

CHAPTER 1

INTRODUCTION

This chapter presents the background and significance of the research, objectives of the study, scope of the study and definition of terms.

Background and Significance of the Research Problem

The most serious public health threat to global stability and advancement is considered to be the HIV/AIDS pandemic (The Council on Foreign Relations 2004). Nations worldwide are faced with the political, economic, social, public health, and scientific difficulties that the HIV/AIDS pandemic can cause. HIV/AIDS cases have been reported in all regions of the world, but most people living with the disease reside in low- and middle-income countries (The Joint United Nations Programme on HIV/AIDS [UNAIDS], 2007). The past few years have brought greater international attention to HIV/AIDS and funding for the disease, but the need is much greater. If more is not done to fight the HIV/AIDS pandemic, it is on course to be one of the worst in history, with millions more people estimated to become infected by the end of this decade (The Council on Foreign Relations 2004). As of the end of 2007, 33.2 million people were estimated to be living with HIV/AIDS worldwide (The Joint United Nations Programme on HIV/AIDS [UNAIDS], 2007), this estimate shows that although the HIV/AIDS prevalence rate globally has evened out, the number of

people living with the disease continues to increase. An estimated 2.5 million people became newly infected with HIV in 2007, and more than two million people died of AIDS-related causes in 2007.

Everyday, over 6,800 people become infected with HIV and over 5,700 people die from AIDS, mostly because of inadequate access to HIV prevention and treatment services (The Joint United Nations Programme on HIV/AIDS [UNAIDS], 2007). Women comprise half of adults estimated to be living with HIV/AIDS worldwide, young people under the age of 25 are estimated to account for half of all new HIV infections worldwide and 2.5 million children under 15 are estimated to be living with the disease (The Joint United Nations Programme on HIV/AIDS [UNAIDS], 2007).

In South-East Asia, the epidemics in Cambodia, Myanmar and Thailand all show declines in HIV prevalence (UNAIDS 2007). In Thailand, the estimated number of people living with HIV is 610,000 (UNAIDS 2008), the patterns of HIV transmission have changed over time, with the virus spreading increasingly to people considered to be at a lower risk. More than four in ten (43%) new infections in 2005 were among women, the bulk of whom probably acquired HIV from husbands or partners who had been infected either during unsafe sex with commercial sex workers or through injecting drug use (WHO, 2007). Roughly one-seventh of new infections occurred in children and according to the recent data, approximately 14,000 children are currently infected with HIV in Thailand (UNAIDS 2008). This situation calls to attention the need to provide treatment to this vulnerable group in order to maintain the maximum level of health possible. Children under 15 in South East Asia are the largest group of children outside of Sub-Saharan Africa living with AIDS and dying

from the disease (UNICEF, 2005). Most new infections are thought to be caused by mother-to-child transmission (MTCT) before or during birth, or through breast feeding. The rate of MTCT ranges from 25-45% in developing countries, therefore it is clear that there is a large and growing number of HIV infected children, and they are often condemned to die due to lack of access to treatment (Médecins Sans Frontières, 2005).

This situation calls to attention the need to provide appropriate treatment to this vulnerable group in order to maintain the maximum level of health possible. The overall management of HIV/AIDS requires good nutrition, proper medication for common illnesses and opportunistic infections, the availability and accessibility of antiretroviral drugs, the medical and social infrastructure that can deliver and monitor treatment measures, and supportive, understanding human care (Kelly, 2006). In children HIV/AIDS is exceptionally destructive, if they do not have proper treatment, care and support, HIV will multiply and destroy the defences to infection, and this will leave the child less able to fight pneumonia and other opportunistic infections (UNICEF, 2005). Nevertheless, globally less than 5% of young HIV positive children in need of pediatric AIDS treatment are receiving it (UNICEF, 2005), Pharmaceutical companies do not make child friendly HIV medication and many children are missing out on ways to keep them healthy. For the children who do receive ART, 95% or higher drug adherence is required for optimum results (Bangsberg et al., 2000). As identified by Watson & Farley, (1999) adherence in HIV positive children is even more difficult for two main reasons; firstly, medication related factors such as palatability, cost, diet prescriptions, timing, side effects and volume and secondly, young children are dependent on caregivers to administer their medication. In

addition, caregivers are often HIV positive and this can create psychosocial difficulties that control the ability to adhere to the treatment (Friedland & Andrews 2001). HIV infected children face significant problems related to the disease including physical problems because they have a weakened immune system making it easy for them to become ill. HIV infected children tend to have more opportunistic infections and higher mortality rate in addition to the common childhood illnesses like measles (Médecins Sans Frontières, 2005).

