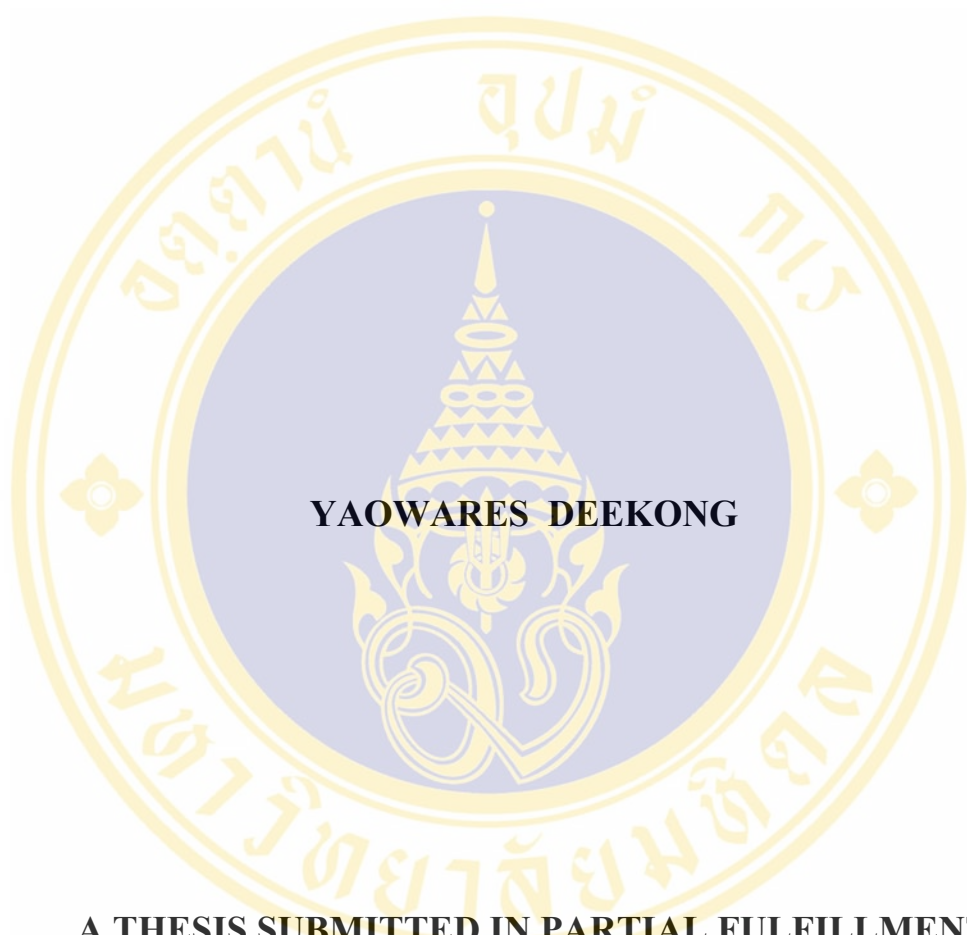


**CAREGIVERS' FACTORS RELATED WITH MEDICATION
ADHERENCE AMONG PATIENTS RECEIVING
HIGHLY ACTIVE ANTIRETROVIRAL THERAPY**



**A THESIS SUBMITTED IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR
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(COMMUNITY HEALTH NURSING)
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ADHERENCE AMONG PATIENTS RECEIVING HIGHLY ACTIVE
ANTIRETROVIRAL THERAPY**

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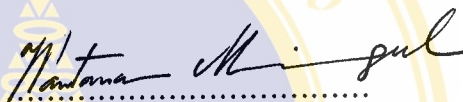
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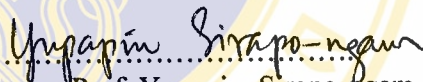
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Yaowares Deekong

**CAREGIVERS' FACTORS RELATED WITH MEDICATION ADHERENCE
AMONG PATIENTS RECEIVING HIGHLY ACTIVE ANTIRETROVIRAL
THERAPY**

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ABSTRACT

The purposes of this study were to describe caregivers of patients receiving HAART in terms of background characteristics (age, gender, education, occupation, income, number of social roles, quality of patient-caregiver relationship, and help with medication adherence), knowledge about HIV/AIDS, social support and medication adherence among patients receiving HAART, and to predict medication adherence among patients receiving HAART by using the caregivers' factors. Subjects were 128 patients receiving HAART and 128 caregivers who came for a follow up visit at Bamrasnaradura Infectious Disease Institute, Thailand. Questionnaires were used to collect data.

In this study, patients' medication adherence ranged from 27.5% to 100% with a mean of 96.94% (SD = 9.1%). About 86.1% of the subjects had good medication adherence ($\geq 95\%$), whereas 13.9% had poor medication adherence ($< 95\%$). The caregivers' age ranged from 18-72 years old. The majority of them were female (68.8%). About 35.2% of the caregivers finished elementary school, and about 62.5% had adequate income. One-fourth of them were household workers (27.3%), and had only one social role (23.4%). Most of them were spouses of the patients (51.6%). Almost all reported a very closed patient-caregiver relationship (88.2%). About 82% helped their patients with medication adherence. Caregivers' education demonstrated a significant relationship to medication adherence among patients receiving HAART. In multiple regression analysis, caregivers' education, social support and help with medication adherence were significant predictors of medication adherence among patients receiving HAART (overall $F_{(3, 128)} = 3.209$; $p = .027$).

These findings can be useful for health care providers to plan for interventions to support the caregivers in order to increase their influence in monitoring and enhancing medication adherence among patients receiving HAART.

KEY WORDS : CAREGIVER / MEDICATION ADHERENCE /
ANTIRETROVIRAL THERAPY / HIV

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ปัจจัยของผู้ดูแลที่มีผลต่อการรับประทานยาอย่างสม่ำเสมอของผู้ป่วยที่รับประทานยาต้านไวรัสเอดส์
**CAREGIVERS' FACTORS RELATED WITH MEDICATION ADHERENCE
 AMONG PATIENTS RECEIVING HIGHLY ACTIVE ANTIRETROVIRAL
 THERAPY**

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บทคัดย่อ

การศึกษานี้ มีวัตถุประสงค์เพื่อศึกษาความสัมพันธ์ระหว่างปัจจัยส่วนบุคคลของผู้ดูแล (อายุ เพศ การศึกษา อาชีพ รายได้ จำนวนบทบาททางสังคม คุณภาพของสัมพันธภาพระหว่างผู้ป่วยและผู้ดูแล การดูแลให้ผู้ป่วยรับประทานยาอย่างสม่ำเสมอ) ความรู้เกี่ยวกับโรคเอดส์ และแรงสนับสนุนทางสังคม กับการรับประทานยาอย่างสม่ำเสมอของผู้ป่วยที่รับประทานยาต้านไวรัสเอดส์ และศึกษาอำนาจการทำนายการรับประทานยาอย่างสม่ำเสมอของผู้ป่วย โดยปัจจัยของผู้ดูแล กลุ่มตัวอย่างเป็นผู้ป่วยที่รับประทานยาต้านไวรัสเอดส์และผู้ดูแล กลุ่มละ 128 ราย ที่มารับบริการตรวจรับยาที่สถาบันบำราศนราดูร

ผลการศึกษาพบว่า ผู้ป่วยรับประทานยาต้านไวรัสอย่างสม่ำเสมออยู่ระหว่างร้อยละ 27.5 ถึง ร้อยละ 100 (ค่าเฉลี่ยเท่ากับ ร้อยละ 96.9 และส่วนเบี่ยงเบนมาตรฐานเท่ากับร้อยละ 9.1) โดยมีผู้ป่วยร้อยละ 86.1 รับประทานยาได้อย่างสม่ำเสมอ ($\geq 95\%$) และ ผู้ป่วยร้อยละ 13.9 รับประทานยาได้อาจไม่สม่ำเสมอ ผู้ดูแลมีอายุระหว่าง 18-72 ปี ส่วนใหญ่เป็นเพศหญิง (ร้อยละ 68.8) จบชั้นประถมศึกษา (ร้อยละ 35.2) มีรายได้เพียงพอ (ร้อยละ 62.5) มีอาชีพทำงานอยู่ที่บ้าน (ร้อยละ 27.3) ประมาณร้อยละ 23.4 มีจำนวนบทบาททางสังคมเพียง 1 บทบาท ส่วนใหญ่เป็นคู่สมรสของผู้ป่วย (ร้อยละ 51.6) มีสัมพันธภาพระหว่างผู้ป่วยกับผู้ดูแลอยู่ในระดับดี (ร้อยละ 88.2) และ ดูแลให้ผู้ป่วยรับประทานยาอย่างสม่ำเสมอ (ร้อยละ 82) การศึกษาของผู้ดูแลมีความสัมพันธ์กับการรับประทานยาอย่างสม่ำเสมอของผู้ป่วยอย่างมีนัยสำคัญทางสถิติ ในการวิเคราะห์สมการการถดถอยพบว่า การศึกษา แรงสนับสนุนทางสังคม และการดูแลให้ผู้ป่วยรับประทานยาอย่างสม่ำเสมอ สามารถร่วมทำนายการรับประทานยาอย่างสม่ำเสมอของผู้ป่วยได้อย่างมีนัยสำคัญทางสถิติ (overall $F_{(3,128)}=3.209$; $p=.027$)

ผลการศึกษาวิจัยครั้งนี้เป็นประโยชน์แก่บุคลากรทางสาธารณสุขในการวางแผนเพิ่มแรงสนับสนุนทางสังคมให้ผู้ดูแลได้รับข้อมูลเกี่ยวกับเรื่องโรคเอดส์ การใช้ยาต้านไวรัสและการดูแลอาการข้างเคียงจากการใช้ยาต้านไวรัส เพื่อให้ผู้ดูแลสามารถติดตามสนับสนุนให้ผู้ป่วยรับประทานยาต้านไวรัสได้อย่างสม่ำเสมอ

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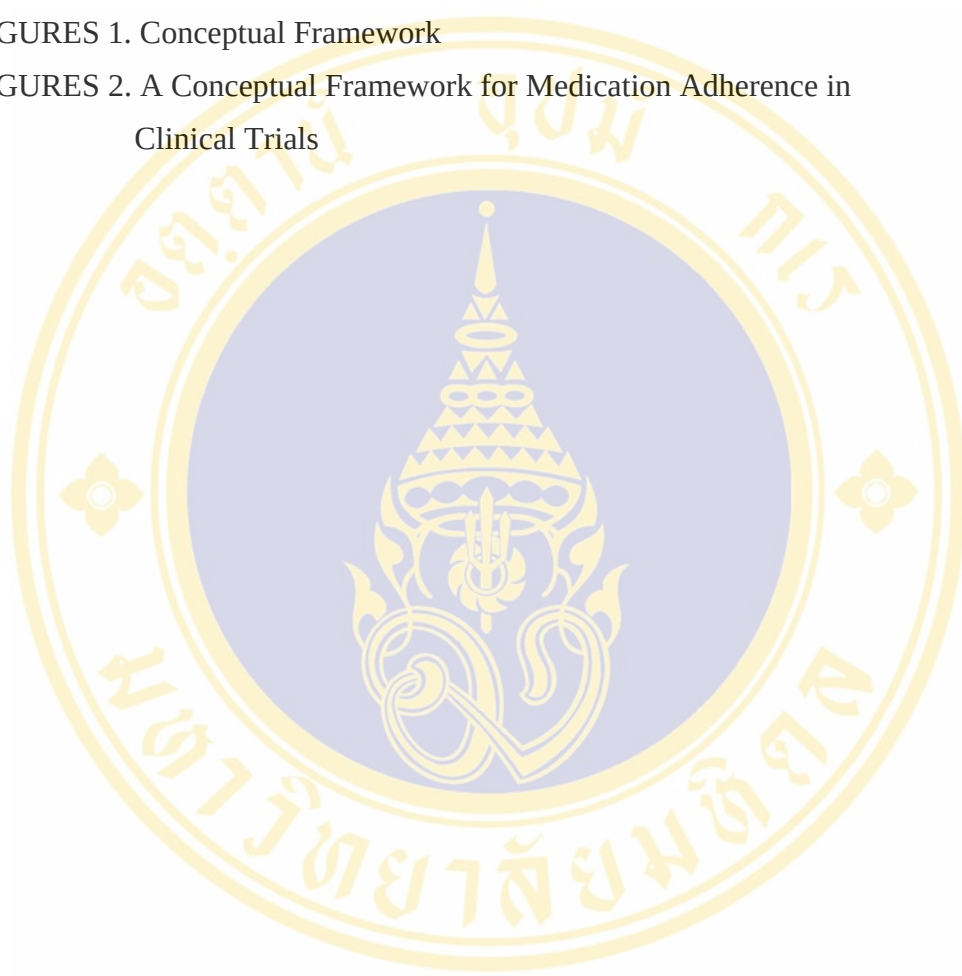
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CHAPTER I

INTRODUCTION

Background and Rationale

Acquired Immune deficiency Syndrome (AIDS), an incurable disease, is a serious problem worldwide. The virus, which causes AIDS, is called the human immunodeficiency virus (HIV). At the end of 2003, it was estimated that 40 millions people globally were living with HIV (http://www.who.int/hiv/facts/en/EPIppt2003_en.ppt). In Asia, an estimation of 7.4 million people are now living with HIV/AIDS (UNAIDS, 2004: 25). In many parts of the developing world, the majority of new HIV infections occur in young adults. Young women especially vulnerable. About one-third of those currently living with HIV/AIDS are aged between 15 and 24 years old. Approximately half of these individuals become infected before age 25 and typically die as a result of a life-threatening illness before the age of 35 (UNAIDS, 1999: 1-5). AIDS continues to spread rapidly among young people (Fox, 2000 cited by Sandra & Juliet, 2000: 236).

In Thailand, the first AIDS case was reported in 1984 and, then the number of patients has increased every year. The cumulative number of AIDS cases reported by the Bureau of Epidemiology in Thailand from 1984 to 30 November 2004 were of 348,605 symptomatic and AIDS cases and 84,170 deaths. It is estimated that there will be 1,109,000 HIV infected persons in the years 2006 (http://epid.moph.go.th/epi32_aids.html). Most HIV infected persons are of working age and are aged 20 to 39 years old. They suffer with complex problems which have physical, mental, social, and economic impact on their lives (Pintobtang, 2002: 2). Meanwhile, the epidemic has led the social, economic and public health problems to the families and communities (Kidhathong, 2003:1; Namjantra, 2003: 1).

The HIV damage immune system, so people with HIV infection easily get sick by opportunistic infections and will die in 3-5 years after infection. Because of

advanced therapies, HIV/AIDS is now classified as a chronic disease and is no longer viewed as a death sentence, people who are HIV-positive have hope for longevity and a cure. It is this hope for a longer life and possible treatment (Bangsberg et al., 2000: 357; Sandra & Juliet, 2000: 236). Recently, antiretroviral medications have been used to delay progression of AIDS and decrease number of full blown AIDS cases.

In 1992, the first antiretroviral medication used to treat HIV in Thailand was zidovudine (ZDV or AZT). ZDV can reduce number of HIV in blood, so it slows down the progression of this fatal disease. However, monotherapy is now considered inadequate; thus, multiple antiretroviral medications have been used in combination therapy (Suda Louisirirotchanakul, B.E. 2542: 191). Highly active antiretroviral therapy (HAART) is currently used to treat HIV/AIDS patients in Thailand (Suttichai Chockkitchai, B.E. 2544: 159). HAART is a potent combination of antiretroviral medications (cocktail) that is introduced with the intent of suppressing viral replication and preventing irreversible damage to the immune system. The regimen usually includes three medications from two different categories. The goals of treatment are optimal adherence to a treatment regimen, suppression of viral load, improved CD4 count, and improved quality of life (Sandra & Juliet, 2000: 236).

Medication adherence among HIV/AIDS patients receiving HAART plays an important role in virologic suppression. An acceptable level of adherence to therapy in chronic illness is consumption of 80% of the prescribed dose. This criterion has been widely used in studies of antihypertensive and oral oncology agent, and in earlier studies of adherence to therapy in patients infected with HIV. However, more recent evidence suggests that 95% or greater to antiretroviral medications adherence had a superior virologic outcome, a greater increase in CD4 lymphocyte count, and a lower hospitalization rate than did patients with lower levels of adherence (Paterson et al., 2000: 21-30).

Poor adherence can lead to the development of drug resistance, limiting the effectiveness of therapy (Sandra & Juliet, 2000: 236). Poor medication adherence limits the effectiveness of treatment, and leads to development of drug resistance. HIV/AIDS patients will be more prone to develop side effects. Suboptimal adherence to antiretroviral medication regimen, such as an occasional missed dose, may cause

drug resistance. Resistance secondary to poor adherence is one of the main reasons for drug failure (Tuldra et al., 1999: 1376-1377).

Studies specific to antiretroviral adherence among HIV- infected patients reported a wide range of prevalence of adherence. Singh and colleague (1996: 261) found that 63% of patients were adherent to antiretroviral therapy. Among HIV- infected adolescents the rates are even lower, with only approximately 41% reporting consistent adherence (Murphy et al., 2001: 27-40). Balestra and colleague (1996 cited by Debra, 2002: 58) found that 53.5% of patients nonadherent.

HIV/AIDS is impacting not only on individuals but entire families. Usually the entire family is involved when a person becomes ill and traditionally, when a person is ill, the family is seen to provide emotional, practical, and social support (Yanwaree, 2002: 27). Furthermore, studies have shown that after diagnosis, HIV/AIDS patients spent 80 percent of their time living with their family and preferred to be either cared for or die at home (Taylor et al., 1997 cited by Yanwaree, 2002: 27). While, most of the care provided for people living with HIV is given by family caregivers, Hongwiwat (1993: 99) found that HIV/AIDS patients who receive support (from family and relatives) was significantly had happier life than who cope by himself/herself without support from family and relatives. Support from parents and other family members and friends are also considered crucial for compliance (Kyngas & Hentinen, 1995: 729; Martinez et al., 2000: 1266-1273 and O' Brien, 1980: 250-252). Catz and colleagues (2000: 124) found that social support distinguished good and poor adherence among patients prescribed new treatment for HIV/AIDS.

It was found that chronic illness affects family's well- being and financial status (Nonglak Pernchompoo, B.E. 2540: 62), and education, age, and family income are factors affecting caregiving ability of caregivers of patients with congenital heart disease (Ubol Asumpinsup, B.E. 2540: 81). For HIV/AIDS, patients have to depend on other people to take care of their physical and mental health in order to live with AIDS at their full potential (Oratai Somnarin, B. E. 2538: 99). As a result, caregivers play very important roles in caring HIV/AIDS patients including promoting antiretroviral medication adherence to delay illness and disease progression.

As medication adherence is an important key to success in HIV/AIDS treatment, more studies exploring factors related medication adherence are urgently needed. Patient characteristics related with good adherence and treatment outcomes include knowledge about the medication, social support, and stable living circumstances (Sackett & Haynes, 1996 cited by Sandra & Juliet, 2000: 236). However, there is no existing research about factors related with patients' medication adherence regarding the caregivers of HIV/AIDS patients receiving HAART. As a community health nurse, it is very important to explore caregivers' factors related to medication adherence among patients receiving HAART. These factors should include caregivers' background characteristics (age, gender, education, occupation, income, social role, quality of patient-caregiver relationship, and help with medication adherence), knowledge about HIV/AIDS, and social support.

Research Framework

Medication adherence is an important determinant of both the degrees and duration of virologic suppression. In addition, numerous studies have found an association between poor adherence and virologic failure. In several studies, non-adherence among patients on HAART was the strongest predictor of failure to achieve viral suppression below the level of detection (Carmona, Knobel & Guelar, 2000; Walsh et al., 2000: 199 cited by http://www.aidsinfo.nih.gov/guideline/adult/AA_07143.pdf).

Adherence is a problem in many clinical setting and anecdotal information suggests that it is a prevalent problem (Markowitz, 2000: 250; Mehta, Moore & Graham, 1999: 1665). Whereas the level of adherence to HAART is closely associated with suppression of the HIV viral load in plasma, a relationship between adherence and disease progression has not been established (Gifford et al., 2000: 386; Haubrich et al., 1999: 1099; Paterson et al., 2000: 21).

Adherence to antiretroviral therapy is a frequent issue in the management of HIV- infected patients in daily life (Olalla et al., 2002: 108). Nonadherence to antiretroviral agents can have serious consequences, including loss of plasma HIV suppression and development of drug- resistant HIV strains. This can in turn lead to disease progression, inability to suppress HIV even with very intensive regimens, and

transmission of resistant HIV to other (Montaner et al, 1998: 930; Shafer et al., 1998: 906).

Nonadherence is explained by the negative real-life experience of the person throughout the treatment (Andreo et al., 2000: 249; Bassetti et al., 1999: 115). Even moderate nonadherence to antiretroviral therapy has significant primary and secondary negative consequences. First, with decreased adherence comes the risk of further compromised cell-mediated immune functioning, leads to opportunistic infections and increase symptomatology (Llorente et al., 1997 cited by Steele, 2001: 618). In addition, pharmacological nonadherence also increases the likelihood of the development of resistant viral strains (Borkowsky, 1998 cited by Steele, 2001: 618).

Imperfect adherence is common. Patient adherence is a complex phenomenon that can be affected by a number of variables, including the difficulty of the treatment regimen, patients' access to social support, and patients' beliefs about the efficacy of the treatment (O' Brien, Petrie & Raeburn, 1992: 435). Surveys have shown that one-third of patients missed doses within 3 days of the survey (Ickovic & Meisler, 1997: 385). Predictors of inadequate adherence to HIV medications include 1) lack of trust between the clinician and patient; 2) active drugs and alcohol use; 3) active mental illness (e.g. depression); 4) lack of patient education and inability of patients to identify their medications; and 5) lack of reliable access to primary medical care or medication (Chesney, 2000: S171; Sapiro et al., 2002: 1484).

