psychological, and social effect of people living with HIV and their families (Munsawaengsub *et al.*, 2012). HIV infected women were often disrupted their interpersonal relationships due to HIV related to stigma. In Indonesia, most of HIV infected women in Indonesia were shocked when they found out their HIV status (Haroen *et al.*, 2008). Furthermore, since women infected with HIV, the perception of rejection community and friends was occurred (Haroen *et al.*, 2008). Older or younger people are risky of experiencing the impacts of HIV. Therefore, in this study age of HIV infected women was not indicated the quality of life. This finding was supported by previous studies which found that age was not related to quality of life in HIV infected women (Nojomi *et al.*, 2008; Xiaoyan and Sato, 2011).

This study found marital status was not significant relationship with all domains of quality of life. This finding was contrary with Model for Quality of Life (Ferrans *et al.*, 2005). The finding also inconsistent with several previous studies which have found that marital status was significantly related to quality of life of people living with HIV (Nojomi *et al.*, 2008; Abboud *et al.*, 2010; Bello *et al.*, 2013). This finding can be explained that the majority of participants (65.8%) were married. Being married had been shown to be risky for women to acquire with HIV infection from their husband (Chandra *et al.*, 2009). As reported by WHO (2012), women in developing countries were more likely vulnerable to HIV infection as a result of secondary transmission from their husband. In Indonesia, HIV infected women were more likely to acquire HIV infection from their husbands or partners (Haroen *et al.*, 2008). Monika (2009) explained that patriarchal system in Medan puts the men in a position higher than women in all aspects social, cultural, and economic. Therefore, women have lower power to negotiate for safer sexual intercourse and women risky for HIV infection. Since women infected with HIV, they were faced various social problems such as social stigma, depression, and poverty (Handajani *et al.*, 2012).

Therefore, HIV infected women who were married and unmarried have a similar quality of life in the similar situation in social activities. That is a possible reason why in this study marital status was not significant relationship with quality of life. This finding also was supported by Xiaoyan and Sato (2011) and Pedram *et al.* (2012) who mentioned that marital status was no significant relationship with quality of life in HIV infected women.

Regarding educational level, this also was not statistically significant in relation to four domains of quality of life that were considered in this study. This finding inconsistent with previous studies that found educational level of HIV infected women had a significant relationship with quality of life (Nojomi *et al.*, 2008; Khumsaen *et al.*, 2012; Bello *et al.*, 2013). A possible reason of different findings can be explained by the effects of HIV. The diagnosis of HIV is regarded as a traumatic event in a person's life. They may have experienced a threat to survival and psychological distress (Hudson *et al.*, 2010). In Indonesia, HIV infected women were not only concerned about HIV complication, but also the fear of dying and disruptions in relationship with their family, friends, and neighbors (Haroen *et al.*, 2008, Oktavia, 2012). Based on that reason, it possible to conclude that although HIV infected women had higher or lower education, it was not a clear indicator for a good quality of life. Similarly, a previous study found that educational level was not associated with quality of life in HIV infected women (Xiaoyan and Sato, 2011).

Based on characteristics of the individual surveyed, employment status was statistically negative relationship with four domains of quality of life. This indicated that HIV infected women who were employed had a poor quality of life. This finding was supported by previous studies which found that employment status was significant associated with quality of life of people living with HIV (Nojomi *et al.*, 2008; Imam *et al.*, 2011; Khumsaen *et al.*, 2012; Reis *et al.*, 2012). Being employed provides financial benefits for HIV infected women. In this study, the majority of HIV infected women were unemployed. The chronic nature of the HIV disease brought new challenges in employment that were related to HIV issues such as

stigmatization and discrimination. HIV infected women were afraid and worried about the stigma and discrimination against them in the workplace and also they would lose their employment. Therefore, HIV infected women more likely to stay at home and also can get enough rest (Chandra *et al.*, 2009). In this respect, HIV infected women who were unemployed were more likely to have a good quality of life.

According to family income, there was not a statistically significant relationship related to four domains including physical domain, psychological domain, social domain, and environment domain. This meant that the HIV infected women in this study were reported as having a good quality of life whether they had high or low family incomes. This finding was inconsistent with previous studies by Hasanah *et al.* (2011), which identified that those people living with HIV who had a lower family income were more likely to have a lower quality of life. Based on North Sumatera Province Central Bureau of Statistics in 2011, the majority of HIV infected women in this study had a moderate level of family income. Since people were diagnosed with HIV, influenced on the economic status or lost their jobs. Particularly HIV infected women often faced difficulties for access to employment and social resources, which also often influences their family income (Haroen *et al.*, 2008, Nojomi *et al.*, 2012). In patriarchy societies, the sources of family income were more likely obtained from men or husband (Monika, 2009). Therefore, in this respect, the most of women in Medan depend on their husband financial support. Moreover, HIV infected women often disrupted their interpersonal relationship. They would eventually have to confront major social issues that included how to deal with possible disapproval or rejection, how to cope with the infection, and how to find the new meaning of life under the threat of infectious disease (Haroen *et al.*, 2008). Since women infected with HIV, they more likely to face this situation. Therefore, even though HIV infected women had higher or lower family income, it could not indicate their quality of life. This study was supported by previous studies which found that family income was not associated with quality of life of people living with HIV (Figuro *et al.*, 2011; Xiaoyan and Sato, 2011).

3. Relationship between fatigue and quality of life in HIV infected women in Medan, Indonesia

Regarding to the finding of this study, fatigue was statistically negative significant relationship with quality of life in HIV infected women in Medan, Indonesia. This indicates that HIV infected women who were reported worst fatigue more likely to have a poor quality of life. The findings supported by previous studies which found that significant association between fatigue and quality of life in HIV infected women (Nokes *et al.*, 2009; Hudson *et al.*, 2010). A possible reason for this finding might be that HIV infected women were not perceived severity of fatigue tended to satisfy with their physical function and led them to reported a good quality of life.

Wilson and Clearly (1995) defined that one symptom is a patient's perception of an abnormal physical, emotional, or cognitive state. In this study, fatigue was described as subjective experiences and perception of tiredness and exhaustion which is unrelieved by a full night sleep or rest. HIV infected women were assigned to rate the fatigue that currently perceived from 0 (no fatigue) to 10 (extreme fatigue) in the last four weeks during data collection. Study by Voss *et al.* (2007) and Hudson *et al.* (2010) mentioned that fatigue is a highly prevalent symptom among people living with HIV, particularly in women. However, in this study, the majority of HIV infected women reported no perceived fatigue. It could be explained that a majority of HIV infected women in this study were infected with HIV for less than 2 years (current infected). This indicated those women were in an earlier stage of HIV or asymptomatic stage (WHO, 2012). Similarly, a study by Solomon *et al.* (2008) found HIV infected women who were currently diagnosed with HIV were more likely to be asymptomatic. Even though in this study most of the HIV infected women did not report a perceived elevated fatigue, strategies for managing fatigue and educating those HIV infected women are an important part of patients' assessment for addressing quality of life issues.

4. Relationship between functional status and quality of life in HIV infected women in Medan, Indonesia

The finding of this study was revealed that functional status had a statistically positive significant relationship with four domains of quality of life, including physical domain, psychological domain, social domain, and environment domain. This indicated that the HIV infected women who were able to perform their function independently were more likely to have a good quality of life. This finding was consistent with previous studies which were conducted on HIV infected women and found that functional status and quality of life were significant relationship (Solomon *et al.*, 2008; Hudson *et al.*, 2010). HIV infected women carried out multiple roles as a wife, taking care of her husband and children, and also maintaining the household. HIV infected women were particularly difficult beings when they suffered from HIV symptoms (Solomon *et al.*, 2008). These situations may have led them to be confronted with higher psychosocial distress such as inability to take care themselves and consequences to their quality of life.

In this study the majority of HIV infected women reported to be independently performing their function. That might be possible because the most HIV infected women in this study were of reproductive age, from 26 to 35 years old, and were not perceived severe fatigue. Furthermore, in Indonesia, particularly in Medan which is the one of patriarchy societies, women have a multiple roles as a wife and a mother. Women were responsible for the care of children and husband even they were infected with HIV (Safarina, 2012). This situation was forcing women to perform independently their functions as a women and people living with HIV. Therefore, HIV infected women who were able to perform their function independently more likely to have a good quality of life. Therefore, although women were diagnosed with HIV, if they still were able to perform their women roles function independently, they would be more likely to have a good quality of life.

5. Relationship between general health perception and quality of life in HIV infected women in Medan, Indonesia

In this study, general health perception was a strong positively significant relationship with four domains of quality of life. This indicated that HIV infected women with better perception on health were had a good quality of life. This finding was consistent with The Revised Wilson and Clearly Model for Health Related Quality of Life (Ferrans *et al.*, 2005) which explained that general health perception was associated with quality of life. This study was consistent with study by Eller and Mahat (2007) which determined that general health perception was significant relationship with the quality of life of people living with HIV. The possible reason for this finding might be that those women did not suffer with fatigue as a common symptom of HIV which is related to their duration of HIV infection. Therefore, in this study more than half of HIV infected women reported their perception of health were a good level. When HIV infected women perceived their general health as a good, they might be more likely satisfied with their quality of life. This finding was consistent with a previous study which found that health perception was related to quality of life (Figuro *et al.*, 2011).

In 1995, Wilson and Clearly described the general health perception as an individual's perception of various aspects of health. It revealed that general health perception is highly subjective and takes consideration of biological and psychological factors in HIV infected women. Therefore, identifying the general health perception of patients is necessary to understand a patient's health experiences that would influence their quality of life (Ferrans *et al.*, 2005).

6. Relationship between social support and quality of life in HIV infected women in Medan, Indonesia

According to relationship analysis between social support and quality of life, the findings indicated that the HIV infected women who perceived higher social

support more likely had a good quality of life. This finding was supported by previous studies which showed that social support was a related to quality of life in HIV infected women (Bajurniwe *et al.*, 2009; Imam *et al.*, 2011; Rao *et al.*, 2012; Wan Zaidi *et al.*, 2012).

Social support refers to the perceived care, comfort, esteem, or help from other people or groups including spouse, family, friends, co-workers, and health care provider (Ahmed *et al.*, 2007). However, social support is mostly influenced by the cultural or social norms that surround the people living with HIV. Because HIV is a disease that often characterized by social stigma, people living with HIV were commonly discriminated against and rejected from family and community. Therefore, receiving social support is problematic for people living with HIV, particularly in women. In this study, the majority of HIV infected women perceived had better support from significant others than family or friends. A possible reason for this finding might be that HIV infected women were doubly stigmatized as people living with HIV and as a women. Particularly in Medan, Indonesia, since women who were diagnosed with HIV tended to blame themselves and feel blamed by others. Similarly, previous studies found that most of the HIV infected women were blamed by others such as family, friends, and society (Chandra *et al.*, 2009; Ko *et al.*, 2007). HIV infected women had more difficulties in receiving support from their own families or friends. Therefore, HIV infected women preferred to get support from significant others, which could refers to health care provider or volunteers from NGOs (Chandra *et al.*, 2009; Leasure *et al.*, 2009). A study by Haroen (2008) found that HIV infected women who were perceived to be satisfied had support from nurses and volunteers of NGOs. This situation might be related to Ministry of Health of Indonesia (MoH, 2009) that has established health policies to support the services in health care system such as improving quality of Voluntary Counseling and Testing (VCT). In the VCT services, health care providers could play a roles to supports people living with HIV and to achieve that purposes, the health care provider could collaborate with NGOs.

7. Strength of study

The phenomena of increasing number of HIV infected women in Indonesia, particularly in Medan, is become an interested for society. This study presented a current research that focused on HIV infected women and quality of life in Medan, North Sumatera, Indonesia. The results are beneficial reference and provide new information about quality of life in HIV infected women in this area. Furthermore, this study employed The Revised Wilson and Clearly Model for Health related Quality of Life by Ferrans *et al.* (2005). This model provides understanding about relation between health and quality of life of individuals and was increasingly used in quality of life research. Therefore, this model was appropriated to achieve the objectives of this study

8. Limitation of study

This study had some limitations. First, this study employed a cross sectional design that collected data only one time. This design might not capture for causal or changes of quality of life in HIV infected women. Second, this study used self-administered questionnaires and a blind collecting data method. These are lack of reliable than the interview method in which the researcher can validate the answers of participants at the time of collecting data. However, the researcher should be concerned which method is appropriate in particular for confidentiality of HIV status. Third, this study was conducted in Medan, North Sumatera, Indonesia and only used one place in collecting data. The majority of participants were married, unemployed, had a moderate level of education, moderate level of family income, and lived in patriarchal societies. The findings of this study might be limited to generalize in other populations that are different geographical areas and cultures.

CONCLUSSION AND RECOMMENDATIONS

Conclusion

This study was a descriptive cross sectional design aimed to identify factors related to quality of life in HIV infected women. The factors consisted of characteristics of individual age, marital status, education level, employment status, and family income), fatigue scale, functional status, general health perception, and social support. The Revised Wilson and Clearly Model for Health Related Quality of Life by Ferrans et al. (2005) was used as a guideline in this study. The participants were 111 HIV infected women aged 20 to 44 years old and were recruited from the community HIV clinic of Adam Malik hospital, in Medan, North Sumatera, Indonesia. The majority of HIV infected women whose aged 26 to 35years old (64 %), married (65.8 5), unemployed (64.9 %), had a moderate level of education (61.3 %) and family income (65.8%), and were diagnosed with HIV less than 2 years prior (54 %).

The findings showed that age, marital status, educational level, and family income were not significant with overall quality of life and four domains of quality of life. However, employment status and fatigue were statistically negative significant relationship with overall quality of life and four domains of quality of life (physical, psychological, social, and environment domains). Furthermore, functional status, general health perception, and social support also were statistically positive significant relationship with quality of life in HIV infected women. Further study needs to be conducted to investigate causality of relationship between variables by longitudinal design or intervention of social support to improve the quality of life.

Recommendations

Based on the findings, the recommendation would be relevant for nursing practice and future research.

1. Nursing practice

In Indonesia, the prevalence of HIV infected women is increasing gradually, developing nursing intervention for HIV infected women should be emphasized in nursing practice. Nurses should understand about quality of life and factors that related to quality of life in HIV infected women to develop suitable nursing intervention and health promotion. Based on the findings of this study, social support was a significant relationship to quality of life in HIV infected women. Therefore, the nurses who responsible for HIV programs should provide information about important of social support to family and peers or community. Then, family and peers should be involved in nursing intervention to provide appropriate support for those women.

General health perception was the one which is an important factor related to quality of life in HIV infected women. Therefore, nurses also should be able to identify their health perception from the patient's view rather than from the health care provider. Nurses should be able to encourage HIV infected women to improve their health perception by counseling program. If general health perception and social support of HIV infected women increase, they can improve their quality of life. Additionally, according to the findings of this study, nurses have a professional responsibility to identify functional status and fatigue of HIV infected women. Nurse should develop assessment and intervention guidelines in order to improve quality of life in HIV infected women. Nurses should provide health education program and supported to maintain their physical health and roles function for HIV infected women to enhance the quality of life.

2. Future research

Future research is needed on large samples of HIV infected to achieve a representative sample of HIV infected women in North Sumatera, Indonesia. The cross sectional design was employed in this study which makes it difficult to determine causality of factors to quality of life. Therefore, longitudinal and intervention studies are needed to investigate the factors affecting quality of life. Consideration of social support, health perception, fatigue, and functional status should be involved in intervention study to improve quality of life in HIV infected women. Moreover, a qualitative study approach to conceive insightful information is needed.

3. Nursing education

The findings of this study should be a references for improving nursing knowledge about quality of life in HIV infected women and factors that are related. This study is also a beneficial reference for nurse educators to provide knowledge for nursing students and young nurses to improve understanding and experience about quality of life in HIV infected women including recognizing factors related to quality of life.

