SOCIAL AND BEHAVIORAL FACTORS RELATED TO QUALITY OF LIFE AMONG HIV INFECTED CHILDREN

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**A THESIS SUBMITTED IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR
THE DEGREE OFMASTER OF SCIENCE
(TROPICAL MEDICINE)
FACULTY OF GRADUATE STUDIES
MAHIDOL UNIVERSITY
2009**

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SOCIAL AND BEHAVIORAL FACTORS RELATED TO QUALITY OF LIFE AMONG HIV INFECTED CHILDREN

was submitted to the Faculty of Graduate Studies, Mahidol University
for the Degree of Master of Science (Tropical Medicine)
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ACKNOWLEDGEMENTS

The success of this thesis was depending on the extensive support and assistance from my major advisor, Assoc. Prof. Wijitr Fungladda and my co-advisor, Assist. Prof. Jaranit Kaewkungwal and Assoc.Prof. Pornthep Chanthavanich. I deeply thank them for their valuable advice and guidance in this research.

I wish to thank Assoc. Prof. Tawee Chotpittayasunon who was the chair of the thesis defence for his kindness, valuable comment and suggestion for improvement my thesis.

I would like to thank Mrs. Ratthanaporn Tangyingyong and all staff of the pediatric infectious disease clinic of Sappasithiprasong Hospital, Warin Chamrap District Hospital, Trakan Phutphon District Hospital, Dat Udom Crown Prince Hospital for cheerfulness and kind support.

I would like to thank Mrs. Ratthanaporn Tangyingyong, Miss Inthira Reungsith, and Mrs.Palidchat Jaisupab for their kindness examination the research instrument and providing suggestions for improvement.

I would like to thank all staff at Srimuang Mai District Hospital, the staff and others M.Sc./Ph.D. students class 2006 of the Faculty of Tropical Medicine for cheerfulness and kindness suggestion my thesis.

I would like to thank High Graduate Student Association of LAO P.D.R., students of Mahidol University for kindness, cheerfulness, and great relationship.

Finally, I am grateful to my Treephak’s family for entirely care and love, and their financial support. The usefulness of this thesis, I dedicate to my father, my mother and all the teachers who have taught me since my childhood.

Chalermkwan Kuntawee

SOCIAL AND BEHAVIORAL FACTORS RELATED TO QUALITY OF LIFE AMONG HIV INFECTED CHILDREN

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ABSTRACT

This study aimed to determine social and behavioral factors related to quality of life (QoL) of HIV infected children, and to assess the quality of life among HIV infected children aged 8-15 years. A cross-sectional study was conducted with a sample size of 110 HIV infected children, and their respective caretakers, who had received medical care services at the Pediatric Infectious Clinic of Sappasithiprasong Hospital, Ubonrachthani Province, Thailand. The study data were collected during October-November 2008, by interviewing caretakers and their children using a structured questionnaire. The data were analyzed using descriptive statistics, and bivariate and multivariate analysis. The results revealed more HIV-infected children were female than male; the average age was 11 years. The majority lived in extended family settings, where the main caretakers were a biological parents, 56.4% of biological parents were being alive. The children were classified as clinical categories B and C (44.4 and 33.3%, respectively). 66% of children had CD4 counts ≥ 500 cell/ µL More of the caretakers were female than male; their average age was 48 years; 67.3% had completed primary school; 47.3% were agriculturalists with an average family income of 3,130 Baht per month; and 82% were relatives of the children. Of the caretakers, 70% were assessed as needing for improving knowledge. Only 60% knew that chronic diarrhea was a symptom of AIDS; 63% and 56%, respectively, knew that sharing injection needle and blood transfusions were risk factors for HIV transmission; only 27% knew that AIDS was not currently curable; 58% knew that candidiasis was an opportunistic infection of AIDS. 51 % were at need for improving level of practices. 59.1% were at moderate level of attitude toward HIV/AIDS. The families of the HIV infected children were at need for improving level of social support (84.5%), since community resources provided limited support, such as clothes, food, financial support, consultation, and information. The HIV infected children's quality of life needed improvement (78.7%). Bivariate analysis found that the factors associated with quality of life were main caretaker, biological parent being alive, age of caretaker, family income, and relationship between caretaker and child. Multiple logistic regression analysis showed that age of caretaker was significantly associated with QoL. The children who were cared by caretakers aged 45 years old and higher had better quality of life than those whose caretakers were 20-45 years old (OR=6.32, 95%CI=1.12-35.62).

In conclusion, the main caretakers, family income, and age of caretakers related to QoL of the children. These results are useful in planning improved QoL for the children. A multi-sectoral approach should be adopted to establish interventions for supporting HIV infected children and their families, and also improving the efficiency of child care.

KEY WORDS : QUALITY OF LIFE / CARETAKERS / HIV/AIDS / CHILDREN

94 pages

ปัจจัยด้านสังคมและพฤติกรรมที่มีผลกระทบต่อคุณภาพชีวิตเด็กที่มีภาวะภูมิคุ้มกันบกพร่อง
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บทคัดย่อ

การวิจัยครั้งนี้มีวัตถุประสงค์ เพื่อศึกษาปัจจัยด้านสังคมและพฤติกรรมที่มีผลต่อคุณภาพชีวิตของเด็กติดเชื้อเอชไอวี และวัดคุณภาพชีวิตของเด็กติดเชื้อเอชไอวี อายุ 8-15 ปี รูปแบบการศึกษาเป็นแบบภาคตัดขวาง ประชากรกลุ่มเป้าหมายคือ เด็กติดเชื้อเอชไอวีและผู้ดูแลเด็ก ที่มารับบริการด้านการแพทย์จากคลินิกโรคติดเชื้อในเด็ก โรงพยาบาลสรรพสิทธิประสงค์ จังหวัดอุบลราชธานี เก็บข้อมูลระหว่างเดือน ตุลาคม ถึง พฤศจิกายน 2551 วิเคราะห์ข้อมูลโดยใช้สถิติร้อยละ ค่าเฉลี่ย ส่วนเบี่ยงเบนมาตรฐาน วิเคราะห์ไคว์สแคว์ และวิเคราะห์มัลติเปิลล็อกจิสติกรีเกรสชัน