In Thailand much progress has been made in providing access to care for the many people living with HIV/AIDS. In 1997, the Thai Communicable Disease Control Department established a clinical research network, and in 2000, health services, including a monitoring system, were developed to enhance the efficacy of triple therapy (Maneesriwongul et al., 2006). Exceptional progress has been made by the Royal Thai Government (RTG) in scaling up access to treatment, achieving the national treatment target of delivering ART to more than 50% of those in need within 2001 to 2004 (MOPH & WHO SEARO, 2005). Since 2003, equal access and proper treatment to all people living with HIV/AIDS (including ART) has been an endorsed promise by the Thai Ministry of Public Health (UNDP, 2004). As of February 2005, 60,000 people with HIV in Thailand had received ART, first line therapy regimes for adults and children are fully subsidized by the RTG (MOPH & WHO SEARO, 2005).

With the introduction of Highly Active Antiretroviral Therapy (HAART) the landscape of HIV treatment has changed. HIV is no longer necessarily a death sentence; HAART has transformed HIV infection into a manageable, but still serious, chronic condition. There has been a dramatic reduction in HIV associated morbidity and mortality since the widespread introduction of HAART (Poppa et al., 2004). As a

result, people living with HIV or AIDS who have access to ART are living longer, and now face many emotional, psychological and developmental challenges that they would otherwise have missed (Riddle and Moon, 1996). Among no age group is this truer than children infected with the disease. Rather than imminent disease progression to death, children who are perinatally infected with HIV are surviving till late childhood, early adolescence and beyond with improved quality of life (Steele & Grauer, 2003). Therefore it is a common misconception that most infected children die rapidly (The Thai Working Group on HIV/AIDS Projection, 2001). Treatment advances particularly the availability of highly active antiretroviral therapy (HAART), have led to a shift in the conceptualization of HIV from a fatal disease to a chronic illness (Shernoff, 2002). With effective medical care and antiretroviral (ARV) treatment, children with HIV currently experience fewer opportunistic infections and lower risk of disease progression (Gortmaker, Hughes & Cervia, 2005). However, the degree to which HAART regimen are effective is influenced by patients' adherence to their medications (Paterson, Swindells & Mohr, 2000).

The new drug combinations are costly, side effects are common and regimes can involve taking numerous medications with difficult dietary restrictions (WHO SEARO, 2004). But, very high levels of adherence to HAART are a prerequisite for a successful virological and immunological response, low adherence increases the risk of treatment failure and disease progression (Paterson, Swindells & Mohr, 2000). It is also likely to lead to further transmission of resistant viruses and to have a negative impact on the cost effectiveness of HAART (International HIV/AIDS Alliance, 2005). Adherence has been called the 'Achilles heel' of antiretroviral therapy because the consequences of low adherence are serious for the individual, for

public health and for the optimal use of limited health care resources (Poppa et al., 2004). Researchers have put forward the notion that ‘the key to success of the new regimens is the ability and willingness of HIV positive individuals to adhere to complex antiretroviral regimens, perhaps for life’ (Friedland & Williams, 1999). Adherence to HAART is an important factor of successful HIV care and has been increasingly recognised as a challenge for many children and caregivers (Nicholson, Mellins, Dolezal, Brackis-Cott, Abrams, 2006). Similarly, knowledge of factors associated with medication adherence could help HIV clinicians to target persons in need of intervention, design these interventions, and help researchers to plan studies of adherence (Ammassari et al., 2002). Studies have suggested that 90-95% adherence is necessary for viral suppression and that lower rates of adherence are harmful (Bangsberg et al., 2000) and sustaining adherence represents a significant challenge for children getting the treatment, their caregivers as well as healthcare providers (Shah, 2007).

Even though the significance of adherence among children on ART, there are few studies which examine adherence levels or factors associated with adherence. Shah (2007) highlights that in order to facilitate adherence to HAART and to improve the outcome of HAART in HIV infected children it is necessary to know possible and relevant issues in pediatric patients that influence adherence and to determine the possible interventions to improve adherence in children. Pre-school and school age children with HIV infection do not typically have primary responsibility for their own care, it is important to understand the issue from the caregivers’ perspective as they are the ones administering the medication (Nicholson, Mellins, Dolezal, Brackis-Cott, & Abrams, 2006). Katko et al., (2001) however did assess caregivers’ knowledge of

children's prescribed ART medication regimens as it relates to adherence. They asked 35 caregivers to name or describe their children's medications and dosages and dosing frequencies. Only 54% (19) were able to accurately provide the medical information and 12 had pharmacy refill ratings of 90% or higher adherence ratings.

The World Health Organization (2002) has recommended more research on ART adherence especially in children so good adherence is achieved and they can maintain a higher quality of life, have less opportunistic infections, therefore less drain on health care resources. According to UNICEF (2005), when strategies on HIV prevention and treatment are drafted, policies made and budgets allocated, the needs of children are being ignored. ARV adherence is not just a treatment, it is also part of the larger picture of 'working full circle to counter the epidemic', namely prevention, care and support and treatment (WHO SEARO, 2004). In addition to correct diagnosis and choice of treatment, adherence with the therapeutic regimen is necessary to improve health (Sawyer and Aroni, 2003). The understandings of barriers to and enablers of high adherence, and the evidence base regarding interventions is limited (Poppa et al., 2004). Compared with the numerous trials of individual drugs, few thorough studies of adherence support have been undertaken and even less on caregiver's knowledge.