LITERATURE CITED

- Abboud, S., S. Nouredine, H.A. Huijer, J. DeJong and J. Mokhbat. 2010. Quality of life in people living with HIV/AIDS in Lebanon. **AIDS Care** 22 (6): 687-696.
- Agustini, I. B. 2013. **Predictors of quality of life of adults with type 2 diabetes mellitus**. MNS. Thesis, Kasetsart University.
- Ahmed, S.M., and J.P. Lemkau. 2007. **Psychosocial influences on health**. 7th Edition. PA: Saunders Elsevier, Inc. Rakel RE, Philadelphia, 35-38.
- Andrinopoulos K., G. Clum, D.A. Murphy, G. Harper, L. Perez, J. Xu, S. Cumingham and J.M. Ellen. Health related quality of life and psychosocial correlates among HIV-infected adolescent and young adult women in the US. **AIDS Educ Prev**. 23(4): 367-381.
- Astoro, N.W., S. Djauzi, Z. Djoerban and W. Podjosudjadi. 2007. Quality of life of HIV patients and influential factors. **The Indonesian Journal of Internal Medicine** 39 (1): 2-7.
- Bajurniwe, F., D.J. Tisch, C.H. King, E.J. Arts, S.M. Debanne and A.K. Sethi. 2009. Quality of life and social support among patients receiving antiretroviral therapy in Western Uganda. **AIDS Care** 21 (3): 271-279.
- Barroso, J and M.R. Lynn. Psychometric properties of the HIV-related fatigue scale. **J Assoc Nurses AIDS Care**. 13(1): 66-75.
- Bello, S.I., M. Pharm and I.K. Bello. 2013. Quality of life of HIV/AIDS patients in a secondary health care facility, Ilorin, Nigeria. **Bayl Univ Med Cent**. 26 (2) : 116-119.

- Bhengu, B.R., B.P. Ncoma, P.A. McInerney, D.J. Wantland, P.K. Nicholas, I.B. Corless. 2009. Symptoms experienced by HIV-infected individuals on antiretroviral therapy in Kwazulu-Natal, South Africa. **Appl Nurs Res.** 24(1): 1-9.
- Bor R., P. Plessis and M. Russell. 2004. The impact of disclosure of HIV on the index patient's self-defined family. **Journal of Family Therapy** 26: 167-192.
- Brown, C.D., R. Belue and O.C. Airhihenbuwa. 2010. HIV and AIDS-related stigma in the context of family support and race in South Africa. **Ethnicity & Health** 15(5): 441-458.
- Burgoyne, R. and R. Renwick. 2004. Social support and quality of life over time among adults living with HIV in the HAART era. **Social Science & Medicine** 58: 1353-1366.
- Burns, N. and S.K. Grove. 2009. **The Practice of Nursing Research: Appraisal, Synthesis, and Generation of Evidence**, 6th ed. Elsevier Inc., United State America.
- Cao, H., N. He, Q. Jiang, M. Yang, Z. Liu, M. Gao, P. Ding, L. Chen and R. Detels. 2010. Stigma against HIV-infected Persons Among Migrant Women Living in Shanghai, China. **Aids Education and Prevention** 22(5): 445-454.
- Centers for Disease Control and Prevention. 2013. **About the Terms, Definitions, and Calculations Used in CDC HIV Surveillance Publications.** Available Source:http://www.cdc.gov/hiv/pdf/prevention_ongoing_surveillance_terms.pdf, August 21, 2013.

- Chandra, P.S., V.A. Satyanarayana, P. Satishchandra, K.S. Satish and M. Kumar. 2009. Do men and women with HIV differ in their quality of life? A study from South India. **AIDS Behav.** 13: 110-117.
- Chen-Fan, A.P., H. Ching Claire Kuo, D.Y. Ting Kao, D.E. Morisky and Y. Ming Arthur Chen. 2011. Quality of life and needs assessment on people living with HIV and AIDS in Malawi. **AIDS Care** 23(3): 287-302.
- Clingerman, E. 2004. Physical activity, Social support and Health related quality of life among persons with HIV disease. **Journal of community health nursing.** 21 (3): 179-197.
- Cohen, S.R., B.M Mount, M.G Strobel and F. Bui. 1995. The McGill quality of life questionnaire: a measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability. **Palliat Med.** 9(3): 207-219.
- Dalmida, S. 2007. **Interrelationship between spirituality, mental health and immune status among women with HIV.** **HIV/AIDS Issues.** Available Source: https://stti.confex.com/stti/congrs07/techprogram/paper_31195.htm, February 15, 2014.
- Delgado, C. 2007. Sense of coherence, spirituality, stress and quality of life in chronic illness. **J Nurs Scholarsh.** 39: 229-234.
- De Boer, J.B., M.A. Sprangers, N.K. Aaranson, J.M.Lange, and F.S. van Dam. 1996. A study of the reliability, validity, and responsiveness of the HIV overview of problems evaluation system (HOPES) in assessing the quality of life of patients with AIDS and symptomatic HIV infection. **Qual Life Res.** 5(3): 339-347.

- Eller, L.S and G. Mahat. 2007. Predictors of life satisfaction in HIV-positive Nepali women. **Journal of the association of nurses in AIDS Care** 18(5): 17-26.
- Eyler, A.E., S. Wilcox, D. Matson-Koffman, K.R. Evenson, B. Sanderson, J. Thompson, et al. 2002. Correlates of physical activity among women from diverse racial/ethnic groups. **Journal of Women Health and Gender Based Medicine** 11(3): 239-253.
- Fekete, M.E., H.M. Antoni, R. Duran, L.B. Stoelb, M. Kumar and N. Schneiderman. 2009. Disclosing HIV serostatus to family members: effects on psychological and physiological health in minority women living with HIV. **International Society of Behavioral Medicine** 16: 367-376.
- Febriana, A. I. 2013. Keikutsertakan pelanggan wanita pekerja seks dalam Voluntary Counseling and Testing (VCT). **Jurnal Kesehatan Masyarakat** 8(2): 161-165.
- Feng, C.M., Y.J. Feng, C.T. Chen, L.P. Lu, Y.N. Ko and H.Y. Chen. 2009. Stress, needs, and quality of life of family members caring for adults living with HIV/AIDS in Taiwan. **AIDS Care** 21(4): 482-489.
- Ferrans, C.E., J. J. Zerwic, J.E. Wilbur and J.L. Larson. 2005. Conceptual model of health-related quality of life. **Journal of Nursing Scholarship** 37 (4): 336-420.
- Ferrans, C and M. Power. 1992. Psychometric assessment of quality of life index. **Res Nurs Health**. 15(1): 29-38.
- Figuro, S., P.B. Luque, T.P. Martin, M. G. Sagrado and J.M. Eiros Bouza. 2011. Assessment of factors influencing health-related quality of life in HIV-infected patients. **HIV Medicine** 12: 22-30.

Gordillo, V., M.E. Fekete, T. Platteau, H.M, Antoni, N. Schneiderman, C. Nostlinger and Euro Support Group. 2009. Emotional support and gender differences in people living with HIV: effect on psychological well being. **Journal of Behavior Medicine** 32: 523-531.

Grove, S.K. 2007. **Statistics for health care research a practical workbook**. Elsevier Inc, United States of America.

Habib, T.Z and M.S. Rahman. 2010. Psycho-social aspects of AIDS as a chronic illness: social worker role perspective. **Antrocom**. 6(1): 78-89.

Handajani, Y.I., Z. Djoerban and H. Irawan. 2012. Quality of life people living with HIV/AIDS: outpatient in Kramat 128 Hospital, Jakarta. **The Indonesian Journal of Internal Medicine** 44(4). 310-316.

Haroen, H., N. Juniarti and C. Windani. 2008. Quality of life in women with HIV/AIDS and Women with partner has HIV/AIDS in West Java, Indonesia, 10 (18): 1-13. Available Source: www.digilib.ui.ac.id, August 21, 2013

Hasanah, I.C., R.A. Zaliha and M. Mahiran. 2011. Factors influencing the quality of life in patients with HIV in Malaysia. **Quality of Life Research** 20: 91-100.

Heavy, E. 2011. **Statistics for Nursing: A Practical Approach**. Jones and Bartlett Learning, United State America.

Hosseinian, S., S. Tabatabei and F. Ravaei. 2011. Effectiveness of supportive psychotherapy on quality of life of women with HIV in Kermanshah. **Procedia Social and Behavioral Sciences** 30: 1902-1907.

- Hsiung, P.C., C.T. Fang, Y.Y. Chang, M.Y. Chen and J.D. Wang. 2005. Comparison of WHOQOL-Bref and SF-36 in patients HIV infection. **Qual Life Res.** 14(1): 141-150.
- Hudson, A.L., K.A. Lee and C.T Portillo. 2004. Symptom experience and functional status among HIV-infected women. **AIDS Care** 15(4): 483-492.
- Hudson, A.L., K. Kirksey and W. Holzemer. 2010. The influence of symptoms on quality of life among HIV-infected women. **Western Journal of Nursing Research** 26(1): 9-23.
- Holzemer, W.L., S.B. Henry, K.M. Nokes, I.B. Corless, M.A. Brown, G.M. Powell-Cupe, J.G. Turner and J. Inouve. 1999. Validation of sign and symptom checklist for person with HIV disease (SSC-HIV). **J Adv Nurs.** 30(5): 1041-1049.
- Ichikawa, M. and C. Natpratan. 2006. Perceived social environment and quality of life among people living with HIV/AIDS in northern Thailand. **AIDS Care** 18(2): 128-132.
- Imam, M.H., M.R. Karim, C. Ferdous and S. Akhter. 2011. Health related quality of life. **Bangladesh Med Res Counc Bull.** 37: 1-6.
- Jenkin, P., T. Koch, and D. Kralik. 2006. The experience of fatigue for adults living with HIV. **J Clin Nurs.** 15(9): 1123-1131.
- Jia, H., C.R. Uphold, Y. Zheng, S.Wu, G.J. Chen, K. Findley and P.W. Dunwan. 2007. A further investigation of health related quality of life over time among men with HIV infection in HART era. **Aids Patients Care and STDS** 19: 395-405.

- Kamaryati, N.P. 2013. **Predictors of the quality of life in the older people with hypertension.** MNS. Thesis, Kasetsart University.
- Khumsaen, N., W. Aoup-por and P.Thammachak. 2012. Factors influencing quality of life among people with HIV (PLWH) in Suphanburi province, Thailand. **Journal of The Association of Nurses in AIDS Care** 23 (1): 63-72.
- Ko, N.Y, H.C. Lee, S.T. Hsu, W.L. Wang, M.C. Huang, and W.C. Ko. 2007. Differences in HIV disclosure by modes of transmission in Taiwanese families. **AIDS Care** 19 (6): 791-798.
- Kring, D.L. 2008. Using the revised Wilson and Cleary Model to explore factors affecting quality of life in persons on hemodialysis. **Journal of Nursing Scholarship** Available Source: <http://libres.uncg.edu/ir>, November 20, 2013.
- Kring, D.L and P.B. Crane. 2009. Factors affecting quality of life in persons on hemodialysis. **J Nephrol Nurs.** 36(1): 15-24.
- Kumarasamy, N., K.K. Venkatesh, A.J. Cecelia, B. Devaleenol, S. Saghayam, et al. 2008. Gender-based differences in treatment and outcome among HIV patients in South India. **Journal of Woman's Health** 17(9): 1471:1475.
- Kusuma, H. 2011. **Relationship between depression and family support with quality of life among HIV/AIDS patients who take health care at Cipto Mangunkusumo Hospital in Jakarta.** Available Source: www.digilib.ui.ac.id , July 23, 2013.
- Lashley., F.R and J.D. Durham. 2010. **The Person with HIV/AIDS : Nursing Perspectives.** 4th Edition. Springer Publishing Company. USA.

- Leasure, R. R. Y. Seideman. M. A. Pascucci. 2009. The process of women living with HIV/ AIDS in a rural environment. **Journal of Cultural Diversity** 16 (2): 79-86.
- Leplege A, N. Rude, E. Ecosse, R. Celnos, E. DOhin and J. Pouchot. 1997. Measuring quality of life from point of view of HIV-positive subjects: the HIV-QL 31. **Qual Life Res.** 6(6): 585-594.
- Li, L., S. Wu, Z. Wu, S. Sun, H. Cui and M. Jia. 2006. Understanding family support for people living with HIV/AIDS in Yunnan, China. **AIDS and Behavior** 10: 509-517.
- Liang, L.J., S.J. Lee, S. Iansirithaworn, D. Wan, M.J. Rotheram and Borus. 2012. Efficacy of an Intervention for Families living with HIV in Thailand: A Randomized Controlled Trial. **AIDS Behavior Journal** 16: 1276-1285.
- Lyons, S.J. 2010. **The role of social support and psychological resources in depression in people living with HIV/AIDS: examining the mediating role of mastery and self-esteem.** Available Source: https://tspace.library.utoronto.ca/bitstream/1807/24230/6/Lyons_Sarah_J_201003_MA_thesis.pdf, January 17, 2014.
- Mandzuk, L.L and D.E. McMillan. 2005. A concept analysis of quality of life. **Journal of Orthopaedic Nursing** 9(1): 12-18.
- Marcelin, F., M. Préau, I. Ravaux, P. Dellamonica, B. Spire and M.P. Carrieri. 2007. Self-reported fatigue and depression symptoms as main indicators of the quality of life (QOL) of patients living with HIV and Hepatitis C: implications for clinical management and future research. **HIV Clin Trials.** 8: 320–327.

- McLeroy, K.R., D. Bibeau, A. Steckler and K. Glanz. 1988. An ecological perspective on health promotion programs. **Health Education Quarterly** 15(4): 351-377.
- Ministry of Health of Indonesia. 2009. **VCT services in Indonesia**. Available Source: <http://pppl.depkes.go.id>, September 26, 2013.
- Ministry of Health of Indonesia. 2011. **Management Standard for HIV patients**. Available Source: <http://pppl.depkes.go.id>, September 20, 2013.
- Ministry of Health of Indonesia. 2012. **Laporan Kasus HIV/AIDS di Indonesia. Dinas Kesehatan Indonesia, Indonesia**. Available Source: <http://pppl.depkes.go.id>, July 23, 2013
- Ministry of Health of Indonesia. 2013. **Laporan Kasus HIV/AIDS di Indonesia. Dinas Kesehatan Indonesia, Indonesia**. Available Source: <http://pppl.depkes.go.id>, January 17, 2014
- Ministry of Health of North Sumatera. 2012. **Rekapitulasi Kasus HIV/AIDS**. Dinas Kesehatan Provinsi, North Sumatera.
- Ministry of Health of Medan. 2013. **Data Kasus HIV/AIDS di Kota Medan**. Dinas Kesehatan Kota Medan. Medan.
- Munsawaengsub, C., B.B. Khair and S. Nanthamongkolchai. 2012. People living with HIV/AIDS in the city of Bangkok: Quality of life and related factors. **J Med Assoc Thai**. 95(6): 127-133.
- Monika, E. 2012. Budaya patriarki dan perilaku politik perempuan dalam pemilukada di Desa Marsangap. **Journal Dinamika Politik** 1 (3): 7-12.

National AIDS Commission. 2007. **HIV/AIDS**. Available Source:

<http://www.aidsindonesia.or.id/>, January 13, 2013.

Nasrodin. 2007. **HIV & AIDS: Pendekatan biologi molekuler, klinis dan social**, edisi 1. Airlangga Univeristy Press. Surabaya, Indonesia.

Nojomi, M., K. Anbary and M. Ranjbar. 2008. Health-related quality of life in patients with HIV/AIDS. **Archives of Iranian Medicine**. 11 (6).