ผลการวิจัยพบว่า เด็กติดเชื้อเอชไอวีเป็นเพศหญิงมากกว่าเพศชายอายุเฉลี่ย 11 ปี อาศัยอยู่ในครอบครัวขยาย มีผู้ดูแลหลักคือบิดามารดาโดยกำเนิด บิดาหรือมารดายังมีชีวิตร้อยละ 56.4 เด็กมีภาวะของโรคระดับ B และระดับ C ร้อยละ 44.4 และ 33.3 ตามลำดับ เด็กร้อยละ 66.7 มีระดับ CD4 count มีค่าตั้งแต่ 500 เซลล์ต่อไมโครลิตรขึ้นไป ผู้ดูแลเป็นเพศหญิงมากกว่าเพศชายมีอายุเฉลี่ย 48 ปี จบการศึกษาระดับประถมศึกษาร้อยละ67.3 ประกอบอาชีพเกษตรกรรมร้อยละ 47.3 รายได้ครอบครัวเฉลี่ยเดือนละ 3,130 บาท ร้อยละ58.2 เป็นญาติกับเด็กที่ดูแล ผู้ดูแลมีความรู้เรื่องโรคเอดส์ในระดับที่ต้องปรับปรุงร้อยละ 70 ได้แก่ความรู้เรื่องอาการของโรคเอดส์ การแพร่เชื้อของโรค การป้องกันและการดูแลผู้ติดเชื้อเอชไอวี ผู้ดูแลมีทัศนคติต่อโรคเอดส์ระดับปานกลางร้อยละ 59 และระดับการปฏิบัติด้านการดูแลสุขภาพเด็กทำได้ในระดับที่ต้องปรับปรุงร้อยละ 51 ครอบครัวได้รับการสนับสนุนทางสังคมในระดับที่ต้องปรับปรุงร้อยละ 84.5 และการสนับสนุนทางสังคมจากชุมชนยังมีน้อยในทุกด้านเช่นเสื้อผ้า อาหาร การเงิน การให้คำปรึกษา และการให้ข้อมูล คุณภาพชีวิตของเด็กติดเชื้อเอชไอวีอยู่ในระดับที่ต้องปรับปรุงร้อยละ 78.7 และปัจจัยที่มีความสัมพันธ์ต่อคุณภาพชีวิต เด็กได้แก่ ผู้ดูแลหลัก การมีชีวิตของบิดาหรือมารดา อายุของผู้ดูแล รายได้ของครอบครัวต่อเดือน และความสัมพันธ์ระหว่างผู้ดูแลกับเด็ก หลังจากใช้การวิเคราะห์ด้วยมัลติเปิลล็อกจิสติกรีเกรสชันพบว่า ปัจจัยที่มีความสัมพันธ์อย่างมีนัยสำคัญต่อคุณภาพชีวิตของเด็กติดเชื้อเอชไอวี คือ อายุของผู้ดูแล ซึ่งเด็กที่มีผู้ดูแลอายุ 45 ปีขึ้นไปมีคุณภาพชีวิตที่ดีกว่าเด็กที่มีผู้ดูแลอายุ 20- 45 ปี

สรุปการศึกษาแสดงให้เห็นว่า ผู้ดูแลหลัก รายได้ของครอบครัว อายุของผู้ดูแล มีความสัมพันธ์ต่อคุณภาพชีวิตของเด็กติดเชื้อเอชไอวี จึงควรนำไปใช้ในการวางแผนเพื่อพัฒนาคุณภาพชีวิตของเด็กติดเชื้อเอชไอวีให้มีคุณภาพชีวิตที่ดีและทุกภาคส่วนควรมีส่วนร่วมในการสร้างสรรค์และพัฒนารูปแบบการสนับสนุนช่วยเหลือแก่ครอบครัวของเด็กติดเชื้อเอชไอวีอย่างต่อเนื่องซึ่งจะช่วยให้การดูแลเด็กเป็นไปอย่างมีประสิทธิภาพมากขึ้น

94 หน้า

CONTENTS

CONTENTS (cont.)

LIST OF TABLES

LIST OF FIGURES

CHAPTER I
INTRODUCTION

Background and rationale

HIV/AIDS pandemic is having devastating effects around the world, particularly in nations and communities with significant epidemics. A large number of HIV infected individuals are unable to live their normal lives in their own social circumstances, which results in poorer physical, mental, social and environmental quality of life.

The impact of HIV on children

The impact on physical well-being

Studied in the United State and Europe have shown that ,in the absences of any intervention, children with rapid progression of the disease have a clinical events, including poor growth, frequent infections, pneumonia due to *Pneumocystis jiroveci*, frequent and prolonged diarrhea, encephalopathy, and early death, and children who do not progress until much later or event later. Certain conditions are much more commom: refractory thrush; recurrent, severe otitis media; recurrent or prolonged diarrhea; pneumococcal and other bacteria sepsis, including pneumonia; subacute paroitis; and a chronic, progressive, steroid-responsive pneumonia termed lymphocytic interstitial pneumonitis (LIP) that may be associated with infection by Epstein-Barr virus and that seen only in children(McIntosh, 2004). Siriyaporn reported in Thailand it is clear that tuberculosis in HIV infected children is a growing problem in their. And the survival times of them shorter than those in the United State and Europe but longer than those in Africa. The clinical events were very similar to those described from Western children (McIntosh, 2004). Moreover, skin disease is a manifestation of an important opportunistic infection and evidence of deterioration of the immune status (Pizzo and Wilfert, 1994).

The impact on emotional

AIDS starts to have an impact on families long before the person with AIDS dies. As the first telling symptoms appear, family stress level rise all around. Parents who are sick and worried may begin to fight with spouses and children. Gillborn suggested that at least educationally, children do better in school after they become orphan, and that going to school and doing well at school is linked to children’s happiness. In the Western, it had been reported that children suffer the greatest distress and the worst long term developmental effects when separated from their mothers.

In Mekong River societies where grandparents and siblings can play an important part in parenting, the effects of maternal deprivation may not be quite so great (Borthwick, 2004).

The impact on schooling

Children’s schooling is generally affected by the disruption that occurs during parental illness and death. A teacher in the worst hit area in Thailand tell of primary school children be distracted and inattentive in class around the time of a parents’ death, and withdraw and depressed afterward. Discrimination can also affect a child’s performance at school. Both HIV-positive and negative children had been teasing at school in Thailand. Some children at the Camillian Centre in Rayong refused to go to school because they felt schoolmates “hated” them. In some cases, adult caregivers remove children from school because they are always getting sick. This then makes it hard for children to catch up after long spells away from school (Borthwick, 2004).

Epidemiology and situation of HIV/AIDS

An estimated 8.6 million (6.0 million–13.0 million) people were living with HIV in Asia in 2006, including the 960,000 (40,000–2.5 million) people who became newly infected in the past year. Approximately 630,000 (430,000–900,000) died from AIDS-related illnesses in 2006(UNAIDS, 2006).

Across the globe, AIDS is responsible for an increasing number of deaths each year. In 2006, the number of children aged below 15 years olds was 2.3 million living with HIV. 530,000 children ages under 15 years around the world were newly infected with HIV and the number of AIDS-related deaths in children was 380,000 (UNAIDS, 2006). At the end of 2005, it was estimated that 580,000 (330,000–920,000) adults and children were living with HIV. The number of new annual HIV infections continues to drop the estimated 18,000 new infections in 2005 were 10% less than in 2004 (UNAIDS, 2006).