It is critical, therefore that more research is undertaken in the area of ART adherence in children not only for the benefit of the infected children and their caregivers but also for the massive reduction in health care costs that good adherence would incur. Mills and colleagues highlighted this in their study by stating that 'research is urgently needed to determine patient-important factors for adherence in developing world settings' (Mills et al., 2006). In addition, in order to assist the

caregivers in helping the children adhere better it is important to learn from them, what works and how to help them overcome the barriers. In other words, liken to the old Chinese proverb: *'To know the road ahead, ask those coming back.'*

Thailand still faces major problems of children infected with HIV, and the greatest number of these children live in the northern part of the country where cultural differences, stigma and lack of adequate adherence knowledge are extensive (MOPH, 2004). For this reason, Chiang Mai was selected as the field of study because of the high prevalence of HIV infection in children in this area. According to the Chiang Mai Provincial Public Health Office (2007), 1,122 children under 14 years old are infected with HIV. It is anticipated that the information gained from this study will enhance the knowledge pool on ART adherence in children from Chiang Mai province. This knowledge pool can be used to assist health professionals better understand difficulties faced by caregivers and therefore develop appropriate ways to help caregivers achieve optimum adherence for the children. Currently, there have been no previous studies on adherence conducted with children in this area of Thailand.

Objectives of the Study

Research Objectives

1. To study the prevalence of HAART adherence among HIV infected children who receive treatment at Maharaj Nakorn Chiang Mai hospital.
2. To study the caregivers' knowledge and understanding regarding HAART.
3. To explore other factors of adherence in children with Human Immunodeficiency Virus (HIV) as reported by caregivers.

Research Questions

1. What is the prevalence of HAART adherence in children?
2. What knowledge and understanding do the caregivers of HIV infected children possess?
3. What are the other factors of adherence in HIV infected children as described by caregivers?

Scope of the Study

This study was conducted with the caregivers of HIV infected children receiving treatment at the pediatric infectious disease clinic, Maharaj Nakorn Chiang Mai hospital, Chiang Mai, Thailand during March to June 2008. Caregivers of children under age 14 years and fitting the inclusion criteria were asked to volunteer to participate in the study.

Definition of Terms

Highly Active Antiretroviral Therapy (HAART): For antiretroviral treatment to be effective long-term, it has been found that more than one antiretroviral drug at a time is needed. This is what is known as combination therapy and the term Highly Active Antiretroviral Therapy (HAART) is used to describe a combination of three or more anti-HIV drugs (Ickovics and Meade, 2002).

Adherence: While most research has focused on adherence to medication, adherence also encompasses numerous health-related behaviours that extend beyond taking prescribed drugs. The operational definition of adherence for this study was the definition of adherence used by the International HIV/AIDS Alliance: ‘Adherence

means taking the doses of drugs and sticking to the treatment plan exactly as prescribed. It means taking the correct amount of drugs, at the correct time and in the correct way and at least 95% adherence is needed for them to work effectively' (International HIV/AIDS Alliance, 2007).

www.aidsalliance.org/graphics/secretariat/publications/FS04_Adherence_2007.doc

Adherent: Children were classified as adherent if they missed less than 3 doses within the last 30 days (successful HIV therapy requires adherence of $\geq 95\%$, UNICEF 2005), had correct pill count as measured by the staff at the clinic, last CD4 count of $\geq 15\%$ and viral load ≤ 400 copies/ml.

Knowledge and understanding: Caregivers' knowledge and understanding in relation to HAART adherence and HIV. For example, caregivers' ability to name or describe the child's HAART medication, corresponding doses, dosing frequency and ability to correctly answer HIV related questions.

Primary caregiver: Primary caregiver referred to the parent, grandparent or significant other who played the primary role in taking care of the HIV infected child and administered their medication.

HIV infected child: In this study the children were under the age of 14, diagnosed as HIV infected and receiving HAART at the pediatric infectious disease clinic, Maharaj Nakorn Chiang Mai hospital.

Factors of adherence: Factors of adherence can be categorized to include:

- 1) Patient factors; e.g. age, education, literacy, social support, attitudes, self-efficacy,
- 2) Treatment regimen; e.g. dosage, side effects, treatment instructions, 3) Patient-provider relationship; e.g. confidence in doctor, continuity of care, communication,

and 4) Clinical setting; e.g. convenient appointments, confidentiality, surroundings (Ickovics and Meade, AIDS Care, 2002).



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