Nokes, K.M., C.C. Coleman, M.J. Hamilton, I.B. Corless, E. Sefick, K.M. Kirskey, P.J. Dole, P.K. Nicholas, N.R. Reynolds, E.H. Bunch, W.L. Holzemer, D.J. Wantland, Y. Fang Tsai, M. Rivero-Mendez and G.E. Canaval. 2011. Age-related effects on symptom status and health-related quality of life in person with HIV/AIDS. **Applied Nursing Research** 24: 10-16.

Norval, DA. 2004. Symptoms and sites of pain experienced by AIDS patients. **S Afr Med J**. 94(6): 450-454.

O' Cofaigh, E and P. Lewthwaite. 2013. Natural history of HIV and AIDS. **Medicine** 41 (8): 411-416.

O' Connell, K. A and S. Skevingthon. 2012. Quality of life instrument to assess wellbeing in adults who are HIV-Positive: a short form of the WHOQOL-HIV (31 items). **AIDS and Behavior** 16 (2). 452-460.

Oktavia, N. 2012. **Factors influencing quality of life among people with HIV/AIDS in Boyolali, Central Java**. Available Source: www.etd.ugm.ac.id, August 24, 2013

Olatunji, B.O., M.J. Mimiaga, C. O'cleirigh and S.A. Safren. 2006. Review of treatment studies of depression HIV. **Top HIV Med**.14(3): 112-124.

- Oluwagbemiga, A.E. 2007. HIV/AIDS and family support systems: A situation analysis of people living with HIV/AIDS in Lagos State. **Journal of Social Aspects of HIV/AIDS** 4 (3): 668-676.
- Olley, B.O., S. Seedat and D.J. Stein. 2006. Self disclosure of HIV seratus in recently diagnosed patients with HIV in South Africa. **Afr J Repord Health**. 8(2): 71-76.
- Patel, R., J. Ratner, C. Gore-Felton, G. Kadrzirange, G. Woelk and D. Katzenstein. 2012. HIV disclosure patterns, predictors, and psychosocial correlates among HIV positive women in Zimbabwe. **AIDS Care** 24(3): 358-368.
- Patel, R., S. Kassaye, C. Gore-Felton, G. Wyshak, G. Kadzirange, G. Woelk and D. Katzenstein. 2009. Quality of life, psychosocial health, and antiretroviral therapy among HIV-positive women in Zimbabwe. **AIDS Care** 21 (12): 1517-1527.
- Patrick, D and P. Erickson. 1993. **Health Policy, Quality of Life: Health Care Evaluation and Resource Allocation**. Oxford University Press, New York.
- Pedram, R., K. Hajifathalian, B. Saeidi, G. Esmaeeli, M. Rasoulinejad, et al. 2012. Quality of life among persons with HIV/AIDS in Iran: internal reliability and validity of an international instrument and associated factors. **AIDS Res**. 8(4): 94-106.
- Pereira, M and M.C. Canavarro. 2011. Gender and age differences in quality of life and the impact of psychopathological symptoms among HIV-infected patients. **AIDS Behav**. 15: 1857-1869.

- Perez, I.R., A.O. Lima, L. Sordo del Castillo, J.R. Bano, M.A. Lopes Ruz and A.A. Jimenez. 2009. No difference in quality of life between men and women undergoing HIV antiretroviral treatment. Impact of demographic, clinical, and psychosocial factors. **AIDS Care** 21(8): 943-952.
- Peterman, A.H., D. Cella, F. Mo, N and N. McCain. 1997. Psychometric validation of the revised functional assessment of human immunodeficiency virus infection (FAHI) quality of life instrument. **Quality of Life Research** 6: 572-584.
- Plach, S.K., P.E. Stevens and S.M. Heidrich. 2006. Social roles and health in women living with HIV/AIDS. **Journal of the Association of Nurses in AIDS Care** 17 (2): 58-64.
- Phaladze, N.A., S. Human, S.D. Dlamini, E.B. Hulela, I.M. Hadebe, N.A. Sukati, L.N. Makoae and N.M. Seboni. 2005. Quality of life and concept of “living well” with HIV/AIDS in Sub-Saharan Africa. **J Nurs Scholarsh.** 37(2): 120-126.
- Polit, D.F and Beck, C.T. 2012. **Nursing research: Generating and assessing evidence for nursing practice.** 9th Edition. Lippincot Company, Inc. Cina, pp 184-185, 279.
- Prachakul, W., J.S. Grant, E. Pryor, L.N. Keltner and L.J. Raper. 2009. Family relationship in people living with HIV in a city in the USA. **AIDS Care** 21(3): 384-388.
- Rao, D., W.T. Chen, C.R. Pearson, J.M. Simoni, K. Fredriksen-Goldsen, K. Nelson, H. Zhao and F. Zhang. 2012. Social support mediates the relationship between HIV stigma and depression/ quality of life among people living with HIV in Beijing, China. **International Journal of STD& AIDS** 23: 481-481.

- Reis, R.K., C.B. Santos and E. Gir. 2012. Quality of life among Brazilian women living with HIV/AIDS. **AIDS Care** 24(5):626-634.
- Rivkin, I.D., J. Gustafson, I. Weingarten and D. Chin. 2006. The effects of expressive writing on adjustment to HIV. **AIDS and Behavior** 10(1): 13-26.
- Robinson, F.P. 2004. Measurement of quality of life in HIV disease. **JANAC**. 15(5): 14-19.
- Saban, K.L., S.M. Penckofer, I. Androwich and F.B. Bryant. 2007. Health related quality of life of patients following selected types of lumbar spinal surgery : A pilot study. **Health and Quality of Life Outcomes** 5 (71).
- Saddki, N., M.M. Noor, T.H. Norbanee and M.A. Rusli. 2009. Validity and reliability of the Malay version of WHOQOL-HIV BREF in patients with HIV infection. **AIDS Care** 21(10): 1271-1278.
- Safarina L. 2012. **Pengalaman hidup perempuan dengan HIV/AIDS di kota Cimahi**. Available Source: <http://www.stikesayani.ac.id/publikasi/e-journal/files/2012/201212/201212-003.pdf>, September 26, 2014.
- Scarinci, E.G., M.T. Quinn Griffin, A. Grogoriu and J.J. Fitzpatrick. 2009. Spiritual well-being and spiritual practices in HIV-Infected Women: A preliminary study. **Journal of the Association of Nurses in AIDS Care** 20(1): 69-76.
- Seok Cha, E. K.H. Kim and J.D. Erlen. 2007. Translation of scales in cross-cultural research: issues and techniques. **Journal Compilation** 386-393.
- Sherbourne, C.D and A.L. Stewart. 1991. The mos social support survey. **Soc Sci Med**. 32: 705-714.

- Siziya, S and Fylkesnes. 2005. Impact of HIV on self-rated health in a high prevalence population with low awareness of own HIV status. **Norsk Epidemiologi**. 15(2): 165-173.
- Smith K.W., N.E. Avis, K.H. Mayer, and L. Swislow. 1997. Use of the MQoL-HIV with asymptomatic HIV-positive patients. **Qual Life Res**. 6(6): 555-560.
- Smith K.W., N.E. Avis and S.F. Assmann. 1999. Distinguishing between quality of life and health status in quality of life research: A meta-analysis. **Quality of Life Research** 8(5): 447-459.
- Solomom, S. and K.K. Venkatesh and L. Brown. 2008. Gender related differences in quality of life domains of persons living with HIV/AIDS in South India in the era prior to greater access to antiretroviral therapy. **AIDS Patient Care and STDs** 22(12): 999-1005.
- Sousa, K.H. and O.M. Kwok. 2006. Putting Wilson and Clearly to the test : Analysis of a Health related quality of life conceptual model using structural equation modeling. **Quality of Life Research** 15: 725-737.
- Spiritia AIDS Foundation. 2006. **About the Basic Knowledge of HIV and AIDS**. Available Source: <http://spiritia.or.id/>, October 13, 2013.
- Stangl, A. L., N. Wamai, J. Mermin, A.C. Awor and R.E. Bunnell. 2007. Trends and predictors of quality of life among HIV-infected adults taking highly active antiretroviral therapy in rural Uganda. **AIDS Care** 19: 626–636.
- Subramanian, T., D.M. Gupte, S.V. Dorairaj, V. Periannan and A.K. Mathai. 2009. Psycho-social support impact and quality of life of people living with HIV/AIDS in South India. **AIDS Care** 21(4): 473-481.

- Sun, H., J. Zhang and X. Dong Fu. 2007. Psychological status, coping and social support of people living with HIV/AIDS in Central China. **Public Health Nursing** 24(2): 132-140.
- Tam, V., M. Larsson, A. Pharris, B. Diendrichs and P. Nguyen. 2012. Peer support and improved quality of life among persons living with HIV on antiretroviral treatment: A randomized controlled trial from north-eastern Vietnam. **Biomed Central** 10 (53).
- Tangkawanich, T., J. Yunibhand, S. Thanasilp and K. Magilvy. 2008. Causal model of health: Health related quality of life in people living with HIV/AIDS in the northern region of Thailand. **Nursing and Health Sciences** 10: 216-221.
- Tostes, A.M., M. Chalub and J.N. Botega. 2004. The quality of life of HIV-infected women is associated with psychiatric morbidity. **AIDS Care** 16(2): 177-186.
- Tran, B. X., A. Ohinmaa, L.T. Nguyen, T.A. Nguyen and T.H. Nguyen. 2011. Determinants of health-related quality of life in adults living with HIV in Vietnam. **AIDS Care** 23(10): 1236-1245.
- Tulman, L., J. Fawcett, and M.D. McEvoy. 1991. Development of the Inventory of Functional Status-Cancer. **Cancer Nurs.** 14: 254-260.
- Tulman, L and J. Fawcett. 2007. Development of the Comprehensive Inventory of Function. **Cancer Nursing** 30(3): 205-212.
- United Nation Program on HIV/AIDS (UNAIDS). 2008. Report on the global HIV/AIDS epidemic 2008. Available Source: http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/dataaimport/pub/globalreport/2008/jc1510_2008globalreport_en.pdf, November 11, 2013.

- Vidrine, D.j., B.c. Amick, E.R. Gritz and R.C. Arduino. 2005. Assessing a conceptual framework of health related quality of life in a HIV/AIDS population. **Qual Life Res.** 14(4): 923-933.
- Voss, J. G., N, A. Sukati, N. M. Seboni, L. N. Makoae, & et al. 2007. Symptom burden of fatigue in men and women living with HIV/AIDS in Southern Africa. **Journal of The Association of Nurses in AIDS Care** 18(4): 22-31.
- Waltz, C.F., O.L. Strickland and E.R. Lenz. 2010. **Measurement in Nursing and Health Research**, 4th Ed. Springer Publishing Company, LLC, New York.
- Wan Zaidi, W.A.A., A. Baharudin, Y. Jamalut, B.M. Nor, F.H. Zulkapli and F.A. Hanapiah. 2012. Quality of life amongst HIV positive patients in Malaysian HIV shelter homes. **Procedia-Social and Behavioral Sciences** 35: 213-220.
- Wig, N., R. Lekshmi, H. Pal, V. Ahuja, C.M. Mittal and S.K. Agarwarl. 2006. The impact of HIV/AIDS in the quality of life: a cross sectional study in north India. **Indian J Med Sci.** 60: 3–12.
- Wilson, I.B and P.D. Clearly. 1995. Linking clinical variables with helath-related quality of life: a concept model of patient outcomes. **J Am Med Assoc.** 273(1): 59-65.
- Wisawatapnimit, P. 2009. **Assessment of family quality of life among families with a member who has cancer.** Ph.D. Thesis, Vanderbilt University, Nashville, Tennessee.
- World Health Organization. 1997. **Measuring Quality of Life.** Division of mental health and prevention of substance abuse. Available Source: http://www.who.int/mental_health/media/68.pdf, November 29, 2013.

World Health Organization Group. 1998. Development of the World Health Organization WHOQOL-BREF quality of life assessment. The WHOQOL Group. **Psychol Med.** 23(2): 551-558.

World Health Organization. 2002. **The World Health Organization Quality of Life for HIV (WHOQOL-HIV) Bref.** Available Source: http://www.who.int/substance_abuse/research_tools/whoQolhivbref/en/, August 18, 2013.

World Health Organization. 2004. **The World Health Organization Quality of Life (WHOQOL)-BREF.** Geneva. Available Source: http://www.who.int/substance_abuse/research_tools?whoqolbref/en/index.html, November 29, 2013.

World Health Organization. 2012. **WHO Clinical Staging of HIV.** Available Source: <http://www.who.int/hiv/pub/guidelines/clinicalstaging.pdf>, December 26, 2013.

World Health Organization. 2012. **Global Status Report of the HIV/AIDS Epidemic.** Available Source: <http://apps.who.int/gho/data/node.main.618?lang=en>, July 24, 2013.

World Health Organization. 2012. **Report of HIV in South-East Region,** Available Source: <http://www.searo.who.int/entity/hiv/data/en/>, November 29, 2013.

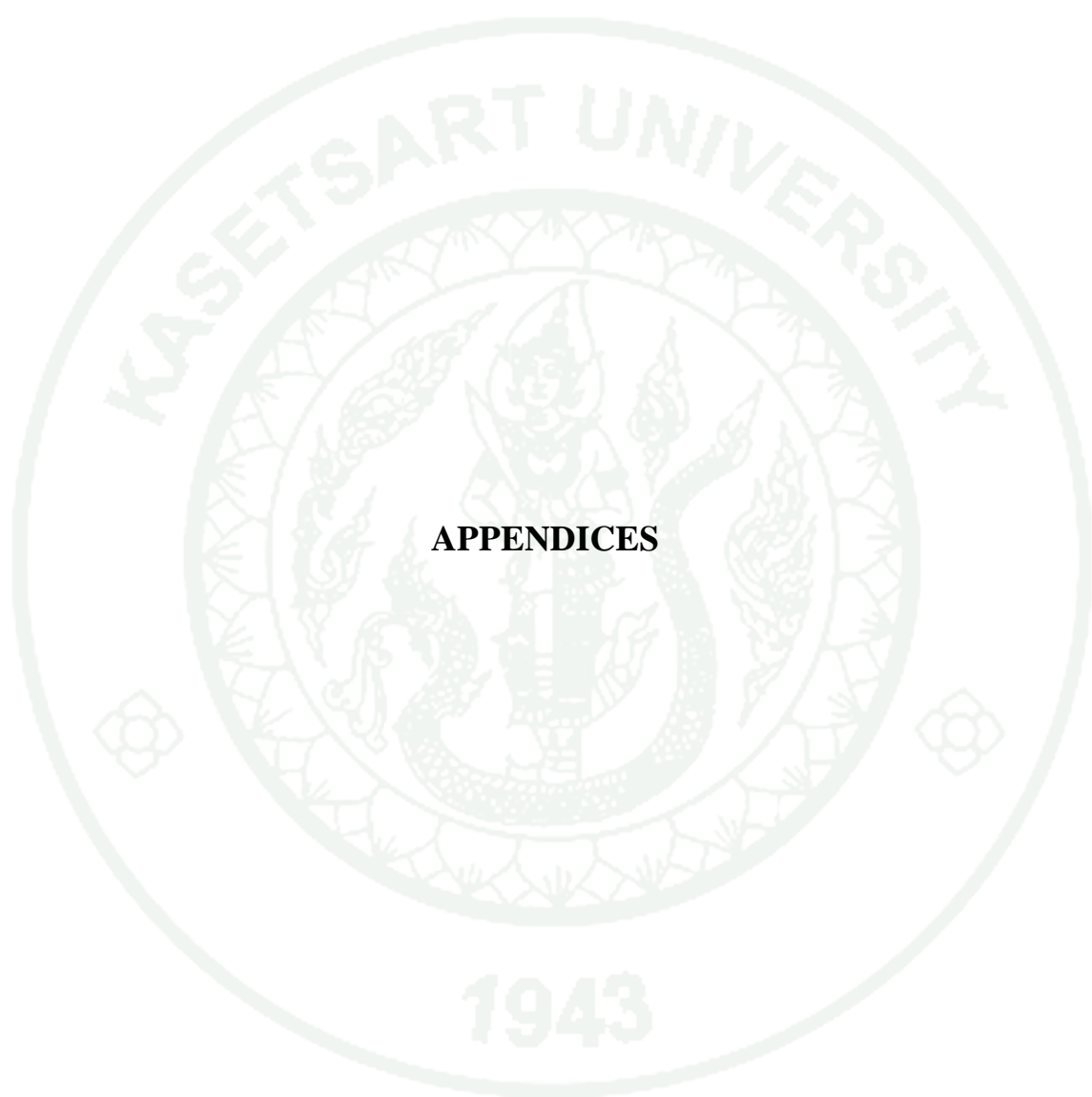
World Health Organization. **Process of translation and adaptation of instruments.** Available Source: http://www.who.int/substance_abuse/research_tools/translation/en, March 19, 2014.