In 2005, The Thai Working Group on HIV/AIDS Projection predicted that the accumulated number of children with HIV infection who were younger than 14 years of age were about 50,620. It was expected that in 2006 there would be 53,400 accumulated HIV-infected children younger than 14 years of age (Bureau of Epidemiology, 2004).

In Thailand, the first report of pediatric AIDS cases occurred in 1988 they born to HIV infected mothers. Since then, the number of pediatric AIDS cases or children related with AIDS increased rapidly (Thisyakorn, 2008).

In 1992, the prevalence of HIV pregnant infected woman in Thailand was 0.7% and increasing to 2.3% on 1996 then declined 10 1.5 on 2001(Pancharoen, 2002).

Thailand established AIDS Clinical Trial Group (ACGT) 076 in 1995, this study pregnant women was took antiretroviral Zidovudine (ZDV) to protect mother to child transmission that reduced the transmission rate to 5-11% (Pancharoen, 2002).

The surveillance of Thailand Ministry of Public Health on 2005 revealed that there was1.18% of HIV infected pregnant women (Bureau of Epidemiology, 2005). There were approximately 1,000,000 births year and approximately 24,000 infants were born to HIV sero-positive mothers. A large proportion of new HIV infections were occurring in people considered to be at low risk of infection. Approximately, one third of new infections in 2005 were in married women who probably were infected by their spouses (UNAIDS, 2006).

Boontham reported on 499 HIV-infected mothers from 23 community hospitals in Ubonratchathani province that were under the national programme for Prevention of Mother-To-Child Transmission (PMTCT) of HIV. From 2001 to 2004, the ratio of HIV infected children was 5.6% (Boontham, 2007).

There were many hospital conducted activities for HIV/AIDS. In particular, Sappasithiprasong Hospital has been playing a role in providing care for HIV children infected and supporting the caretakers. The hospital revealed that the accumulative number of children who received medical care in April, 2007 was 232, which could be categorized into 136 HIV infected children with antiretroviral regimen, while the remaining were HIV infected children without antiretroviral regimen and HIV infected children whose CD-4 count had not reached the criteria of treatment with antiretroviral regimen (Sappasithiprasong hospital, 2008).

From 2004-2007 Sappasithiprasong Hospital conducted project for promoting quality of life of HIV affected children and families, the activities concerned to establishment of the relationship and empowerment, and providing knowledge of HIV/AIDS to family members of HIV-infected children and the affected children themselves (Sappasithiprasong hospital, 2005).

Thus it is believed that children who are orphaned or affected should remain in their community with confidence and self-esteem and to be raised by their families. Family will be able to provide care better if they have confidence and understand about the children. Although children infected with HIV cannot be completely cured of the disease, the children should be happy and well cared-for while they are still alive to optimize their quality of life (Aeamlaor, 2001).

There were a small number of studies related to the quality of life (QoL) of HIV infected children. Most of the studies were conducted in the Northern region of Thailand. This study aims to assess quality of life in HIV infected children and compare with the difference areas of study. These may lead to appropriately promotion and improve quality of life in HIV infected children and families.

Objectives

General objective

To determine the social and behavioral factors related to quality of life in HIV infected children.

Specific objectives

1. To assess the quality of life in HIV infected children.
2. To determine association of socio-demographic characteristics of children and quality of life in HIV infected children.
3. To determine association of socio- demographic characteristics of caretakers and quality of life in HIV infected children.
4. To determine association of knowledge, attitudes and practices toward HIV/AIDS of caretakers and quality of life in HIV infected children.

5. To determine association of social supports and quality of life in HIV infected children.

Research questions

1. How is the quality of life in HIV infected children?
2. Are there socio-demographic characteristics of caretakers and children, knowledge, attitudes and practices toward HIV/AIDS of caretakers, social support associate the quality of life in HIV infected children?

Hypotheses

1. There are association between socio-demographic characteristics of children (age, gender, extend or nuclear family, number of caretakers, severity of illness, antiretroviral use) and quality of life in HIV infected children.
2. There are association between socio-demographic characteristics of caretakers (age, gender, education, occupation, income, relationship between caretakers and children), knowledge, attitudes and practices toward HIV/AIDS of caretakers and quality of life in HIV infected children.
3. There is an association between social support and quality of life in HIV infected children.

Variables of the study

Independent variables

1) Socio-demographic characteristics of children

- Age
- Gender
- Extended or nuclear family
- Number of caretaker
- Severity of illness
- Antiretroviral use

2) Socio-demographic characteristics of caretakers

- Age
- Gender
- Education
- Occupation
- Family income
- Relationship between caretakers and children

3) Knowledge, attitudes and practices toward HIV/AIDS of caretakers

4) Social support

- Family (relative's support)
- Neighbors support
- Community support
- Government support
- Non-government support

Dependent variable

- Quality of life in HIV infected children

Operational Definitions

1) Socio-demographic characteristics of children

Age is defined as a children who age of 8 years, not exceed 15 years by time of the study.

Gender is defined as a gender of HIV infected children categories to male/female.

Extended or nuclear family refers to a structure of family HIV/AIDS children that categorizes to a nuclear family which has one generation such as mother, father, daughter/son, and an extended family which has more two generation of relatives living such as mother, father, daughter/son, grandparent, aunt/uncle and others either within the same household or very close to one another.

Number of caretaker is defined as a number of caretakers who assisted the main caretakers. They give a full time or part time caring a child for at least 6 months before a study.

Severity of illness refers to CDC Classification of AIDS.

Antiretroviral use is defined as a specific treatment of HIV infected children. And duration of start using antiretroviral to present.

2) Socio-demographic characteristics of caretakers

Caretakers are defined as persons who direct care and perform complete assistance for patient both physical care, respond to needs of patient such as emotional support, doing housework, assistance for daily living activities, and are full time or part time caring the children for at least 6 months before the study.

Age is defined as caretaker’s age at the time of study.

Gender is defined as a gender of caretakers which categories as male/female.

Education refers to level of education of caretakers.

Occupation refers to the job which caretakers work regularly and earn monthly income.

Family income is defined as a monthly income of household

Relationship between caretaker and children is defined as relationship of caretakers who care for HIV infected children categorized as biological parents, relatives, other or unknown.

3) Knowledge, attitudes and practices toward HIV/AIDS of caretakers refers to caretakers’ understanding about HIV/AIDS manifestation, treatment, prevention, and caring people living with HIV/AIDS.