The factors related with nonadherence are as follows: young age, patients with lower education, minimal financial resources, alcohol consumption, a lack of perceiving the treatment's effectiveness, absence of impact on anticipation of the future or emotional life, difficulties as far as in keeping up the medications or the treatment's integration into daily life, the impossibility of stopping the treatment, a duration of treatment > 2 years, hepatitis C co-infection and problematic side effects. Unmarried patients, those living in poor socio-economic environment (living on welfare, poor housing conditions) and those who declared a lack of social support from partner, family and friends, were more likely to be nonadherence (Spire et al., 2002: 1484).

Martinez and colleagues (2000: 199) study found that social support was significantly related with adherence to antiretroviral drugs. Positive self-efficacy or patients' belief in their ability to adhere to therapy, was significantly related with adherence to antiretroviral therapy and PCP prophylaxis (Eldred, 1998: 121). Satisfaction with the patient-physician relationship was strongly correlated with increased medication adherence (Mostashari et al., 1998: 344). The strongest correlates of medication adherence had to do with whether the patient experienced side effects, and what their response would be if they experienced symptoms that might be side effects resulting from their medication (Altice et al., 2001: 52).

Reviews of a number of studies medication adherence among patients receiving HAART classify factors related with medication adherence into 5 categories, namely: patient characteristics; provider- patient relationship; treatment regimen; clinical setting and disease (Ickovic & Meisler, 1997: 385-391; Williams, 2001: 37).

Patient's knowledge about HIV/AIDS and social support have been found to have positive relations with medication adherence and Hongwiwat (1993: 39) found that AIDS cases with social support (family and relatives) was significantly had happy life more than who cope by himself/herself only without social support. This study is to explore caregivers' characteristics, knowledge about HIV/AIDS and social support in relation to medication adherence among patients receiving HAART using the following research framework as shown in Figure 1.

Caregivers' background characteristics.

- Demographic data (age, gender, education, income, occupation)
- Number of social roles
- Quality of patient- caregiver relationship
- Help with medication adherence

Knowledge about HIV/ AIDS

- Disease and treatment
- Antiretroviral medication use
- Side effect and management

Social support

- Emotional support
- Appraisal support
- Informational support
- Instrumental support

Medication adherence

Figure 1. The conceptual framework

Research Question

- 1) What are caregivers' background characteristics, knowledge about HIV/AIDS, social support, and medication adherence among patients receiving HAART?
- 2) Can caregivers' variables background characteristics: (age, gender, education, occupation, income, number of social roles, quality of patient-caregiver relationship, and help with medication adherence), knowledge about HIV/AIDS, and social support predict medication adherence among patients receiving HAART?

Objectives

- 1) To describe caregivers of patients receiving HAART in terms of background characteristics (age, gender, education, occupation, income, social role, quality of patient- caregiver relationship, and help with medication adherence), knowledge about HIV/AIDS, social support, and medication adherence among patients receiving HAART.
- 2) To predict medication adherence among patients receiving HAART by using the caregivers' factors.

Expected Outcome and Benefits

The expected outcomes and benefits of this study are that findings of caregivers' specific factors related to medication adherence will be useful in guiding nursing interventions for the caregivers to enhance medication adherence among patients receiving HAART in Thailand.

Definition of Terms

Conceptual and operational definitions of the terms used in this study:

Caregivers refer to the non- health professional people who are voluntarily providing care to AIDS patients. These caregivers may be a spouse, father, mother, sister, brother or friend.

Age is time span in years between the year of birth and the year at time of the data was collected as reported by the subjects.

Gender is identified as male or female.

Education is number of years of the self- reported highest education level that the caregivers achieved in the Thai educational system.

Occupation is the reported work that the caregivers earn for living, such as government service, merchant, agriculture, general labor, or unemployed.

Income an amount of money that the caregivers received per month.

Number of social role is a number of caregivers' roles in their family and society such as wife, husband, father, mother, sister, brother, and/or other roles in society. For example, a caregiver, who is a wife of the patient, also has children, lives with her parents, and works as a volunteer health worker. This caregiver has 4 social roles.

Relation to patient is a relationship between a patient and a caregiver such as a parent, a spouse, a child, a relative or a friend.

Quality of patient- caregiver relationship are the feelings of closeness and contact between the caregiver and the patient. Scores of quality of patient- caregiver relationship range from 1 to 10. Score 1-4 indicates poor relationship, 5-7 indicates fair relationship and 8-10 indicates good relationship.

Help with medication adherence refers to activities that caregivers performed to assist the patients to adhere to their medication. Operationally, help with medication adherence can be any activities that the caregivers have done to help the patients in taking their medication.

Knowledge about HIV/AIDS is defined as an information about HIV/AIDS disease and treatment, antiretroviral medication use, side effects and management of side effects. Operationally, knowledge about HIV/AIDS is defined as the composite score on the 38 items of Knowledge about HIV/AIDS Scale developed by Maneesriwongul and colleagues (2003). Scores on this scale range from a low of 0 to high of 38.

Social support is defined as interaction between caregivers and others such as relatives, family members, friends and health personnel, which brings about support to care for patients and enhance patients' medication adherence. In this study, social support is comprised of four components: (1) emotional support, (2) appraisal support, (3) informational support, and (4) instrumental support. Operationally, social support is defined as the composite score on the 55 items of Social Support Scale developed

by Maneesriwongul and colleagues (2003). Scores on this scale range from a low of 55 to high of 275.

Medication adherence is defined as an average of medication adherence score, measure by visual analog scale and patient self-report of percent of antiretroviral medication taken in the past month.



CHAPTER II

LITERATURE REVIEW

This chapter covers literature related to Acquired Immunodeficiency Syndrome (AIDS), medication adherence, caregiver of HIV/AIDS patients, and caregivers' factors related with patients' medication adherence as follows:

Part 1. Acquired Immunodeficiency Syndrome (AIDS)

AIDS is an infection that caused by a virus called the human immunodeficiency virus (HIV). The effect of HIV infection on the immune system of the body, such as in the CD4 or T- helper lymphocyte is quite devastating and results in profound depletion of CD4 the hallmark of HIV- related disease. The striking loss of these key cells of the immune system results in a profound suppression of immune function. As a result of immunosuppression, HIV infected persons are prone to opportunistic infections from bacteria, virus, and parasites. These opportunistic diseases are such as tuberculosis, pneumocystis carinii, cryptococcal meningitis, kaposi's sarcoma (Flaskerud & Ungvarski, 1995: 1; WHO, 1996: 37-38).

1.1 Disease progression

Disease progressions are classified into six categories as follow:
(<http://www.tthivclinic.com/overview.html>)

1. Acute primary HIV infection is the first stage of HIV disease, when the virus first establishes itself in the body. The period of time between when a person is first infected with HIV and when antibodies against the virus are produced by the body usually between 6- 12 weeks. Up to 70% of people newly infected with HIV will experience some "flu-like" symptoms. These symptoms, which usually last no more than a few days, might include fevers, chills, night sweats and rashes (not cold-like symptoms) (http://www.sfaf.org/aids101/hiv_disease.html).

2.Asymptomatic HIV disease is usually with no clinical signs and symptoms. CD4 cells generally decline at a rate of 40-80 cells/mm³ per year in untreated individuals. This stage is labeled "asymptomatic", HIV viral replication is continuing constantly and the immune system is slowly weakening (http://www.tthhivclinic.com/overview_asympt.htm).

3.Early Symptomatic HIV disease Those who have a CD4 count > 500 cells/mm³ have less than a 5% chance of developing AIDS within the next 18-24 months. Constitutional complaints of variable severity may be seen include: fevers, night sweats, headache, malaise, fatigue, diarrhea, weight loss (greater or equal to 10 lb over 6-8 weeks), etc (http://www.tthhivclinic.com/overview_early.htm).

4.Middle Symptomatic HIV disease At this stage, the CD4 count is between 200-500 cells/mm³. Most individuals are still without symptoms. Other symptoms that may occur during this stage include: herpes zoster, recurrent herpes simplex lesions, candidiasis (oral and/or vaginal), oral hairy leukoplakia, various constitutional symptoms previously described (http://www.tthhivclinic.com/overview_middle.htm).

5.Late Symptomatic HIV disease At this stage, the CD4 count is between 50-200 cells/mm³. The patients with the late symptomatic stage of HIV infection are now at an increased risk of opportunistic infections (http://www.tthhivclinic.com/overview_late.htm). The five most commonly- reported opportunistic infections in Thailand are mycobacterium tuberculosis pulmonary or extrapulmonary, pneumocystis carinii, cryptococcal meningitis, candidiasis of trachea, bronchi/lung and pneumonia recurrent (bacteria) > 1 time/year (http://epid.moph.go.th/epi32_aids.html). Constitutional symptoms usually worsen. Wasting and AIDS dementia complex may be other serious problems encountered. Human papilloma virus associated malignancies (cervical and anal) may occur (http://www.tthhivclinic.com/overview_late.htm).

6.Advanced HIV disease In addition to all the previous conditions, several new opportunistic infections may occur in the last stage. Cytomegalovirus disease, disseminated mycobacterium avium complex (MAC), cryptococcal meningitis, progressive multifocal leukoencephalopathy (PML), and several other conditions are associated with this severe degree of immunosuppression. Several opportunistic infections occur concomitantly. At this stage, treatment is usually suppressive and supportive rather than curative.

Patients may also suffer from many medication-induced side-effects which may be challenging to sort out and modify. The psychosocial ramifications of this degree of illness and debilitation are great and require intensive counseling and support (http://www.tthivclinic.com/overview_adv.htm).

1.2 Highly Active Antiretroviral Therapy (HAART)

Treatment of HIV infection can be classified into four categories: antiretroviral treatment, therapy for opportunistic infections and malignancies, prophylaxis of opportunistic infections, and hematopoietic stimulating factors (Katz & Hollander, 2002: 1340-1351). This study will focus on HIV/AIDS therapy with antiretroviral medication.

HAART works inside infected CD4 cells by inhibiting the action of enzymes necessary for HIV replication. Three classes of antiretroviral agents are currently available for the treatment of HIV infection: nucleoside and nucleotide analogs ([NRTIs](#)), non-nucleoside reverse transcriptase inhibitors ([NNRTIs](#)) and protease inhibitors ([PIs](#)), thus triple drug therapy offers the best chance of reducing the multiplication of the virus and allowing the immune system to stay healthy (Kirton, 2001: 69; <http://www.manbir-online.com/std/hiv.3.htm> and <http://hivmedicine.com/textbook/haart/classes.htm>).

Table 1 Current Antiretroviral drugs in Clinical Use

(MOPH, B.E. 2546: 36)

Nucleoside analogued reverse transcriptase inhibitors (NRTIs)	Non-Nucleoside analogued reverse transcriptase inhibitors (NNRTIs)	Protease inhibitors (Pis)
Zidovudine Stavudine Didanosine Zalcitabine Lamivudine Abacavir	Efavirenz Nevirapine Delavirdine	Nelfinavir Indinavir Ritonavir Lopinavir/ ritonavir Saquinavir Amprenavir

1. Nucleoside Reverse Transcriptase inhibitors (NRTIs) become part of HIV's DNA and derail its building process. Damaged viral DNA cannot take control of the cell's DNA (<http://www.hivmedicine.com/textbook/haart/nrti.htm>). The followings are some of the NRTIs:

1.1 Zidovudine The oldest and most thoroughly investigated HIV drug. AZT can be used to prevent maternal- fetal HIV transmission. However, it remains an important component of many HAART regimens even today, particularly as it has good CNS penetration and relatively low mitochondrial toxicity (good long-term tolerability). Its side effects may include nausea and vomiting abdominal discomfort, headache, myalgia, dizziness, macrocytic anemia (MCV almost always elevated), rarely and neutropenia. Elevations in LDH, CPK and transaminases may occur. Episodes of lactic acidosis are rare (Hoffmann & Kamps, 2003: 349-350).

1.2 Didanosine This drug should always be used in combination with other medications to treat HIV infection. Combination with Stavudine can be problematic as there are cumulative toxicities. Its side effects may include diarrhea, nausea, headache, rash, and pancreatitis, even after longer periods on treatment. Peripheral polyneuropathy, and lactic acidosis are rare especially in combination with Stavudine (Hoffmann & Kamps, 2003: 316-317).

1.3 Zalcitabine One of the first antiretroviral drugs. It is now used very rarely due to complicated dosing regimen, the risk of polyneuropathy and cross-resistance with Didanosine. It is possibly less potent than Didanosine and Stavudine. Its side effects may include peripheral neuropathy (in up to 30 %), stomatitis with oral ulcers (in up to 4 %), pancreatitis (in <1 %). Rash, lactic acidosis, and hepatic steatosis are rare (Hoffmann & Kamps, 2003: 348).

1.4 Stavudine Stavudine is a thymidine analog like Zidovudine. Subjective tolerability is good. The drug was long considered at least equivalent to Zidovudine. Newer guidelines are more cautious, due to neuropathy and data on mitochondrial toxicity (lipoatrophy, lactic acidosis), particularly in combination with Didanosine. Its side effects may include peripheral neuropathy, especially in combination with Didanosine (up to 24 %). Stavudine has been linked to lipoatrophy more frequently than other NRTIs. However, the following side effects occur less frequently than with Zidovudine: diarrhea, nausea, vomiting, and headache. Very rare, but potentially fatal: lactic acidosis which occurs mostly in combination with Didanosine (especially in pregnancy). Further side effects are hepatic steatosis, and pancreatitis (Hoffmann & Kamps, 2003: 339-340).

1.5 Lamivudine A well-tolerated drug, but with rapid development of resistance. Lamivudine is frequently used as a component of the combined preparation tablets Combivir and Trizivir. Its side effects may include fatigue, nausea, vomiting, diarrhea, headache, insomnia, myalgia and arthralgia. Peripheral polyneuropathy, pancreatitis and lactic acidosis are rare (Hoffmann & Kamps, 2003: 324-326).

1.6 Abacavir Abacavir is otherwise well tolerated, possibly causing less mitochondrial toxicity, and therefore quite likely to have a better future than other NRTIs. Unfortunately, there is cross-resistance with many other NRTIs. Its side effects may include hypersensitivity syndrome (HSR) in approximately 2 to 6 % of the patients. This usually occurs within the first six weeks following the initiation of treatment. Pruritus and rash are common, but do not always occur. The HSR may present with just fever and a slowly developing malaise. Gastrointestinal complaints (nausea, vomiting, diarrhea, and abdominal pain) and fatigue are also possible, but are not necessarily linked to the HSR. Elevated liver function tests,

insomnia and dizziness are rare. There is probably a genetic predisposition towards development of the HSR (Hoffmann & Kamps, 2003: 307-308).

2. Non Nucleoside Reverse Transcriptase inhibitors (NNRTIs)

These attach to the reverse transcriptase enzyme, preventing the enzyme from converting HIV RNA into DNA (<http://www.hivmedicine.com/textbook/haart/nnrti.htm>).

2.1 Nevirapine Nevirapine is a frequently prescribed NNRTI. Nevirapine is very useful for simplification of successful HAART regimens. It has a good long-term tolerability with a favorable lipid profile. Its side effects may include mainly hepatotoxicity, and rash. Less frequently reported side effects are fever, nausea, drowsiness, headache, and myalgia. These side effects may occur with or without hepatotoxicity and/or rash. γ GT is frequently elevated (Hoffmann & Kamps, 2003: 330-332).

2.2 Delavirdine Delavirdine is rarely used, and it has been completely marginalized by the other two NNRTIs, Nevirapine and Efavirenz. However, the drug has some theoretical potential: it is fairly well tolerated (no hepatotoxicity, no CNS problems), and increases levels of indinavir and saquinavir. Its side effects may include rash, usually occurring within the first six weeks of treatment. In uncomplicated cases, treat symptomatically with antihistamines. If systemic effects such as fever, conjunctivitis, myalgia and arthralgia occur, delavirdine should be discontinued. In addition to these side effects: nausea, and elevated transaminases may occur (Hoffmann & Kamps, 2003: 314-315).

2.3 Efavirenz Efavirenz is a frequently used NNRTI, with uncontested antiretroviral potency. It has multiple CNS side effects, for which the pathogenesis is not sufficiently understood. Drug interactions have been documented for a variety of drugs commonly prescribed to HIV patients. Its side effects may include nightmares, confusion, dizziness, somnolence, abnormal thinking, impaired concentration, insomnia, and depersonalization. These CNS symptoms usually resolve substantially after a few weeks. A rash (in 15 %) may also occur in the first few weeks, but severe cases of blistering, desquamation and ulceration are rare. Elevation of liver function tests and biliary enzymes, especially γ GT; hypercholesterinemia, hypertriglyceridemia may occur (Hoffmann & Kamps, 2003: 318-319).

3. Protease inhibitors (PIs) work at a later stage in the replication process, preventing the protease enzyme from cutting HIV viral proteins into the virions that infect new CD4 cells. New copies of HIV will be defective and unable to infect other CD4 cells (<http://www.hivmedicine.com/textbook/haart/pi.htm>).

3.1 Saquinavir One of the first PIs, and the only one with two available formulations. Intolerable pill burden if unboosted. Cross-resistance with other PIs is frequent. Its side effects may include mainly gastrointestinal: diarrhea, nausea, abdominal discomfort, and meteorism. Rarely elevation of transaminases or γ GT, headache may occur. As with other PIs, lipodystrophy, dyslipidemia and reduced glucose tolerance may occur with long-term treatment (Hoffmann & Kamps, 2003: 337-338).

3.2 Ritonavir Ritonavir has become an important drug for boosting other protease inhibitors. In these combinations, when lower doses are used, side effects of ritonavir are tolerable. Numerous drug interactions must be considered. Its side effects may include nausea, vomiting, diarrhea, headache, perioral paresthesia and electric sensations on arms and legs. Elevated transaminases and γ GT, often significant dyslipidemia, reduced glucose tolerance and, rarely, diabetes mellitus. Lipodystrophy may occur with long-term treatment (Hoffmann & Kamps, 2003: 334-336).

3.3 Lopinavir Lopinavir is a very effective and relatively well tolerated PI. Lopinavir is an ideal drug for salvage therapy, as it has astonishing potency in PI-experienced patients with multiple resistance mutations. It remains to be proven whether or not Lopinavir is superior to other boosted PIs in the initial therapy. Disadvantages include high lipid levels and drug interactions. Its side effects may include mainly diarrhea, nausea, and dyslipidemia, also: headaches, and elevated transaminases (Hoffmann & Kamps, 2003: 326-328).

3.4 Indinavir Indinavir is effective and well-investigated PI. The use of Indinavir is slightly limited due to skin, kidney and intestinal problems. Indinavir is generally used with ritonavir boosting, which simplifies dosing. Its side effects may include nephrolithiasis (in up to 25 %), less frequently: nephrotoxicity with elevated serum creatinine, diarrhea, nausea, and vomiting. A sicca syndrome occurs relatively frequently (dry skin, mouth, eyes); ingrown toenails and paronychia;

rarely alopecia asymptomatic hyperbilirubinemia, lipodystrophy ("Crixbelly"), dyslipidemia, and disorders of glucose metabolism (Hoffmann & Kamps, 2003: 321-322).

3.5 Nelfinavir A relatively well tolerated and well investigated PI, but is slightly less potent than boosted PIs. A Nelfinavir-based PI regimen is less potent than NNRTI regimens. Due to its favorable resistance profile (after failure of Nelfinavir treatment, other PIs may still have good efficacy), it is well suited as a first-line PI. Its side effects may include diarrhea, meteorism, and nausea may also occur. Lipodystrophy, dyslipidemia, reduced glucose tolerance. Diarrhea, meteorism, and nausea also occur. Lipodystrophy, dyslipidemia, reduced glucose tolerance (Hoffmann & Kamps, 2003: 329).

3.6 Amprenavir Due to the high quantities of pills required, unboosted dosing with Amprenavir is hardly acceptable today. When boosted with Ritonavir, Amprenavir is well suited for salvage therapy because of its interesting resistance profile. Its side effects may include mostly gastrointestinal, including nausea, vomiting, diarrhea, flatulence, tenesmus, and perioral paresthesia. Occasionally: headache, fatigue, and, in 5-10 % of patients, a rash occurs usually in the second week of treatment. Stevens- Johnson syndrome is rare (<1 %). In combination with Ritonavir: levels of cholesterol, triglycerides and transaminases are more frequently elevated; lowered glucose tolerance; rarely diabetes mellitus; and lipodystrophy (Hoffmann & Kamps, 2003: 309-311).

GPO-VIR The Government Pharmaceutical Organization (GPO), a division of the Thai Ministry of Public Health, designed GPO-vir in order to incorporate three antiretrovirals into a single tablet. GPO-vir contains Stavudine (30-40 mg), Lamivudine (150 mg) and Nevirapine (200 mg), which together form a suitable highly active antiretroviral therapy (HAART) regimen for many patients in need of treatment (GPO-VIR, 2002).

Contraindications and precautions:

1. It is contraindicated in patients with known hypersensitivity to Nevirapine, Lamivudine or Stavudine.
2. Use with extreme caution in patients with hepatic and/or renal function impairment, bone marrow depression, pancreatitis or a history of pancreatitis, peripheral neuropathy or a history of peripheral neuropathy.
3. Should be used in pregnancy only if clearly needed. Nursing women who treated with GPO-VIR should be instructed to discontinue nursing.
4. Patients who interrupt GPO-VIR therapy for more than 7 days, should restart the combination dosing with recommended separated drug dosage for 28 days before changing to GPO-VIR (GPO-vir, 2002).