Wu, A.W., D.A. Revicki, D. Jacobsen and F.E. Malitz. 1997. Evidence for reliability, validity, and usefulness of the Medical Outcomes Study HIV Health Survey (MOS-HIV). **Qual Life Res.** 6(6): 481-493.

Xiaoyan, X and M.K. Sato. 2011. Quality of life and related factors among people living with HIV in China. **Journal of Nursing and Healthcare of Chronic Illness** 3: 513-520

Zimet, G.D., N.W. Dahlem, S.G. Zimet and G.K. Farley. 1988. The Multidimensional Scale of Perceived Social Support. **Journal of Personality Assessment** 52: 30-41.

Zimpel, R.R and M.P. Fleck. 2007. Quality of life in HIV-positive Brazilians: application and validation of the WHOQOL-HIV, Brazilian version. **AIDS Care** 19: 923-930.



APPENDICES



Appendix A
Questionnaires

Demographic Information Questionnaire

Instruction: Fill the blank and tick (\checkmark) with the appropriate answer in the box!

Code number : _____ (Fill by researcher)

Date of collection : _____

1. Current age : _____ years old

2. Marital status : 1. Single 2. Married

3. Divorced 4. Widowed

3. Years of education: _____ (1) 1-5 years (Illiterate)
 _____ (2) 6-12 years (Elementary School)
 _____ (3) 13-15 years (Seconday School)
 _____ (4) 16-18 years (High Schol)
 _____ (5) > 18 years (College or University)

4. Employment status : 1. Employeed 2. Unemployed

5. Monthly family income : 1. < Rp. 1,000,000
 2. Rp. 1,000,000 – Rp. 2,999,000
 3. Rp. 3,000,000 – Rp. 4,999,000
 4. Rp. 5,000,000 – Rp. 6,999,000
 5. Rp. 7,000,000 – Rp. 9,999,000
 6. \geq Rp. 10,000,000

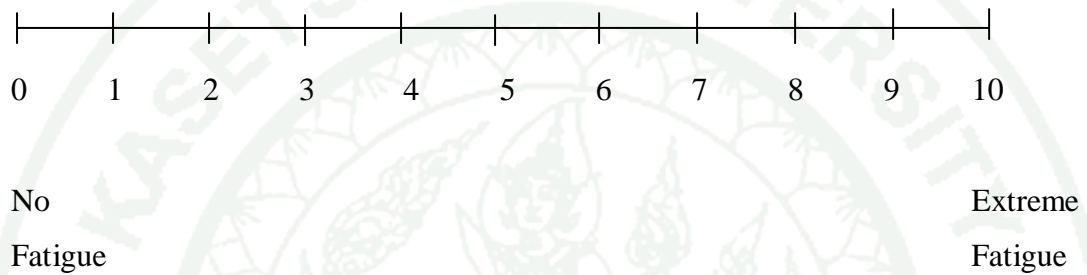
6. In what year do you think you were infected? _____

7. How do you believe you were infected with HIV? (circle one only)
 Sex with a man/ Injecting drugs/ Blood products/ Other (specify) _____

Fatigue Rating Scale

Choose one appropriate number which can describe your condition right now by using circle. We ask that you think about your symptom in the last four weeks.

How would you rate your current fatigue?



Inventory of Functional Status

Please think about the time since you diagnosed with HIV and tick [√] each box the following items.

| No | Functional activities | Not at all | Just beginning | Partially | Fully |
|----|---|------------|----------------|-----------|-------|
| | Household | | | | |
| 1 | Care of children | | | | |
| 2 | Care of husband | | | | |
| 3 | Care of relatives | | | | |
| 4 | Cleaning the house | | | | |
| 5 | Tidying the house | | | | |
| 6 | Laundry | | | | |
| 7 | Doing dishes | | | | |
| 8 | Cooking | | | | |
| 9 | Household business (paying bills, banking) | | | | |
| 10 | Grocery shopping | | | | |
| 11 | Shopping, other than groceries | | | | |
| 12 | Doing errands | | | | |
| 13 | Driving the car | | | | |
| 14 | Heavy house work | | | | |
| | Social and Community | | | | |
| 15 | Caring for pets | | | | |
| 16 | Community service organization | | | | |
| 17 | Religious organization | | | | |
| 18 | Socializing with friends | | | | |
| 19 | Socializing with relatives | | | | |
| 20 | Social clubs | | | | |
| 21 | Hobbies | | | | |
| | Personal Care | | | | |
| 22 | Exercise as much as usually did before | | | | |
| 23 | Have difficulty bathing/showering | | | | |
| 24 | Having difficulty dressing myself | | | | |
| 25 | Eat much as I usually did before | | | | |
| 26 | Eat the same types of food as usually did before | | | | |
| 27 | Spend as much time relaxing as usually did before | | | | |

| No | Functional activities | Not at all | Just beginning | Partially | Fully |
|---------------------|---|------------|----------------|-----------|-------|
| 28 | Spend most of the day in my pajamas/nightgown/bathrobe | | | | |
| 29 | Walk as much as usually did before | | | | |
| 30 | Sleep less at night | | | | |
| 31 | Rest or sleep during the day | | | | |
| Occupational | | | | | |
| 32 | Accomplishing as much as usual | | | | |
| 33 | Acting irritably to ward my work associate | | | | |
| 34 | Working fewer hours | | | | |
| 35 | Doing my job as carefully and accurately as usual | | | | |
| 36 | Working for only short periods of time and taking frequent breaks | | | | |
| 37 | Having much enthusiasm for job | | | | |
| 38 | Carrying out my usual job responsibility | | | | |
| 39 | Participating professional/ union activities | | | | |

General Health Perception

How would you rate your health on a scale from 1 to 10, with 1 = poor and 10 = excellent? Circle the number that describe your health.

1 = poor health

2

3

4

5

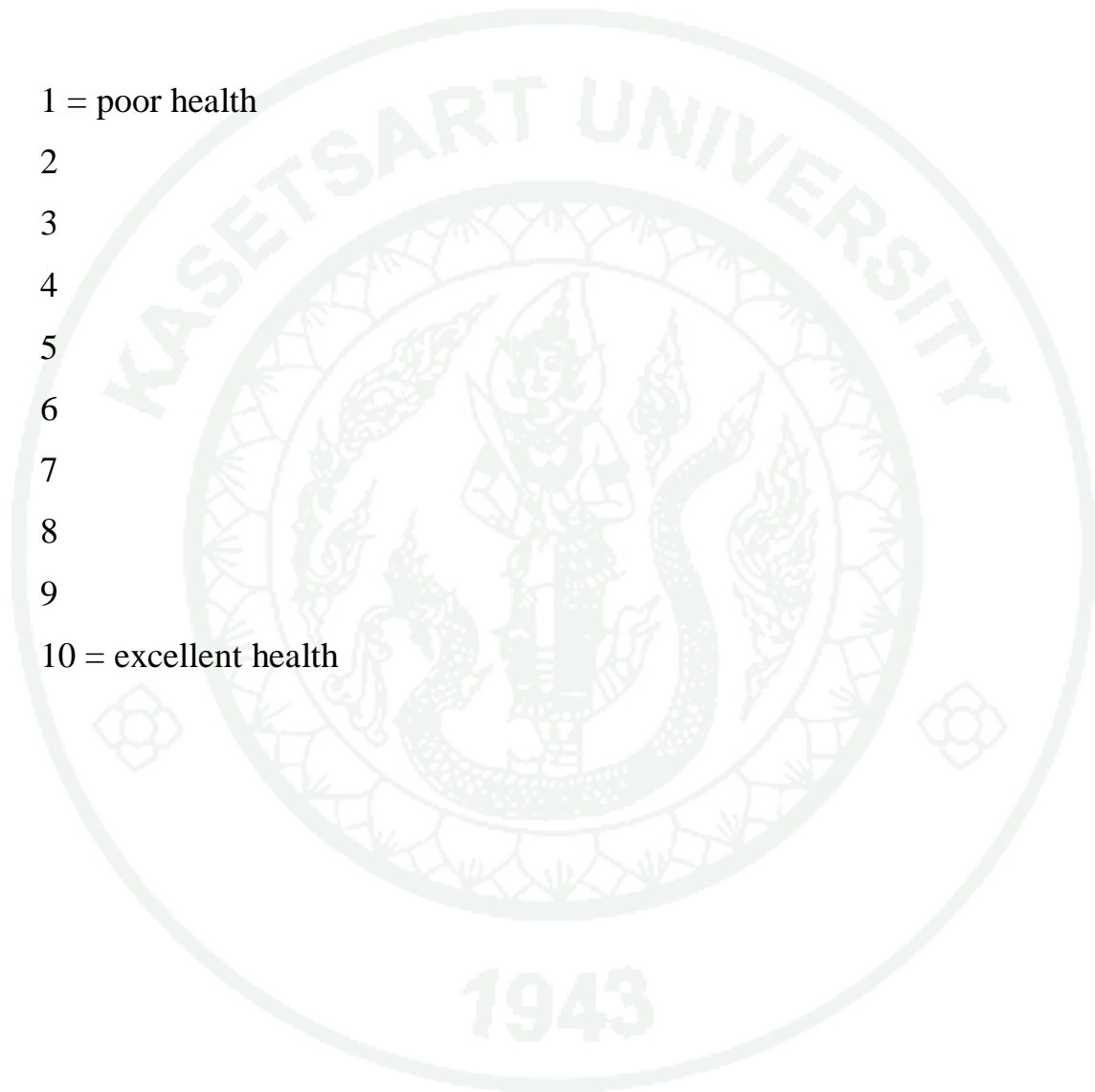
6

7

8

9

10 = excellent health



Multidimensional Scale of Perceived Social Support

Read each statement carefully. Indicate how you feel about each statement. Please tick [√] in the most appropriate column for each of the following questions.

“1” if you **Very Strongly Disagree**

“2” if you **Strongly Disagree**

“3” if you **Mildly Disagree**

“4” if you are **Neutral**

“5” if you **Mildly Agree**

“6” if you **Strongly Agree**

“7” if you **Very Strongly Agree**

| No | Items | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|----|--|---|---|---|---|---|---|---|
| 1 | There is a special person who is around when I am in need. | | | | | | | |
| 2 | There is a special person with whom I can share my joys and sorrows. | | | | | | | |
| 3 | My family really tries to help me. | | | | | | | |
| 4 | I get the emotional help and support I need from my family. | | | | | | | |
| 5 | I have a special person who is a real source of comfort to me. | | | | | | | |
| 6 | My friends really try to help me. | | | | | | | |
| 7 | I can count on my friends when things go wrong. | | | | | | | |
| 8 | I can talk about my problems with my family. | | | | | | | |
| 9 | I have friends with whom I can share my joys and sorrows. | | | | | | | |
| 10 | There is a special person in my life who cares about my feelings. | | | | | | | |
| 11 | My family is willing to help me make decisions. | | | | | | | |
| 12 | I can talk about my problems with my friends. | | | | | | | |

World Health Organization Quality of Life-Bref

The following questions ask how you feel about your quality of life, health, or other areas of your life. Please choose the answer that appears most appropriate by circle one number in each line. If you are unsure about which response to give to a question, the first response you think of is often the best one.

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

| No | Question | Very poor | Poor | Neither poor nor good | Good | Very good |
|----|--|-----------|------|-----------------------|------|-----------|
| 1 | How would you rate your quality of life? | 1 | 2 | 3 | 4 | 5 |

| No | Question | Very dissatisfied | Dissatisfied | Neither satisfied nor dissatisfied | Satisfied | Very Satisfied |
|----|---|-------------------|--------------|------------------------------------|-----------|----------------|
| 2 | How satisfied are you with your health? | 1 | 2 | 3 | 4 | 5 |

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

| No | Question | Not at all | A little | A moderate amount | Very much | An extreme Amount |
|----|--|------------|----------|-------------------|-----------|-------------------|
| 3 | To what extent do you feel that physical pain prevents you from doing what you need to do? | 5 | 4 | 3 | 2 | 1 |
| 4 | How much do you need any medical treatment to function in your daily life? | 5 | 4 | 3 | 2 | 1 |
| 5 | How much do you enjoy life? | 1 | 2 | 3 | 4 | 5 |
| 6 | To what extent do you feel your life to be meaningful? | 1 | 2 | 3 | 4 | 5 |

| No | Question | Not at all | A little | A moderate amount | Very much | Extremely |
|----|---|------------|----------|-------------------|-----------|-----------|
| 7 | How well are you able to concentrate? | 1 | 2 | 3 | 4 | 5 |
| 8 | How safe do you feel in your daily life? | 1 | 2 | 3 | 4 | 5 |
| 9 | How healthy is your physical environment? | 1 | 2 | 3 | 4 | 5 |

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

| No | Question | Not at all | A little | Moderately | Mostly | Completely |
|----|--|------------|----------|------------|--------|------------|
| 10 | Do you have enough energy for everyday life? | 1 | 2 | 3 | 4 | 5 |
| 11 | Are you able to accept your bodily appearance? | 1 | 2 | 3 | 4 | 5 |
| 12 | Have you enough money to meet your needs? | 1 | 2 | 3 | 4 | 5 |
| 13 | How available to you is the information that you need in your day-to-day life? | 1 | 2 | 3 | 4 | 5 |
| 14 | To what extent do you have the opportunity for leisure activities? | 1 | 2 | 3 | 4 | 5 |