4) Social support

- Family (relative’s support) refers to support from family members and relatives.
- Neighbors support refers to support from neighbors.
- Community support refers to support from community where they live (i.e. support from housewife group, support from religious organization, village health volunteers, and community committee).
- Government support refers to support from government (official) organization (i.e. Administrative of sub-district organization, Administrative of district organization, profession health provider).
- Non-government support refers to support from non-governmental organization (i.e. Global foundation act pass the self help group of people living with HIV/AIDS (PLWA)).

5) Quality of life (QoL)(Vani *et al*., 2001; Zhan, 1992) is defined as the way in which children's view their own health and the degree to which they are satisfied with it. It includes five dimensions: 1) physical functioning, 2) emotional functioning, 3) social functioning, 4) school functioning, 5) life satisfaction with social interaction, family life and supports.

Expected outcome and benefit

1. The result will be used to appropriately promote and develop the quality of life in HIV infected children. It will be used as a guideline to develop home health care for children families.
2. The result may help to understand the impact of caretakers on quality of life in HIV infected children toward the socio-demographic characteristics and KAP.

CHAPTER II

LITERATURE REVIEW

This research aims to investigate the social and behavioral factors related to quality of life of HIV infected children, which covers the scope of literature review as follow:

1. Information of AIDS
    1.1 Mechanism of HIV infection
    1.2 HIV transmission
    1.3 HIV infection in children
2. Concept of quality of life in children
3. Health Belief Model
4. Factors related to quality of life in HIV infected children
    4.1 Socio-demographic characteristics of children
    4.2 Socio-demographic characteristics of caretakers
    4.3 Knowledge, Attitudes, Practices
    4.4 Social support
5. Related studies

1. Information of AIDS

AIDS is the acronym for Acquired Immune Deficiency Syndrome. This term is used to indicate only the most severe disease or end –state disease manifestation of infection with 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 these cell-the hallmark of HIV-related disease. The striking loss of these key cells of the immune system results in opportunistic infections from bacteria, virus, parasites and opportunistic diseases such as tuberculosis and Kaposi’s Sarcoma (Rojanapittayakorn, 1989).

1.1Mechanism of HIV infection

HIV has specific tropism for CD_4 - positive cells, which include lymphocytes. One infected T-lymphocyte expressing surfaces gp120 may bind to other CD_4^+ cell (CD_4 is the receptor for HIV on T lymphocytes). The HIV fuses with the target cell's membrane, enters to the host cell's cytoplasm, sheds its envelop coat, and releases its content. The reserve transcriptase enzyme then creates double-stranded DNA based on the viral load (genome RNA). The double strand DNA integrates into the host cell's DNA where it is called proviral DNA. All of these human immunodeficiency viruses share the characteristic of producing a slow viral disease, which provides the opportunity for otherwise mild microorganisms to cause severe or life threatening illness**.** Noninfectious complications of HIV may be due to immunologic abnormalities or may occur through other mechanisms(Falskerrud, 1995).

1.2 HIV transmission

Even though HIV has been found in a variety of body fluids such as saliva, urine, feces, and tears, non-sexual transmission of HIV by these body fluids is improbable. The presence of HIV in genital secretions and in blood, and to a lesser extent breast milk, is significant for the spread of HIV. The lack of transmission is related in part to the paucity of HIV-infected cells in such secretions. Even though the amount of virus is small in body secretions and presents a very small risk with routine household contact, prolonged contact or contact in sexually intimate situations with such fluids should be avoided.

1.2.1 Blood borne transmission

The primary risk group for HIV transmission via blood is intravenous drug users sharing infected needles. The estimates of infectivity per intravenous drug injection range from 0.63 to 2.4%. Use of instruments such as tattoo needles that are not properly disinfected also carries a potential risk. Health care workers with percutaneous exposures to HIV-containing blood, however, have an average rate of infection of only 0.23%.

1.2.2 Sexual transmission

HIV is primarily a sexually transmissible disease. Although sexual intercourse between males has remained the greatest risk for transmission in developed nations of Western Europe and the United States, heterosexual transmission is increasing in those regions but still remains less common than in Africa, Asia, or parts of the Caribbean. Transmission of HIV can occur from male to male, male to female, and female to male. Female to female transmission remains extremely rare, though women with same-sex contact are also often bisexual and have additional risk factors for HIV infection. Among males having sex with males in the U.S. in the 1990's, the prevalence of HIV infection remained high at 7.2%, and the prevalence of unprotected anal intercourse over the prior 6 month period was 41% (Klatt, 2007).

1.2.3 Vertical transmission

Mothers with HIV infection pass the virus to their babies transplacentally, at the time of delivery through the birth canal, or through breast milk. In the absence of breast-feeding, intrauterine transmission accounts for 25 to 40 % of infections, while 60% to 75% of infections occur during labor and delivery. In Thailand, the virologic test for HIV-1 DNA after 48 hours in infants by Polymerase Chain Reaction (PCR) showed that 35% of the infants were infected with HIV-1DNA in-utero (Kosaralak, 2002). In early stage of the HIV epidemic, the mother-to-child transmission rate was 21%-45 %, then declined to 21%-28% following the use of infant-feeding formulas to replace breast milk of HIV-positive mothers. Vertical transmission of HIV-1 from mother to child due to breastfeeding was estimated to occur in 14% to 16% of women with HIV-1 infection who breast-fed and 29% in women with acute maternal HIV-1 infection. In Thailand, HIV transmission from mother to child from breastfeeding was reported at 3%-9% per years, with the average mean of 7%-22% (Pancharoen, 2002).

Perinatal transmission of HIV resulting in congenital AIDS occurs, on average, in about one fourth of babies born to HIV-1 infected mothers, with actual rates of transmission varying from 7 to 71%. The likelihood of vertical HIV-1 transmission is reduced in half with delivery by elective cesarean section, as compared with other modes of delivery. Also, an amniocentesis procedure, premature rupture of membranes, preterm labor, genital warts, and the presence of sexually transmitted diseases during pregnancy also increase the risk for transmission. Transmission most likely occurs in late third trimester and intrapartum.

1.3 HIV infection in children

1.3.1 Pathogenesis

HIV virus enters into the susceptible host and infects the host's lymphocytes (predominantly CD4 T-cells). After initial infection, there is a phase of high replication leading to acute viral liked illness. However, the body's immune system subsequently recognizes the virus as a foreign object and builds an immune response by a complex interplay of various cytokines and proteins and leads to a latent phase whereby a balance is struck between the acute viral replication and immune response.

During the latent phase, the HIV virus lives predominantly in the lymphoid tissues and multiplies. Once the fine balance between viral replication and immune response is overcome, peripheral blood over-pooling and viremia occurred, resulting in the destruction of CD4 T-cells and immunosuppression. CD4 T-cells, also called helper cells, are the cells that lead to activation of CD8 T cells for cell-mediated immunity and also assist in the conversion of B-cells to plasma cells and generation of humoral immunity. With destruction of CD4 cells, both cell-mediated immunity and humoral immunity are affected and a person becomes susceptible to opportunistic infections including viral, fungal, bacterial and parasitic infections and also has increased susceptibility to malignancies.