Table 2 Current Antiretroviral Drugs in Clinical Use and Common Side Effects
(MOPH, B.E. 2546: 40)

Antiretroviral drugs		Trade name	Side effects
Zidovudine	AZT or ZDV	Retrovir Antivir	Nausea, vomiting, abdominal discomfort, headache, myalgia, dizziness, macrocytic anemia
Didanosine	DdI	Videx	Diarrhea, nausea, pancreatitis, peripheral polyneuropathy
Zalcitabine	DdC	Hivid	Peripheral neuropathy, stomatitis, pancreatitis
Stavudine	d4T	Zerit	Peripheral neuropathy
Lamivudine	3TC	Epivir Combivir	Fatigue, nausea, vomiting, diarrhea, headache, insomnia
Abacavir	ABC	Ziagen	Hypersensitive syndrome, gastrointestinal complaints, fatigue
Nevirapine	NVP	Viramune	Hepatotoxicity, rash
Delavirdine	DLV	Rescriptor	Rash, fever, conjunctivitis, myalgia
Efavirenz	EFV	Stocrin	Nightmares, confusion, dizziness, insomnia, rash

Antiretroviral drugs		Trade name	Side effects
Indinavir	IDV	Crixivan	Nephrolithiasis, diarrhea, nausea, vomiting
Nelfinavir	NFV	Viracept	Diarrhea, meteorism, nausea
Lopinavir/Ritonavir	LPV/RTV	Kaletra	Diarrhea, nausea, dyslipidemia, headache
Amprenavir	APV	Agenerase	Nausea, vomiting, perioral paresthesia, headache, fatigue, rash

1.3 Managing the Adverse Effects of Antiretroviral Therapy

A patient's understanding of the possible side effects of medications and the management of them also has a significant effect on adherence (Williams, 2001: 37). Managing the adverse effects of antiretroviral therapy includes gastrointestinal effects of antiretroviral therapy, pancreatitis, hematologic effects of therapy, renal effects, peripheral nervous system effects, central nervous system effects metabolic and endocrine effects, lipid disorders and altered glucose metabolism.

Gastrointestinal effects of antiretroviral therapy

Most antiretroviral agents produce GI disturbances. Nausea is particularly notable with Zidovudine (46%), Nevirapine (20%), Amprenavir (38%-73%), Ritonavir (26%), Saquinavir soft-gel capsules (10%-18%), and Indinavir (12%) (Fortovase, 1997; Agenerase, 1999; Norvir, 1999). The most common side effect of AZT induction is nausea (Groopman, 1990: S500-506; Richman et al., 1987: 192-197). This nausea is usually transient, subsiding within the first four weeks of treatment. Administration of AZT with food can help alleviate this adverse effect. Eating smaller but more frequent meals also helps to reduce nausea.

Watery diarrhea is associated with the use of Saquinavir-SGC (20%), Indinavir (25%), Ritonavir (45%), Amprenavir (33%-56%), and Nelfinavir (26%-32%). Severe diarrhea is most commonly associated with Nelfinavir, but in general this adverse reaction does not result in weight loss (Jarvis & Faulds, 1998: 147-167; Viracept, 1998).

Diarrhea can also occur with Didanosine, because of the magnesium-hydroxide buffer added to the tablet formulation. It is anticipated that patients taking this drug will experience less diarrhea on two of the 200-mg tablets than on four 100-mg doses, because there is an equal amount of diarrhea-inducing buffer in the 200-mg and 100-mg tablets. Reducing the pill count should reduce Gastrointestinal irritation.

Pancreatitis

Pancreatitis has been associated with ddI therapy, occurring in 2.3% of patients (Jarvis & Faulds, 1998: 147-167). This reaction is dose-related. Several factors can increase the risk that individuals taking ddI will develop pancreatitis. These include alcohol ingestion, a prior history of pancreatitis, advanced HIV disease, and CD4 counts below 50 cells/mm³ (Dassopoulos & Ehrenpreis, 1999: 78-84; Whitefield, Bechtel & Starich, 1997: 122-127).

This adverse event generally occurs after one to six months of ddI therapy, and it usually resolves within one to three weeks after drug discontinuation. Didanosine-induced pancreatitis can be fatal (Dassopoulos & Ehrenpreis, 1999: 78-84). Protease inhibitors can cause a significant increase in serum triglycerides, and hypertriglyceridemia—specifically, triglyceride levels greater than 1,000 mg/dL—may be associated with pancreatitis (Churchill et al., 1998: 518-519).

Hematologic effects of therapy

Anemia and neutropenia are the major toxicities associated with AZT therapy (Gelmon et al., 1989: 555-561; Groopman, 1990: S500-S506; Richman et al.; 1987: 192-197). They are directly related to dosage and duration of therapy and are more likely to occur in patients with lower baseline CD4 count, hemoglobin concentration, and granulocyte count. Anemia most commonly develops after four to six weeks of treatment and appears to be related to impaired erythrocyte maturation, as evidenced by increasing macrocytosis in patients taking AZT

Because these hematologic toxicities are seen in a significant number of patients taking AZT, especially during the induction phase, all individuals assigned to a AZT- containing regimen— including those on Combivir —should be monitored very closely during the first eight weeks of treatment. Protease- inhibitor- containing regimens have also been associated with increased bleeding and hematomas in patients with hemophilia (Ginsburg et al., 1997: 338-339; Stanworth, Bolton & Hay, 1998:

109-114). Care providers should counsel patients with hemophilia and HIV infection who are taking protease inhibitors that a larger amount of factor products may be required to control bleeding. However, patients rarely need to switch to a protease-sparing regimen when episodes of bleeding do occur (Pai & Nahatat, 1999: 325-328).

Renal effects

The most common preventable adverse effect of Indinavir sulfate therapy is nephrolithiasis. Although the liver does metabolize Indinavir sulfate, 19% of the drug is excreted in urine, and once excreted, Indinavir is highly insoluble—which is why it tends to form crystals or stones.

Physicians should warn patients of the potential risk of kidney stones with Indinavir therapy, and all individuals assigned to an Indinavir-containing regimen should be reminded at every clinic visit to drink at least 1.5 liters (48 ounces) of liquid every day (Crixivan, 1998). Patients should be counseled to strain their urine to determine if a stone has passed, and regular evaluations of renal function should be performed. With severe or recurrent symptoms, another protease inhibitor should be substituted for Indinavir (Rich et al., 1997: 2228).

Peripheral nervous system effects

Peripheral neuropathy has been noted with ddI (14%-34%), ddC (17%-31%), and d4T (15-21%). When neuropathies do develop, they appear to be dose-related (Lambert et al., 1990: 1333-1340; Merigan & Skowron, 1990: S11-S15). These neuropathies generally have a “stocking-glove” distribution, primarily in the feet. Paresthesias and peripheral neuropathy are also reported with 3TC.

These drugs should be withheld in individuals who develop severe neuropathic pain, because nerve damage can be irreversible if the drugs are not discontinued. It can take up to 18 weeks for peripheral- neuropathy- associated pain to subside after patients are taken off of the offending drug or drugs (Lambert et al., 1990: 1333-1340).

When patients are assigned an antiretroviral regimen that includes one or more of the nucleoside analogs that can cause peripheral neuropathy, they should be told to be on the watch for signs of nerve damage, and they should be instructed to report any symptoms to their primary care provider.

Central nervous system effects

Efavirenz is the antiretroviral agent most likely to produce CNS symptoms, which occur in 52% of treated patients. These symptoms generally manifest within one to two days of the initiation of therapy, and tend to resolve over the next two to four weeks (Ziagen, 1998). Symptoms include drowsiness, dizziness, impaired concentration, insomnia, and vivid dreams or nightmares.

To reduce the severity of CNS effects, the drug should be administered at bedtime. Efavirenz may produce a hang-over effect the following day, so patients should be counseled not to operate heavy machinery or drive until the effect of the drug subsides. Patients who experience significant anxiety, depression, or suicidal ideation should be taken off Efavirenz (Colebunders & Verdonck, 1999: 869).

Metabolic and endocrine effects

A number of significant metabolic disorders are associated with antiretroviral therapy. These include mitochondrial dysfunction, lactic acidosis, hyperlipidemia, abnormal glucose utilization, and body-fat redistribution. Mitochondrial dysfunction and lactic acidosis occur in patients taking nucleoside reverse-transcriptase inhibitors; the other reactions are most frequently reported in individuals taking protease inhibitors. If a patient receiving one or more of the nucleoside analogs develops tachypnea, dyspnea, or a fall in serum bicarbonate concentrations, lactic acidosis should be suspected and the drug or drugs should be discontinued (Churchill, 1998: 518-519; Mirete, 1998: 810-811; Retrovir, 1998).

Lipid disorders

Protease inhibitors produce large increases in total cholesterol and triglyceride concentrations in many individuals (Sullivan & Nelson, 1997: 938-939; Echevarria, Hardin & Smith, 1999: 859-863). In particular, the use of Ritonavir has been associated with 30% to 40% increases in cholesterol and 200% to 300% increases in serum triglyceride concentrations (Danner, 1995: 1528-1533). When starting any patients on any multidrug antiretroviral combination that includes a protease inhibitor, providers should obtain baseline lipid panels and liver-function tests, and they should repeat these tests after four weeks of therapy.

Fat redistribution

Protease inhibitors are also associated with disfiguring changes in fat distribution in some individuals. Fat redistribution may be a result of the direct action of the protease inhibitors on lipid production or it may be an indirect result of the partial immune reconstitution that occurs with reduced viral replication (Aboulafia & Bundow, 1999: 970). These fat depositions usually occur during the first 2 to 12 months of therapy, and they generally produce little or no weight gain— suggesting a rough equivalency between fat loss in some areas and fat accumulation in others (Wurtz, 1998: 1735-1736). Although the fat redistribution bears a superficial resemblance to Cushing syndrome, no elevations in serum cortisol concentrations have been observed in patients taking protease inhibitors (Stephenson, 1998: 641-642; Yanovski et al., 1999: 1925-1931).

Altered glucose metabolism

A syndrome of insulin resistance, hyperlipidemia, and lipodystrophy has been identified in patients taking protease inhibitors (Carr, 1998: F51-F58; Flexner, 1998: 1281-1292). These disorders may appear individually or in combination. All patients starting antiretroviral therapy with a drug combination that includes a protease inhibitor should have baseline and follow-up blood glucose concentrations measured, to help assess if insulin resistance or hyperglycemia is likely to develop.

Part 2. Medication adherence

Health professionals first became concerned about uncooperative patients with tuberculosis in the 1980s, and increased concerns about non adherence after the introduction of curative antibiotics for tuberculosis in 1945 (Lerner, 1996: 257). Later, the introduction of multiple new antibiotics in the 1950s led to studies of non adherence in patients with infections other than tuberculosis (Lerner et al., 1998: 573). Literature regarding non adherence found that 40% to 50% of patients do not adhere to either short-term antibiotic regimens or long-term therapies for asthma, diabetes, or hypertension (Eraker et al., 1984: 258; Stephenson et al., 1993: 2779).

Medication adherence is the necessary interface between efficacious therapies and treatment effectiveness. Potentially serious health consequences can result from adherence failures (Rapoff & Barnard, 1991; Varni & Wallander, 1984 cited by Rapoff, 1998:379). The cost-effectiveness of medical care can be adversely affected by non-adherence (Rapoff & Barnard, 1991; Smith, 1985 cited by Rapoff, 1998: 379). Money may be wasted on unused medications or other therapies which are not followed. Physician visits and hospitalizations may also be increased for nonadherence patients (Sly, 1988 cited by Rapoff, 1998: 379).

These serious health and economic consequences of nonadherence illustrate the importance of identifying correlates of adherence, particularly those which can be modified to improve adherence to therapeutic regimens. These efforts have the potential of increasing treatment efficacy, reducing disease-related morbidity and mortality, reducing unnecessary health care costs, and improving the yield from clinical drug trials (Rapoff, 1998: 387).

Prolonged treatments for chronic diseases are a particular adherence challenge (Miller, 1997: 43). Approximately half of the patients with chronic diseases have problems following their prescribed regimen to the extent that they are unable to obtain optimum clinical benefit (Dunbar et al., 2000: 48). Medication nonadherence in the treatment of chronic diseases compromise the effectiveness of therapy. The factors related with compliance can be divided into internal and external factors. The internal factors include patient characteristics such as age, social background, value, attitudes and emotions caused by the disease. External factors include, for example, the impact of health education, the relationship between the patient and the health care

personnel and the support from the family, health care personnel and friends (Kyngas & Lahdenpera, 1999: 833). Nonadherence was found to be related with longer duration of the disease, earlier age of onset, later referral to a specialist care (Eldred et al., 1998: 117).

When access to HAART is assured, adherence emerges as a key to clinical management and public health, because the dynamic and chronic nature of HIV infection needs potent and continuous therapy for the duration of viral replicative capability. Patients who are not properly adherent to their HAART regimens or receive less than effective combinations of HAART may not reach therapeutic benefit (Wainberg & Friedland, 1998: 1977). Thus, medication adherence has become a major issue in the treatment of HIV-infected individuals and the most important determinant of the outcome of HAART (Mannheimer et al., 2002: 1115). Adherence to antiretroviral medications is believed to be a crucial component in maintaining therapeutic drug levels, ensuring virologic suppression and reducing the risk of drug resistance (Altice & Friedland, 1998 cited by Mannheimer et al., 2002: 1115; Gifford et al., 2000: 386). Adherence to antiretroviral medications is essential for optimal treatment of HIV infection. Adherence is important determinant of both the degree and duration of virologic suppression. Excellent adherence has been shown to increase the likelihood of sustained virologic control, which is important for reducing HIV-related morbidity and mortality (Department of Health and Human Services, 2002: 10).

Singh and colleagues (1999: 824) found that patients with chronic HIV disease do not fully adherence to their HAART regimens. Surveys have shown that one-third of patients missed doses within 3 days of the survey (Ickovics & Meisler, 1997: 385). The reasons for missed doses were predictable include forgetting, being too busy, being out of town, being asleep, being depressed, having adverse side effects, and being too ill (Chesney, 2000: S171). Havlir and colleagues (1998: 1261) found that incomplete adherence to HAART medications can have serious consequences and development of drug-resistant HIV strains. This can in turn lead to disease progression, inability to suppress HIV even with very intensive regimens, and transmission of resistant HIV to other.

Nonadherence is common among persons treated with HAART (Ickovics & Meade, 2002: S98). Therapeutic benefit may not be obtained in patients not properly adherent to their antiretroviral medications. Nonadherence to HIV treatment may increase risk of HIV transmission, as nonadherent patients have higher concentrations of HIV RNA in their semen or cervical secretions (Quinn et al., 2000: 921). Nonadherence accelerates the development of drug-resistant strains of HIV, and persons with resistant virus can spread resistance among those whom they infect (Wainberg & Friedland, 1998: 1977). Because of the occurrence of cross-resistance, insufficient adherence to one antiretroviral agent may eliminate not only that drug, but also other agents within the same class from the therapeutic arsenal for that individual (Altice & Friedland, 1998: 503-505).

Poor adherence leads to the development of drug resistance, limiting the effectiveness of therapy (Walsh et al., 2000 cited by Henry, 2002: 10). The percentage of patients who fail to self-administer as prescribed is somewhere between 20%-80% (Cramer et al., 1989: 3273; Wright, 1993: 909). Similarly, among those taking HAART, 40%-60% are less than 90% adherent (Bangsberg et al., 2000: 357; Bartlett, 2002: S2; Gordillo, 1999: 1763). The level of adherence required for success, however, is thought to be a staggering 95% or greater (Bartlett, 2002: S2). In HIV-infected patients who received HAART, suboptimal adherence was a strong predictor of treatment failure (Frank, 2002: S10). Obviously, HAART was the expense of long-term adherence, resulting in the burden of managing complex regimens and heavy pill, and treatment-limiting toxicities (Currier, 2002; S1).

Murphy and colleagues (2000: 47-58) reported that success of HAART relies on HIV-infected patients being able to adhere to complicated treatment regimens for extremely long periods of time. Four main categories of barriers and aids to adherence emerged: patient characteristics, the healthcare provider-patient relationship (Barriers related to the healthcare provider-patient relationship included patient satisfaction with their provider, as well as quality of communication with the provider), the healthcare system, and issue related to the medication regimens. In addition, healthcare system barriers caused difficulty in maintaining adherence.

Andreo and colleagues (2001: 249-62) found that factors related with non-adherence are as follows: young age, minimal financial resources, alcohol consumption, a lack of perceiving the treatment's effectiveness, absence of impact on anticipation of the future or emotional life, difficulties as far as in keeping up the medications or the treatment's integration into daily life, the impossibility of stopping the treatment, a duration of treatment > 2 years, hepatitis C co-infection and problematic side effects. Martinez and colleagues (2000: 1270) found that age was significantly related with adherence to antiretroviral drugs. Pattana Phokaew, (B.E. 2537: 3) found that the compliance on Tuberculosis treatment of the unemployed patients was significantly better than the employed patients and income per month was significantly related to the patient's compliance on treatment.

Catz and colleagues (2000: 124) found that severity of side-effects distinguished patients prescribed new treatment for HIV disease with good and poor adherence. However, Miller and colleagues (2002: 1) found that most patients would tolerate severe side-effects, inconvenience, and large pill burden to have a potent antiretroviral regimen. Patients generally preferred regimens with fewer side-effects to those with less inconvenience.

Studies of patients receiving multidrug regimens have provided some evidence for adherence related with social support, beliefs and knowledge about medications, and overall knowledge about health (Kalichman et al., 1999: 267; Singh et al., 1999: 824). Pattana Phokaew (B.E. 2537: 3) found that knowledge was positively related to patients' compliance on treatment of tuberculosis among HIV/AIDS patients. Martinez and colleagues (2000: 1270) found that knowledge of medication schedule was significantly related with adherence to antiretroviral drugs. Roberts (2000: 155) found that inadequate patient knowledge was one of the five main barriers in HIV-positive patients to adhere to antiretroviral regimens. Murdaugh (1998: 59) stated that knowledge of medications and their side effects is a major factor affecting medication adherence.

Hongwiwat (1993: 3) found that AIDS patients who have social support (from family and relatives) significantly had happier life than who cope by himself/herself only without social support. Catz and colleagues (2000: 124) found that social support distinguished good and poor adherent among persons prescribed

new treatment for HIV disease. Singh and colleagues (1999: 124) found that satisfaction with social support, problem- focused coping, and active-behavioral coping were correlated significantly with medication adherence, whereas loss of motivation, hopelessness, and avoidant coping were correlated with nonadherence.

Many factors have been shown to influence medication adherence among patients receiving HAART for long-term success with any of the antiretroviral therapy. In summary, these factors can be conceptualized as (a) patient characteristics, (b) treatment regimens, (c) patient-provider relationship, (d) clinical setting, and (e) features of the disease (Ickovics & Meade, 2002: 98; Ickovics & Meisler, 1997: 385). A multifactorial framework for medication adherence in AIDS clinical trials proposed by Ickovics and Meade (2002: 98) illustrates linkages of these concepts as presented in Figure 2.

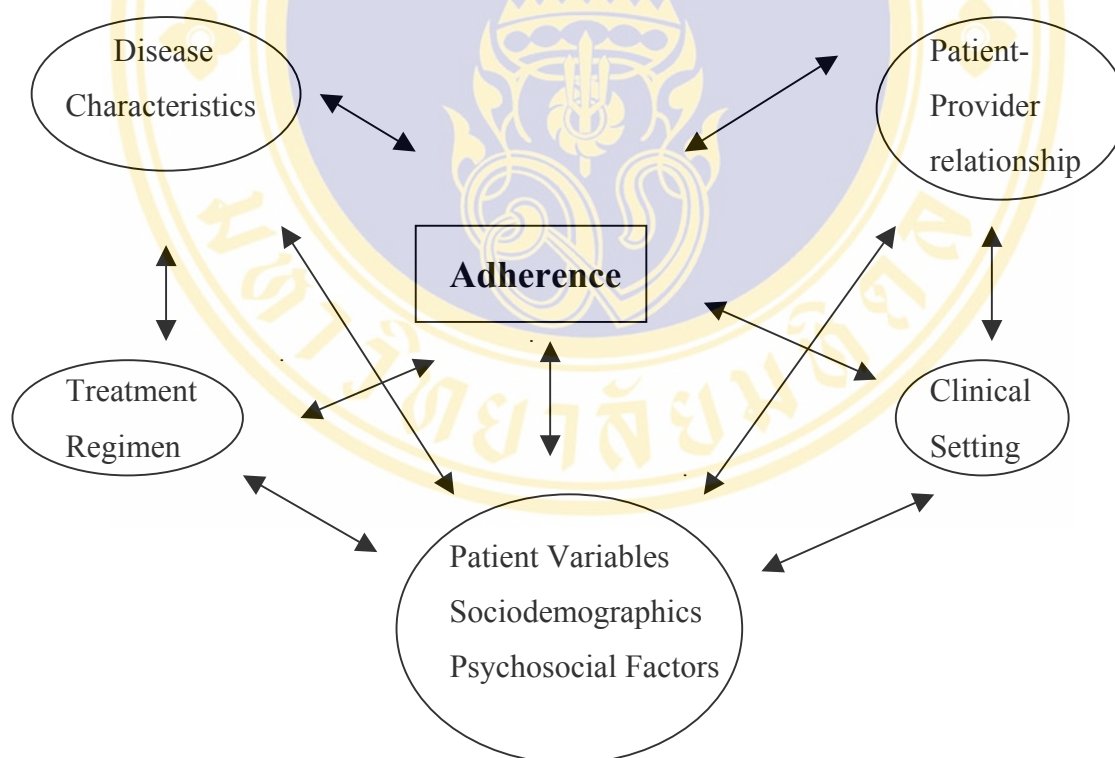


Figure 2. A Conceptual Framework for Medication Adherence in Clinical Trials

There is still no gold standard measurement of medication adherence. Several methods have been utilized with different success (Melkinow et al., 1994 cited by Mannheimer et al., 2002: 1115-1121). Although more objective methods such as direct observation and therapeutic drug monitoring yield more reliable results

compared to indirect methods, such as self-report, electronic monitoring and pill counting (Bond & Hussar, 1991 cited by Mannheimer et al., 2002: 1115-1121), the direct methods are practical in only some situations, and not generally practical.

Direct observed technique is highly labor intensive and impractical outside an institutional or residential settings. Therapeutic drug monitoring using plasma drug testing can be costly, is useful only if the pharmacokinetic profile is well defined and cannot discern whether patient is taking medication only right before blood specimen is obtained and omitting other doses (Friedland & Williams, 1999: S61; Williams, 1999: 113-129).