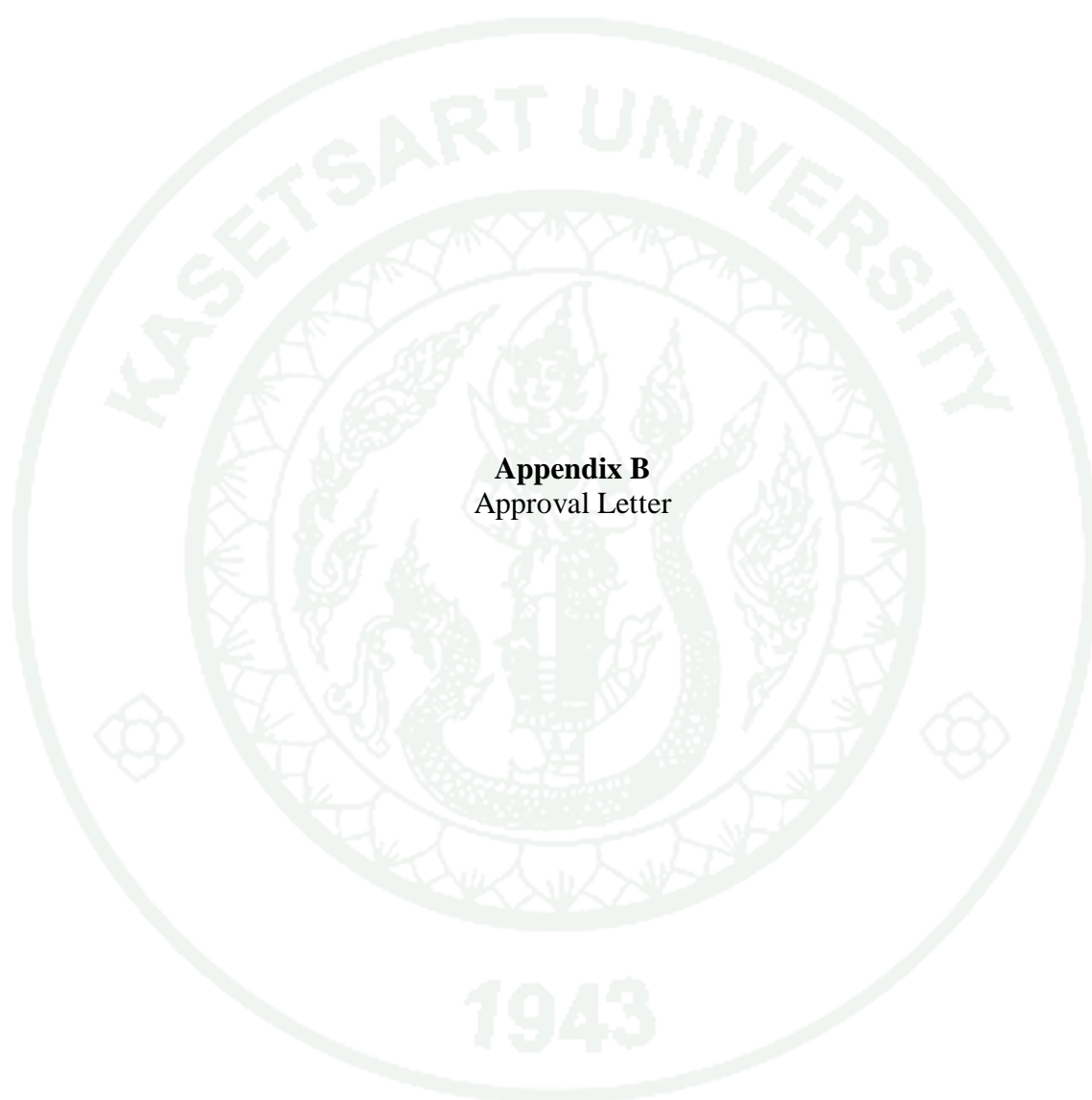
| No | Question | Very poor | Poor | Neither poor nor good | Good | Very good |
|----|--------------------------------------|-----------|------|-----------------------|------|-----------|
| 15 | How well are you able to get around? | 1 | 2 | 3 | 4 | 5 |

| No | Question | Very dissa- tisfied | Dissa- tisfied | Neither satisfied nor dissatisfied | Satisfied | Very Satis- fied |
|----|--|---------------------------|-------------------|---|-----------|------------------------|
| 16 | How satisfied are you with your sleep? | 1 | 2 | 3 | 4 | 5 |
| 17 | How satisfied are you with your ability to perform your daily living activities? | 1 | 2 | 3 | 4 | 5 |
| 18 | How satisfied are you with your capacity for work? | 1 | 2 | 3 | 4 | 5 |
| 19 | How satisfied are you with yourself? | 1 | 2 | 3 | 4 | 5 |
| 20 | How satisfied are you with your personal relationships? | 1 | 2 | 3 | 4 | 5 |
| 21 | How satisfied are you with your sex life? | 1 | 2 | 3 | 4 | 5 |
| 22 | How satisfied are you with the support you get from your friends? | 1 | 2 | 3 | 4 | 5 |
| 23 | How satisfied are you with the conditions of your living place? | 1 | 2 | 3 | 4 | 5 |

| No | Question | Very dissa- tisfied | Dissa- tisfied | Neither satisfied nor dissatisfied | Satisfied | Very Satis- fied |
|----|--|---------------------------|-------------------|---|-----------|------------------------|
| 24 | How satisfied are you with your access to health services? | 1 | 2 | 3 | 4 | 5 |
| 25 | How satisfied are you with your transport? | 1 | 2 | 3 | 4 | 5 |

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

| No | Question | Never | Seldom | Quite often | Very often | Always |
|----|--|-------|--------|----------------|---------------|--------|
| 26 | How often do you have negative feelings such as blue mood, despair, anxiety, depression? | 5 | 4 | 3 | 2 | 1 |



Appendix B
Approval Letter



COA No. 47 / 2014

ETHICAL REVIEW BOARD

Baromarjonnani College of Nursing Nopparat Vajira

681 Ramintra Road, Khannayao, Bangkok 10230, Thailand, Tel. 02-540-6500 ext 222

Certificate of Approval The Institutional Review Board of the Baromarjonnani College of Nursing Nopparat Vajira 681 Ramintra Road, Khannayao, Bangkok Thailand, has approved the following study which is to be carried out in compliance with the International guidelines for human Research protection as Declaration of Helsinki, The Belmont Report.

Study Title: Factors Related to Quality of Life in HIV Infected Women in Medan, North Sumatera, Indonesia


Study Center: Indonesia


Principal Investigator: Ms. Siska Evi Martina

Document Reviewed:

1. Principal Investigator (PI)
2. Proposal Version 3
3. Patient Information Sheet Version 3

The principal investigator (PI) must report the status of the project and apply for the continued Approval annually before the anniversary date of approval through cut study period.

Signature.....
(BENJAMAS SIRIKAMONSATHIAN)
Chairperson of Ethical Review Board

Signature.....
(NITTIYA NOYSIROOM)
Secretary of Ethical Review Board

Date of Approval: 25 July 2014

Approval Expire Date: 24 July 2015

1943

**MINISTRY OF HEALTH OF INDONESIA
DIRECTORATE GENERAL OF HEALTH
ADAM MALIK HOSPITAL**

Address: Bunga Lau No. 17, Medan, 20136
Tlp. (061) 8360381 Fax (061) 8360405

LETTER STATEMENT

No. LB.02.03.II.4.2014

The undersigned,

Name : Dr. Purnamawati, MARS
NIP : 19570331 1985 01 2011
Possition : Director of Adam Malik Hopital Medan
Address : Bunga Lau No. 17 Medan

I hereby declare that the student/ researcher:

Name : Siska Evi Martina
Instituion : Master of Nursing Science International Program Kasetsart
University Thailand
Title : Factors Related to Quality of Life in HIV Infected Women

It is true that she was conducted the research in Adam Malik Hospital according to the procedures and regulations of Adam Malik Hospital Medan.

Thus, this letter is made to be used properly.

Medan, September 2014

Directore of Adam Malik Hospital

Dr. Purnamawati, MARS



KEMENTERIAN KESEHATAN RI
DIREKTORAT JENDERAL BINA UPAYA KESEHATAN
RUMAH SAKIT UMUM PUSAT
H. ADAM MALIK

Jl. Bunga Lau No. 17
 Medan 20136

Telp. (061) 8360381
 (061) 8360405

SURAT KETERANGAN

No. LB.02.03.II.4. *9/28*

Yang bertanda tangan dibawah ini :

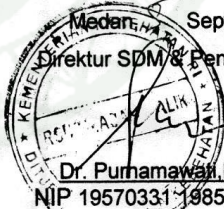
N a m a : Dr.Purnamawati, MARS
NIP : 19570331 1985 01 2001
Jabatan : Direktur SDM & Pendidikan RSUP H Adam Malik Medan
Alamat : Jl. Bunga Lau No. 17 Medan.

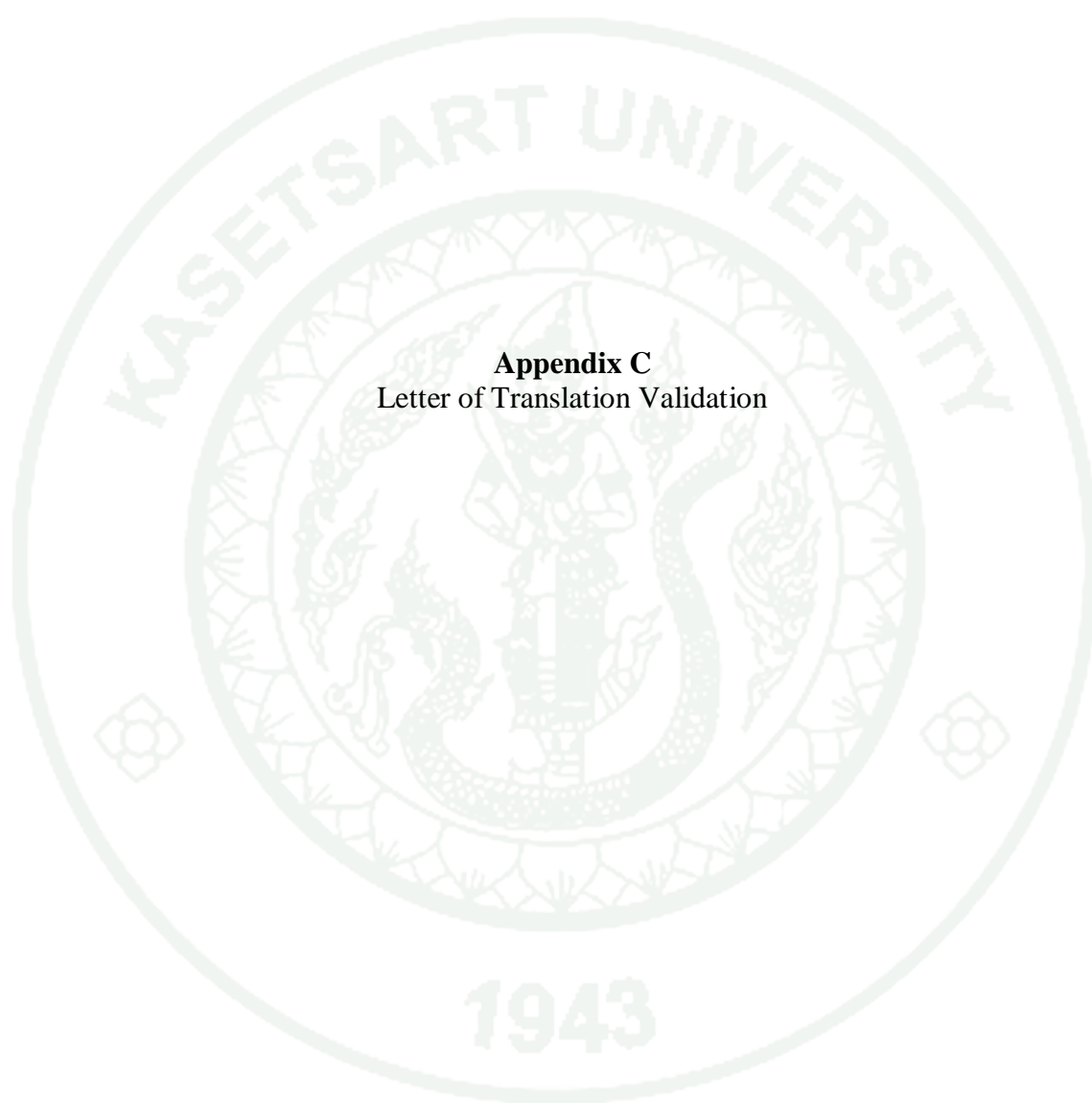
Dengan ini menerangkan bahwa Mahasiswa / Peneliti :

N a m a : Siska Evi Martina
Institusi : Master of Nursing Science International Program
 Kasetsart University Thailand
Judul : "Factors Related to Quality of Life in HIV Infected Women"

Benar telah selesai melaksanakan penelitian di lingkungan RSUP H.Adam Malik sesuai prosedur dan ketentuan penelitian yang berlaku di RSUP H.Adam Malik Medan.

Demikian surat keterangan ini dibuat sesuai dengan sebenarnya, untuk dapat dipergunakan seperlunya.

Medan, *9/28* Sept 2014
 Direktur SDM & Pendidikan,

Dr. Purnamawati, MARS
 NIP 19570331 1985 01 2001



Appendix C
Letter of Translation Validation



THE MINISTRY OF EDUCATION AND CULTURAL
OF THE REPUBLIC OF INDONESIA
HKBP NOMMENSEN UNIVERSITY
DIKLAT BAHASA

Jl. Sangnawaluh Nomor: 4, Pematang Siantar, North Sumatera, Tlp. (0622) 50232
Fax. (0622) 7552017 Email: uhn@nommensen.org

Number : 15/FKIP/VI/2014

Reference : Validation of translation

Declaration Letter

I, the undersigned

Name : DUMARIS E. SILALAH, S.Pd., MPd

NIDN : 0114077901

Position : Staff of Diklat Bahasa of HKBP Nommensen University

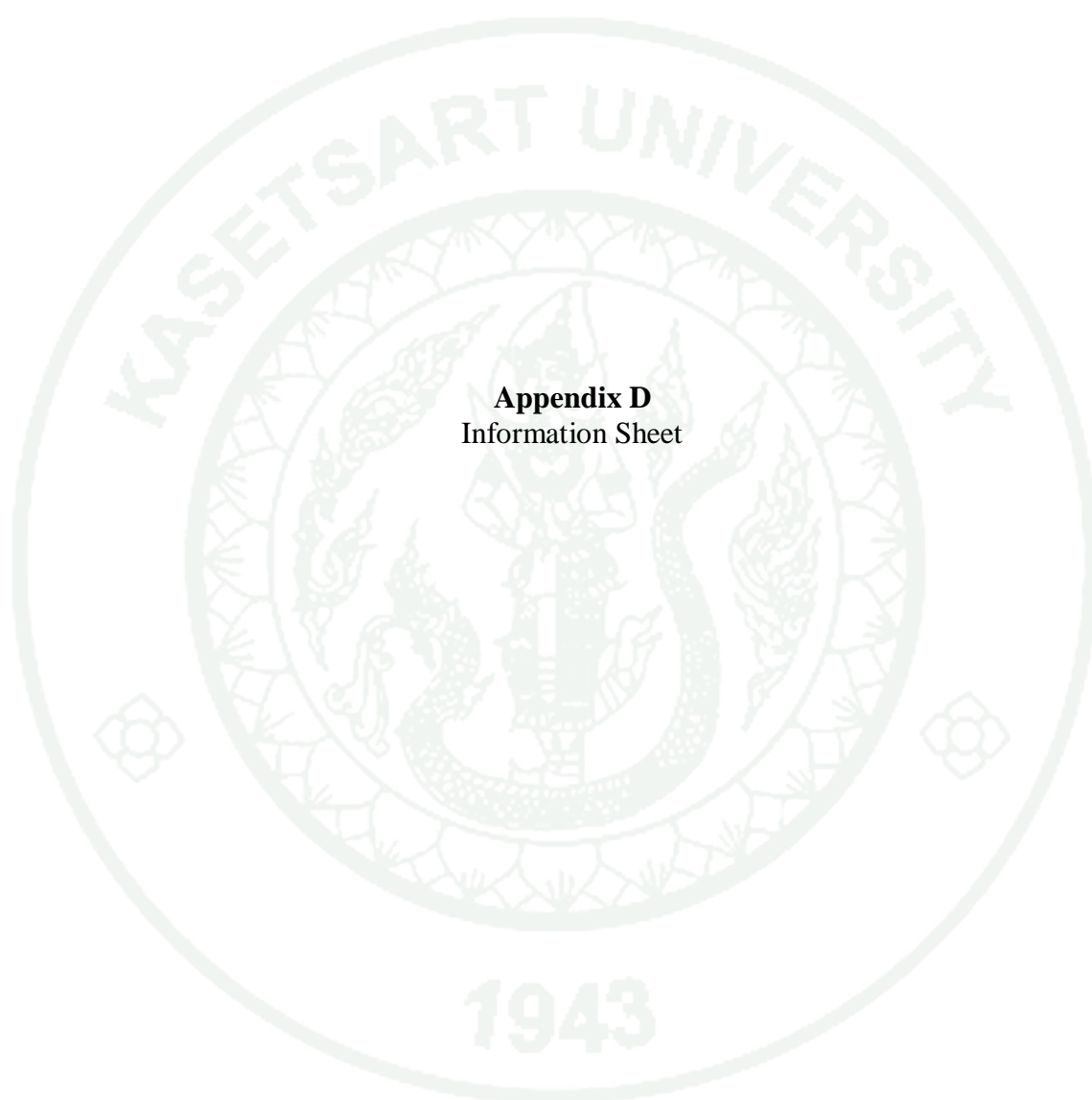
I hereby declare that it is true that I was appointed as an authorized translator at the Language Laboratory of HKBP Nommensen University. I am in charge as the translator of some documents from English into Bahasa Indonesia. This Declaration Letter is truly drawn up and it can be applied where necessary.