In children, the latent phase is usually not seen, as there are several differences as compared to adults.

1. Children usually acquire the infection vertically whereas predominant mode of transmission in adults is sexual route.

2. Children have an immature immune system at the time of infection with the virus. Thus, with initial exposure to the virus, children have a prolonged viremia phase, the immune system is not able to mount an adequate immune response and thus progression to AIDS is faster (Shah, 2008).

1.3.2 Diagnosis of HIV infection in children

The Ministry of Public Health, Thailand set up two guidelines of laboratory diagnosis (Chasombat. 2004)

1. Guidelines of laboratory diagnosis for children aged <18 months

Laboratory diagnosis for HIV infection in children aged <18 months, for HIV–exposed infants aged 14-16 weeks, is based on the following virologic tests: HIV

Deoxyribonucleic Acids (DNA) Polymerase Chain Reaction (PCR), HIV RNA PCR, P24 antigen, and viral culture. The gold standard is HIV RNA PCR in which HIV infection can be diagnosed if there are 2 positive results of PCR from separate blood tests. The children are not HIV-infected if 2 negative results of PCR are detected from separate blood tests. The first test will be performed when the children are more than 1 month old, and the other blood test will be performed at more than 4 months of age for children with no sign or symptom of HIV infection.

Another virologic test for HIV infection is P24. The presence of P24 antigen by the boosted immune complex-dissociation (ICD) blood test is used to assist the diagnosis of HIV infection in children. Results have shown that this test is no less effective than PCR. Furthermore, the test is easy to perform and is less expensive. Therefore, the test can be used as a substitute for the PCR test. The HIV-serology test is suggested for all cases when children are 12 months old. If a positive result is still confirmed at 18 months of age, it indicates that the children are actually infected with HIV.

2. Guidelines of laboratory diagnosis for age >18 months

The guideline of laboratory diagnosis for age >18 months is as follow:

2.1 HIV antibody test should be done during both the screening test and the confirmatory test.

- Screening test. The tests most commonly used are Enzyme Linked Immunosorbent Assay (ELISA), Particle Agglutination (PA), Immunofluorecence and Immuno-precipitation. For ELISA, obtaining positive result twice is needed to prove the positivity. If the first test is positive but the second test is negative, the ELISA result will be considered as negative.

- Confirmatory test. The screening test usually is very sensitive but the specificity may not be 100%. Its result can be false positive or false negative. Hence, it is necessary to have various confirmatory tests such as ELISA test on another occasion or use the Particle Agglutination (PA), Immunofluorecence and Western blot tests that are widely known and commonly accepted.

2.2 HIV Antigen test

2.3 Test for relevant immunity cell such as CD4 and CD8 lymphocytes. Apportions between CD4 and CD8 lymphocytes should be lower than 0.5.

1.3.3 Classification of HIV infection in children

The Center for Disease Control and Prevention (CDC) of the United States of America has established the following criteria for classification system of Human Immunodeficiency Virus Infection in children age < 13 years (CDC.1994).

Table 1 Pediatric classification of HIV infection

Immunologic Categories	Clinical Categories			
	N: No signs/ Symptoms	A: Mild signs/ symptoms	B: Moderate signs/ symptoms	C: Severe signs/ symptoms
1.No suppression	N1	A1	B1	C1
2.Moderate suppression	N2	A2	B2	C2
3.Severe suppression	N3	A3	B3	C3

Table 2 Immune categories based on age-specific CD4 T-lymphocyte and percentage

Immunologic Categories	Age of children					
	< 12 months		1-5 years		6-12 years	
	No./µL	(%)	No./µL	(%)	No./µL	(%)
CATEGORY 1: No suppression	≥1,500	(≥25)	≥1,000	(≥25)	≥500	(≥25)
CATEGORY 2: Moderate suppression	750-1,499	(15-24)	500-999	(15-24)	200-499	(15-24)
CATEGORY 3: Severe suppression	<750	(<15)	<500	(<15)	<200	(<15)

Table 3 Clinical categories in children with HIV infection age < 13 years

Category N: No symptomatic

Children who have no signs or symptoms considered to be the result of HIV infection or who have only one of the conditions listed in Category A.

Category A: Mildly symptomatic

Children with two or more of the conditions listed below but none of the conditions listed in Categories B and C.

- Lymphadenopathy (>=0.5 cm at more than two sites; bilateral = one site)
- Hepatomegaly
- Spleenomegaly
- Dermatitis
- Parotitis
- Recurrent or persistent upper respiratory infection, sinusitis, or otitis media

Category B: Moderately symptomatic

Children who have symptomatic conditions other than those listed for Category A or C that are attributed to HIV infection. Examples of conditions in clinical Category B include but are not limited to:

- Anemia (<8 g/dL), neutropenia (<1,000/mm^3), or thrombocytopenia (<100,000/mm^3) persisting for at least 30 days
- Bacterial meningitis, pneumonia, or sepsis (single episode)
- Candidiasis, oropharyngeal (thrush), persisting for more than 2 months in children over 6 months of age
- Cardiomyopathy
- Cytomegalovirus infection, with onset before 1 month of age
- Diarrhea, recurrent or chronic
- Hepatitis
- Herpes simplex virus (HSV) stomatitis, recurrent (more than two episodes within 1 year) HSV bronchitis, pneumonitis, or esophagitis with onset before 1 month of age
- Herpes zoster (shingles) involving at least two distinct episodes or more than one dermatome
- Leiomyosarcoma

- Lymphoid interstitial pneumonia (LIP) or pulmonary lymphoid hyperplasia complex
- Nephropathy
- Nocardiosis
- Persistent fever (lasting more than 1 month)
- Toxoplasmosis, onset before 1 month of age
- Varicella, disseminated (complicated chickenpox)

Category C: Severely symptomatic

Children who have any condition listed in the 1987 surveillance case definition for acquired immunodeficiency syndrome e, with the exception of LIP (Which is a category B condition).

The World Health Organization has developed a system for diagnosing probable HIV infection in children based only on clinical signs for use in developing countries. AIDS diagnosis is likely if a child is found to have at least two majors signs and two minor signs, without any immune impairment from others causes. Major and minor signs are as follow (Pancharoen, 2002):

Major signs:

1. Weight loss >10% or failure-to-thrive
2. Chronic diarrhea for longer than one month, whether constant or intermittent.
3. Prolonged fever without a known cause for longer than on month, whether intermittent or continuous in which the definition of fever is body temperature of 37.5 ℃ or more.
4. Chronic lower respiratory tract infection or related symptoms combined with pulmonary imaging study that spontaneously reveal bilateral reticulonodular pulmonary infiltration for 2 or more months, in absence of any microorganisms and not respond to antimicrobial therapy or recurrent infection at location of previous lesion or at a new location for two or more times within 1 year after remission.

