CHAPTER 1

INTRODUCTION

Background and Significance of the Research Problem

Globally, 5 million youths are living with HIV/AIDS (United Nation's Children's Fund, 2011). In addition, the occurrence of nearly 41% of new HIV infections among youth living with HIV (YLWHA) means that every 30 seconds, another youth is diagnosed as HIV-positive (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2011). In Thailand, despite the stable and slightly declining trend of HIV prevalence among people aged 15-49 years, the highest incidence of sexually transmitted disease is occurring in the 15-24 year age group, arising as a result of enormously risky behaviors among youth, such as sex-partner mixing without condom use (UNAIDS, 2012). According to data from the Thai Ministry of Public Health (2012), an increasing number of 10-24 year-old children and young adults are becoming infected with HIV, which represents a growing HIV/AIDS epidemic. In Chiang Mai, 23,715 people were diagnosed with AIDS from 1988 – 31 March 2012. Of these cases, 9.8% were between ages of 10-24 (Chiang Mai Provincial Public Health Office, 2012). Although the number of new cases is falling, the number of people living with HIV has not decreased due to improvements in treatment. YLWHA have to suffer with HIV/AIDS into the adult and older person age

groups. However to live longer and healthier lives, YLWHA require long term therapy, especially HIV treatment regarding ARV, and promote their health.

Antiretroviral drugs (ARVs) are capable of suppressing HIV duplication if used correctly. They increase the survival rate of persons living with HIV/AIDS and promote their quality of life (World Health Organization [WHO], 2008). A high degree of ARV drug-taking (more than 95%) is necessary for successful treatment (Hicks et al., 2007). Although taking ARVs decreases the HIV duplication rate, poor adherence to the ARV regime causes drug resistance and increases the amount of the virus in blood circulation, which results in treatment failure (Hicks et al., 2007; Phongsamart, Wittawatmongkol, Vanprapar, & Chokephibulkit, 2011). Drug resistance among people living with HIV/AIDS (PLWHA) decreased the effectiveness of ARVs, leading to death. According to the study of 186 YLWHA aged between 16-24 years in America, youth who had lower than 95% adherence to ARVs had increased amounts of HIV in their blood (MacDonell, Naar-King, Murphy, Parsons, & Huszti, 2011). The number of CD4 white blood cells was significantly reduced (Singh, Berma, & Swindells, 1999) and the death rate rose (Garcia de Olalla et al., 2002; Hogg et al., 2001). According to a small study of YLWHA in Thailand by Rongkavilit et al. (2007), YLWHA showed poor ARV adherence overall. After taking ARVs for more than three months, it was found that one in three YLWHAs had treatment adherence of less than 95 percent. Similarly, The Raksthai Foundation (2009) reported that out of 140 adolescents aged 7-19 years old living with HIV/AIDS in four provinces in Northern Thailand, only 66% showed ARV adherence. Twenty-four percent of these did not take their medications at the appropriate times.

As the above-mentioned data indicated that inconsistent ARV adherence among YLWHA in Thailand contributes to ARV drug resistance, it is necessary to encourage YLWHA to be self-disciplined in taking ARVs.

Growing up with HIV is challenging, and these challenges affect the long-term health, lifestyle and life expectancy of the YLWHA Most youth who are identified as HIV-infected might show no signs of illness and likely have a poor understanding of HIV. These YLWHA do not realize the importance of ARV medication because they still feel healthy. They may also feel afraid of and reject their HIV diagnosis. Corresponding to the study of Gao, Nau, Rosenbluth, Scott, and Woodward (2000), the number of PLWHA who are receiving continual medication is rather small compared to the number reported, especially among YLWHA, as they do not know about self-care and ARV medication, and are not confident about the effectiveness of the ARVs they receive.

The reasons for antiretroviral treatment (ART) non-adherence include: 1) lack of knowledge about the availability and effectiveness of ART. Fifty percent of YLWHA misunderstood how to use ARVs. One-third were confused about the goals of treatment and the effectiveness of ARVs (Zalazar et al., 2011); 2) lack of motivation, various manifestations of sickness, stress, and stigmatization occur in the social sphere in which youths live. These factors including being separated socially resulting in YLWHA who lack the motivation to take ARV continuously and regularly (Apinundecha, Laohasiriwong, Cameron, & Lim, 2007; Outlaw et al., 2010). They do not talk about their condition with their family members or people close to them, and so they felt incapable of taking ARVs without help (Rongkavilit et al., 2010); 3) lack of skills regarding taking ARVs disabled them from managing the situation and the

side effects associated with the drugs, the complex medication regimens, and drug adverse effects (Okonkwoh, 2011), leading them to forget to take the drugs, and change their daily activities (Murphy et al., 2003). It is clear that it is necessary to educate youth about ARVs, motivating them to take the ARVs continuously and regularly, and improve the skills related to taking ARVs. Such education will improve their adherence in taking ARVs.