P. Siantar.-North Sumatera, 11 June 2014



Sincerely

DUMARIS E. SILALAH, S.Pd., M.Pd



Appendix D
Information Sheet

Information Sheet

Title of Research Project: Factors related to quality of life in HIV infected women in Medan, North Sumatera, Indonesia

Principle researcher's name: Siska Evi Martina

Office address: Salemba Raya 41, Jakarta 10440, Indonesia

Home address: Pintu Air 20, Medan District, 20218, North Sumatera, Indonesia

Telp (office): +6221-392-4094

Telp (Home):-

Cell phone: +6681-634-4617 (Thailand) **Email:** evi_sastro@yahoo.com

+6281-381-385801 (Indonesia)

You are being invited to take part in a research project. Before you decide to participate it is important for you to understand why the research is being done and what it will involve, please take time to read carefully and do not hesitate to ask the nurses if anything is unclear or if you would like more information.

The research project involves HIV infected women to provide information about quality of life and factors associated with their quality of life, including characteristic of the individual, fatigue, functional status, general health perception and social support. This study is descriptive research and sample are women diagnosed with HIV. Data will be collected using questionnaires. The objective of this study is to determine factors related to quality of life in HIV infected women in Medan, North Sumatera, Indonesia.

Details of participants

I plan to invite and enroll about at least 111 HIV infected women who come to routine clinical care visit at community HIV clinic, Adam Malik Hospital, Medan, North Sumatera, Indonesia. The inclusion criteria of participants in this study are a) an adult HIV infected women aged 18 to 45 years old, b) diagnosed with HIV at least three months, d) able to speak, write and read in Bahasa Indonesia, and e) willing to participate in this study. The exclusion criteria is HIV infected women who should be hospitalized after meeting with physicians. In Medan, number of HIV infected women tend to increase each year (MoH of Medan, 2013). HIV infected women suffer with the stigma and impact on their quality of life. Therefore, you are invited to participate in this study because your personal information is fit with the inclusion criteria and I believe you can provide useful information to understand factors related to quality of life of HIV infected women. If you would like to participate in this study, nurses who responsible in HIV program will facilitate you to get the questionnaires which has been provided on the table in the room B at community HIV clinic.

Procedures upon participants

I have gotten permission from the Director of Adam Malik Hospital, Medan, North Sumatera, Indonesia and the Head of community HIV clinic Adam Malik Hospital, Medan. North Sumatera, Indonesia to conduct data collection. I have introduced and contacted with nurses who are responsible for the HIV program in the community HIV clinic of Adam Malik Hospital, Medan. I also explained the detail of the research topic, purposes, benefits, and procedure to the nurses. In this study, no one know that you participate in this study. I do not need to meet with you. You can read provided information sheet and if you decide to participate in this study you can take the questionnaires which has been provided on the table in the room B.

If you are willing to take part in the study, you can read carefully information about the study including objectives, benefits, procedures of the study, and the right of participant. After that, you can take the questionnaires which has been provided on the table. However, if your information do not meet with the inclusion criteria in this study, no need to feel denied from this study.

If any question not clear for you or you do not understand, you can ask the nurse in this time to help you by clarification and explain more detail for you.

You can take questionnaire with you and fill it at your convenience time such as before or after meet with physician or during waiting the medicine. You will take about 45-60 minutes to complete the questionnaires. These questionnaires will ask you about your personal information including age, marital status, educational level, occupation, and family income, and your fatigue symptom, health perception, functional status related to women function and social support that you have from family, friends, and others.

Participation to the study is voluntary. You have the right to deny and/or withdraw from the study at any time, without giving any reason. You may feel uncomfortable to answer some questions you can skip to not answer them. There will be no impact on you. If you decide to withdraw from the study, you will still receive health care services at community HIV clinic of Adam Malik Hospital, Medan, North Sumatera, Indonesia without any consequences.

If you have any question or would like to obtain further information of this study, you can contact the nurses in community HIV clinic. If the nurses can not give clear information, they can reach me at any time. After you have finished completing the questionnaires, you can put the questionnaires on the table. Then, you can take the souvenir from the box to thank you for your time and effort for participating in this study.

Your answer will be anonymous and confidential. There is no scope that anyone can link your identity and your information. The data will be maintained through the usage of computer password protection. All questionnaires will be kept in sealed envelop in a locked file cabinet for 3 years after finished this study then they will be destroyed. Only I and my advisor will be able to access to the questionnaires and the data. In case of publication, the result of the study will be reported as a total picture of the study. I will not provide any short of information that could identify you.

Risk and/or undesirable consequences of this study

There will be no serious physical risk to you during you participate in this study. However, you may feel fatigue, you can stop to answer the question and you can take a rest or call the nurses. Nurses will help you to obtain appropriate assistant. You might be continue to answer the questionnaire if you feel like to do when you feel better.

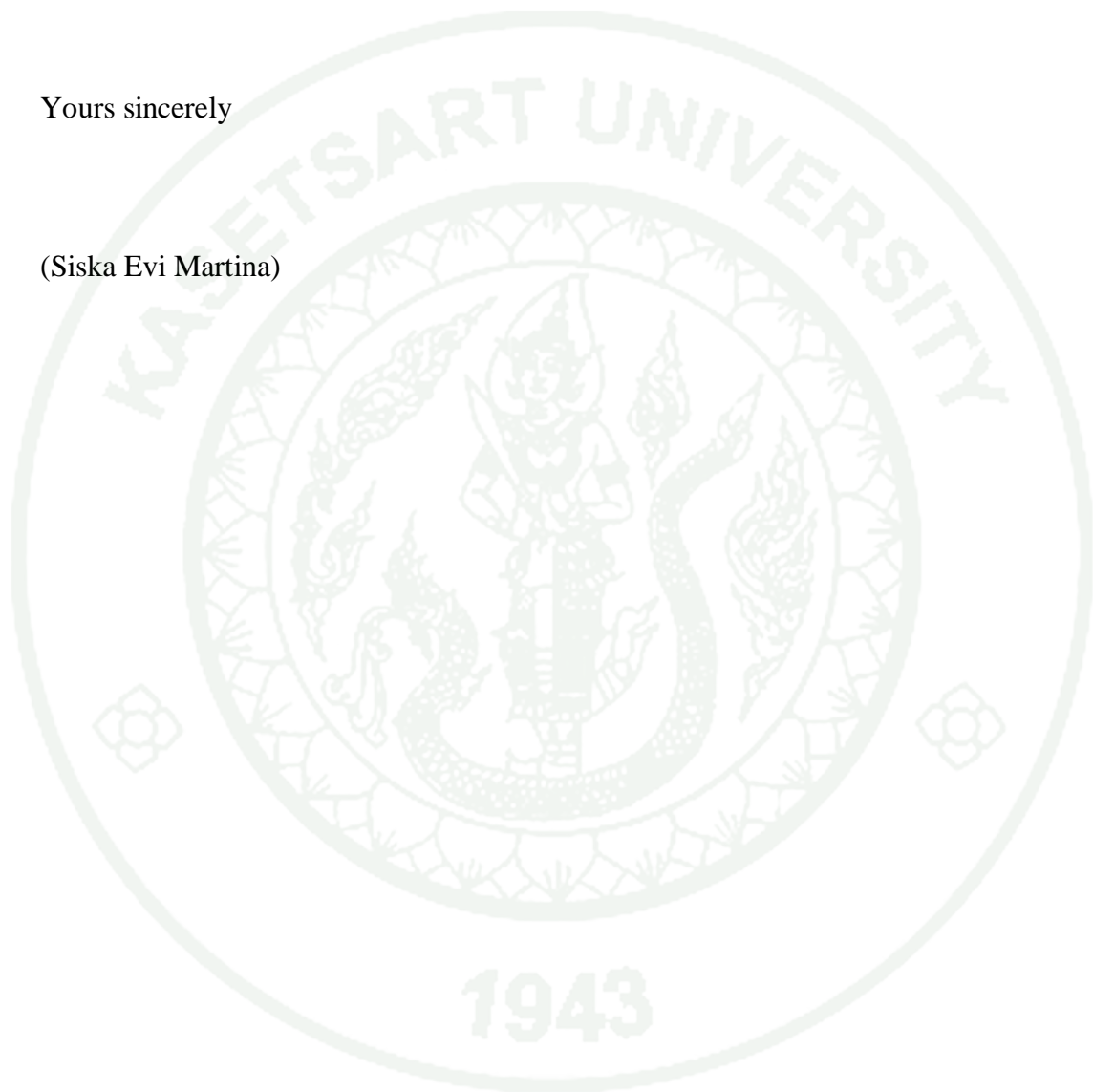
Benefit of this study

There is no direct benefit to you in this study but your contribution will be helpful to identify the significant factors related to quality of life in HIV infected women and also will be helpful for nurses and health care providers to better understand about quality of life of HIV infected women and factors that related to quality of life especially in Medan, North Sumatera. It will provide useful information to develop nursing services that appropriate for HIV infected women have been treating at the community HIV clinic of Adam Malik Hospital, Medan, North Sumatera, Indonesia.

If, I do not perform upon participants as indicated in the information, you can report the incident to the Ethics Review Committee for research Involving Human research Subjects, Boromarajonani College of Nursing Nopparat Vajira 681 Ramintra Road, Khanayao, Bangkok 10230. Thailand, Tel + 662-540-6500 ext 257, 246.

Yours sincerely

(Siska Evi Martina)



Information Sheet of Research Study (in Bahasa Indonesia)**Lembar Informasi bagi Responden**

Judul Penelitian: “Faktor-faktor yang berhubungan dengan kualitas hidup wanita dengan HIV di Medan, Sumatera Utara, Indonesia”

Nama Peneliti: Siska Evi Martina

Alamat Kantor: Salemba Raya 41, Jakarta 10440, Indonesia

Alamat Rumah: Pintu Air 20, Medan, 20218, Sumatera Utara, Indonesia

Telp (kantor): +6221-392-4094

Telp (rumah):-

Cell phone: +6681-634-4617 (Thailand) **Email:** evi_sastro@yahoo.com

+6281-381-385801 (Indonesia)

Anda diundang untuk berpartisipasi dalam penelitian ini. Sebelum Anda memutuskan untuk ikut, penting bagi Anda untuk memahami tentang penelitian ini dan apa yang akan Anda lakukan dalam penelitian ini. Silahkan luangkan waktu Anda untuk mengetahui informasi berikut ini dengan seksama dan jangan ragu untuk menanyakan kepada perawat jika ada sesuatu yang kurang jelas atau jika Anda membutuhkan informasi lebih lanjut.

Penelitian ini melibatkan respon wanita dengan HIV dengan kualitas hidup dan faktor yang berhubungan dengan kualitas hidup mereka seperti karakteristik individu, kelelahan, status fungsional, pemahaman kondisi kesehatan, dan dukungan sosial. Penelitian ini adalah penelitian yang menggambarkan kondisi tersebut di atas dan respondenya adalah wanita dengan HIV. Pengumpulan data menggunakan beberapa kuesioner. Tujuan penelitian ini adalah menentukan faktor-faktor yang berhubungan dengan kualitas hidup wanita dengan HIV di Medan, Sumatera Utara, Indonesia.

Kriteria responden

Kriteria responden dalam penelitian ini adalah: a) wanita dengan HIV berusia 18 to 45 tahun, b) terdiagnosa HIV minimal 3 bulan, c) mampu berbicara, menulis, dan membaca dalam Bahasa Indonesia, dan d) bersedia berpartisipasi dalam penelitian ini. Kriteria yang tidak termasuk dalam penelitian ini adalah wanita dengan HIV yang setelah pemeriksaan dengan dokter diputuskan untuk dirawat di rumah sakit. Saya berencana melibatkan minimal 111 orang wanita dengan HIV yang datang ke pelayanan kesehatan masyarakat untuk HIV di Adam Malik, Medan, Sumatera Utara, Indonesia. Jumlah wanita dengan HIV di Medan cenderung meningkat tiap tahun (Dinas Kesehatan Kota Meda, 2013). Wanita dengan HIV menderita dengan stigma yang berdampak bagi kualitas hidup mereka. Oleh karena itu, Anda diundang dalam penelitian ini karena Anda adalah sumber informasi terbaik yang berada dalam kriteria dan saya percaya bahwa Anda dapat memberikan data yang berguna untuk penelitian ini.

Prosedur penelitian

Untuk mendapatkan calon responden, sebelumnya saya telah mendapatkan ijin dari pimpinan rumah sakit Adam, Malik, Sumatera Utara, Indonesia dan kepala bagian pelayanan kesehatan masyarakat untuk HIV di rumah sakit Adam, Malik, Sumatera Utara, Indonesia untuk melakukan penelitian. Setelah saya mendapatkan ijin, saya akan menghubungi dan bertemu dengan perawat yang bertanggung jawab pada program HIV di pelayanan kesehatan masyarakat di rumah sakit Adam, Malik, Sumatera Utara, Indonesia. Saya akan memperkenalkan diri saya dan menjelaskan secara singkat tentang topik, tujuan, manfaat dan prosedur penelitian kepada perawat termasuk bahwa saya tidak perlu bertemu dengan responden. Responden yang bersedia berpartisipasi dalam penelitian ini akan membaca lembar informasi yang saya sediakan dan menjawab kuesioner yang tersedia. Saya akan bertanya kepada perawat apakah ada pertanyaan dan memberikan penjelasan tentang pertanyaan tersebut. Saya telah menyediakan kuesioner pada meja di ruang B.

Jika Anda bersedia mengambil bagian dalam penelitian ini, Anda bisa membaca lembar informasi dengan seksama terkait penelitian dengan jelas seperti tujuan, manfaat, prosedur penelitian, dan perlindungan sebagai responden. Setelah itu, Anda bisa mengambil kuesioner yang tersedia di meja. Namun, apabila Anda ternyata tidak termasuk dalam kriteria penelitian ini, Anda tidak perlu merasa ditolak dari penelitian ini.

Jika ada pertanyaan pada kuesioner yang tidak Anda mengerti atau tidak dapat dibaca dengan jelas, Anda bisa bertanya pada perawat dan perawat akan memberikan penjelasan.

Setelah Anda memahami semua informasi mengenai penelitian ini, Anda bisa mengambil dan menjawab kuesioner yang tersedia pada waktu yang sesuai dengan keinginan Anda seperti sebelum atau setelah pemeriksaan dengan dokter. Anda membutuhkan 45-60 menit untuk menjawab keseluruhan kuesioner. Kuesioner ini akan menanyakan Anda tentang informasi umum Anda seperti (umur, status pernikahan, pendidikan, pekerjaan, dan pendapatan keluarga), gejala kelemahan yang Anda rasakan, kepuasan kesehatan Anda, status fungsional yang masih dapat Anda lakukan berkaitan dengan fungsi sebagai wanita, dan dukungan yang Anda dapatkan dari keluarga, teman, dan yang lainnya. Anda juga diperbolehkan untuk mengajukan pertanyaan dan perawat akan memberikan penjelasan.