Minor signs are:

1. Generalized lymphadenopathy, hepatomegaly or spleenomagaly.
2. Oro-pharyngeal candidiasis.

3. Repeated common infections such as otitis media, pharyngitis wich do not respond to antimiocrobial therapy.
4. Persistent cough over 1 month.
5. Generalized skin infection.
6. Confirm maternal HIV infection during pregnancy or prior delivery or HIV infection in children or detection of HIV antibodies in children.

In Thailand, the diagnosis of HIV infection is based on the laboratory finding combining with the clinical assessment of signs and symptoms to early detect HIV infection and start antiretroviral treatment as soon as possible, which can help the children maintain good health and good quality of life. As a result, they will not be a burden to the society.

1.3.4 Prognosis of the disease in children

Prognosis of HIV infection in children is different from that in adults. Symptoms of HIV infection in children are uncertain and indefinite. Signs of complications involved with many systems may be detected, which are the direct result from HIV infection or immune impairment and opportunistic infection. Clinical characteristics of children with HIV infection are separated into 2 groups as follows (Chotpitayasunondh, 2001):

1. Rapid progressor, which has immediate and severe onset of illness that may express when children are at the age of 2-3 months. These illnesses may include failure to thrive, oro-pharyngeal candidiasis, chronic diarrhea, and pneumonia. The children in this group contracted the virus in-utero. The virus has damage the development of the immune system and the children often die within 1-2 year.

2. Slow progressor, which has gradual progress of symptoms with less severity of the disease. The symptoms usually show when the children get older. The children in this group may have such symptoms as low body weight, hepatomegaly, spleenomegaly, lymphadenopathy, lymphoid interstitial pneumonia (LIP), parotitis and rash. The children contracted the virus during labor or postpartum phase.

HIV-infected children who do not receive any form of treatment can usually be divided into three categories (Newell, 2004):

- About 25-35% of HIV-infected children are rapid progressors who develop severe immunosuppression and several opportunistic infections in the first year of life.

Without treatment, about 50% of infected children will die by age two in Africa. Infants infected in utero are more likely to be rapid progressors;

- Approximately 25-45% of HIV-infected infants who do not receive treatment develop symptoms early in life and progress to death by three to five years of age;
- Between 5% and 25% of HIV-infected children are long-term survivors who live beyond eight years of age without treatment.

In other countries, there are some studies about the prognosis of HIV infection in children. Barnhart conducted a study regarding to the progression of HIV infection disease through clinical stage from birth to death among 2,148 perinatally HIV infected children (Barnhart, 1996). The study revealed that 50% of children born with HIV infection expressed signs and symptoms within the first five years and the progression of the disease from birth until expression of clinical signs and symptoms in category C was about 6.6 years. In the absence of any intervention, the majority of perinatally HIV infected children develop HIV-related symptoms by six months of age. Delayed diagnosis of HIV infection, poor nutrition, and high levels of severe bacterial, respiratory and gastrointestinal tract infections are likely reasons for the higher early mortality (Spira, 1999).

In Thailand, Lumpiganon, Kosararuk, and Lhaopiboon conducted a study to explore survival in 90 children with AIDS by follow-up, starting from birth. All of the children showed the first signs of HIV infection when they were 4 months old. They met the criteria of the WHO for AIDS diagnosis when they were 13 months old (Loompikanon *et al.,* 2000). The differences of HIV/AIDS progression in children who were perinatally infected may depend on various factors in term of infection between the virus and infected children, child rearing, and appropriate antiretroviral treatment.

2. Concept of quality of life

2.1 The definition and concept of quality of life

The World Health Organization has defined quality of life as ‘an individual’s perception of their position in life in the context of the culture and value system in which they live and in relation to their goal, expectations, standards and concerns. It is broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, personal believes and their relationship to salient feature of their environment'. This definition reflects the view that quality of life refers to a subjective evaluation, which is embedded in a cultural, social and environmental context (WHO, 1998).

Patterson has defined quality of life as an abstract and complex term representing individual responses to the physical, mental and social factors which contribute to 'normal' daily living (Holmes, 2003).

Shin and Johnson suggested that quality of life comprised ''the possession of resources necessary to the satisfaction of individual needs, wants and desires, participation in activities enabling personal development and self-actualization and satisfactory comparison between oneself and others'', all of which are dependent on previous experiences and knowledge (Holmes, 2003).

Zhan defined quality of life as the degree to which a person's life experience is satisfying. It was explained that there were both multi-dimensional quality of life and context-related quality of life, since human experiences are dynamic and complex (Zhan, 1992).

Zhan developed a model of quality of life based on the definition of quality of life as 'the degree to which a person's life experiences are satisfying'. Zhan described quality of life as a multidimensional concept that cannot be completely measured by either a subjective or an objective approach. He identified dimensions of quality of life as life satisfaction, self concept i.e. psychological well-being, health and functioning i.e. physical well-being, and socio-economic factors i.e. social well-being. According to this model, quality of life is also influenced by one's personal background, health, social situation, culture, environment (Figure 1).

Physical health is viewed as an objective indicator of quality of life. Thus this concept has been operationalized in terms of the activities in daily life, physical mobility, and/or absence of diseases. Mental (psychological) health include various aspects such as mood states, depression, anxiety, anger, joy and cognitive and mental status, orientation, memory, and confusion. Social health (functioning) includes aspects such as managing interpersonal, family, work, and school relationships, and participating in support groups or volunteer activities. School functioning is particularly considered as an important aspect of social health among school children (Ferrans, 1985).

Life satisfaction is the more stable component, and thus the indicator most frequently included in studies of youths' perceived quality of life. It consists of specific domains of life such as family, environment, friend, and self (Suldo, 2006). Life satisfaction is responsive to changes in external conditions. It is influenced by personal background characteristics, environment and health functioning status.

In summary, the quality of life measurements in children should be approached from many perspectives including physical health, mental health, and social dimensions: especially school functioning is considered as an important social health among school children.