Indirect methods, such as self-report, pharmaceutical records, pill counting and electronic monitoring are less objective; however, less labor intensive and less expensive, except electronic monitoring. All adherence measures and all research regarding adherence are subject to limitations. Most of these measures tend to give overestimation of adherence, and define non adherence as missing doses, not including taking doses at the wrong times (Bartlett et al., 2002: S2-S10). Thus, measurement of medication adherence has been an unsolved challenge due to the wide range of reported rates and success.

As there is no “gold standard” for the measurement of medication adherence (Melkinnow et al., 1994: 99), several methods have been used with varying success. Bangsberg and colleagues (2000: 357) reported the median rate of medication adherence of 89% by self-report, 73% by pill counts, and 67% by Medication Event Monitoring System (MEMS). However, Arnsten and colleagues (2001: 1417-1423) reported that medication adherence estimates measured by both self-report and MEMS were significantly correlated with current viral load ($r = .43 - r = .60$). Interestingly, self-report, which is widely utilized in community settings (Eldred et al., 1998: 117; Gordillo et al., 1999: 1763; Holzemer et al., 1999: 185; Monforte et al., 1998: 1631) and clinical trials (Haubrich et al., 1999: 1099; Montaner et al., 1998: 930), has been presented with higher medication adherence estimates than MEMS (Melbourne et al., 1999: 329). Walsh and colleagues (2002: 267-277) found that medication adherence measured by the visual analog scale (VAS) was strongly associated with pill counts ($p < .001$) and MEMS ($p < .001$).

The VAS proportion of doses taken was piloted among 40 patients receiving HAART. Its criterion validity was tested against medication adherence recorded by MEMS caps and pill counts using Kappa statistics. These measurements of medication adherence are complementary, providing different perspectives, and potentially enhancing the value of each other Maneesriwongul & Williams (2004). Thus, use of more than one measure of medication adherence is highly recommended (Williams, 1999: 113-129).

In accordance with recent HIV literature (Mehta et al., 1997: 1665-1670), good adherence is defined as taking more than 90% of the pills prescribed in any regimen. However, according to the International AIDS Society- USA Panel Guidelines, 'less than excellent adherence may result in virus breakthrough and the emergence of drug-resistant strains' (Carpenter et al., 1997: 1962-1969). The level of adherence required for success, however, is thought to be a staggering 95% or greater (Bartlett, 2002: S2-S10; Beer et al., 2000: 360). According to a study by Paterson and colleagues (2000: 21-30) that used MEMS caps (Aprex) to electronically measure medication adherence among initially antiretroviral-naïve and antiretroviral-experienced patients found that very high level of adherence (>95%) to protease inhibitors were needed to achieve virologic suppression, and small differences in levels of adherence (e.g. >95% adherence versus 90%-95% adherence) were associated with substantial differences in virologic outcome (78% virologic suppression at >95% adherence versus 45% at 90%-95% adherence). This study will use a cut point of 95% to classify patients who had good medication adherence.

Part 3. Caregivers of HIV/AIDS Patients

HIV/AIDS is considered as a chronic disease. The care of HIV/ AIDS patients will take long time. Thus, a family is a primary source of care which helps patients live with HIV/AIDS (Onyango & Waliji, 1988 cited by Yanwaree, 2002: 27). Relationship between HIV/AIDS patients and family was suggested as a significant factor related to acceptance of the patients by their family (Lerwitworapong, 2001). Moreover, when HIV/AIDS patients live outside hospital, the family plays a part in how HIV/AIDS patients feel and how they adjust to the disease (Green & McCreaner, 1996 cited by Yanwaree, 2002: 27).

Caregivers serve as an integral part of continuity of care for HIV/AIDS patients at home (Fukfon, 2001: 4). Involvement of the family of HIV/AIDS patients can actually complement in providing care and support to HIV/AIDS patients (Ahmed, 2001). They are very important in helping or providing care for HIV/AIDS patients (Mohammad, 1998:3; Pikaun Nuntachaipun, B.E. 2539: 13; Stewart et al., 1995: 1101; Theis et al., 1997: 76). Bunruang (1999: 5) found that caregivers are necessary to provide continuous biological, psychological and social care for HIV/AIDS patients. Puntusen and colleagues (1996 cited by Fukfon, 2001: 33) addressed that caregivers' roles include giving willpower, food, clothing, body cleaning, medicine and herb. Additionally, caregivers care for patients by taking them to hospitals for treatment, proving them a chance to share ideas or decision- making on family's task (Junchanakit, 1998 cited by Fukfon, 2001: 4). Therefore, caregivers are significant persons of HIV/AIDS patients.

A family caregiver, or informal caregiver, is a relative, friend, or significant other who provides an unpaid, but essential component of care for a recipient who is physically or mentally impaired and has limitations in performing activities of daily living, necessitating ongoing assistance in the home or community (Davis, 1992: 2; Horowitz, 1985: 194-195). Caregivers can be classified into two categories (Davis, 1992: 2; Horowitz, 1985: 201), by level of caring responsibilities and time spent in caring. Primary caregivers are main and continuous providers who spend more time in caring of the patient than the others, whereas secondary caregivers are a part of the caregiver network and serve as an assistant to a primary caregiver. The patient may

have only a primary caregiver or both primary and secondary caregivers depending upon the social network of patients and their caregivers.

Most research in Thailand and around the world found that 70-80% of family caregivers are middle aged women. Most of them are adult children and elderly wives (Anderson et al., 1995: 847; Bugge et al., 1999: 1517; Gasemgitvatana et al., 1996: 76; Jom Suwanno, B.E.2540: 45; Kuaprom, 1999: 22; Maneewan et al., 1994: 236; Wongjunlongsin, 1999: 50). Women are expected to provide care more than men because they have long been recognized as the head nurse in most families (Litman, 1974 cited by Walker et al., 1995: 403). A major factor influencing the family consideration to take a role of caregiver is marital status. A single daughter is more likely to be a caregiver than a married daughter (Soldo & Myllyluoma, 1983: 606; Horowitz, 1985: 220-221). Individuals who are unemployed or work at home are more likely to play a role of caregiver than individuals who work outside (Saset, 1998: 219). Positive attitudes for providing care, and the physical and mental health status can also influence individuals in taking caregiver roles.

According to Davis (1992: 2) the caregivers' s role and responsibility are classified into 4 groups as follows.

1. Direct care includes personal daily activities such as cleaning, eating, exercising and helping to take care of themselves by giving them some needed facilities, and providing specific care for each disease.
2. Emotional support is psychological care which includes activities that assess patient's feelings, avoid things that may decrease the patient's self- esteem; provide encouragement or give sympathy by saying or showing that they agree with them and are ready to assist them if they need.
3. Mediating with formal organizations is activity encourage something to be successful by giving money and providing everything necessary include managing financial resources, contacting service people for home repairs, and filling out legal forms or other documents.
4. Financial assistance is support on medical expenses.

Traditionally, when a person is ill, the family is expected to provide emotional and social support (Yanwaree, 2002: 4). Some studies have shown that after being diagnosed, HIV/AIDS patients spent 80 percent of their time living with family and preferred to either be cared for or die at home (Brugha, 1994: 129; Taylor et al., 1997: 59-60). These studies found that the family caregivers feel stress and anxiety when knowing that their family members infected with HIV, fear of getting HIV infection when taking care of their infected family members, and confront with economic problems and hopelessness in helping their HIV/AIDS family members (London et al., 1998: 481; Stajduhar & Davies, 1998: 8). Family caregivers usually washed, fed, and changed clothes of their HIV/AIDS patients without asking for or expecting compensation (Onyango & Waliji, 1988 cited by Yanwaree, 2002: 27). Thus, most of the care provided at home for HIV/AIDS patients is given by family caregivers.

Part 4. Caregivers' Factors Related to Patients' Medication Adherence

4.1 Caregivers' Background Characteristic

From the review of literature, there is no existing research about factors related to medication adherence, concerning caregivers of HIV/AIDS patients receiving HAART. However, there are some evidences of study concerning caregivers of patients with other chronic diseases. These may be useful and applicable to HIV/AIDS patients. In this study, caregivers' factors related with medication adherence among patient receiving HAART are as follows: age, gender, education, income, occupation, number of social roles, quality of patient- caregiver relationship, help with medication adherence, knowledge about HIV/AIDS, and social support.

Age

Age is related to caregivers' ability in taking care of the dependent patients because it is an indicator of maturity or ability in managing different stimuli. Psychological condition, perception, ability in understanding and making a decision, and self care increase in accordance with age. These will reach the peak in adults and decrease in elderly (Orem, 1991: 239 –246). Teenagers of 13 – 20 years of age are at the period of adaptation to the bodily changes, the turning point from being children to adolescents. As a result, their emotion easily changes and their imagination is high. In addition, they are self-focused, joyful with friends, and curious while their maturity, life skills and social experience are limited. Adults of 21 – 40 years of age are more matured and responsible - ready for having a family and working. People of this age are adjustable to different situations, persevering, quick and capable for learning and problem solving. Concerning care giving ability, these people will be able to make the right decision, easily understand the treatment procedure and highly cooperate in the plan for the sake of health. Late adult people are becoming aging and less active. While they have more mental problems, they lose their self-care ability

It was found that age can be an indicator for caregiving ability as it has a negative relationship with caregiving ability among mothers caring for children with chronic illness (Hass, 1990: 162). Younger mother caregiving ability is better than elder mother. On the contrary, age is found to have a positive relationship with caregiving ability of Thai mothers caring for children with chronic illness (Achariya Pratumwan, B.E. 2534: 51). Caregivers' age may be related to medication adherence among patients receiving HAART.

Gender

In Thailand, it is believed that gender is one factor related with caregiving ability for dependent patients (Nilrut Vatcharapichat, B.E. 2543: 45). Different gender can influence differences in belief, attitude and value. Traditionally, women are responsible for the housework and taking care of all family members while men are to earn income for the family. Therefore, men tend to have higher hardness than women in adaptation for being a caregiver (Wimolrut Puravutpanit, B.E.2539: 23). Men caregivers usually do the job as a sole job while women caregivers can do their daily routine household work such as cooking, washing and cleaning, in addition

to caregiving work (Dwyer & Seccomb, 1991 cited by Phiangjai Tirapaiwong, B.E. 2540: 37). Many studies revealed that female caregivers have a key role in giving care to dependent patients and help develop caregiving of family member (Akeau Unahalekhaka et al., B.E.2542: 145; Hoyert & Seltzer, 1992: 74; Keith, 1995: 185; Namitta L. Sakun, B.E. 2544: 64; Orathai Somnarin, B.E. 2537: 55; Prarechait Junjarat, B.E. 2537: 26; Prathung Pimpoo, B.E. 2541: 54). Caregivers' gender appears to be an important factor in caregiving, may be related to medication adherence of patients receiving HAART.

Education

Education is another factor that can affect a person's perception and understanding of health and illness. With knowledge about diseases and illnesses, a caregiver will have ability of self care and caring of dependent patients. An educated person can better understand the situation, and seek knowledge and skills for problem solving and caregiving adjusting to suit the need of dependent patients (Orem, 1995: 239). Jenkin (1987: 95-97) addressed that poorly- educated persons were less able to perceive and understand the recurrence of difficulties, they might be limited in resolving potential problems. Similarly, Whetstone, Olow and Anne (1989: 962) found that a person with high education could apply his/her knowledge in caregiving as they could perceive and understand better. Therefore, highly- educated people can seek information that they need and take better care of their health than less educated people (Suwan, 1983: 182). Sakawrat Puangchan (B.E. 2538: 68) also found that level of education of the mother of chronically- ill child was positively significant with her caregiving ability. Caregivers' education may be related to medication adherence among patients receiving HAART.

Income

Income is also a factor that influences individuals' potential in caregiving of dependants and on their basic life in meeting their own needs (Orem, 1985: 186). In accordance with Pender (1982: 161-162), it was revealed that socio-economic status was major factor of person's caregiving ability for dependent patients. A person with high socio- economic could afford facilities as well as health services that are suitable for the dependent patients. Choosri Tiwsakul (B.E. 2539: 52)

found that the family income was related with child care behavior. Oberst and colleague (1989: 334) assessed the relationship between social status and caregiving burdens perceived by the caregivers of cancer patients undergoing chemotherapy, and found that those with lower social status tended to perceive the situation as more dangerous or threatening than those whose social status was at a middle level. Ekberg (1986: 334) examined boredom in taking care of chronically-ill patients, and discovered that the economic status of the family was an important factor which caused boredom in caregivers, and this could affect the quality of care that the patient received. Thus, caregivers' income may be related to medication adherence among patients receiving HAART.

Occupation

Occupation is a factor that affects life in responding to basic human needs. The better skill is more concerned with the issue of technical competency of physicians and are better able to choose physicians whom they judge to have expertise. Occupations of caregivers may support different ways of caregiving. Santinak (1987: 40) found that differences in occupation led to differences in how ill women used private services. Additionally, the group of patients that work in professional, academic, or business fields are more likely than people of other occupations to choose health-care services that provided by physicians (Polpeum, 1993: 72). Caregivers, such as housekeepers who can do their work with unlimited time are better able to manage their time for caregiving than those who have limited-time routine work, such as government officials, state enterprises (Pirint Kintana, B.E. 2543: 67). Therefore, free-lance professions or jobs without time limit condition may positively affect a person's caregiving ability. In addition, individuals who are unemployed or work at home are more likely to take on the role of caregiver than individuals who work outside (Saset, 1998: 219). Therefore, occupation of caregivers may be related to medication adherence among patients receiving HAART.

Number of Social Roles

Number of Social Roles involves socially defined and expected activities done according to the status. They are activities that are defined and expected (Shareampon, B.E. 2541: 58). It enables people to have social interaction and also enables the likely behavior prediction. Every human being play different

roles in family and society such as roles of children, father, mother, brother, sister, teacher, police, nurse and etc. The caregivers that have more number of social roles will have shorter time to look after the patients than the caregivers that fewer number of social roles (Nilrat Vatcharapichat, B.E. 2543: 47). Thus, number of social roles of the caregivers may be related to medication adherence among patients receiving HAART.

Quality of Patient-Caregiver Relationship

Family is a basic factor of dependent system among family members when illness has occurred in the family (Orem, 1995: 203-204). The relationship between the caregiver and the patient is an important factor for a dependent system in the family. The relationship before the patients' sickness is one variable that can affect caregiving ability. Good relationship between the patient and their caregiver will encourage caregiving as the caregiver is willing and committed to caregiving due to their love and attachment. On the other hand, poor relationship will result in the caregiver's stress during caregiving because of perception that caregiving is functional and obligatory.

Pratt and colleagues (1993: 376) assessed decision-making influence strategies of caregiving daughter and their elderly mothers and found that the relationship between daughters and mothers had a positive correlation to the mother's behavior perception and livelihood decision. Kramer (1993: 367) conducted a study of the spouse relationships of 72 wives caring for husbands with Alzheimer's disease, and reported that poor quality of the prior relationship was associated with quality of life of caregivers and caregiving satisfaction. Pohl and colleagues (1995: 68) studied the patient- caregiver relationship of 98 daughters of elderly mothers, and found the relationship was in both positive and negative aspects. It was found that attachment between the daughter and the mother could directly predict caregiving. Attachment and conflict could predict positive beliefs on caregiving but only conflict could predict negative beliefs about caregiving. Phiangjai Tirapaiwong (B.E.2540: 58) assessed the patient- relationship of family caregivers of stroke patients. It was found that caregivers had the high mean score on the caregiving had the high mean score on the patient-caregiver relationships. Chaipemsak (2002: 89) assessed roles of family support in the control of hypertension. Findings reported that patients with primary

hypertension have a medium of family support (73.75%). Factors contributing to the role of family support are such as family relation, perception of hypertension severity, age and family structure. These factors could predict 40.3% of the role of family support in the control of hypertension. Quality patient-caregiver of relationship may be related to medication adherence among patients receiving HAART.

Help with medication adherence

Caregivers' help with medication adherence plays an important role in enhancing medication adherence as Kyngas (2000: 262) regarded family support as a crucial factor of compliance among chronically ill adolescents. Kyngas (2000: 264) also suggested that support from the parents was related to compliance among adolescents with rheumatoid arthritis.

Pornsuda Krittigamas and Suparat Kanjanavanit (B.E. 2547: 175-184) found that one of the factors contributing to non-full adherence is caregivers' forgetfulness, or business (33%). Patchara Rumakom (B.E. 2546: 151) discovered that rate of medication adherence among patients receiving HAART who had a caregiver (s) reminding them about taking medication is better than the rate of those who did not have a caregiver (s).

Papangkorn (2003: 114) examined caregivers' experience in caring for dependent elderly persons, and found that care by the caregivers included preparing medications, managing follow-up, and giving treatments. Caregivers' help with medication adherence appears to be an important factor in caregiving, and may be related to medication adherence among patients receiving HAART.

In conclusion, this study is to explore relationships between caregivers' characteristics (age, gender, education, occupation, income, role, quality of patient-caregiver relationship, help with medication adherence, knowledge about HIV/AIDS, and social support) and patients' HIV/AIDS medication adherence.

4.2 Knowledge about HIV/AIDS

Knowledge is one of the major factors that promotes adherence to treatment regimens (Zimba & McInerney, 2001: 83). Knowledge is a key to aiding adherence (Lipton et al., 1995: 485). A lack of knowledge about the disease and limited finances were primary reasons for nonadherence to guidelines for diabetic eye care (Julie et al, 1994: 229). Knowledge about HIV disease and HAART regimens

may influence adherence (Eldred et al., 1998: 121; Wagner et al., 2002: 105). Specifically, knowledge of HAART and belief that HAART is effective and that poor adherence may promote viral resistance and treatment failure have been shown to affect patients' ability to adhere to their medication (Wagner et al., 2002: 105). Patients who understand how their medications help them are more likely to adhere to their regimens. Memory of medical information is a prerequisite for good adherence to prescribed treatment (Roy & Kessels, 2003: 219).

A patient's understanding of the possible side effects of medications and the management of them also has a significant effect on adherence (Williams, 2001: 37). In one study, patients who were told how to manage Gastrointestinal distress and diarrhea were successful in beginning and maintaining their regimen (Davis et al., 1997: 254). Without this information, patients may either stop following regimen as prescribed or reduce doses without consulting their providers (Williams, 2001: 37). Roberts (2000: 155) found that inadequate patient knowledge was a main barrier reported by patients.

Pattana Phokaew (B.E.2537: 3) found that knowledge was significantly and positively related to patients compliance on treatment of tuberculosis among HIV/AIDS patients. Youth were significantly less knowledgeable than adults, and young males tended to be less knowledgeable than young females. This higher compliance rate may be partially due to the significantly higher TB knowledge level found for the adult sample, as well as to the finding that the adult sample showed higher perceptions of vulnerability to TB (Murphy et al., 2000: 59). Knowledge of antiretroviral therapy action was related to antiretroviral therapy adherence; whereas knowledge of PCP prophylaxis action was not significantly related to adherence to antiretroviral therapy (Eldred et al., 1998: 121).

However, some studies found that knowledge about HIV treatment was not significantly related to adherence (Mellins et al., 1989: 371). Women who had missed their medications did not differ from women who were adherent in knowledge about treatment, but both groups were significantly better informed about HIV treatment than were women not currently receiving treatment (Kalichman et al., 2001: 62). The lack of health-related knowledge has been indicated as a barrier to women achieving adaptive health outcome (Raveis et al., 1998: 549).

Knowledge about HIV was related with adherence to HAART (Weiss et al., 2003: 673). Murdaugh (1998: 361) also found that knowledge of medication and side effects is major influence on medication adherence. In addition, patients who receive adequate knowledge about their treatment regimens and believe that they are listened to and respected by their physicians are more likely than others to comply with medical advice (Falvo et al., 1980: 187).

Good knowledge and problem solving skills of the caregiver, the duration of the treatment has been linked with poor treatment adherence (Thompson & Gustafson, 1996 cited by Farley, 1999: 201). Greater knowledge of HIV treatments is related with higher adherence to combination of antiretroviral therapy among members of HIV-positive mixed status couples (Carballo-Diequez, 2002: 105).

In this study caregivers' knowledge about HIV/AIDS will be explored regarding disease and treatment, antiretroviral medication use, side effect of antiretroviral medications and management of these side effects. To some extent, these are thought to have significant relationships to medication adherence among patients receiving HAART in Thailand.

4.3 Social Support

The concept of social support has emerged as a major health related psychosocial variables. Kahn (1979: 85) defined social support as an interpersonal transaction that includes the expression of positive affect by one person toward another. Schaefer and colleagues (1981: 381) conceptualized social support as social support to a human being in society when they come across tenseness (stressful situations). Pender (1987: 396) defined social support as concerning a person's general perception or belief that people in their social network would provide assistance in times of need, or on the other hand, received or enacted support. While House (1981: 24-26) stated that social support consists of interpersonal interaction that include one or more of the following: emotional support (feelings of empathy, love, trust, caring and support), instrumental help (aid in kind, exchanges, money, labor and time), information (advice, strategies, and suggestions for coping), and appraisal support (affirmation, feedback, and social comparison).

In summary, social support means that persons in society give and share their help and tender care with each other in many different ways, such as; tender loving care, participation in social activities, acceptance of their value, information received and a variety of help, such as material, financial, as well as time spent. Thus, social support would help a person to have better health behaviors of well being (Buaphut, 2002: 16).

Components of Social Support:

House (1981: 24-26) conceptualized social support as being subdivided, and included the following four classes:

1. Emotional Support: Which involves providing empathy, caring, loves, and trust seems to be the most important. Emotional support is included in one form or another in all the schemes reviewed, and its impact on stress and health is clearly documented in succeeding chapters. When individuals think of people being “supportive” toward them, they think mainly of emotional support.

2. Appraisal Support: involves only transmissions of information, rather than the affect emotional support or the aid involved in instrumental support. However, the information involved in appraisal support is relevant to self- evaluation- what social psychologists have termed social comparison. This is, other people are sources of information that individuals use in evaluating themselves. Such information can be implicitly or explicitly evaluative. Work supervisors, for example, may tell workers that they are doing good (or poor) work, or they may tell workers what constitutes the performance of an average worker and let them decide for themselves whether they are above or below average.