Responden dalam penelitian ini didampingi dan Anda memiliki hak untuk menolak dan/ atau menarik diri dari penelitian ini setiap saat, tidak perlu memberikan alasan apapun, dan tidak akan ada dampak buruk pada Anda. Jika Anda memutuskan untuk mengundurkan diri dari penelitian, Anda akan tetap menerima pelayanan kesehatan di pelayanan kesehatan masyarakat untuk HIV di rumah sakit Adam Malik, Sumatera Utara, Indonesia.

Jika Anda memiliki pertanyaan atau ingin mendapatkan informasi lebih lanjut, perawat akan menemui Anda pada waktu yang Anda inginkan. Anda juga bisa menghubungi perawat yang bertanggung jawab dalam program HIV di pelayanan kesehatan masyarakat untuk HIV di rumah sakit Adam Malik, Sumatera Utara, Indonesia. Setelah Anda selesai menjawab kuesioner, silahkan letakan kuesioner dan silahkan mengambil kenang-kenangan yang tersedia di kotak sebagai ucapan terima kasih atas partisipasi Anda dalam penelitian ini.

Jawaban yang Anda berikan adalah tanpa nama dan rahasia. Tidak ada orang lain bisa mengetahui tentang diri Anda dan informasi yang Anda berikan. Keamanan data akan dijamin dengan menggunakan kata kunci pelindung di komputer. Semua kuesioner akan disimpan pada amplop tertutup dan disimpan di lemari berkas yang terkunci selama 3 tahun setelah penelitian ini selesai dan akan dihancurkan setelah itu. Hanya saya dan advisor yang dapat melihat kuesioner tersebut. Apabila penelitian ini akan di publikasikan dan/ atau hasil penelitian akan di laporkan sebagai gambaran keseluruhan. Saya tidak akan memberikan informasi apapun tentang Anda.

Resiko dan/atau kejadian yang tidak diharapkan dalam penelitian

Penelitian ini tidak membahayakan kondisi fisik Anda. Namun, Anda mungkin merasa tidak nyaman untuk menjawab, Anda boleh melewati untuk tidak menjawab pertanyaan tersebut. Apabila Anda merasa letih, Anda bisa berhenti untuk menjawab pertanyaan dan beristirahat. Perawat akan membantu anda dan bisa melanjutkan menjawab pertanyaan apabila Anda sudah merasa lebih baik dan ingin tetap melanjutkan menjawab.

Manfaat penelitian ini

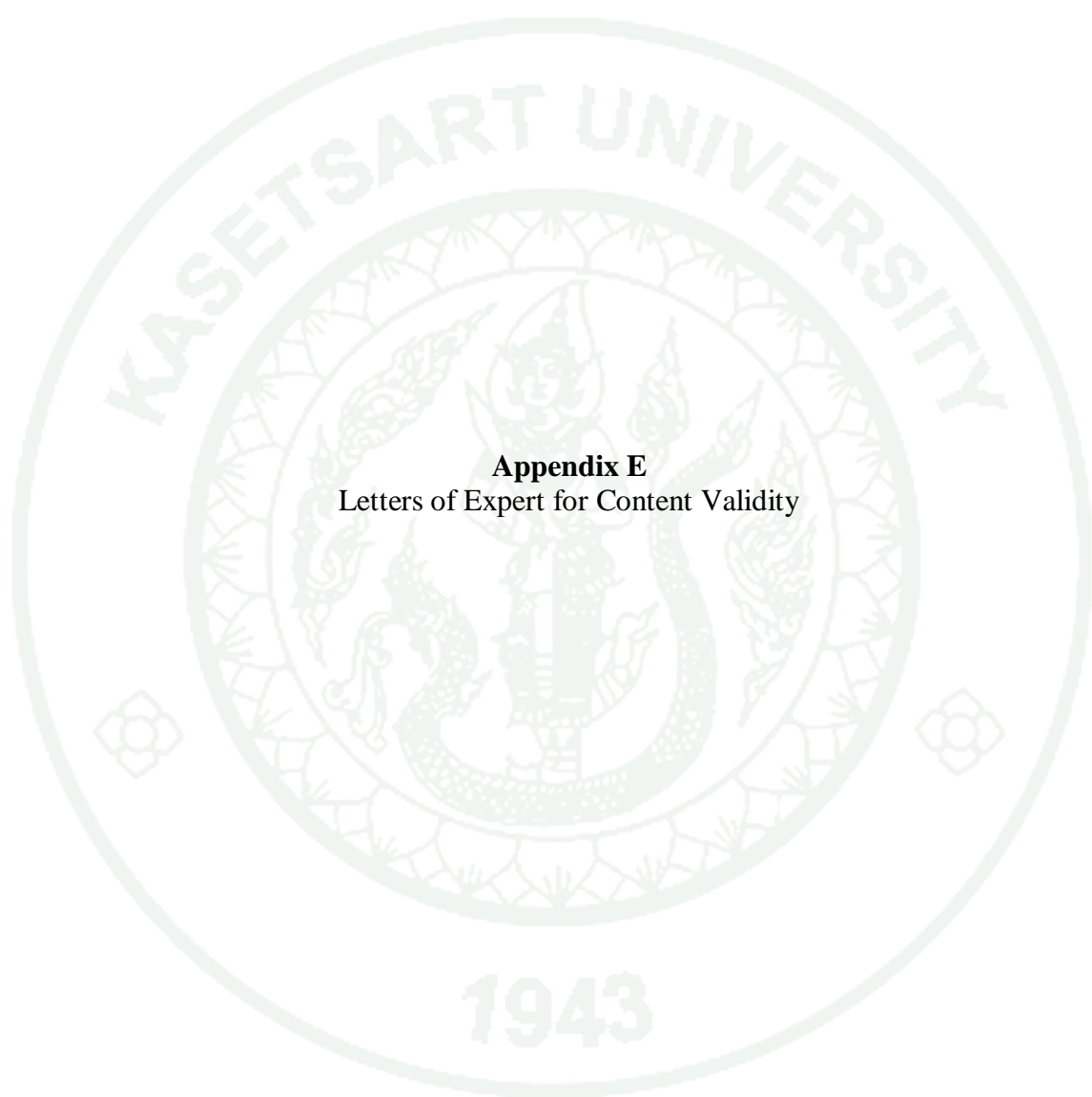
Penelitian ini tidak memberikan manfaat langsung bagi Anda, tetapi keterlibatan Anda akan sangat membantu untuk mengetahui faktor-faktor yang berhubungan dengan kualitas hidup wanita dengan HIV dan juga sangat bermanfaat

bagi perawat dan penyedia layanan kesehatan untuk lebih memahami kualitas hidup wanita dengan HIV dan factor-faktor yang berhubungan dengan kualitas hidup khususnya di Medan. Hal ini akan memberikan informasi yang berguna untuk mengembangkan pelayanan keperawatan yang sesuai untuk wanita dengan HIV di pelayanan kesehatan masyarakat untuk HIV rumah sakit Adam Malik, Sumatera Utara, Indonesia.

Jika saya tidak memperlakukan Anda seperti yang ditunjukkan dalam lembar informasi, Anda dapat melaporkan kejadian tersebut kepada Komite Etik Penelitian, Boromarajonani College of Nursing Nopparat Vajira 681 Ramintra Road, Khanayao, Bangkok 10230. Thailand, Tel + 662-540-6500 ext 257, 246.

Hormat saya

(Siska Evi Martina)



Appendix E
Letters of Expert for Content Validity



No.0203.0932/ 488

Boromarajonani College of Nursing Nopparat Vajir
681 Ramintra Road, Kannayao, Bangkok 10230
THAILAND

1 May 2014

Mr. Agung Waluyo, Ph. D

Subject: Letter of Invitation to be an expert review for a research instrument

Dear Mr. Agung Waluyo, Ph. D

Boromarajonani College of Nursing Nopparat Vajira, an Affiliation Institution of Kasetsart University, Thailand would like to ask for your kind support in serving as an expert review for a research instrument to be used for a Master's thesis. The instrument is proposed by Ms. Siska Evi Martina, a student in Master of Nursing Science program in Family and Community Health Nursing (International Program) of Boromarajonani College of Nursing Nopparat Vajira. Her thesis entitled "Factors related to quality of life in HIV infected women in Medan, North Sumatera, Indonesia."

I would be most grateful for your kind support in reviewing the aforementioned research instrument. If you have any queries please do not hesitate to contact Dr. Sunanta Thongpat, thesis advisor, at sunanta.t@bcnnv.ac.th or + 66-85-2511633

Yours Sincerely,

Monthana Hemchayat

Monthana Hemchayat

Director Boromarajonani College of Nursing Nopparat Vajira

Dr. Sunanta Thongpat
Deputy Director of Graduate study
Boromarajonani College of Nursing Nopparat Vajira

No.0203.0932/ 487



Boromarajonani College of Nursing Nopparat Vajira
681 Ramintra Road, Kannayao, Bangkok 10230
THAILAND

1 May 2014

Melati Hutagalung
Coordinator of Volunteer for GIV division, Caritas PSE, Medan
Indonesia

Subject: Letter of Invitation to be an expert review for a research instrument

Dear Melati Hutagalung

Boromarajonani College of Nursing Nopparat Vajira, an Affiliation Institution of Kasetsart University, Thailand would like to ask for your kind support in serving as an expert review for a research instrument to be used for a Master's thesis. The instrument is proposed by Ms. Siska Evi Martina, a student in Master of Nursing Science program in Family and Community Health Nursing (International Program) of Boromarajonani College of Nursing Nopparat Vajira. Her thesis entitled "Factors related to quality of life in HIV infected women in Medan, North Sumatera, Indonesia."

I would be most grateful for your kind support in reviewing the aforementioned research instrument. If you have any queries please do not hesitate to contact Dr. Sunanta Thongpat, thesis advisor, at sunanta.t@bcnvn.ac.th or + 66-85-2511633

Yours Sincerely,

Monthana Hemchayat

Monthana Hemchayat

Director Boromarajonani College of Nursing Nopparat Vajira

Dr. Sunanta Thongpat
Deputy Director of Graduate study
Boromarajonani College of Nursing Nopparat Vajira

No.0203.0932/ 486



Boromarajonani College of Nursing Nopparat Vaj
681 Ramintra Road, Kannayao, Bangkok 10230
THAILAND

1 May 2014

Dr. Albertus Wenan
Physician of Sint Carolus Hospital
Indonesia

Subject: Letter of Invitation to be an expert review for a research instrument

Dear Dr. Albertus Wenan

Boromarajonani College of Nursing Nopparat Vajira, an Affiliation Institution of Kasetsart University, Thailand would like to ask for your kind support in serving as an expert review for a research instrument to be used for a Master's thesis. The instrument is proposed by Ms. Siska Ev Martina, a student in Master of Nursing Science program in Family and Community Health Nursing (International Program) of Boromarajonani College of Nursing Nopparat Vajira. Her thesis entitled "Factors related to quality of life in HIV infected women in Medan, North Sumatera, Indonesia."

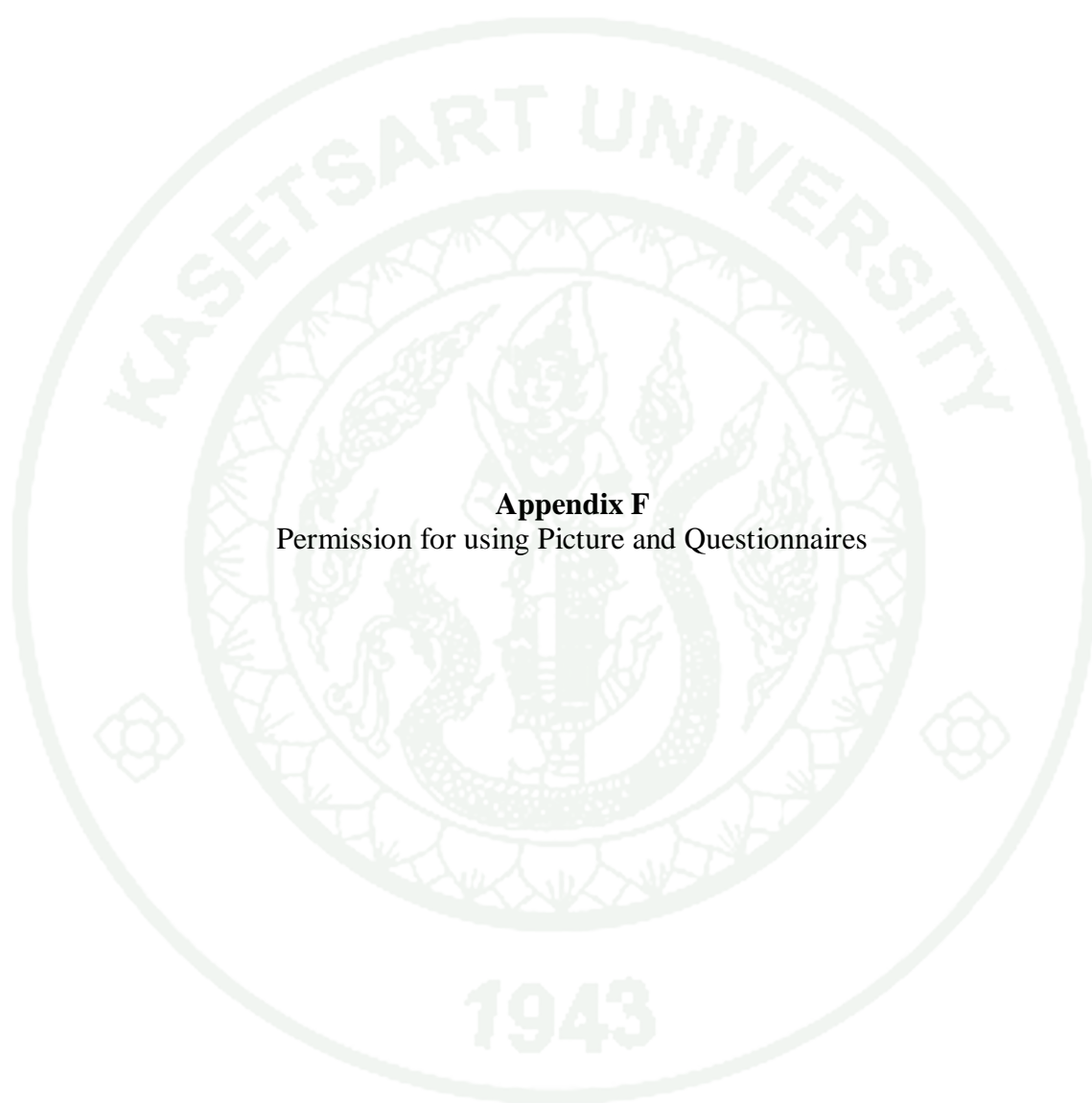
I would be most grateful for your kind support in reviewing the aforementioned research instrument. If you have any queries please do not hesitate to contact Dr. Sunanta Thongpat, thesis advisor, at sunanta.t@bcnnv.ac.th or + 66-85-2511633

Yours Sincerely,

Monthana Hemchayat

Director Boromarajonani College of Nursing Nopparat Vajira

Dr. Sunanta Thongpat
Deputy Director of Graduate study
Boromarajonani College of Nursing Nopparat Vajira



Appendix F
Permission for using Picture and Questionnaires

HRQOL MODEL

Sent: 2 Desember 2013 3:50, "Ferrans, Carol" <cferrans@uic.edu> wrote:

Dear Ms. Martina,

I am pleased to grant you permission to use our model as described in your email below. Good luck with your work.