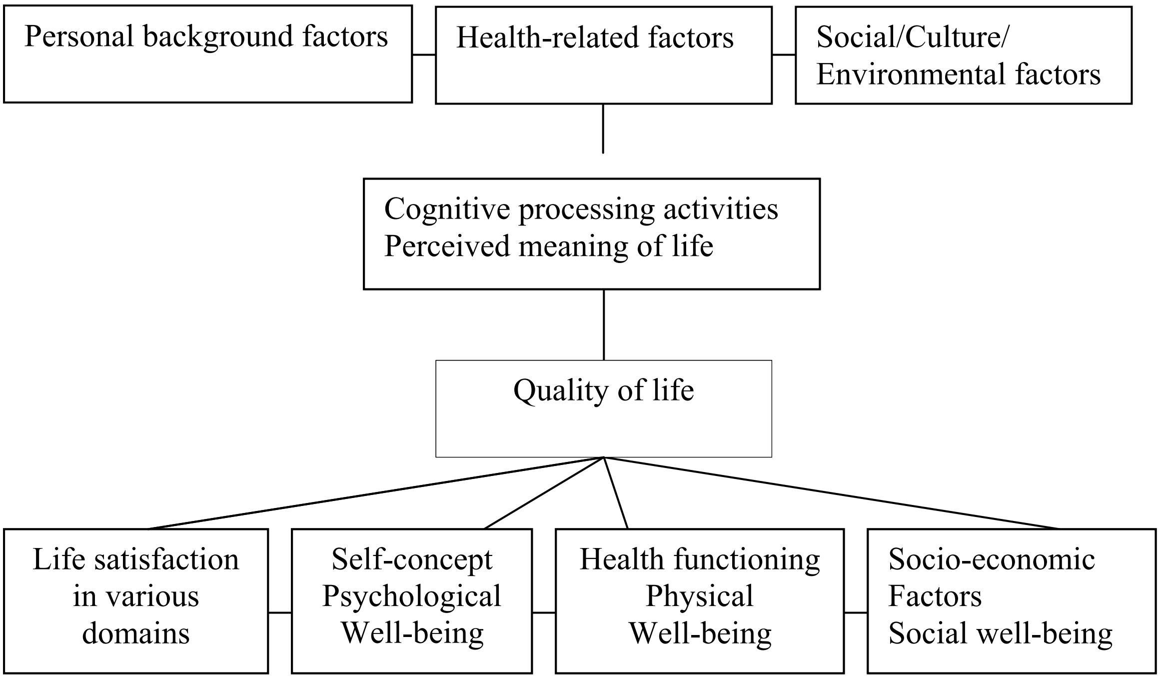

Figure 1 Conceptual model of Quality of life in children

Source: Zhan L. Quality of life: conceptual and measurement issue. Journal and Advanced Nursing 1992: 17: 795-800.

Measurement of quality of life in HIV/ AIDS

The concept of quality of life has been defined in purely objective terms by measuring such items as income, employment, education, physical function, housing and purity of air (Zhan, 1992).

In the past, measuring quality of life of patients was focused on one dimension of patient's life: the ability to perform activities of daily living (ADL) (Mingxia, 1997). Quality of life involves a perception of needs that are currently being met. Perceived quality of life is defined as the extent to which the person's assessed level of satisfaction with life and sense of well-being is positive (Cowan, 1992). More research findings have revealed that health is a major and important concept of quality of life (Zhan, 1992).

Health, similarly, has been taken as an indicator of quality of life often based upon the WHO holistic definition of health which recognized that there was more to health than the 'simple' absence of disease. WHO broadened the definition to include more than physiological criteria, it emphasized many areas in which healthcare practice can have little impact even though almost all aspects of life may impact upon an individual's 'complete physical, mental and social well-being'(WHO, 1947).

World Health Organization has developed the quality of life scale or WHOOL for use in different culture since 1992. The standard version was comprised of 100 items. Later, WHO has developed a shorter 26-items version (WHOOL-BREF) for a field survey by selecting 26 items from the original 100 standard items. This instrument has 4 components: physical health, psychological health, social relationship, and environment (Aeamlaor, 2001).

The National Education Committee Office of Thailand has established the policies and a child development plan that aims to develop the quality of life of Thai children. As the basic minimum needs of each child should be met, in B.E.2533, the National Youth Committee Promotion and Coordination stated that every child born had basic needs, and the criteria for basic needs and services are composed of 7 dimensions: nutritional and health status; physical well-being; development of intellectual, mind, emotional, social condition; education; culture; preparation for a career; and basic rights in politics (Weingkeaw, 1997).

Pediatric Quality of life Interventory 4.0(The PedsQL ^{TM} 4.0) Generic core scales was designed to measure the core physical, mental and social health dimensions as delineated by the World Health Organization, and to additionally include role (school) functioning. The 23-item PedsQL ^{TM} 4.0 encompassed both physical function (8 items) and psychosocial functioning (15 items), as well as mental (5 items), and school functioning (5 items). The mentioned scale was one of the tools for generic health-related quality of life measurements (Vani *et al.*, 2001).

Sociologists and psychologists had primarily described quality of life in terms of life satisfaction and happiness considering how well individual aspirations and/or expectations had been fulfilled (Holemes, 2005). Multidimensional Student's Life Satisfaction Scale (MSLSS) is a tool for quality of life measurement that evaluates life satisfaction of a student. The MSLSS was a 40-item questionnaire, which consisted of five domains (family, school, friends, self, and living environment) (Huebner, 2001).

The quality of life of people with HIV/AIDS is a complex of disease, poverty, stigma, discrimination, and lack of treatment combined with family, work, and social activities (Phaladze, 2005). For this reason, in the development and implementation of a reliable and valid cross-cultural quality of life measurement, it is necessary that the measurement tool can be used not only to assess the physical and medical needs of HIV/AIDS people, but also their psychological, social, environmental and spiritual areas of life (Casado, 2005).

3. Health belief model

The Health Belief Model was one of the first models that adapted theory from the behavioral sciences to health problems, and it remains one of the most widely recognized conceptual frameworks of health behavior. It was originally introduced in the 1950s by psychologists working in the U.S. Public Health Service (Hochbaum, Rosenstock, Leventhal, and Kegeles).It was a psychological model that attempts to explain and predict health behaviors by focusing on the attitudes and beliefs of individuals.

Health Belief Model has been applied to studies of all types of health behavior. A person's motivation to undertake health behavior can be divided into three main categories: individual perceptions, modifying behaviors, and likelihood of action.

Individual perception is a factor that affects the perception of illness of a disease, it deals with importance of health to the individual, perceived susceptibility, and perceived severity. Modifying factors include demographic variables, perceived threat, and cue to action. The likelihood of action refers to the probability of exhibiting appropriate health behaviors, i.e. the likelihood of taking the recommended preventive health action. The combination of these factors cause a response that often manifests into action, provided that it is accompanied by a rational alternative course of action.

The HBM states that the perception of a personal health threat is itself influenced by at least three factors: general health value, which include interest and concern about health; specific health belief about vulnerability to a particular health threat; and beliefs about the consequences of the health problem. Once an individual perceives a threat to his/her health and is simultaneously cued to action, and his/her perceived a benefit outweighs the losses, then that individual is most likely to undertake the recommended preventive health action. There may be some variables (demographic, sociopsychological, and structural) that can influence an individual's decision.