Not only do most YLWHA non-adhere to ARVs, they also engage in HIV risk behaviors. The transition from childhood into adulthood, and the accompanying physical, mental, and environmental changes cause emotional sensitivity (Irwin et al., 1997). These changes cause behaviors that are not beneficial for HIV treatment, including irregular ARV intake, increased HIV risk behaviors as well as use of narcotic drugs or inappropriate substances, sharing syringes and needles, and unsafe sexual behavior (Rongkavilit et al., 2007; Tanney, Narr-King, Murphy, Parsons, & Janistte, 2009).

The studies of Murphy et al. (2001); Rotheram-Borus, Murphy, Kennedy, Stanton, and Kuklinski (2001); Rongkavilit et al. (2007) found that YLWHA engaged in risky behaviors that affected their health, including a high rate of sexual activity, a decreasing rate of condom usage, and drinking alcohol. Similarly, the study of Lightfoot, Swendeman, Rotheram-Borus, Comulada, and Weiss (2005) found that YLWHA have emotional problems and low quality of life. They have unprotected sex and ingest inappropriate medicines or substances, including heroin and alcohol. In Chiang Mai Province, Thailand, it was found that of 44 HIV-infected adolescents, 18.5% drank alcohol and 3.7% had already begun to have sex. Most of the adolescents in this group (96.3%) knew about AIDS infection but they had little

knowledge of venereal diseases, and 48.1 percent of adolescents never admitted to their HIV infection status (Lee & Oberdofer, 2009). Their HIV risk behaviors included unprotected sex, and sharing syringes and needles, behaviors which have been documented to cause HIV infection rates to rise and the virus to become resistant to ARV action (Agwu et al., 2008; Angel et al., 2000).

From the existing studies it can be seen that the HIV risk behaviors among YLWHA are influenced by several factors, including having lower income (Plowden, Fletcher, & Miller, 2005), depression and anxiety (Hosek, Herper, & Domanico, 2005; Murphy et al., 2005), lack of education (Plowden et al., 2005), and stigma (Fongkaew et al., 2014; Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007; Rongkavilit et al., 2010) Additionally, previous research indicates that HIV stigma, non-disclosure, care-giver stress, and peer relations are essential to understanding how to improve HIV treatment adherence for YLWHA within their specific contexts (Murphy et al., 2003; Reisner et al., 2009; Rudy, Murphy, Harris, Muenz, & Ellen, 2009). YLWHA who struggle with maintaining good HIV treatment adherence may face more than a single barrier, and are a major concern for the health care system. Health care providers need to appreciate the barriers of HIV treatment adherence within the whole contextual issue present in their lives.

Previous research related to enhancing HIV treatment adherence behavior strategies, both of researchers and health care providers, examined the promotion of self-discipline in HIV treatment and reducing risk behaviors among YLWHA by teaching them about ARVs and the consequences of non-adherence. It also aimed to motivate and train YLWHA to improve their adherence in taking ARVs and reducing risk behavior by using the following methods. The previous studies applied the

concepts of Fisher et al. (2006) also improving self-discipline in taking ARVs (Kalichman, Cherry, & Cain, 2005; Parsons, Golub, Rosof, & Holder, 2007; Wagner et al., 2006). Fisher et al. (2006) proposed the Information-Motivation-Behavioral Skills Model (IMB model), which emphasizes providing information of need to YLWHA, encourages ARV behavioral skills among YLWHA, and motivates them to take ARVs. These components work together to improve adherence and skills leading to an increase in the number of their CD4 blood cells. The research of Roger, Miller, Murphy, Tanney, and Fortune (2001), examined the self-transformation program by applying the concept of the Transtheoretical Model (TTM), incorporating AIDS and ARV knowledge. It emphasized self-evaluation and the skills in taking ARVs. The result showed that 49% of the YLWHA who participated in the program increased their s ARV adherence. Another study by Gray, Janicke, Fennell, Driscoll, and Lawrence (2011) examined seven weekly intervention sessions based on the behavioral-family system theory, employing an HIV/HAART education to improve problem-solving and family communication so as to address adolescent-reported barriers to adherence. This study also considered the effectiveness of allocation of treatment responsibility. Additionally, there were only four participants in the study, and different tools were utilized to help remind participants to take ARVs. The research by Puccio et al. (2006) examined the effect of using mobile phones to remind the YLWHA to take their medicine. The results showed that very few YLWHA forgot to take the medicine during the 8th weeks. However, this research did not solve the problems of the patients directly since discipline in taking ARVs might not last long. Web-based education on the topic of ARV adherence, among YLWHA significantly increased their adherence (Shegog, Markham, Leonard, Bui, & Paul, 2012). Another