3. Informational Support: means providing a person with information that the person can use in coping with personal and environmental problems. In contrast to instrumental support, such information is not in and of itself helpful, rather it helps people to help themselves. For example, informing an unemployed person of job opportunities or more generally teaching them how to find a job is informational support. Obviously, providing information may imply emotional support and may, at times, constitute instrumental support (for example, if person’s major need is information) as the case of tutoring or coaching vocational or academic knowledge.

4.Instrumental Support: is the most clearly distinguished from emotional support, at least in theory, involving instrumental behaviors that directly help the person in need. Individuals give instrumental support when they help other people do their work, take care of them, or help them pay their bills. It is important to recognize, however, that a purely instrumental act also has psychological consequences. Thus, giving a person money can be a sign of caring or a source of information and appraisal (very possibly of a negative variety, communicating to persons that they are in need of money and dependent on others for it).

Cronnenwett (1985: 93-99) developed the Social Network Inventory (SNI) based on House's conceptualization of social support, which were instrumental support relabeled as material support, and appraisal support relabeled as comparison support, to increase the clarity of meaning of these terms for laypersons. The definitions used were: Emotional: the person communicates love, caring, trust, or concern for you. Material: the person helps you directly, such as through gifts of money, help with house chores, help with your work, and so on. Information: the persons tells you things you need to know, helps you solve your problems by sharing information or finding things out for you. Comparison: the person helps you learn about yourself just by being someone in the same situation or someone with experiences. He or she is like you in some important way and you feel supported because you can share ideas and feelings with someone like yourself. Logsdon and colleagues (1994: 449-457) also classified social support based on House (1981: 24-26) and Cronnewett (1985: 95-99) into four categories. These were emotional, material, information and comparison support.

Social support is a widely- accepted concept in nursing and other disciplines, and found to have significant relationship with positive health behaviors among general population and patients with chronic diseases such as cancer, diabetes mellitus, hypertension and HIV. These studies will review in the following aspects:

Positive Health Behaviors

Suphaaksorn (2001: 84-85) tested an application of protection motivation theory and social support for AIDS preventive behavior modification among conscripts in Ratchaburi province. It was found that after the program, conscripts who received the health education program applying protection motivation theory with social support had statistically significant changes in perceived susceptibility to HIV infection, self-efficacy in AIDS preventive behavior, response efficacy of AIDS preventive behavior and AIDS preventive behavior in contrast to the comparison group. Teraroganawong (2001: 66) examined factors related to osteoporosis preventive behaviors among pre-menopausal women. It was found that social support was one of the significant factors related to osteoporosis preventive behaviors ($p < .01$). Cholticha Wangwiwake (B.E. 2537: 74,77) examined the relationships between physical health status, social support and mental health self-care behaviors of the elderly at Thammasat University hospital. It was found that age, education, marital status and social support were significantly related to the mental health self-care behaviors of the elderly. Prasatkettkan (2001: 67-68) also examined the relationships between selected basic conditioning factors, self-efficacy, social support and self-care behavior in the Thai muslim elderly in the Bangkok metropolitan area, and revealed that social support had significant relationship with self-care behavior of elderly persons. Emotional support, esteem support, social support or net work and informational support were positively related to self-care behavior at the .01 level of statistical significance and the level of relationship was at a medium level ($r = .506, .720, .726, .530$ respectively and $p < .001$). Tangible support was positively related to self-care behavior at the .01 level of statistical significance and the level of relationship was at a low level ($r = .187, p < .001$). Social support, self-efficacy, and age can share the variance of self-care behavior at 66.8% at a statistically significant level of .001 ($p < .001$).

Cancer

Kitrungrote (2000: 68-70) assessed severity of side effects, self-esteem, social support, and role adaptation of cervical cancer patients receiving radiation therapy, and revealed that the combination of social support, self-esteem, and severity of side effects accounted for 54.8% of the variance in role adaptation of cervical cancer patients receiving radiation.

Aree Mungkietisakul (B.E. 2543: 73) assessed social support and adaptation in adolescents with cancer and Vilailucksana Chanpuang (B.E. 2534: 94) assessed the relationship between perception of disease, spouse support and adaptation of breast cancer patients. These findings suggested that there was a significantly positive correlation between social support and adaptation ($r = .440$, $p < .001$) and ($r = .603$, $p < .001$), respectively. Nittaya Kongchum (B.E. 2539: 53-54) assessed health related hardiness, social support, selected factors, and adaptation in patients with breast cancer receiving chemotherapy. The stepwise multiple regression showed that health related hardiness and social support were significantly accounted for 19 percent of the variance of the patients' adaptation.

Chularuk Kaveevivitchai (B.E. 2536: 48) assessed relationships among selected factors, uncertainty in illness, social support and adaptation in breast cancer women receiving chemotherapy and found that social support was negatively correlated with uncertainty in illness ($r = -.37$, $p < .001$) and positively correlated with adaptation ($r = .28$, $p < .001$). Kesorn Suvithayasiri (B.E. 2537: 64,79-80) assessed the relationships between social support, health locus of control and stress of the gynecologic cancer patients on chemotherapy, and reported that the cancer patients had received strong moral and emotional support since they had been diagnosed as gynecologic cancer patients, and found that other tangible supports such as financial and instrumental aid were lacking. The results of stepwise multiple regression analysis showed that 15.5 percent of the patients' stress was accounted for by two significant predictors: social support and health locus of control. Prasungsit (2001: 83) assessed effects of social support program on improvement of body image perception in adult patients with permanent colostomy. It was reported that after the program, patients who received social support care had a higher score for body image

perception than the patients who received conventional care during the same period of time ($p < .001$).

Diabetic Mellitus

Sutheerat Kaewpralome (B.E 2538: 63) examined relationships among self- esteem, social support and self- care behavior of Diabetic elderly Uttaradit hospital Muang District Uttaradit province and revealed positively significant correlations among social support and self- care behavior at .001 level ($r = .320$). The results of stepwise multiple regression analysis revealed that social support and education were significant predictors of self- care behavior. Thipapon Wonghognkun and colleague (B.E. 2535: 26-29) determined relationships among basic conditioning factors, social support, self- care agency and quality of life in diabetic patients. It was reported that social support showed significantly positive correlation with self- care agency and quality of life. When all basic conditioning factors, social support and self- care agency were entered into a stepwise multiple regression model to predict quality of life, only social support and age were significant predictors.

Normchit Skulpant (B.E. 2535: 89) assessed the relationships between social support, related factors and self- care behavior of the diabetic patients and Intaraporn Promprakarn (B.E. 2541: 109,115) examined the relationships between health perception, social support and self- care behavior among elderly with diabetes mellitus. Both found that there was a significant positive correlation between social support and self- care behavior. Pornpit Chevacomnuen (B.E. 2535: 42) assessed daily hassles, social support, health status and glucoregulation in noninsulin diabetic patients. It was found that social support was positively correlated with health status.

Hongrapipat (2001: 149-151) assessed the effectiveness between self- efficacy theory and social support as applied to health education program on behavioral modification among type2 diabetes mellitus patients attending services at Sikhoraphum hospital of Surin province, and revealed that the patients who received a health education program with social support had significantly better in knowledge about diabetes mellitus, social support, behavior of dietary control, physical exercise, medication taking and feet care than prior to participating in the health education program and comparison group. In addition, Waeladee (2001: 122) tested an application of self- efficacy theory and social support to behavioral modification

among type2 diabetes mellitus patients in Samko hospital, Angthong province. It was reported that after the program, the patients who received the health education program applying the self- efficacy theory and social support had statistically decreased fasting blood sugar levels compared to their levels before the program and to those of the comparison group.

Hypertension

Chirapa Hongtrakul (B.E. 2532: 38,42) examined relationship among selected basic conditioning factors, social support and self- care agency in essential hypertension patients. It was reported that duration of education, income and social support were positively correlated with self- care agency. When all basic conditioning factors and social support were entered into the regression model to predict self- care agency, only duration of education, income and social support were significant predictors. All variables accounted for 26% of variance in self- care agency which was statistical significant. Prasopsuk Srisaenpang (B.E. 2535: 45, 49) daily hassles, social support, health status and blood pressure control in essential hypertensive patients. It was report that social support was moderately correlated with health status in positive direction ($r = .39$, $p < .001$). Significant predictors of health status in the stepwise regression analysis were social support, daily hassles and types of hospital service. These variables accounted for 25.7% of variability in health status.

Duangkamon Channimit (B.E. 2538: 117-118) assessed influence of a supporting group on self- care behavior of hypertension clinic, Uttaradit Hospital, and reported that after attending the support group, hypertensive patients revealed statistically significant higher mean scores of behavior changes, the self- care, patient- relative relationship, and supporting behavior from the relatives ($p < .001$), and the level of controlled blood pressure than those of the comparison group ($p < .05$).

Suwimon Santiwes (B.E. 2545: 60, 62) assessed effect of self-efficacy enhancement and social support on exercise behavior of hypertensive elderly. It was found that the hypertensive elderly after receiving the self-efficacy enhancement and social support had significantly higher exercise behavior scores than that of before ($p < .001$), and significantly higher than that of the control group ($p < .001$).

The Relationship between Social Support and HIV/AIDS related variables

Marayat Wongsabutr (B.E. 2539: 65, 67) examined relationships among social support, hope and self-care behavior of persons with AIDS receiving treatment at Phrabatnampu Temple Lop-Buri province. It was reported that there was a positively significant relationship between social support and hope ($p < .001$), and between social support and self-care behavior of persons with AIDS ($p < .001$). Atirat Wattanapailin (B.E. 2539: 160-162) evaluated the influence of social support on coping process among asymptomatic HIV-positive persons, and reported that asymptomatic HIV-positive persons were rendered social supports from spouse, parents, brother, sisters, sons, daughters, asymptomatic HIV-positive persons- fellows and public health personnel. These social supports have influences on their coping process through the extent of assessment and coping process, i.e. 1) Influence on the acceptance of HIV infection; 2) Influence on the redefinition of new description of HIV infection; 3) Influence on diversion of interest/ concentration from HIV; 4) Influence on changes in healthcare of the asymptomatic HIV-positive persons; 5) Influence on new hope and will power of asymptomatic HIV-positive persons; 6) Influence on asymptomatic HIV-positive persons' confidence that when symptoms surface, they will not be isolated; and 7) Influence on self-esteem and self-pride.

Sumonta Kabinlapat (B.E. 2541: 80-81) assessed stress, social support and coping behaviors of mothers with HIV-seropositive. It was found that most HIV-seropositive mothers reported a moderate level of stress and social support. The stepwise multiple regression showed that 32.59 percent of problem-focused coping behavior was accounted for by social support ($p < .001$) and 22.15 percent of emotional-focused coping behavior was accounted for by social support and stress level ($p < .05$). Piyanun Limruagrang (B.E. 2540: 66) assessed the relationship between social support and maternal adaptation of HIV-infected mothers. It was reported that there were significantly positive correlation between overall social support and maternal adaptation ($r = .531$, $p < .001$). When focusing on each aspect of social support, it was found that there were significantly positive correlation between instrumental support, emotional support, as well as informational support with maternal adaptation at .001, .001 and .01 level ($r = .556$, .488, and .347).

Rossukhon Pichaipat (B.E. 2543: 72) assessed relationships between role perception, social support, outcome of pregnancy with self-care agency and post partum self-care of HIV mothers. It was reported that social support was related with post partum self care. Kingkaew Chaicharoen (B.E. 2543: 137) examined the relationships between health perceptions, social support and health-promotion behaviors of clients with HIV sero-positive: a case study at Camillian social center, Rayong, and found that social support was correlated positively with health perceptions ($r = .762$, $p < .01$), and health-promoting behaviors ($r = .889$, $p < .01$). Premreital Noimuenwai (B.E. 2536: 59) assessed social support, self-care deficit and quality of life in HIV-infected persons, and found that social support was correlated negatively with self-care deficit ($r = -.44$, $p < .001$) and social support was correlated positively with quality of life ($r = .41$, $p < .001$). Ratana Vongpitakros (B.E. 2543: 90,104) assessed the relationships between health belief, social support and HIV pregnant women's practical behavior at Nakorn Pathom hospital and revealed positively significant correlations among health belief, social support and practical behavior at .01 level.

Caregivers and social support as a beneficial source for individual that is one basic conditioning factor influencing on any practices responding to the self-care behavior (Orem cited by Hunucharunkul, 1988: 14). Social support is a positive health behavior that influences states of health and illness (Wongwiggan, 2003; 24). Not only does social support do patient good self-care, but social support also do caregivers good caring behaviors. Caregivers are capable in providing good care and support; consequently, patients can develop good self-care (Yanwaree, 2002: 27).

Krongchit Chomsamut (B.E. 2535: 87) assessed the effectiveness of social support from relatives on diabetic controlling behavior among elderly patients at diabetes clinic at Chulalongkorn hospital, and revealed that diabetes mellitus patients who received support from caregivers who attended DM-specific health education program demonstrated statistically better practice than those whose relatives did not receive educational support. Patients' average blood sugar level was also decreased. It should be noted that after attending DM-specific health education program, relatives significantly provided better support to patients regarding dieting, taking medication,

exercise, oral hygiene, foot caring, urine sugar test and keeping appointment to see the doctor than before.

Wattana Klaidee (B.E. 2530: 129-130) assessed the effectiveness of health education program and support from caregivers on diabetic patient's behaviors at Inburi hospital, Singburi province, and found that overall diabetic control condition of diabetic patients who received health education program and support from relatives was significantly better than diabetic patients who received a regular health education program. Additionally, overall diabetic controlling practice of diabetic patients who received health education program and advices from patient's relatives was better than diabetic patients who received a regular health education program in term of practice on taking medicine, dieting, exercise, foot care, and recognizing signs of hypoglycemia.

In addition, social support has been found to have significant positive relationship with caregivers' ability in caring of cerebral palsy children (Chaleaom Wongchantra, B.E. 2539: 68-69). Jintana Tangvoraphonkcahi & Dusanee Mukasombat (B.E. 2539: 51) assessed the effectiveness of social support on anxiety and depression of mother having leukemic children. They found that mothers who received the social support from their husbands had statistically significant less anxiety and depression level than mothers who received the social support from the nurses after receiving the social support for 2 weeks and 4 weeks.

Darika Thanbuasawan (B.E.2540: 43) assessed relationships among social support, duration of caregiving, severity of disability and fatigue in caregivers of hospitalized spinal cord injured patients, and revealed that there was a statistically significant negative relationship between perceived social support and fatigue of caregivers. Theepprapin Sukkheo (B.E. 2543: 39-44) examined relationship between social support and burden among caregivers of the Schizophrenic patients, and reported that overall social support was negatively correlated to burden ($r = -.378$, $p < .01$) while instrumental support was moderately negative correlated to burden ($r = -.405$, $p < .01$) and emotional support and socially support were negatively correlated to burden at low level ($r = -.274$ and $r = -.282$, $p < .01$). Neither information support nor esteem support was correlated to burden. Wanpen Yuenyongsan (B.E. 2545: 37) assessed social support of caregivers of person with schizophrenia, and

reported that the overall mean score of social support was at high level. The social support in each mode that was at high level included social integration, attachment, reassurance of worth, opportunity of nurturance, and the obtaining of guidance/assistance; and the social support resources that caregivers received mostly were healthcare personnel, neighbors/ co-workers, relatives, and community services respectively.

Patcharin Kittithongsopon (B.E. 2541: 80) assessed social support and childrearing behaviors of toddlers of HIV-infected mothers. These findings suggest that there was significant positive correlation between overall social support and child-rearing behavior ($p < .001$). When focusing on each aspect of social support, it found that there were significant positive correlation between social support in terms of information support, tangible support, and network support and child-rearing behaviors ($p < .001, .001, .001$).

Pratueng Pimpo (B.E. 2541: 62) assessed relationship between social support and behaviors of relatives in caring HIV/AIDS clients. It was reported that the majority of HIV/AIDS clients' relatives reported receiving social support in fair level in terms of information (71.2%), knowledge and advice (67.9%), emotional (57.7%) and received financial and facility support in taking care of HIV/AIDS clients (58.8%). There was a significant positive relationship between the social support and taking care behavior of HIV/AIDS clients' relatives.

Since social support has played a major role in health promotion (Cholticha Wangwiwake, B.E. 2537: 74,77; Praisri, 2001: 68; Prasatkettkan, 2001: 67-68; Suphaaksorn, 2001: 84-85; Teraroganawong, 2001: 66), self care (Duangkamon Channimit, B.E. 2538: 117-118; Hongrapipat, 2001: 149-151; Marayat Wongsabutr, B.E. 2539: 65, 67; Normchit Skulpant, B.E. 2535: 89; Rossukhon Pichaipat, B.E. 2543: 72; Sutteerat Kaewpralome, B.E. 2538: 63; Waeladee, 2001: 122;), and caregiving ability (Chaleaom Wongchantra, B.E. 2539: 48; Patcharin Kittithongsopon, B.E. 2541: 80; Pratueng Pimpo, B.E. 2541: 62). Caregivers' social support may be related to medication adherence among patients receiving HAART. Thus, this relationship should be explored.

In conclusion, from review of literature, there is no existing research about the caregivers' factors related to medication adherence among patients receiving HAART. Patients' medication adherence can be more successfully achieved if these patients gain support from the caregivers. Therefore there is a need to explore caregivers' factors related to medication adherence among patients receiving HAART.



CHAPTER III

MATERIAL & METHODS

This is a cross-sectional study to: 1) describe caregivers of patients receiving HAART in terms of background characteristics (age, gender, education, occupation, income, number of social roles, quality of patient-caregiver relationship, help with medication adherence), knowledge about HIV/AIDS, social support, and medication adherence among patients receiving HAART; and 2) predict medication adherence among patients receiving HAART by using the caregivers' factors.

Settings of the study

The subjects of the study will be recruited at the Ambulatory Care Unit and the Out Patient Department of medicine at Bamrasnaradura Infectious Disease Institute. These clinics provide regular services for patients receiving HAART everyday from 08.00 a.m.-04.00p.m. There were approximately 1,200 patients receiving HAART at Bamrasnaradura Infectious Disease Institute.

Population and Samples

The populations of this study are all patients receiving HAART and caregivers who accompany the patients to have a follow up visit at the Ambulatory Care Unit and the Out Patient Department of medicine at Bamrasnaradura Infectious Disease Institute. Samples of patients receiving HAART and their caregivers were recruited into this study by using a purposive sampling.

A sample of the patients was recruited into this study based on the following inclusion criteria:

1. patients who have been receiving HAART more than 1 month.
2. understand Thai language.
3. have good cognitive. The patients who are 60 years old and older were screened for mental status by using The Set Test (Isaacs & Akhtar, 1972 cited by Phongphanngam, 2004: 41-42) (see Appendix A).

4.willing to participate in this study.

A sample of the caregivers was recruited into this study based on the following inclusion criteria:

1.persons who are regarded by the patients receiving HAART as their caregivers, and provided such care activities (bathing, helping in daily activities, dressing, preparing food and medication, providing transportation) for more than 1 month, and accompanied the patients to the clinics without hiring.

2.are 18 years old or older.

3.understand Thai language

4. have good cognitive. The caregivers who are 60 years old and older were screened for mental status by using The Set Test (Isaacs & Akhtar, 1972 cited by Phongphanngam, 2004: 41-42) (see Appendix A).

5.willing to participate in the study.

Sample size

The samples of patients and their caregivers were selected by using a purposive sampling. The sample size was calculated rule of thumb (Green, 1991:499) as follow

$$N \geq 50 + 8 (m)$$

m = number of independent variables

In this study, there were 10 independent variables, so the sample sizes were approximately 130 subjects for both patients and caregivers, therefore this study included 128 pairs of subjects patients and caregivers.

Instrument

The instruments used in this study consisted of three sets of questionnaires: a questionnaire for caregivers, a questionnaire for patients receiving HAART, and screening test for patients and caregivers who were 60 years old and older. Details about the questionnaires are as follows:

Questionnaire for caregivers

1. Personal background characteristics questionnaires (See Appendix B).

This is to collect demographic data (age, gender, educational level, occupation, income, number of social roles, quality of patient- caregiver relationship).

2. Help with medication adherence (See Appendix C). This includes activities that the caregivers performed to assist the patients to adhere to their medication. A single question was used to ask, “Do you help your patients in taking his or her medication?” If the caregivers helped the patients, they were asked to specify how they helped the patients?

3. Knowledge about HIV/ AIDS questionnaires (See Appendix D).

An instrument measuring Knowledge about HIV/AIDS to be used in this study was developed based on literature reviews by Maneesriwongul and colleagues (2004). Knowledge about HIV/AIDS includes (1) disease and treatment (Eldred et al., 1998: 117; Mathews et al., 2002: 157-172; Roberts, 2000: 155; Wagner et al., 2002: 105), (2) antiretroviral medication use (Martinez et al., 2000: 1266; Mathews et al., 2002: 157-172), (3) side effect of antiretroviral medications and management (Davis & Lau, 1997: S122; Murdaugh, 1998: 59; Wagner et al., 2002: 105).

This instrument is a self-administered questionnaire that composed of 38 items to measure knowledge about AIDS in terms of: the disease and progression (13 items), usage of antiretroviral medications (12 items), and side effects of antiretroviral medications and its management (13 items) using three point scales: “yes”, “no” or “don’t know” (see Appendix D). Each item was scored for correct/incorrect responses. A correct response was scored as one while an incorrect response or “don’t know” was scored as zero. Eighteen items were negatively worded.

This questionnaire was validated for its content validity by 6 experts (2 physicians, 2 nursing faculty members, and 2 nurses specializing in AIDS care). Subsequently, it was piloted among 48 patients receiving HAART and 19 caregivers (caregivers of some of these patients) at the Out Patient Department, Bamrasnaradura Infectious Disease Institute. Internal consistency coefficient alphas of the three subscales are .73, .71 and .79 respectively with an overall coefficient alpha of .86 which indicates adequate reliability for a newly-developed instrument. Possible scores on this scale range from a low of 0 to a high of 38. A higher score means higher knowledge about AIDS.