Sincerely,

Carol Estwing Ferrans, PhD, RN, FAAN
 Professor and Associate Dean for Research
 Co-Director, UIC Center of Excellence in Eliminating Health Disparities
 Director, Community Engagement and Research Core, UIC Center for Clinical and Translational Science
 University of Illinois at Chicago
 College of Nursing (M/C 802)
 845 S. Damen Avenue (Room 606)
 Chicago, IL 60612
 Phone 312.996.8445
 Fax 312.996.4979

From: evi hingis [mailto:evi_sastro@yahoo.com]

Sent: Sunday, December 01, 2013 7:42 AM

To: Ferrans, Carol

Subject: Permission for using HRQOL model

Dear, Professor Carol Estwing Ferrans, RN, PhD, FAAN

My name is Siska Evi Martina from Indonesia, and i am Master students in Thailand. This period, i run writing my master thesis about Predicting factors of Quality of life among HIV-infected women. In my study, i would like utilize the revised Wilson and Cleary Model for Health Related Quality of Life (HRQOL) as a framework to guide this research. Then to identify the predicting factors of quality of life among HIV-infected women. I would like to ask permission to utilize a picture of the model published in Journal of Nursing Scholarship (2005) vol 37 (4), pp 336-342 in my thesis. Thank you for your kindness and God bless you.

Best regards

Siska Evi Martina

Master student at Kasetsart University, Thailand

email: evi_sastro@yahoo.com

WHOQOL-BREF

From: whoqol <whoqol@who.int>

Sent: Thu, Mei 8 2014 22:40,

Dear Siska Evi,

Please find attached the Bahasa-Malay version, along with related material which is only available in English.

Thank you and best regards,

Sibel Volkan (Mrs)
WHOQOL

From: evi hingis [mailto:evi_sastro@yahoo.com]

Sent: 28 April 2014 17:50

To: whoqol

Subject: Asking permission to use WHOQOL

Dear, WHO

My name is Siska Evi Martina and i am writing my master thesis with entitle "Predictors of Quality of Life in HIV Infected Women in Medan, Indonesia. My research will be conducted in Indonesia. In this great opportunity I would like to ask permission to use and reproduce the WHOQOL-Bref questionnaire in my study and also in Bahasa Version. Thank you very much for your attention.

Best regards
Siska Evi Martina

INVENTORY FUNCTIONAL STATUS

On Mar 1, 2014, at 9:04 AM, "evi hingis" <evi_sastro@yahoo.com> wrote:

Dear, Dr. Tulman

Thank you very much for your response. I will utilize IFS questionnaire to measure functional status of HIV infected women in Medan, Indonesia. Actually, my research is Predictors of quality of life in HIV infected women. Therefore, one of objective this study to determine functional status is predicting factors of quality of life in HIV infected women. If i obtain permission i will translate the questionnaire from English as an original to Bahasa by translator (Indonesian people who expert in English as a lecture of Linguistic department). After that, a second bilingual will translate by Indonesian nursing faculty who had studied in USA more than 3 years. If i find some error meaning in back-translate version, i will discussion and negotiation between both of translator. This is my plan for conduct this study. Thank you for your time and kindness. I hope i can receive your email soon.

Kind regards
Siska Evi Martina

From: Tulman, Lorraine
To: Saya
Sent: 2 Mar, at 10:29 PM

Hi

The IFS was developed for use with women who were recently diagnosed with cancer. The activities on it were based on typical activities that American women engage in.

Therefore I hope you can consider and modify it is suitable for the aims of your study.

Best of luck with your work!

Lorraine Tulman

MULTIDIMENSIONAL PERCEIVED SOCIAL SUPPORT SCALE

From: "Zimet, Gregory D" <gzimet@iu.edu>
Date: Wed, 12 Feb 2014 18:58:19 +0000
To: 'evi hingis' <evi_sastro@yahoo.com>
Subject: RE: asking for permission

Dear Siska Evi Martina,

You have my permission to use the MSPSS in your thesis. I have attached a copy of the scale. The simple scoring instructions are on the 2nd page. Also attached is a description of scoring options, which might be helpful to you. Finally, I have included a document that lists several articles that have reported on the psychometric properties of the MSPSS.

I hope your thesis research goes well.

Best regards,

Greg Zimet

Gregory D. Zimet, PhD

Professor of Pediatrics & Clinical Psychology

Section of Adolescent Medicine

Indiana University School of Medicine

Health Information & Translational Sciences

410 W. 10th Street, HS 1001

Indianapolis, IN 46202

USA

Phone: +1-317-274-8812

GENERAL HEALTH PERCEPTION

From: Ferrans, Carol
To: Saya
Sent: 1 Mar 2014, at 8:19 PM

Dear Ms. Hingis,

Thank you for your email. There are several instruments that measure General Health Perception, some have only one item and others have more than one item. Typically, the one item would ask "Please rate your health in general" on a scale from poor to excellent.

Good luck with your work!

Sincerely,

Carol Estwing Ferrans, PhD, RN, FAAN

Professor and Associate Dean for Research

Co-Director, UIC Center of Excellence in Eliminating Health Disparities

Director, Community Engagement and Research Core, UIC Center for Clinical and Translational Science

University of Illinois at Chicago

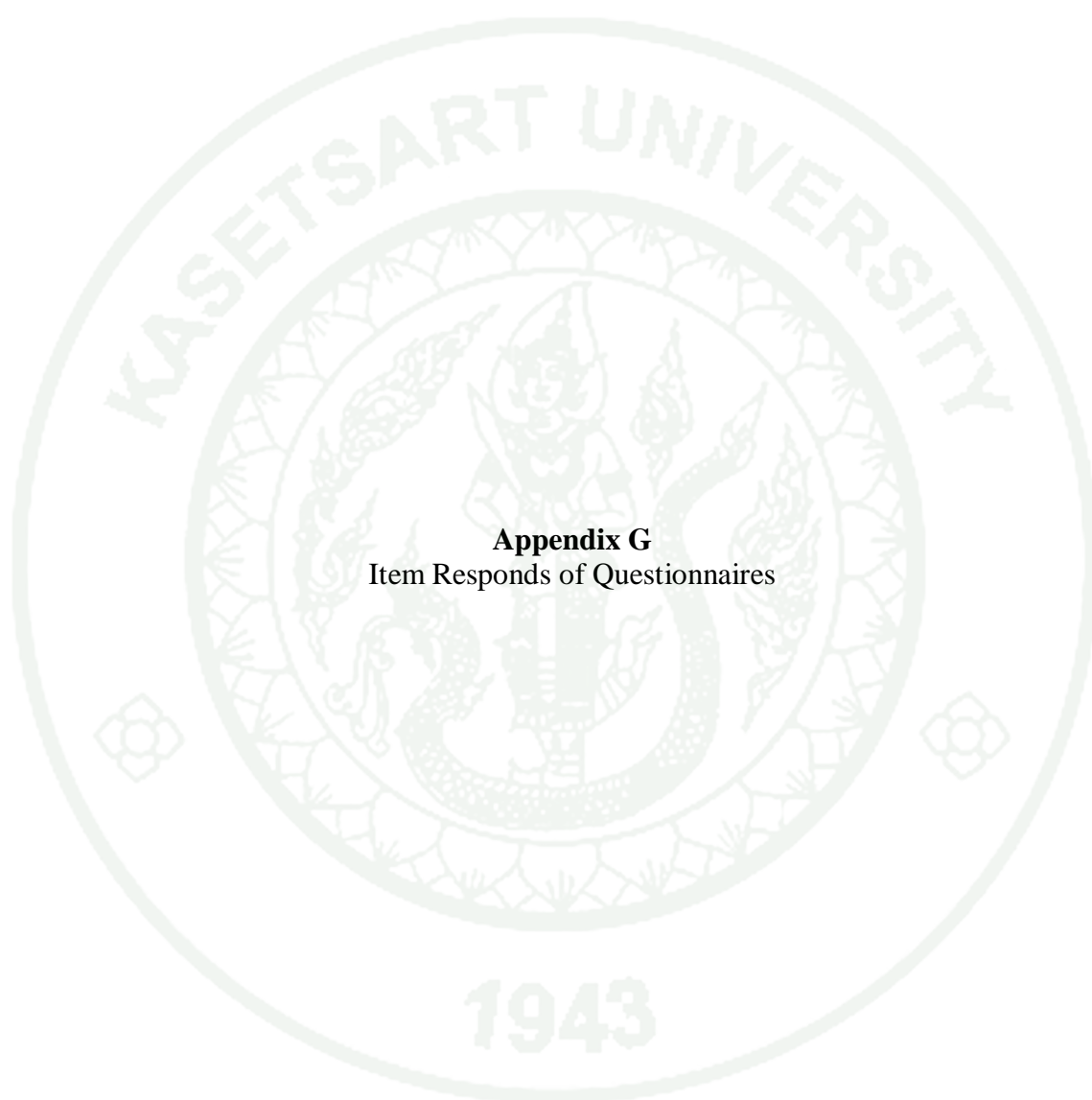
College of Nursing (M/C 802)

845 S. Damen Avenue (Room 606)

Chicago, IL 60612

Phone 312.996.8445

Fax 312.996.4979



Appendix G
Item Responds of Questionnaires

Appendix Table G1 Frequencies and percentages of item responds of World Health Organization Quality of Life-Bref among HIV infected women (N = 111)

| No | Items | Poor | | Good | |
|----|--|------|------|------|------|
| | | N | % | N | % |
| 1 | Rate the quality of life | 72 | 64.9 | 39 | 35.1 |
| 2 | Satisfied with my health | 73 | 65.8 | 38 | 34.2 |
| 3 | Feel that physical pain prevents me from doing what I need to do | 51 | 45.9 | 60 | 54.1 |
| 4 | Need any medical treatment to function in my daily life | 61 | 55 | 50 | 45 |
| 5 | Enjoy my life | 68 | 61.3 | 43 | 38.7 |
| 6 | Feel my life meaningful | 50 | 45 | 61 | 55 |
| 7 | Able to concentrate | 46 | 41.4 | 65 | 58.6 |
| 8 | Feeling safe in daily life | 62 | 55.9 | 49 | 44.1 |
| 9 | Healthy of physical environment | 61 | 55 | 50 | 45 |
| 10 | Have enough energy for everyday life | 42 | 37.8 | 69 | 62.2 |
| 11 | Able to accept bodily appearance | 51 | 45.9 | 60 | 54.1 |
| 12 | Enough money to meet my needs | 95 | 85.6 | 16 | 14.4 |
| 13 | Available the information that I need in day-to-day life | 42 | 37.8 | 69 | 62.2 |
| 14 | Have the opportunity for leisure activities | 81 | 73 | 30 | 27 |
| 15 | Able to get around | 44 | 39.6 | 67 | 60.4 |
| 16 | Satisfied with your | 55 | 49.5 | 56 | 50.5 |
| 17 | Satisfied with ability to perform daily living activities | 42 | 37.8 | 69 | 62.2 |
| 18 | Satisfied with capacity for work | 44 | 39.6 | 67 | 60.4 |

Appendix Table G1 (Continued)

| No | Items | Poor | | Good | |
|----|--|------|------|------|------|
| | | N | % | N | % |
| 19 | Satisfied with my self | 52 | 46.8 | 59 | 53.2 |
| 20 | Satisfied with personal relationships | 59 | 53.2 | 52 | 46.8 |
| 21 | Satisfied with sex life | 79 | 71.2 | 32 | 28.8 |
| 22 | Satisfied with the support from your friends | 78 | 70.3 | 33 | 29.7 |
| 23 | Satisfied with the conditions of living | 70 | 63.1 | 41 | 36.9 |
| 24 | Satisfied with access to health services | 23 | 20.7 | 88 | 79.3 |
| 25 | Satisfied with transportation | 58 | 52.3 | 53 | 47.7 |
| 26 | Have negative feelings such as blue mood, despair, anxiety, depression | 66 | 59.5 | 45 | 40.5 |

This table presents each item of WHOQOL-Bref which is applied to identify the quality of participants. Most of participants rated a good score in the statement about satisfaction with access to health services (79.3%), followed by statements “enough energy for everyday life” (62.2%), and “ability to perform daily living activities (62.2%). Those items refers to asses of quality of life in physical domain. This findings in line with the distribution of quality of life of participants that presented a good quality of life in physical domain. However, almost all of participants (85.6%) were rated a poor quality of life in statement “ enough money to meet what your needs”.

Appendix Table G2 Frequencies and percentages of item responds of Multidimensional Perceived Social Support among HIV infected women (N = 111)

| Items | Very strongly disagree | Strongly disagree | Mildly Disagree | Neutral | Mildly agree | Strongly agree | Very strongly agree |
|---|------------------------|-------------------|-----------------|---------|--------------|----------------|---------------------|
| | N (%) | N (%) | N (%) | N (%) | N (%) | N (%) | N (%) |
| Family support | | | | | | | |
| My family really tries to help me. | 0 (.00) | 4 (3.6) | 7 (6.3) | 5 (4.5) | 24(21.6) | 61(55) | 10 (9.0) |
| Get the emotional help and support from family. | 1 (0.9) | 2 (1.8) | 9 (8.1) | 4 (3.6) | 21(18.9) | 65(58.6) | 9 (8.1) |
| Can talk about my problems with my family. | 1 (0.9) | 9 (8.1) | 8 (7.2) | 3 (2.7) | 32(28.8) | 52(46.8) | 6 (5.4) |
| My family is willing to help me make decisions. | 0 (.00) | 8 (7.2) | 7 (6.3) | 3 (2.7) | 30 (27) | 59(53.2) | 4 (3.6) |
| Friend support | | | | | | | |
| My friends really try to help me. | 0 (.00) | 40 (36) | 26 (23.4) | 4 (3.6) | 18(16.2) | 21(18.9) | 2(1.8) |
| Can count on my friends when things go wrong. | 1 (0.9) | 36(32.4) | 27(24.3) | 4 (3.6) | 10(9.0) | 30(27) | 3 (2.7) |
| Have friends with whom I can share my joys and sorrows. | 0 (.00) | 44(39.6) | 26(23.4) | 1(0.9) | 14(12.6) | 24(21.6) | 2(1.8) |
| Can talk about my problems with my friends. | 0 (.00) | 42(37.8) | 27(24.3) | 4(3.6) | 15(13.5) | 21(18.9) | 2 (1.8) |

Appendix Table G2 (Continued)

| Items | Very strongly disagree | Strongly disagree | Mildly Disagree | Neutral | Mildly agree | Strongly agree | Very strongly agree |
|--|------------------------|-------------------|-----------------|---------|--------------|----------------|---------------------|
| | N (%) | N (%) | N (%) | N (%) | N (%) | N (%) | N (%) |
| Significant other support | | | | | | | |
| Any special person who is around when needed | 0 (.00) | 2 (1.8) | 8 (7.2) | 4 (3.6) | 26(23.4) | 62(55.9) | 9 (8.1) |
| Any special person with whom can share the joys and sorrows | 0 (.00) | 4 (3.6) | 7 (6.3) | 3 (2.7) | 23(20.7) | 66(59.5) | 8 (7.2) |
| Have a special person who is a real source of comfort to me. | 0 (.00) | 3(2.7) | 7 (6.3) | 3 (2.7) | 24(21.6) | 59(53.2) | 15(13.5) |
| Any special person in my life who cares about my feelings. | 0 (.00) | 5 (4.5) | 5 (4.5) | 3 (2.7) | 29(26.1) | 59(53.2) | 10(9.0) |

According to table above, the data showed that the most of participants reported higher score in statement about “special person with whom I can share the joys and sorrows” there is special person with whom I can share my joys and sorrows”, which indicated that the participants perceived high support from significant others. The lowest of participants reported in the statement “I can talk about my problems with my friends” (18.9%). This indicated that participants were perceived low support from friends.

CURRICULLUM VITAE

NAME : Miss Siska Evi Martina

BIRTH DATE : December 26, 1985

BIRTH PLACE : Jakarta

| EDUCATION | : <u>YEAR</u> | <u>INSTITUTE</u> | <u>DEGREE</u> |
|------------------|----------------------|---------------------------------------|----------------------|
| | 2009 | Sint Carolus School of Health Science | BSN |

POSITION/TITLE : Lecturer

WORK PLACE : Sint Carolus School of Health Sciences

SCHOLARSHIP/AWARDS : Indonesia Government Scholarship 2012-2014