method was used in study of Purdy et al. (2008) that required the YLWHA to take ARVs in the presence of someone, and it was found that YLWHA had increased adherence as a result.

Various HIV risk behavior reduction strategies exist. For example, the Motivational Enhancement Therapy (MET) is a four-session manualized intervention that combines Motivational Interviewing (MI) with personalized feedback on client behavior and goal-setting. A healthy choice program has recently shown promise in reducing sexual risk behavior, the viral load, alcohol and marijuana, and other substance use, and improving HIV-related health in YLWHA with results immediately post-treatment. These effects were maintained after treatment termination (Naar-King et al., 2008). In Thailand, the research of Khaihin (2011) applied the concept of empowerment to make YLWHA confident and aware of their power to control their lives and improve ARV adherence. It was found that YLWHA in the experimental group had average risk behavior scores lower than the control group ($p<0.01$). In addition, the study of Hanmon (2011) encouraged self-management by using medical management with problem-solving skills. PLWHA were allowed to use accessible information sources when problems arose during illness. It offered skills and practices as appropriate to each person and motivation for behavioral adjustment. The study found that the experimental group had average score of risk behavior in spreading and receiving HIV was lower than the control group ($p<0.05$).

Besides clinical response measurement, prior research used various tools to improve continual ARV drug intake and measured HIV treatment behaviors by self-reporting (Morisky, Green, & Levine, 1986), electronic monitoring caps (Wagner et al.,

2006), assessment of continual treatment ACTG (Miller & Hays, 2000), and measuring the amount of medicine used (Singh et al., 1999).

The existing literature provides much encouragement for improving ARV adherence through simple methods, such as teaching ARV knowledge (Shegog et al., 2012), motivating taking ARVs (Khaihin, 2011; Lyon et al., 2003), using techniques to take medicine on time (Puccio et al., 2006; Purdy et al., 2008), and using multiple methods to improve self-discipline in taking ARVs (Kalichman et al., 2005; Parsons et al., 2007; Roger et al., 2001; Wagner et al., 2006).

However, there were still some common limitations. Firstly, all of the studies applied in ARV treatment adherence were created by experts or health care providers for people living with HIV. There are few evidence-based interventions that are available for YLWHA. (Milam et al., 2005; Naar-King et al., 2006; Wagner et al., 2006). Secondly, no study or intervention has been made that integrates ARV drug adherence improvement with HIV risk behavior reduction strategies, consisting of teaching, motivating, and improving self-discipline in taking ARVs, and reducing HIV risk behavior. About participation in expressing YLWHA opinions, people related to HIV treatment in the situational, social and cultural contexts of YLWHA continue provide sustainable treatment. Thirdly, all of the current interventions have been implemented uniformly to all study participants, rather than adjusted to the needs for intervention and maintenance training based on individual adherence performance, so these research designs do not provide opportunity for participant collaboration to raise awareness of their behaviors. Fourthly, despite the growing body of literature on the complex factors of HIV treatment adherence among YLWHA, existing studies lack adequate qualitative study exploring the barriers,

needs and concerns of HIV treatment adherence from YLWHA's perspective in the Thai context that reflects local understanding (Rongkavilit et al., 2010).

Thus, the needs and concerns of HIV treatment adherence must be investigated among YLWHA are needed to develop an enhanced HIV treatment adherence program specific to the needs and concerns of HIV treatment adherence among the Thai YLWHA. Given the above problems associated with both YLWHAs' HIV treatment adherence problems, and YLWHAs' risky behaviors, limitation of previous studies and suggestions from effective programs that are suitable for this population make it important to design a HIV treatment adherence and HIV risk reduction program based on the existing theoretical framework that integrates local knowledge and participants' experience through a process of: 1) mutual learning by identifying HIV treatment adherence barriers, and factors related to HIV treatment non-adherence and HIV risk behaviors; 2) sharing knowledge; and 3) determining and analyzing needs.