4. Social Support (See Appendix E).

An instrument measuring social support to be used in this study was developed based on literature reviews by Maneesriwongul and colleagues (2004). Social support covers four aspects (House, 1981: 24-26): (1) emotional support i.e. esteem, affect, trust, concern, and listening, (2) appraisal support i.e. affirmation, feedback, and social comparison, (3) informational support i.e. advice, suggestion, directives, and information, and (4) instrumental support i.e. aid in kind, money, labor, time, and modifying environment. Sources of support include spouse or partner, other relatives, friends, neighbors, co-workers, service, caregivers, and health and welfare professionals. The definition and content of supportive acts described by House (1981: 24-26) and House and Kahn (1985: 83-108) is used to guide a development of this questionnaire to measure social support among HIV-infected patients with HAART.

This instrument is a self-administered questionnaire that composed of 55 items to measure social support among caregivers of HIV-positive patients receiving HAART in terms of: emotional support (15 items), appraisal support (14 items), informational support (14 items), and instrumental support (12 items) using five-point Likert's scales ranging from "strongly agree", "agree", "not sure", "disagree" to "strongly disagree" (see Appendix E). Responses were scored for 5, 4, 3, 2, and 1, respectively. Five items were negatively worded.

This questionnaire was validated for its content validity by 6 experts (2 physicians, 2 nursing faculty members, and 2 nurses specializing in AIDS care). Subsequently, it was piloted among 19 caregivers of patients receiving HAART at the Out Patient Department, Bamrasnaradura Infectious Disease Institute. Internal consistency coefficient alphas of the four subscales are .69, .87, .87, and .78 respectively with an overall coefficient alpha of .91 which indicates adequate reliability for a newly-developed instrument. Possible scores on this scale range from a low of 55 to a high of 275. A higher score means higher social support.

Questionnaire for patients

Medication adherence (See Appendix F). An average of adherence measured by patient self report and a visual analog scale was calculated and used to indicate medication adherence among patient receiving HAART in this study. A reason for using both measurements was that some patients with visual loss due to CMV retinitis can be included in this study.

1. Patient self-report: Patient self-report is the most commonly used assessment of medication adherence although it has been found to have less inaccuracy as a result of imprecise or inconsistent questioning, forgetfulness or intention to provide socially reliable answers (Lay 1988 cited by Mannheimer et al., 2002: 1115-1121). In this study the patients were asked to give an estimation about how many percent of medication that they took in the past month from 0% to 100%. It can be interpreted as 0% means no medication taken, 50% means half of medication, and 100% means every single dose taken.

2. The visual analog scale (VAS) The visual analog scale of proportion of doses taken in the preceding month was used to measure medication adherence by Walsh and colleagues (2002: 269-277). Patients were asked to put a cross on the line below at the point showing your best guess about how many percent of medication you have taken in the last month. It can be interpreted as 0% means no medication taken, 50% means half of medication, and 100% means every single dose taken. It was also inversely associated with plasma HIV RNA ($p = .01$). According to Williams (1999: 113-129), assessment of medication adherence should be very concrete, be very specific, give permission for lapses in adherence, identify unique problem areas, and assess for unexpected side effects. Visual analog scale could also be used to reveal patient self-report (Walsh et al., 2002: 269-277). The VAS was also used by Maneesriwongul and Williams (2004) to measure medication adherence among patients receiving HAART in Thailand, and significantly validated with viral load ($p < .05$).

Screening test for caregivers who are 60 years old and older

The Set Test (See Appendix A) was developed by Isaacs & Akhtar (1972 cited by Phongphanngam, 2003: 41). It was a quantitative, verbal method to screen mental status in older adults. Asking the elderly to name as many items as they could recall in each of the four categories or sets performed this test: fruits, animals, colors, and towns (cities). One point was assigned for each correct item. No points were given or deducted if the items were repeated. The researcher told the patients so if they repeated the items. There was no time limit. The maximum score that could be achieved in each category was 10; the maximum total score was 40. Isaacs and Kennie (1973: 468) recommended that the elderly who scored equal to or more than 25 were mentally normal and had no dementia.

Validity and reliability testing

Isaacs and Kennie (1973: 467-470) used this test in studying 189 persons, aged 65 and older, in the East End of Glasgow. A total score under 15 corresponded closely to a clinical diagnosis of dementia. Scores between 15 and 24 reflected less similarity to dementia, while no subject with score of 25 or higher were found to be demented. Furthermore, Hays (1984: 96-97) used the Set Test in more than 100 older adults and found it to be extremely helpful. The Set Test could be a good tool for screening mental status in older adults in community and institutional care. Performance on the test was consistent. Persons with high scores did well in every category, whereas those with low scores did poorly in all. Therefore, the Set Test was a practical, sensitive, reliable, and applicable mental status test because of the question regarding ordinary living, and it could be performed rapidly and fairly easily.

In Thailand, Arunee Nakaphongse (B.E. 2539: 41-42) and Sumana Saenmanoch (B.E. 2541: 42-43) used the test to evaluate the mental status of the subjects and they found that average administration time was about two to three minutes, and it took no more than five minutes. In the present study the elderly caregivers took two to four minutes to complete the Set Test.

Cognitive performance may be seen as a maker for overall functional vulnerability. The studies reported that caregivers that had mental impairment had limited capacity to respond to the demands of caregiving (Brown, 1988: 15). In this study, the researcher used the Set Test in screening the caregivers' mental status

because it had minimal bearing on educational status, culture, and norms. The subjects who had scores of the Set Test less than 25 were excluded. Because of the physical ability to perform such task as dressing, satisfactory functional status requires cognitive abilities such as sequencing, sorting, selection, and judgment.

Protection of Human Subjects

This study is a part of the project entitled “Medication adherence among people living with HIV” (Protocol No. ID 06-46-31) which was approved by the Ethical Clearance Committee on Human Rights Related to Researches, Faculty of Medicine Ramathibodi Hospital, Mahidol University on June 18, 2003, and received a permission by the Ethical Committee at the Bamrasnaradura Infectious Institute in July 2003. This study was conducted based on the protection of human rights (see Appendix G). Eligible patients receiving HAART and their caregivers were invited to participate in the study. The researcher explained the purpose of the study, the research process, benefits, time used to complete the questionnaire, method of answering the questionnaire, and the right to refuse to participate in the study. All participants who agreed to participate gave their consent and were assured that data would be kept strictly confidential and would only be reported as a group data.

Data Collection

A permission for collecting data was obtained from the director of Bamrasnaradura Infectious Disease Institute. The Director of Nursing and the head-nurse of the Ambulatory Care Unit and Out Patient Departments of Bamrasnaradura Infectious Disease Institute in each setting were informed. The researcher explained about the study to the nursing staff in the Ambulatory Care Unit and Out Patient Departments of Bamrasnaradura Infectious Disease Institute. Caregivers who met the criteria were approached to explain the nature of the study and the data collecting procedures.

Data collection procedures were conducted in the following sequence:

1. Identify patient receiving HAART from medical record according to inclusion criteria.

2. The patients were asked to refer their caregivers who accompany to the clinic with them to the researcher.

3. The researcher explained the patients and their caregivers about the nature of the study and data collecting procedures. The patients and their caregivers were asked to indicate their willingness to participate, and to sign a consent form when they agree to participate in this study.

4. When the patients and their caregivers consent to participate in this study, the researcher gave questionnaire forms to them and explain about the questionnaires. If they have any question about the questionnaires, the researcher would be available to explain to them. During the data collection if the subjects want to stop giving information, the researcher will terminate this process. This will not have any effect on the treatment that the patients received.

5. The questionnaire forms were delivered in this sequence. For the patients, they were asked about their medication adherence in the past month. For the caregivers, Part 1 Personal background characteristics, Part 2 Help with medication adherence, Part 3 Knowledge about HIV/AIDS, Part 4 Social supports. It took about 30-45 minutes to complete these questionnaires. For those who are 60 years old and older, they were screened with a Set Test for mental status prior to data collection.

6. When the questionnaires were completed, the researcher edited them and processed the data for analysis.

Data Analysis

All data were analyzed by using the Statistical Package for Social Science for Window Program 11.0 (SPSS/FW).

1. Descriptive statistics

The descriptive information for background characteristics such as demographic data, number of social roles, quality of patient- caregiver relationship, help with medication adherence, knowledge about HIV/AIDS, social support and medication adherence were analyzed by using frequency, percentage, mean and standard deviation as appropriate.

2. Inferential statistics

For inferential statistical analysis, variables which are not in interval or ratio scale of measurement were recoded as follows:

Occupation: Caregivers who did household work without other job were recoded into “household workers”, while others were classified into “others”.

Income: caregivers who reported having adequate income with and without saving were recorded to “adequate income” group, while others were classified into “inadequate income” group.

Relationships between caregivers’ background characteristics, knowledge about HIV/AIDS and social support, and medication adherence among patients receiving HAART, were tested using Pearson Product Moment correlation prior to multiple regression. The assumptions for appropriate use of multiple regression analysis were tested.

Stepwise multiple regression analysis was used to examine predictability of the caregivers’ factors on medication adherence among patients receiving HAART.

CHAPTER IV

RESULTS

This cross-sectional study was conducted: 1) to describe caregivers of patients receiving HAART in terms of background characteristics (age, gender, education, occupation, income, number of social roles, quality of patient-caregiver relationship, and help with medication adherence), knowledge about HIV/AIDS, social support, and medication adherence among patients receiving HAART; and 2) to predict medication adherence among patients receiving HAART by using the caregivers' factors. Data were analyzed by using both descriptive and inferential statistics. The results of data analysis were presented in 3 parts as following:

Part 1: Caregivers' Background Characteristics

Part 2: Knowledge about HIV/AIDS

Social Support

Medication Adherence

Part 3: Caregivers' Factors Predicting Medication Adherence among Patients Receiving HAART

Part 1: Caregivers' Background Characteristics

About 466 patients receiving HAART were approached. However, only 134 patients were accompanied by their caregivers, and were invited to participate in this study. One hundred and twenty-eight caregivers met the inclusion criteria.

Caregivers' age ranged from 18-72 years old ($M = 38.66$, $S.D. = 11.22$). Of these 128 caregivers, more than a half were young adults (59.4%), and 32.8% were older adults. A few caregivers were younger adults (2.3%) and elderly (7.8%). The majority of them were female (68.8%). Their level of education varied from none (1.6%), elementary school (33.6%), junior high school (14.8%), senior high school (15.6%), certificate (11.7%), diploma (4.7%), bachelor degree (16.4%) to master's degree (1.6%). Income ranged from zero to 70,000 bahts per month ($M = 8989.5$, $S.D. =$

11749.5). While about one-fifth of the subjects did not have income (18.8%), the rest earned less than 3,000 bahts (14.7%), 3,001-6,000 bahts (25.0%), 6,001-10,000 (18.8%), and more than 10,000 bahts per month (22.7%). Nearly two-thirds of them had adequate income: 19.5% also had some saving, but 43.0% had no saving. The rest had poor income: 28.1% had poor income with debts, but 9.4% without debt. One-fourth of them were household workers (27.3%). While the rest worked as merchants (21.0%), general workers (22.7%), government services (9.4%), company employees (7.0%), farmers (4.7%), state enterprise employees (1.6%), students (1.6%) and others.

About a quarter of the caregivers had only one social role, the rest had two social roles (38.3%), three social roles (36.7%), and four social roles (0.8%). About 0.8% played only a caregiver role with no any other social roles. A half of the caregivers were spouses (51.6%). The rest were relatives (23.4%), parents (14.1%), children (6.3%), and friends (4.7%). Nearly all reported very good patient-caregiver relationship on a high score of eight (10.2%), nine (8.5%), and ten (69.5%). Very few reported poor patient-caregiver relationship on a low score of one (1.6%), two (0.8%), and four (0.8%). Three-fourths of them helped the patients with medication adherence (82%) by reminding about medication (31.1%), reminding and preparing medication (14%), preparing medication (11.2%), preparing and paying for medication (8.7%), reminding, preparing and paying for medication (6.6%), taking/accompanying the patients to a clinic (4.0%), and calling (1.6%). About 4.8% played other activities in helping the patients with medication adherence.

One-thirds of them had activity of help with medication adherence by reminding about medication (31.1%), reminding and preparing medication (14%), preparing medication (11.2%), taking/accompanying the patients to a clinic (3.2%), preparing food and medication (2.4%), and other activities of caregiving (34.1%). Caregiving hours per day ranged from 0.5 to 24 hours ($M = 13.28$, $S.D. = 9.41$), as shown in Table 3.

Table 3 Caregivers' Background Characteristic (N = 128)

Characteristics	Number	Percentage
Age (years)		
20 or younger	3	2.3
21-29	24	18.8
30-39	49	38.3
40-49	33	25.8
50-59	9	7.0
60 or older	10	7.8
Range 18-72, M = 38.66, S.D. = 11.22		
Gender		
Male	40	31.2
Female	88	68.8
Education (level)		
Uneducated	2	1.6
Elementary school	43	33.6
Junior high school	19	14.8
Senior High School	20	15.6
Certificate in Vocational Education	7	5.4
Higher Certificate in Vocational Education	8	6.3
Diploma	6	4.7
Bachelor Degree	21	16.4
Master's Degree	2	1.6

Table 3 Caregivers' Background Characteristic (continued)

Characteristics	Number	Percentage
Monthly income		
None	24	18.8
1 –3,000	19	14.7
3,001-6,000	32	25.0
6,001-10,000	24	18.8
>=10,000	29	22.7
Range 0-70,000, M = 8989.53, S.D. = 11749.54		
Adequacy of income		
Adequate with saving	25	19.5
Adequate without saving	55	43.0
Inadequate without debt	12	9.4
Inadequate with debts	36	28.1
Occupation		
Household workers	35	27.3
Merchants	27	21.0
General workers	29	22.7
Government services	12	9.4
Company employees	9	7.0
Farmers	6	4.7
State enterprise employees	2	1.6
Student	2	1.6
Others	6	4.7

Table 3 Caregivers' Background Characteristic (continued)

Characteristics	Number	Percentage
Number of Social Roles		
None	1	0.8
One	30	23.4
Two	49	38.3
Three	47	36.7
Four	1	0.8
Range 0-4, M = 2.13, S.D.=0.81		
Relation to patient		
Spouses	66	51.6
Relatives	30	23.4
Parents	18	14.1
Children	8	6.3
Friends	6	4.6
Quality of patient- caregiver relationship		
1	2	1.6
2	1	0.8
4	1	0.8
5	2	1.6
6	3	2.3
7	6	4.7
8	13	10.2
9	11	8.5
10	89	69.5
Range 1-10, M = 9.15, S.D. = 1.74		

Table 3 Caregivers' Background Characteristic (continued)

Characteristics	Number	Percentage
Help with medication adherence		
No	23	18
Yes	105	82
Activity of help with medication adherence		
Reminding about medication	44	31.1
Reminding and preparing medication	18	14.0
Preparing medication	14	11.2
Preparing and paying for medication	11	8.7
Reminding, preparing, and paying for medication	7	6.6
Taking/accompanying the patients to a clinic	5	4.0
Calling	2	1.6
Others	6	4.8

Table 3 Caregivers' Background Characteristic (continued)

Characteristics	Number	Percentage
Caregiving activity related to medication		
Reminding about medication	44	31.1
Reminding and preparing medication	18	14.0
Preparing medication	14	11.2
Taking/accompanying the patients to a clinic	4	3.2
Preparing food and medication	3	2.4
Paying for medication	1	0.8
Reminding about medication and taking/accompanying the patients to a clinic	1	0.8
Reminding about medication and preparing food and medication	1	0.8
Taking/accompanying the patients to a clinic and paying for medication	1	0.8
Taking/accompanying the patients to a clinic, preparing and reminding medication	1	0.8
Others	49	34.1

Table 3 Caregivers' Background Characteristic (continued)

Characteristics	Number	Percentage
Caregiving hours per day		
Range 0.5-24 hours, M = 13.28, S.D. 9.41		

Part 2: Description of Caregivers' Knowledge about HIV/AIDS, Social Support, and Medication Adherence among Patients Receiving HAART.

Mean, standard deviation, range of knowledge about HIV/AIDS, social support, and medication adherence were illustrated in table 4. Knowledge about disease and treatment scores reported by the caregivers ranged from 3 to 13 with a mean score of 9.91 (S.D. = 2.23). Knowledge about antiretroviral medication use scores reported by the caregivers ranged from 1 to 12 with a mean score of 7.85 (S.D. = 2.39). Knowledge about side effect of antiretroviral medications and management scores reported by the caregivers ranged from 0 to 13 with a mean score of 9.18 (S.D. = 2.91). Overall knowledge about HIV/AIDS scores reported by the caregivers ranged from a low of 5 to a high of 37 with a mean of 26.94 (S.D. = 6.27).

Emotional support reported by the caregivers ranged from 37 to 75 with a mean score of 60.87 (S.D. = 9.30). Appraisal support reported by the caregivers ranged from 21 to 70 with a mean score of 52.16 (S.D. = 10.45). Informational support reported scores by the caregivers ranged from 18 to 70 with a mean score of 53.47 (S.D. = 10.58). Instrumental support reported scores by the caregivers ranged from 18 to 58 with a mean score of 40.02 (S.D. = 9.20). Overall social support reported by the caregivers ranged from a low of 129 to a high of 263 with a mean of 206.52 (S.D. = 30.05).

Table 4 Descriptions of Caregivers' Knowledge about HIV/AIDS, Social Support, and Medication Adherence among Patients Receiving HAART (n=128)

Variables	Possible Range	Actual Range	Mean	S.D.
Knowledge about HIV/AIDS	0-38	5-37	26.94	6.27
-Disease and treatment	0-13	3-13	9.91	2.23
-Antiretroviral Medication Use	0-12	1-12	7.85	2.39
-Side effects of Antiretroviral Medication and management	0-13	0-13	9.18	2.91
Social support	4-275	129-263	206.52	30.05
-Emotional support	1-75	37-75	60.87	9.30
-Appraisal support	1-70	21-70	52.16	10.45
-Informational support	1-70	18-70	53.47	10.58
-Instrumental support	1-60	18-58	40.02	9.20

The above data showed that caregivers' knowledge about HIV/AIDS was in fairly good level. The scores of social support reported by caregivers were moderate. While, medication adherence scores reported by the patients receiving HAART whose caregivers participating in this study ranged from a low of 27.5 to a high of 100 with a mean of 96.94 (SD = 9.10). About 86.1 % of the patients adhered to their medication at 95% or better, while the rest adhered to their medication poorer as shown in Table 5.

Table 5 Medication Adherence

Variable	Number	Percentage
Medication adherence		
≥ 95%	110	86.1
< 95%	18	13.9
(Range 27.5-100, Mean = 96.94, SD = 9.10)		

Part 3: Caregivers' Factors Predicting Medication Adherence among Patients receiving HAART

This part is to respond to the second objective, "to predict medication adherence among patients receiving HAART by using the caregivers' factors".

Correlations between caregivers' factors and medication adherence among patients receiving HAART, and correlations among all caregivers' factors were tested prior to conducting multiple regression analysis. It was revealed in a bivariate analysis that caregivers' education has a significant negative relationship with medication adherence among patients receiving HAART ($r = -.185$, $p < .05$). Results in Table 6 showed that these correlations among all independent factors were mild to moderate (range from $-.267$ to $.338$). Therefore, all of these variables were included in multiple regression analysis using a stepwise method.

Table 6 Person Product Moment Correlation between Studied Variable of Caregivers of Cases of HIV/AIDS with Antiretroviral drugs (n = 128)

Variables	1	2	3	4	5	6	7	8	9	10	11
1. medication adherence	1.00										
2. age	.091	1.00									
3. gender	-.095	.019	1.00								
4. education	-.185*	-.245**	.154	1.00							
5. income	-.095	-.178*	.209*	.208*	1.00						
6. occupation	.041	-.180*	.338**	.083	.213*	1.00					
7. number of social roles	.122	.068	-.195*	-.267**	-.073	-.095	1.00				
8. quality of patient-caregiver relationship	-.034	-.245**	-.029	.104	.057	.053	.036	1.00			
9. help with medication adherence	.125	.031	-.036	-.033	-.152	.032	-.125	.122	1.00		
10. knowledge about HIV/AIDS	-.083	-.109	-.042	.342**	-.137	.131	-.031	.092	.191*	1.00	
11. Social support	.145	-.034	-.013	.085	.138	.057	.207*	.247**	.057	.230**	1.00

*p<.05, **p<.01

Gender 1= male, 0 =female; Income 1= adequate, 0 = inadequate;

Occupation 1 = others, 0 = household workers; Help with medication adherence 1=help, 0=no help

From stepwise multiple regression analysis, only 3 caregivers' factors were able to predict medication adherence among patients receiving HAART. They were education, social support and help with medication adherence. Education, the first variable entered the model explained 3.1 percent of variance in medication adherence among patients receiving HAART. Social support was the second variable entered the model. It additionally explained 2.2 percent of variance in medication adherence among patients receiving HAART. The last variable entered the model was help with medication adherence which additionally explained 1.2 percent of variance in medication adherence among patients receiving HAART. The final model could explain percent of variance in medication adherence among patients receiving HAART ($F_{(3,128)}=3.209$), as presented in Table 7.

Table 7 Stepwise Multiple Regression Predicting Medication Adherence among Patients Receiving HAART

Variables	df	R	R ²	Adjust R ²	R ² Change	F	F change	B
Education	(1,128)	.196	.038	.031		5.038		-.433
Social support	(2,128)	.245	.060	.045	.022	3.988	1.050	.049
Help with medication adherence	(3,128)	.268	.072	.050	.012	3.209	.779	2.598

Overall F_(3,128) = 3.209; p = .027

In order to test autocorrelations, Durbin-Watson test was performed. This regression model revealed Durbin-Watson test statistics of 2.134 which indicated negative autocorrelations. To test multicollinearity among independent variables, collinearity statistics was calculated. It was shown that tolerance values of education, social support and help with medication adherence were .991, .989 and .995 respectively. When tolerance values was closed to one, multicollinearity was not problem in this multiple regression analysis although some dependent variables had mild to moderate correlations.

CHAPTER V

DISCUSSION

This study was conducted at the Ambulatory Care Unit and the Out Patient Department of medicine at Bamrasnaradura Infectious Disease Institute. Purposes of this study were 1) to describe caregivers of patients receiving HAART in terms of background characteristics (age, gender, education, occupation, income, number of social roles, quality of patient- caregiver relationship, and help with medication adherence), knowledge about HIV/AIDS, social support, and medication adherence among patients receiving HAART; and 2) to predict medication adherence among patients receiving HAART by using the caregivers' factors. Descriptive and inferential statistics were used to analyze the data. In bivariate analysis, it was demonstrated that only caregivers' education was significantly related to medication adherence among patients receiving HAART. However, in multiple regression analysis, it was revealed that caregivers' education, social support and help with medication adherence were the factors that contribute to the prediction of medication adherence among patients receiving HAART. This chapter presents discussion of relationships of caregivers' characteristics, knowledge about HIV/AIDS, social support, and medication adherence among patients receiving HAART.

Caregivers' Background Characteristics

There were 128 patients receiving HAART and their caregivers participating in this study. Caregivers' age ranged from 18-72 years old with a mean age of 38.66 years old (S.D. =11.22). This finding is accordant with other studies of the caregivers of the patients with HIV/AIDS (Akeau Unahalekhaka et al., B.E.2542: 145; Fukfon, 2001: 49), and with Cerebrovascular disease (Jom Suwanno, B.E. 2540: 46;Kopachon, C, 2002: 104). Of these 128 caregivers, more than a half of them (59.4%) were young adult (39 years old or younger). This finding is accordant with other studies among caregivers of patients with HIV/AIDS (Fukfon, 2001: 49; Namitta L. Sakun, B.E.

2544: 64; Orathai Somnarin, B.E. 2537: 55; Patcharin Kittithongsopon, B.E. 2541: 61; Prathung Pimpoo, B.E. 2541: 54; Sakawrat Puangchan, B.E. 2538: 53).

The majority of the subjects were female (68.8%). This finding is similar to other studies among caregivers of patients with HIV/AIDS (Akeau Unahalekhaka et al., B.E.2542: 145; Bunting, 2001: 131; Fukfon, 2001: 49; Kespichayawatana, 2001; Naiwatanakul et al., 2001; Namitta L. Sakun, B.E. 2544: 64; Orathai Somnarin, B.E. 2537: 55; Prarechait Junjarat, B.E. 2537: 26; Prathung Pimpoo, B.E. 2541: 54), and with other chronic illnesses (Hoyert& Seltzer, 1992: 74; Jom Suwanno, B.E. 2540: 46; Keith, 1995: 185; Kopachon, 2002: 65; Sangboon, 2002: 72; Wanpen Yuenyongsan, B.E. 2545: 29).

Their level of education varied from none (1.6%) to a master degree (1.6%). One-third (33.6%) of them had finished elementary school. This result was accordant with other studies among caregivers of patients with HIV/AIDS (Akeau Unahalekhaka et al., B.E.2542: 145; Fukfon, 2001: 81; Namitta L. Sakun, B.E. 2544: 64; Orathai Somnarin, B.E. 2537: 55; Prathung Pimpoo, B.E. 2541: 54), and with other chronic illnesses (Jom Suwanno, B.E. 2540: 46; Kopachon, 2002: 65; Sakawrat Puangchan, B.E. 2538: 53; Sangboon, 2002: 72; Songwattanayut, 2002: 59; Wanpen Yuenyongsan, B.E. 2545: 29), but was inaccordant with a study by Patcharin Kittithongsopon (B.E. 2541: 102) which found that majority of the caregivers finished high school.

Income ranged from zero to 70,000 bahts per month ($M = 8989.53$, $S.D. = 11749.54$). However, about one-fifth of the subjects did not have income (18.8%), and 14.7% earned less than 3,000 bahts. This result was similar to other studies (Fukfon, 2001: 49; Sangboon, 2002: 72; Songwattanayut, 2002: 59; Wanpen Yuenyongsan, B.E. 2545: 29). Nearly two-third of them had adequate income: 19.5% also had some saving, but 43.0% had no saving. The rest had poor income: 28.3% had poor income with debts, but 9.4% without debt. This result was similar to other studies (Jom Suwanno, B.E. 2540: 46; Sakawrat Puangchan, B.E. 2538: 53; Sangboon, 2002: 72; Songwattanayut, 2002: 59).

The majority of the caregivers were household workers (27.3%). This result was similar to other studies (Namitta L. Sakun, B.E. 2544: 64; Patcharin Kittithongsopon, B.E. 2541: 102; Prathung Pimpoo, B.E. 2541: 54). However, this

finding is inaccordant with studies by Akeau Unahalekhaka and colleagues (B.E.2542: 145) and Wanpen Yuenyongsan (B.E. 2545: 29) which found that the majority of the caregivers were general work (46.4%-48%) while others found that the majority of the caregivers were farmers (53.4%) (Fukfon, 2001: 49; Jom Suwanno, B.E. 2540: 46; Sakawrat Puangchan, B.E. 2538: 53).

About a quarter of the caregivers had only one social role, the rest had two social roles (38.3%), three social roles (36.7%), and four social roles (0.8%). About 0.8% played only one role as a caregiver with no any other number of social roles. This result was accordant with a study of maternal behavior in caring for children with congenital heart disease (Ubol Asumpinzub, B.E. 2540: 58).

Almost all caregivers reported relatively closed patient-caregiver relationship on a high score of eight (10.2%), nine (8.6%), and ten (69.5%). Very few caregivers reported poor patient-caregiver relationship on a low score of one (1.6%), two (0.8%), four (0.8%), and five (1.6%). This result was similar to a study among caregivers of patients with cerebrovascular accident (Phiangjai Tirapaiwong, B.E. 2540: 82). However, this finding is inaccordant with a study among caregivers of patients with HIV/AIDS by Orratai Rhucharoenponpanich (B.E. 2541: 211) which found moderate relationship between patients and caregivers.

Three-fourth of the caregivers helped the patients with medication adherence (82%) by reminding about medication (31.1%), reminding and preparing medication (14%), preparing medication (11.2%), preparing and paying for medication (8.7%), reminding, preparing and paying for medication (6.6%), taking/accompanying patients to a clinic (4.0%), and calling (1.6%). About 4.8% played other activities in helping with medication adherence. Their caregiving hours per day from 0.5 to 24 hours ($M = 13.28$, $S.D. = 9.41$). No existing knowledge about this could be found in the literature.

Knowledge about HIV/AIDS

Knowledge about HIV/AIDS includes: 1) Knowledge about disease and treatment 2) Knowledge about antiretroviral medication use and 3) Knowledge about side effect of antiretroviral medications and management. The possible scores of overall knowledge about HIV/ AIDS ranged from 0 to 38. This study found that the scores of overall knowledge about HIV/AIDS reported by the caregivers ranged from 5 to 37 with a mean score of 26.94 (S.D. = 6.27). Knowledge about disease and treatment ranged from 3 to 13 with a mean score of 9.91 (S.D. = 2.23). This finding is similar to a study conducted by Akeau Unahalekhaka and colleagues (B.E.2542: 145) which found that knowledge about disease and treatment was moderate among family members of patients with HIV/AIDS. Fukfon (2001) also reported that 60% of the family caregivers had no knowledge related to AIDS caring, but Mohammad (1998: 32) found that knowledge about disease and treatment was high among family members of the patients with HIV/AIDS.

Knowledge about antiretroviral medication use ranged from 1 to 12 with a mean score of 7.85 (S.D. = 2.39). Knowledge about side effect of antiretroviral medications and management ranged from 0 to 13 with a mean score of 9.18 (S.D. = 2.91). This study found that the caregivers had fairly good knowledge about disease (AIDS) and treatment, but poorer in terms of antiretroviral medication use, side effect of antiretroviral medication and management. No information about these could be found in the existing literature.

Social Support

Social support includes: 1) emotional support, 2) appraisal support, 3) informational support, and 4) instrumental support. The possible scores of social support ranged from 4 to 275. This study found that the scores of overall social support reported by the caregivers ranged from 129 to 263 with a mean score of 206.52 (S.D. = 30.05). Emotional support ranged from 37 to 75 with a mean score of 60.87 (S.D. = 9.30). Appraisal support ranged from 21 to 70 with a mean score of 52.16 (S.D. = 10.45). Informational support ranged from 18 to 70 with a mean score of 53.47 (S.D. = 10.58). Instrumental support ranged from 18 to 58 with a mean score of 40.02 (S.D. = 9.20). It was revealed that the caregivers had fairly good overall

social support. Emotional support was the highest social support that the caregivers received, whereas appraisal support and informational support were moderate, and instrumental support was the poorest among all aspects.

This finding is accordant with studies among caregivers of patients with HIV/AIDS conducted by Prathung Pimpoo (B.E. 2541: 54) and Sumonta Kabinlapat (B.E.2541: 69) which found that the caregivers had moderate social support in terms of emotional and informational support, and had poorer support in terms of instrumental support. However, this finding is inaccordant with studies among caregivers of patients with HIV/AIDS conducted by Patcharin Kittithongsopon (B.E. 2541: 101) and Piyanun Limruagrang (B.E.2540: 86) which found that the caregivers had high social support in terms of emotional, informational support and instrumental support. This finding is also inaccordant with studies among caregivers of schizophrenic patients (Theepprapin Sukkheo B.E. 2543: 49; Wanpen Yuenyongsan, B.E. 2545: 44).

Medication adherence

The possible scores of medication adherence from 0 to 100 percent while reported scores by the patients ranged from 27.50 to 100 with a mean score adherence of 96.94 percent (S.D. =9.10). Similarly, Oyugi and colleagues (2004) found that a mean score adherence among patients receiving HAART was 93.5 percent. Bangsberg and colleagues (2000: 357) also reported that the median rate of self-report medication adherence was 89%.

As suggested by Paterson and colleagues (2000) that very high level of adherence ($\geq 95\%$) was required to achieve virologic suppression, a cut-off point of better than 95% or better was used to classify good adherence. This study found that about 86.1% of the patients had good medication adherence ($\geq 95\%$), whereas 13.9% had poor medication adherence ($< 95\%$).

Caregivers' Background Characteristic (age, gender, education, occupation, income, number of social roles, quality of patient-caregiver relationship, help with medication adherence), knowledge about HIV/AIDS and social support related to medication adherence among patients receiving HAART.

In bivariate analysis, this study found that education was the only one caregivers' factor that had a significant relationship to medication adherence among patients receiving HAART ($r = -.185$; $p < .05$).

Education is a factor that can affect a person's perception and understanding of health and illness. With knowledge about diseases and illnesses, a caregiver will have the ability of self care and caring of dependent patients. An educated person can better understand the situation, and seek for knowledge and skills for problem solving and caregiving adjusting to suit the need of dependent patients (Orem, 1995: 239). Jenkin (1987: 95-97) addressed that poorly educated persons were less able to perceive and understand the recurrence of difficulties, they might be limited in resolving potential problems. Similarly, Whetstone and Olow (1989: 962) found that a person with high education could apply his/her knowledge in caregiving as they could perceive and understand better. Therefore, highly educated people can seek information that they need and take better care of their health than less educated people (Suwan, 1983: 182). Sakawrat Puangchan (B.E. 2538: 68) also found that level of education of the mother of chronically- ill child was positively significant with her caregiving ability. Education was significantly positive related to behavior caregiving (Orathai Somnarin, B.E. 2538: 62; Patcharin Kittithongsopon, B.E. 2541: 102; Sakawrat Puangchan, B.E. 2538; Ubol Asumpinzub, B.E. 2540: 81).

However, this study found a negative relationship of caregivers' education and medication adherence among patients receiving HAART. This may be explained that caregivers with higher education have to work as caregivers' education was significantly related with occupation ($p < .01$). Thus, they do not have enough time to take closed care of their patients.

In this study, caregivers' age was not significantly related to medication adherence among patients receiving HAART. This result might be explained that medication adherence among patients receiving HAART does not depend upon age of

the caregivers. This finding was similar to reported by Orathai Somnarin (B.E. 2538: 62) and Sakawrat Puangchan (B.E. 2538). However, this result was inaccordant with Hass (1990, 162) which found that age can be an indicator for caregiving ability as it has a negative relationship with caregiving ability for children with chronic illness. Younger mother caregiving ability better than elder mother. Sririluk Sriedunrong (B.E. 2546: 135) also found that caregivers' age negatively correlated with knowledge to care for HIV-positive children. On, the contrary, age is found to have a positive relationship with Thai mothers' caregiving ability for children with chronic illness (Achariya Pratumwan, B.E. 2534: 51). Age also has a significant positive relationship to behavior caregiving (Chaleaom Wongchantra, B.E. 2539: 80; Patcharin Kittithongsopon B.E. 2541: 102; Ubol Asumpinzub, B.E. 2540: 81).

In this study, caregivers' gender was not significantly related to medication adherence among patients receiving HAART. This result might be explained that medication adherence among patients receiving HAART does not depend upon gender of the caregivers. This finding was similar to a the findings by Orathai Somnarin (B.E. 2538: 62) and Sririluk Sriedunrong (B.E. 2546: 135) although it is believed that gender is one factor related with caregiving ability for dependent patients (Nilrut Vatcharapichat, B.E. 2543: 45), and a number of studies revealed that female caregivers play a key role in giving care to dependent patients and help develop caregiving of family members (Akeau Unahalekhaka et al., B.E.2542: 145; Buranajaru, 1997: 46; Hoyert& Seltzer, 1992: 74; Keith, 1995: 185; Namitta L. Sakun, B.E. 2544: 64; Orathai Somnarin, B.E. 2537: 55; Prarechait Junjarat and colleague, B.E. 2537: 26; Prathung Pimpoo, B.E. 2541: 54).

In this study, caregivers' occupation was not significantly related to medication adherence among patients receiving HAART. This result might be explained that medication adherence among patients receiving HAART does not depend upon occupation of the caregivers. This finding was similar to the findings by Rossukhon Pichaipat (B.E. 2543: 35) and Ubol Asumpinzub (B.E. 2540: 81). In contrast, Pirint Kintana (B.E. 2543: 67) and Saset (1998: 219) found that occupation was related to caregiving.

In this study, caregivers' income was not significantly related to medication adherence among patients receiving HAART. This result might be explained that medication adherence among patients receiving HAART does not depend upon income of the caregivers. This finding was similar to the findings by Chaleaom Wongchantra (B.E. 2539: 80); Sakawrat Puangchan, B.E. 2538: 55 and Sririluk Sriredunrong (B.E. 2546: 135) although Pender (1982: 161-162) regarded socio-economic status as a major factor of person's caregiving ability for dependent patients. Income has a significant positive relationship to caregiving behaviors (Orathai Somnarin, B.E. 2538: 62; Patcharin Kittithongsopon, B.E. 2541: 102; Ubol Asumpinzub, B.E. 2540: 81).

In this study, caregivers' number of social roles was not significantly related to medication adherence among patients receiving HAART. This result might be explained that medication adherence among patients receiving HAART does not depend upon social role of the caregivers although Nilrat Vatcharapichat (B.E. 2543: 47) addressed that caregivers who had more number of social roles would have shorter time to look after patients than caregivers who had fewer social roles.

In this study, quality of patient-caregiver relationship was not significantly related to medication adherence among patients receiving HAART. This result might be explained that medication adherence among patients receiving HAART does not depend upon quality of patient-caregiver relationships. However, other studies found that patient-caregiver relationships was related to caregiving (Phiangjai Tirapaiwong, B.E. 2540: 58; Pohl and colleagues, 1995: 68).

In this study, caregivers' help with medication adherence was not significantly related to medication adherence among patients receiving HAART. This result might be explained that medication adherence among patients receiving HAART does not depend upon caregivers' help with medication adherence. Similarly, Patchara Rumakom (B.E. 2546: 151) discovered that medication adherence rate among patients receiving HAART who had a caregiver (s) reminding them about taking medication is better than the rate of those who did not have a caregiver (s), but not significant. However, Kyngas (2000: 264) found that support from the parents was significantly related with compliance among adolescents with rheumatoid arthritis.

Although, caregivers' age, gender, occupation, income, number of social roles, quality of patient-caregiver relationship, and help with medication adherence were not significantly related to medication adherence among patients receiving HAART, they might be indirectly related to medication adherence among patients receiving HAART.

Knowledge about HIV/AIDS related to medication adherence among patients receiving HAART.

In this study, caregivers' knowledge about HIV/AIDS was not significantly related to medication adherence among patients receiving HAART. This result might be explained that medication adherence among patients receiving HAART do not depend upon knowledge about HIV/AIDS. It was confirmed by Mellins et al. (1989: 371) that knowledge about HIV treatment was not significantly associated with adherence. However, Pattana Phokaew (B.E.2537: 3) found that knowledge was significantly and positively related to patients compliance on treatment of tuberculosis among HIV/AIDS patients. Eldred and colleagues (1998: 121) found that knowledge of antiretroviral therapy action was associated with antiretroviral therapy adherence. Murdaugh (1998: 361) stated that knowledge of medications and their side effects is a major factor in adherence. Caregivers had no knowledge related to HIV/AIDS caring (Fukfon, 2001: 81). This study found similar to Fukfon (2001) that the caregivers had fairly good knowledge about disease (AIDS) and treatment, but poorer in terms of antiretroviral medication use, side effect of antiretroviral medication and management.

Social support related to medication adherence among patients receiving HAART.

In this study, caregivers' social support was not significantly related to medication adherence among patients receiving HAART. This finding might be explained that medication adherence among patients receiving HAART do not depend upon caregivers' social support. This finding was similar to a report by Rossukhon Pichaipat (B.E. 2543: 35). Although social support was significantly positive related to behavior caregiving Patcharin Kittithongsopon (B.E. 2541: 102) and Pratueng Pimpo (B.E.2541: 62), this study did not find a significant relationship between caregivers' social support and medication adherence among patients receiving HAART in bivariate analysis.

Incorporated predictors of medication adherence among patients receiving HAART.

The result revealed that 3 of 10 caregivers' variables were significant incorporated predictors of medication adherence among patients receiving HAART: education, social support and help with medication adherence. Among these, caregivers' education was the most dominant predictor firstly entered the model, following by social support and help with medication adherence. This model explained approximately 7.2 percent of variances in medication adherence among patients receiving HAART. The findings might suggest that providing health education regarding benefits of medication adherence is not adequate for patients receiving HAART. Although social support and help with medication adherence did not show significant relationship with medication adherence among patients receiving HAART in the bivariate correlational analysis, they were included as the second and the last predictors of this multiple regression model respectively. Similarly, Molassiotis and colleagues (2002) revealed that one of the significant predictors of adherence was family support. However, there was no existing literature about caregivers' factors predicting medication adherence among patients receiving HAART.

In bivariate analysis, caregivers' age, gender, occupation, income, number of social roles, quality of patient-caregiver relationship, help with medication adherence and knowledge about HIV/AIDS were not able to demonstrate a significant relationship to medication adherence among patients receiving HAART. To some extent, some of these caregivers' factors might have had indirect relationships to medication adherence among patients receiving HAART, as knowledge about HIV/AIDS was found to have a significant correlation with caregivers' help with medication adherence. Caregivers' help with medication adherence and social support were incorporated with education as significant predictors of medication adherence among patients receiving HAART.

Limitation of the Study

1. A cross-sectional design was used in this study to describe caregivers' background characteristics, knowledge about HIV/AIDS and social support and medication adherence among patients receiving HAART, and predict medication adherence by the caregivers' factors. Using this design, a conclusion about causal relationship cannot be drawn. This design also has a limitation in making an assessment of changes of medication adherence among patients receiving HAART over-times.
2. This study focused on caregivers' factors in relation to medication adherence among patients receiving HAART. These factors may have less impact on patients' medication adherence compared to patients' own factors.
3. This study was conducted among the caregivers and patients who came for a follow-up visit at the Bamrasnaradura Infectious Disease Institute which is considered as a national institute specializing in infectious diseases, thus the findings of this study may not be generalized to other settings in Thailand.

CHAPTER VI

CONCLUSION

Research Conclusion

This cross-sectional study was conducted 1) to describe caregivers of patients receiving HAART in terms of background characteristics (age, gender, education, occupation, income, number of social roles, quality of patient-caregiver relationship, and help with medication adherence), knowledge about HIV/AIDS, social support, and medication adherence among patients receiving HAART; and 2) to predict medication adherence among patients receiving HAART by using the caregivers' factors. One hundred twenty eight patients receiving HAART and their caregivers who came for a follow up visit at Bamrasnaradura Infectious Disease Institute were recruited in to this study.

In this study, patients' medication adherence ranged from 27.5% to 100% with a mean of 96.94% (SD = 9.1%). About 86.1% of the subjects had good medication adherence ($\geq 95\%$), whereas 13.9% had poor medication adherence ($< 95\%$). In bivariate analysis, it was found that caregivers' education was the only one of all personal background characteristics that had a significant relationship to medication adherence ($r = -.185$, $p < .05$) while other personal background characteristics did not show any significant relationship to medication adherence among patients receiving HAART.

Concerning caregivers' knowledge about HIV/AIDS, there was no significant relationship between knowledge about HIV/AIDS and medication adherence among patients receiving HAART could be detected ($r = -.083$) although a significant relationship between these variables was reported by Pattana Phokaew (B.E.2537: 3) and Eldred and colleagues (1998: 121). Pattana Phokaew (B.E.2537: 3) found that knowledge was significantly and positively related to patients compliance on treatment of tuberculosis among HIV/AIDS patients, and Eldred and colleagues (1998: 121) found that knowledge of antiretroviral therapy action was significantly related with antiretroviral therapy adherence.