This study utilizes action research with the purpose of enhancing HIV treatment adherence and reducing HIV risk behaviors among YLWHA. Action research focuses on specific situations and localized solutions (Stringer, 2007). It was designed specifically to bridge the gap between theory, research and practice, and incorporates both humanistic and naturalistic scientific methods that emphasis the involvement and collaboration of researcher and practitioners, solution of practical problems, change in practice, and development of theory (Holter & Schwartz-Barcott, 1993). Action research provides an effective way to help meet the health care needs of those who are marginalized in the health society (Minkler & Wallerstein, 2005). The aims of any action research program are to bring about practical improvement,

innovation, change or development of social practice and the practitioners' better understanding of their practices (Zuber-Skerrit, 2011).

Consequently, applying action research to enhance HIV treatment adherence and reduce HIV risk behaviors is an effective method to expand the range of knowledge and understanding. Technical Collaborative Action Research is a method that promotes a more efficient and effective practice by encouraging personal participation in the process. In the process, the researcher identifies the problem and a specific intervention, then the practitioners are involved and together they agree to facilitate the work with the implementation of intervention. The interaction between the researcher and the practitioners is aimed at gaining the practitioners' interest in the research and agreement to facilitate and help with its implementation. Additionally, the major effort is on validation and refinement of existing theories (Berg, 2004). This type of action research emphasizing collaboration between the researcher and practitioner improves health care behaviors and medical services, corresponding to needs and the pre-specified theoretical framework.

Therefore, this study applies the IMB model as a theoretical framework for developing the content infrastructure of the program. The IMB model of HIV treatment adherence and HIV risk behaviors specifies the interrelationship of the information and motivation, working through behavioral skills to affect adherence to HIV treatment and reduce HIV risk behaviors. The model is a guide to the idea of well-informed, well-motivated behavior that is expressed mainly through the development of behavioral skills to influence and maintain HIV treatment adherence and HIV risk reduction behaviors among youth living with HIV/AIDS. This model is a well-established conceptualization for enhancing HIV treatment and reducing risk

behavior among people living with HIV world-wide, especially in Thailand (Fisher et al., 2004; Fisher & Fisher, 1999; Rongkavilit et al., 2010).

Research Objectives

The overall goal of this study is to develop a program for enhancing HIV treatment adherence and reducing HIV risk behaviors among youth living with HIV/AIDS.

The specific objectives of this study are outlined as following:

1. To assess and analyze the situations, needs, and surrounding factors regarding HIV treatment adherence and risk behaviors among youth living with HIV/AIDS.

2. To develop a program and strategy for improving HIV treatment adherence and reducing HIV risk behaviors among youth living with HIV/AIDS, corresponding to the social-cultural context.

3. To study the possibilities and appropriateness of the program for improving HIV treatment adherence and reducing HIV risk behaviors among youth living with HIV/AIDS.

Research Questions

1. What are the situations of HIV treatment adherence and risk behaviors among youth living with HIV/AIDS in the study setting?

2. What are the needs and concerns of participants in relation to the proposed HIV treatment adherence program?

3. What are the critical elements and strategy of the program for enhancing HIV treatment adherence and reducing HIV risk behaviors that are defined by participant groups based on a literature review of the practices for enhancing HIV treatment adherence and reducing HIV risk behaviors?

4. Is the proposed program for enhancing HIV treatment adherence and reducing HIV risk behaviors based on the action research approach feasible and appropriate for the target population?

Definition of Terms

HIV treatment adherence. It is defined as the extent to which a person's behavior coincides with, follows, and responds to the prescribed antiretroviral regimens, in conjunction with monitoring and management of HIV disease and its symptoms. In this study, HIV treatment adherence can be measured by using pill count record form and Thai ACTG adherence scale.

HIV risk behaviors. It refers to the behavior of YLWHA which indicates an increase of susceptibility to HIV infection and to the virus becoming resistant to ARV action. HIV risk behaviors will be measured by HIV risk behaviors questionnaire, attitudes toward condom-use questionnaire, and the sexual self-efficacy scale questionnaire.

A youth living with HIV/AIDS. It is defined as a person aged between 15 to 24 years diagnosed as HIV positive or with HIV positive serostatus.

Program for enhancing HIV treatment adherence and reducing HIV risk behaviors. It is a theoretically-based program to enhance HIV treatment adherence and reduce HIV risk behaviors among YLWHA, based on the information-motivation-behavioral skills model and the needs assessment obtained from YLWHA, caregivers, and health care providers.