The results also revealed that 3 of 10 caregivers' education variables were significant incorporated predictors of medication adherence among patients receiving HAART. Among these, education was the most dominant predictor of medication adherence. It firstly entered the model and explained 3.1 percent of variance in medication adherence, followed by social support (2.2%), and help with medication adherence (1.2%), respectively. This model explained approximately 7.2 percent of variances in medication adherence among patients receiving HAART.

Recommendations for Nursing Action

This study found that caregivers' education was found to have a significant relationship with medication adherence in bivariate analysis, three caregivers' variables which were education, social support, and help with medication adherence were significant predictors of medication adherence. Although the result that knowledge about HIV/AIDS was significantly related to medication adherence was reported by Pattana Phokaew (B.E.2537: 3) and Eldred and colleagues (1998: 121), a significant between these variables was not revealed in this study.

Therefore, more nursing interventions should be provided to both the patients receiving HAART and their caregivers. These interventions should not focus only on provision of education but also on enhancing social support aspects. Program enhancing social support aspects should be seriously taken into account in monitoring and promoting medication adherence among patients receiving HAART, at every settings where patients receiving HAART and their caregivers come for health services.

Recommendations for Future Study

Future studies should be replicated in other types hospitals or primary care settings which are of different in natures and locations – both up country and metropolitan so that the result can reflect the over-all nature of HIV/AIDS patients, and caregivers nationwide and be applicable in linking into the national policy to plan for effective implementations in downscaling the serious effects of HIV/AIDS, and to treat this disease as a chronic illness. A longitudinal study maybe considered in further studies since medication adherence changes over time.

In addition, patients attending an evening service period (16:00 – 20:00) and Saturday clinic should be included in the future study so that medication adherence of both employed and unemployed patients can be better explored. The patients attending an overtime service period (16:00 – 20:00) and Saturday clinic maybe more likely to come with their caregivers.

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ตัวของผู้ป่วยมะเร็งเต้านมที่ได้รับยาเคมีบำบัด. วิทยานิพนธ์ปริญญาวิทยาศาสตร

มหาบัณฑิต สาขาพยาบาลศาสตร์ บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล.

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APPENDIX A

The Set Test

แบบทดสอบหมวดหมู่

คำชี้แจง ให้บอกชื่อของสี สัตว์ ผลไม้และจังหวัดที่ท่านทราบ

สี	1.....	สัตว์	1.....
	2.....		2.....
	3.....		3.....
	4.....		4.....
	5.....		5.....
	6.....		6.....
	7.....		7.....
	8.....		8.....
	9.....		9.....
	10.....		10.....
คะแนน.....		คะแนน.....	
ผลไม้	1.....	จังหวัด	1.....
	2.....		2.....
	3.....		3.....
	4.....		4.....
	5.....		5.....
	6.....		6.....
	7.....		7.....
	8.....		8.....
	9.....		9.....
	10.....		10.....
คะแนน		คะแนน.....	
คะแนนรวม.....	คะแนน		

APPENDIX B

Personal Background Characteristics Questionnaires

ข้อมูลส่วนตัวของญาติผู้ดูแลผู้ติดเชื้อ

คำชี้แจง โปรดเติมข้อความลงในช่อง.... หรือทำเครื่องหมาย ✓ ลงใน () ที่ตรงกับความจริงเกี่ยวกับท่าน

1. เพศ (1) ชาย (2) หญิง
2. ท่านมีอายุ ปี
3. สถานภาพสมรส (1) โสด (2) คู่ (3) หม้าย (4) ม่าย (5) แยก
4. ระดับการศึกษาที่ท่านสำเร็จ (1) ไม่ได้รับการศึกษา (2) ประถมศึกษา (3) มัธยมศึกษาตอนต้น (4) มัธยมศึกษาตอนปลาย (5) ปวช. (6) ปวศ. (7) ปวท. (8) อนุปริญญา (9) ปริญญาตรี (10) ปริญญาโท (11) ปริญญาเอก
5. อาชีพ (1) แม่บ้าน (2) ค้าขาย (3) รับจ้างทั่วไป (4) เกษตรกรรม (5) รับราชการ (6) รัฐวิสาหกิจ (7) พนักงานบริษัท (8) นักเรียน/นักศึกษา (9) อื่นๆ ระบุ.....
6. รายได้ต่อเดือนโดยประมาณ บาท
7. รายได้ที่ท่านได้รับ (1) พอใช้และมีเงินเหลือเก็บ (2) พอใช้แต่ไม่มีเงินเหลือเก็บ (3) ไม่พอใช้แต่ไม่มีภาระหนี้สิน ระบุวิธีแก้ปัญหา..... (4) ไม่พอใช้และมีหนี้สิน

8.บทบาทในครอบครัว (ตอบได้มากกว่า 1 ข้อ)

- | | |
|----------|----------------|
| (1) บิดา | (2) มารดา |
| (3) สามี | (4) ภรรยา |
| (5) บุตร | (6) อื่นๆ..... |

9.ความสัมพันธ์กับผู้ติดเชื้อเอดส์

(1) บุตร	(2) ภรรยา สามี
(3) บิดา มารดา	(4) ญาติ
(5) เพื่อน	

10.ความรู้สึกรักใคร่ โกลัซิด สนับสนุนของท่านและผู้ติดเชื้อเอดส์อยู่ในระดับใด โปรดทำเครื่องหมาย X ในช่องตัวเลขให้ตรงกับความรู้สึกของท่านมากที่สุด

1	2	3	4	5	6	7	8	9	10
น้อย									มาก

11.ในแต่ละวันท่านมีภาระกิจอะไรบ้างในการดูแลผู้ติดเชื้อเอดส์ตั้งแต่เช้าจนถึงเข้านอน

.....

.....

.....

.....

.....

.....

.....

.....

12.ในแต่ละวันท่านดูแลผู้ติดเชื้อเอดส์ประมาณ..... ชั่วโมงต่อวัน

APPENDIX C

Help with medication adherence

การช่วยให้ผู้ติดเชื้รับประทานยา

ท่านได้ดูแลให้ผู้ติดเชื้อเอดส์ในการรับประทานยา

(1) ไม่

(2) ใช่ ระบุวิธี.....



APPENDIX D

Knowledge about HIV/AIDS

ความรู้เกี่ยวกับโรคเอดส์

คำชี้แจง โปรดทำเครื่องหมาย ✓ ลงในช่องว่าตามระดับความเป็นจริง

ข้อ	คำถาม	ระดับความคิดเห็น		
		ใช่	ไม่ใช่	ไม่รู้
1.	ความรู้เกี่ยวกับโรคเอดส์			
.	โรคเอดส์เป็นโรคที่สามารถรักษาให้หายขาดได้ในปัจจุบัน			
.				
12.	ยาต้านไวรัสเอดส์สามารถรักษาโรคติดเชื้อฉวยโอกาสให้หายได้			
13.	เมื่อได้รับยาต้านไวรัสเอดส์ ไม่จำเป็นต้องป้องกัน/รักษาโรคติดเชื้อฉวยโอกาสอื่นอีก			

ข้อ	คำถาม	ระดับความคิดเห็น		
		ใช่	ไม่ใช่	ไม่รู้
1.	ความรู้เกี่ยวกับการใช้ยาต้านไวรัสเอดส์			
.	ในขณะที่รับประทานยาป้องกัน/รักษาโรคติดเชื้อฉวยโอกาส ผู้ติดเชื้อไม่ควรรับประทานยาต้านไวรัสเอดส์			
.				
11.	การหยุดรับประทานยาต้านไวรัสบางตัว ไม่ทำให้เชื้อไวรัสเอดส์ดื้อยา			
12.	การหยุดรับประทานยาต้านไวรัสเอดส์ในช่วงสั้นๆ ไม่ทำให้เชื้อไวรัสเอดส์ดื้อยา			

ข้อ	คำถาม	ระดับความคิดเห็น		
		ใช่	ไม่ใช่	ไม่รู้
1.	ความรู้เกี่ยวกับผลข้างเคียงของยาและการจัดการต่ออาการข้างเคียงของยา ผู้ติดเชื้อบางรายที่รับประทานยาต้านไวรัสเอดส์อาจมีอาการข้างเคียงต่างๆ ได้			
.				
.				
.				
12.	ผู้ติดเชื้อสามารถนำตัวอย่างยาต้านไวรัสเอดส์ไปซื้อได้เองจากร้านขายยา โดยไม่จำเป็นต้องมาพบแพทย์			
13.	เมื่อผู้ติดเชื้อที่สามารถดูแลตนเองได้เมื่อมีอาการข้างเคียงซึ่งไม่รุนแรงจากการรับประทานยาต้านไวรัสเอดส์ เช่น คลื่นไส้ อาเจียน อ่อนเพลีย สามารถรับประทานยาต่อไปได้			

APPENDIX E

Social Support

แบบวัดการสนับสนุนทางสังคม

คำชี้แจง โปรดทำเครื่องหมาย ✓ ลงในช่องว่างที่ตรงกับความคิดเห็นของท่าน

ข้อ	คำถาม	ระดับความคิดเห็น				
		มั่นใจ ว่าใช่	คิดว่า ใช่	ไม่แน่ใจ	คิดว่า ไม่ใช่	มั่นใจ ว่าไม่ใช่
1.	1.การสนับสนุนทางสังคม ด้านอารมณ์ เมื่อรู้สึกเหนื่อยล้า และเมื่อที่ต้องดูแลผู้ติดเชื้อมีเพื่อนหรือญาติคอยปลอบและให้กำลังใจ					
2.						
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15.	ท่านวิตกกังวลเกี่ยวกับอนาคตของท่าน					

ข้อ	คำถาม	ระดับความคิดเห็น				
		มั่นใจ ว่าใช่	คิดว่า ใช่	ไม่แน่ใจ	คิดว่า ไม่ใช่	มั่นใจ ว่าไม่ใช่
1.	2.การสนับสนุนในการประเมินผล ผู้ติดเชื้อแสดงความชื่นชมต่อการดูแลที่ได้รับจากท่าน					
2.						
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13.	ทุกครั้งที่ท่านพาผู้ติดเชื้อที่ท่านดูแลไปพบแพทย์ แพทย์จะเตือนให้ท่านพาผู้ติดเชื้อมารับยาต้านไวรัสตามนัด					

ข้อ	คำถาม	ระดับความคิดเห็น				
		มั่นใจ ว่าใช่	คิดว่า ใช่	ไม่แน่ใจ	คิดว่า ไม่ใช่	มั่นใจ ว่าไม่ใช่
1.	3.การสนับสนุนทางด้านข้อมูล ข่าวสาร สมาชิกในครอบครัวให้คำแนะนำท่านในการดูแลผู้ติดเชื้อได้					
2.						
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15.	ท่านได้รับความรู้เกี่ยวกับผลเสียของการรับประทานยาต้านไวรัส เอดส์ไม่สม่ำเสมอ					

ข้อ	คำถาม	ระดับความคิดเห็น				
		มั่นใจ ว่าใช่	คิดว่า ใช่	ไม่แน่ใจ	คิดว่า ไม่ใช่	มั่นใจ ว่าไม่ใช่
1.	4.การสนับสนุนทางด้านเครื่องมือ ท่านได้รับอุปกรณ์ เครื่องใช้ในการดูแลผู้ติดเชื้อจากเจ้าหน้าที่ สาธารณสุข					
2.						
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.						
11.	สมาชิกในครอบครัวช่วยเหลือแบ่งเบาภาระงานในบ้าน					

APPENDIX F

Medication Adherence

การวัดความสม่ำเสมอในการรับประทานยา

คำชี้แจง ให้ทำเครื่องหมาย X บนเส้น และเขียนจำนวนเปอร์เซ็นต์การรับประทานยาด้านไวรัสอย่างสม่ำเสมอ (ถ้าเส้นนี้เท่ากับ 100 เปอร์เซ็นต์)

1. ใน 30 วันที่ผ่านมา ท่านรับประทานยาด้านไวรัสครบทุกเม็ด ทุกมือตามเวลาที่กำหนด คิดเป็นกี่เปอร์เซ็นต์ เช่น จำนวนมือทั้งหมด 60 มือ ถ้าท่านรับประทานยาครบทุกมือภายใน 30 วัน คิดเป็น 100 เปอร์เซ็นต์
2. ใน 30 วันที่ผ่านมา ท่านรับประทานยาด้านไวรัส ครบทุกเม็ด ทุกมือตามเวลาที่กำหนด คิดเป็นกี่เปอร์เซ็นต์



APPENDIX G

การพิทักษ์สิทธิของกลุ่มตัวอย่าง

ข้าพเจ้านางสาวเยาวเรศ ดิลง นักศึกษาพยาบาลหลักสูตรพยาบาลศาสตรมหาบัณฑิต สาขาการพยาบาลอนามัยชุมชน ภาควิชาพยาบาลศาสตร์ คณะแพทยศาสตร์ โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล กำลังศึกษาวิจัยเรื่อง “ปัจจัยของผู้ดูแลที่มีผลต่อความสม่ำเสมอในการรับประทานยาของผู้ติดเชื้อเอชไอวี” ซึ่งการรับประทานยาต้านไวรัสนั้นจำเป็นต้องรับประทานให้ตรงเวลา และต่อเนื่องสม่ำเสมอเพื่อให้ได้ประสิทธิภาพสูงสุดและถ้ารับประทานไม่ต่อเนื่องจะทำให้เชื้อมีชีวิต เมื่อเชื้อมีชีวิตจะทำให้การรักษาด้วยยาต้านไวรัสไม่ได้ผล ข้าพเจ้าขอเชิญท่านเป็นผู้ให้ข้อมูลในการศึกษาครั้งนี้ ผลการศึกษาจะช่วยให้พยาบาลและบุคลากรทีมสุขภาพเข้าใจเกี่ยวกับสถานการณ์การใช้ยาต้านของผู้ติดเชื้อเอชไอวี/เอดส์ เพื่อเป็นประโยชน์ในการให้ความช่วยเหลือและดูแลในการรับประทานยาต้านไวรัสของผู้ติดเชื้อเอชไอวี/เอดส์ต่อไป

เมื่อท่านเข้าร่วมในการศึกษา ท่านจะได้รับการสัมภาษณ์ 1 ครั้ง ใช้เวลาประมาณ 30 นาที ในการสัมภาษณ์จะทำที่โรงพยาบาลในห้องที่มีประตูปิดมิดชิด การเข้าร่วมงานวิจัยนี้ ท่านมีสิทธิ์ตอบรับหรือปฏิเสธโดยไม่มีผลกระทบต่อการรักษาของท่านแต่อย่างใด หากท่านยินดียะให้ความร่วมมือขอให้ท่านลงนามเพื่อแสดงถึงการให้ความร่วมมือในการวิจัย และท่านยังมีสิทธิที่จะยกเลิกการเข้าร่วมหรือยุติการสนทนาเมื่อใดก็ได้ตามที่ท่านต้องการ ข้อมูลจากการสัมภาษณ์จะถูกเก็บเป็นความลับ ไม่มีการเปิดเผยชื่อจริงของท่าน และจะนำเสนอผลการวิจัยแบบภาพรวมเท่านั้น ข้อมูลทั้งหมดจะถูกทำลายเมื่อการศึกษาวิจัยแล้วเสร็จ

ยินดีให้ความร่วมมือในการวิจัย

ขอขอบคุณในความยินดีเป็นผู้ให้ข้อมูลของท่าน

.....

.....

ผู้ให้ข้อมูล

เยาวเรศ ดิลง

วันที่.....

ผู้วิจัย

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คณะแพทยศาสตร์ โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล
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เอกสารรับรองโดยคณะกรรมการจริยธรรมการวิจัยในคน

คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี
มหาวิทยาลัยมหิดล

๐๓๗๗/๒๕๕๖ (I)

ชื่อโครงการ	การใช้ชาดำนไวรัสอย่างสม่ำเสมอและต่อเนื่องในผู้ติดเชื้อเอชไอวี
เลขที่โครงการ/รหัส	ID ๐๖-๔๖-๓๑ ข
ชื่อหัวหน้าโครงการ	อาจารย์ ดร.วันทนา มณีศรีวงศ์กุล
ที่ทำงาน	ภาควิชาพยาบาลศาสตร์ คณะแพทยศาสตร์ โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล

ขอรับรองว่าโครงการดังกล่าวข้างต้นได้ผ่านการพิจารณาเห็นชอบโดยสอดคล้องกับแนวปฏิบัติ
เชิงจริยธรรม จากคณะกรรมการจริยธรรมการวิจัยในคน คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี

ลงนาม	
ประธานกรรมการจริยธรรมการวิจัยในคน	(ศาสตราจารย์นายแพทย์กฤษฎา รัดนโฬาร)
ลงนาม	
คณบดีคณะแพทยศาสตร์โรงพยาบาลรามาธิบดี	(ศาสตราจารย์นายแพทย์ประคิด วาทีสาธกิจ)
วันที่รับรอง	๑๔ มิถุนายน ๒๕๕๖



คณะแพทยศาสตร์ โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล
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ที่ จวก ๒๑๑๘/๒๕๕๖

คณะกรรมการจริยธรรมการวิจัยในคน

วันที่ ๒๕ กรกฎาคม ๒๕๕๖

เรื่อง แจ้งผลการพิจารณาของคณะกรรมการจริยธรรมการวิจัยในคน

เรียน อาจารย์ ดร. วันทนา นทีศรีวงศ์กุล

อ้างถึงโครงการวิจัยเรื่อง การใช้ผ้ากันไวรัสอย่างสม่ำเสมอและต่อเนื่องในผู้ติดเชื้อเอชไอวี

หมายเลขโครงการวิจัย ID๐๖-๔๖-๑๑๒

ในนามของคณะกรรมการจริยธรรมการวิจัยในคน ผมขอแสดงความยินดีที่โครงการวิจัยดังกล่าวข้างต้นของท่านได้ผ่านความเห็นชอบ จากคณะกรรมการแล้ว

เพื่อให้สอดคล้องกับระเบียบปฏิบัติคณะแพทยศาสตร์โรงพยาบาลรามาธิบดี ว่าด้วยการศึกษาวิจัยและการทดลองในมนุษย์ พ.ศ. ๒๕๕๔ คณะกรรมการฯ ขอให้ท่านปฏิบัติตามข้อแนะนำดังต่อไปนี้

๑. การดำเนินการวิจัยจะต้องเป็นไปตามโครงการวิจัยที่ผ่านการพิจารณาจากคณะกรรมการจริยธรรมการวิจัยในคนแล้ว
๒. การดำเนินการวิจัยจะต้องไม่เบี่ยงเบนไปจากโครงการวิจัยหรือมีการเปลี่ยนโครงการวิจัยก่อนที่การแก้ไขเพิ่มเติมโครงการวิจัยนั้นจะได้รับการอนุมัติและเห็นชอบจากคณะกรรมการจริยธรรมการวิจัยในคนก่อน ยกเว้นในกรณีจำเป็นที่จะต้องกระทำไปก่อนเพื่อจัดเตรียมทรัพยากรหน้าที่เกิดขึ้นกับผู้ยินยอมคนให้ทำวิจัย
๓. ในกรณีที่มีการเปลี่ยนแปลงชื่อโครงการจากชื่อเดิมที่เสนอไว้ ต่อคณะกรรมการฯ ต้องแจ้งชื่อมายังคณะกรรมการฯ เพื่อออกหนังสือรับรองให้เสมอ
๔. ผู้ยินยอมคนให้ทำวิจัยจะต้องได้รับเอกสารแจ้งข้อมูล/คำแนะนำแก่ผู้ยินยอมคนให้ทำวิจัย (Patient/Participant Information Sheet) และลงนามในหนังสือยินยอมโดยได้รับการบอกกล่าวและเต็มใจ (Informed Consent Form) ก่อนเริ่มดำเนินการวิจัย
๕. ในเอกสารแจ้งข้อมูล/คำแนะนำแก่ผู้ยินยอมคนให้ทำวิจัย (Patient's Information Sheet) จะต้องพิมพ์ข้อความดังต่อไปนี้ไว้ ด้วยทุกครั้ง

“ ถ้าท่านมีข้อข้องใจหรือมีความกังวลเกี่ยวกับวิธีดำเนินการวิจัยของโครงการวิจัยนี้ ท่านสามารถติดต่อได้ที่ ประธานกรรมการจริยธรรมการวิจัยในคน คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี งานบริการวิชาการและวิจัย ชั้น ๕ (ห้อง ๕๐๐) ศูนย์การแพทย์สิริตติ โทรทัศน์ ๐๒-๒๐๑ ๐๕๔๐ ในเวลาทำการ”

๖. ความลับของผู้ยินยอมคนให้ทำวิจัย จะต้องถูกปกปิดไว้ตลอดเวลา ยกเว้นถ้าเป็นคำสั่งตามกฎหมาย

สุดท้ายนี้ ขอให้โครงการวิจัยของท่านประสบผลสำเร็จตามมุ่งหมายอันจะนำมาซึ่งความเจริญก้าวหน้าทางวิชาการ และเพื่อประโยชน์ของมนุษยชาติสืบต่อไป

ขอแสดงความนับถือ

(ศาสตราจารย์ กฤษณา รัตนโอฬาร)
ประธานกรรมการจริยธรรมการวิจัยในคน



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**Documentary Proof of Ethical Clearance Committee on Human Rights
Related to Researches Involving Human Subjects
Faculty of Medicine, Ramathibodi Hospital, Mahidol University**

0377/2003 (I)

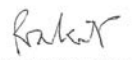
Title of Project	Medication Adherence among People Living with HIV
Protocol Number	ID 06-46-31
Principal Investigator	Mrs. Wantana Maneesriwongul
Official Address	Department of Nursing Faculty of Medicine, Ramathibodi Hospital Mahidol University

The aforementioned project has been reviewed and approved by Committee on Human Rights Related to Researches Involving Human Subjects, based on the Declaration of Helsinki.

Signature of Chairman
Committee on Human Rights Related to
Researches Involving Human Subjects


Prof. Krisada Ratana-olarn, M.D., FRCST, FICS.

Signature of Dean


Prof. Prakrit Vathesatogkit, M.D., ABIM., FRCP.

Date of Approval

June 18, 2003

BIOGRAPHY

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