Perceived Susceptibility – Each individual has his/her own perception of the likelihood of experiencing a condition that would adversely affect one's health. Individuals vary widely in their perception of susceptibility to a disease or condition. Individuals in the moderate susceptibility category admit will to a statistical possibility of disease susceptibility. Those individuals in the high susceptibility category will feel that there is real danger and that they will experience an adverse condition if they contract a given disease.

Perceived Seriousness – Perceived seriousness refers to the belief a person holds concerning the effects a given disease or condition would have on one's state of affairs. These effects can be considered from the point of view of the difficulties that a disease would create. For instance, pain and discomfort, loss of work time, financial burdens, difficulties with family, relationship, and susceptibility to future conditions. It is important to include these emotional and financial burdens when considering the seriousness of a disease of condition.

Perceived Benefits of Taking Action – Taking action toward the perception of disease or toward dealing with an illness is the next step to take after an individual has accepted the susceptibility of a disease and recognized its seriousness. The direction of action that a person chooses will be influenced by the belief regarding the action.

Barrier to Taking Action – Recommended health action may not take place, even though an individual may believe that the benefits to taking action are effective, if there are barriers to taking such action. Barriers related to the characteristics of treatment or preventive measures may be inconvenience, high expense, unpleasantness, pain or upsetting conditions. These characteristics may lead a person away from taking the desired action.

Cues to action – an individual's perception of the level of susceptibility and seriousness provide the force to act. Benefits (minus barrier) provide the path of action. However, it may require "a cue to action" for the desired behavior to occur. These cues may be internal and external (Rosenstock *et al.*, 1994).

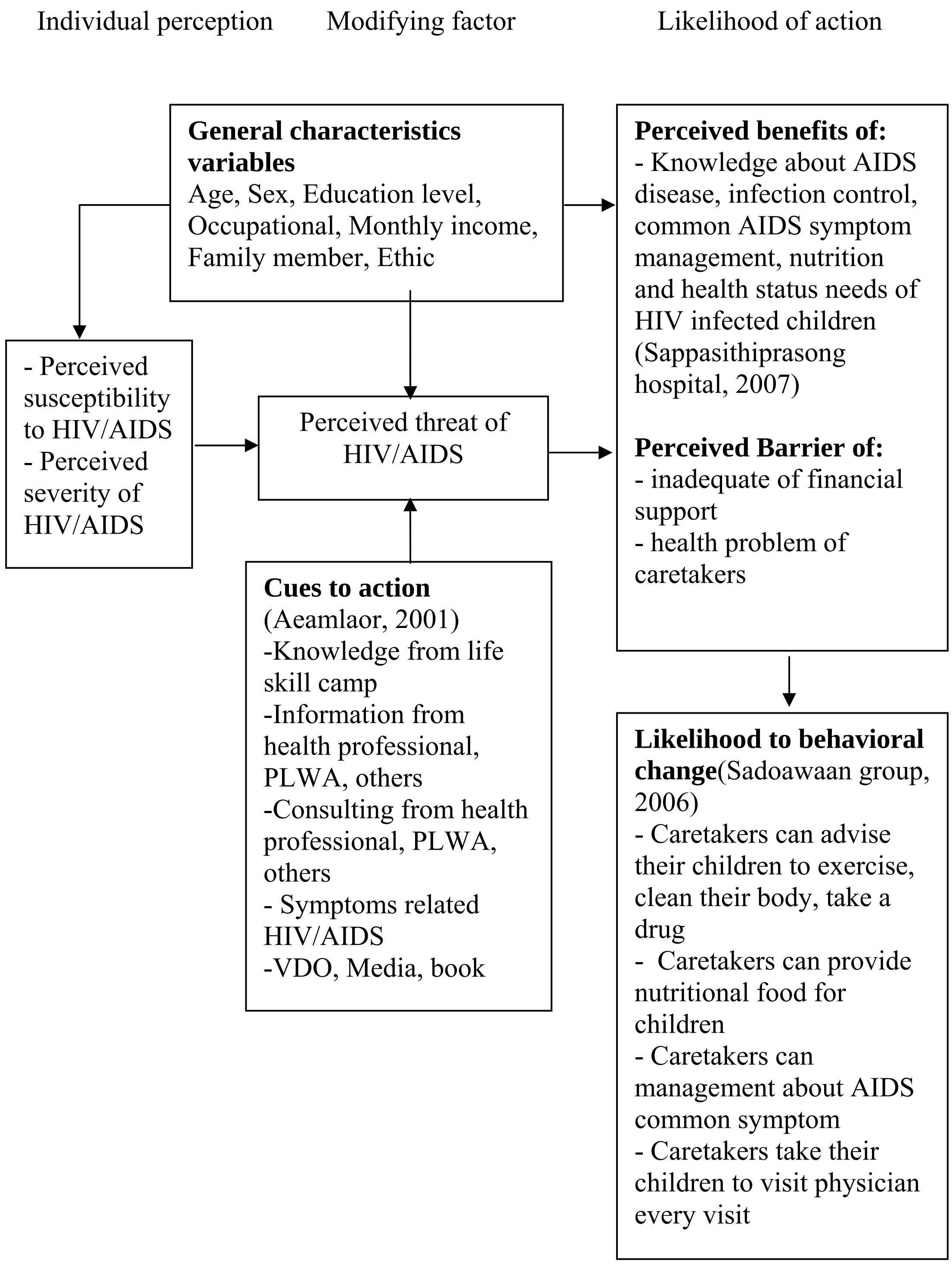

Figure 2 Health Belief Model

4. Factors related to quality of life in HIV infected children

4.1 Socio-demographic characteristics of children

4.1.1 Age.

Orem stated that when children became older, they would have more development of intelligence, maturity of thoughts, reason of concrete thinking, ability to evaluate situation and make decision, and self- responsibility (Orem, 1985). Phupaiboon found that the age of the child was a factor that had negative relationship with the role of the parents. Parents tended to decrease helping and caring for their child when the child became older (Phupaiboon, 1990). Children with HIV infection who were in school age did not need so much physical support but, they needed more emotional support than infants and toddlers (Caliando, 1998). A study has found that relationships with friends and children's health status had an effect on the development and well being of school age children, as most children in fifth through seventh grade found themselves to have many friend at school (Svavarsdottir and Orlygsdottir, 2006).

4.1.2 Gender

From a study of factors influencing nutritional status of infants aged up to 5 years, it was shown that boys received food and had better nutritional status better than girls (Yodteur, 1990). Another study in rural Henan Province, China, showed that there were differences between orphan boys and non-orphan boys, and girls in some nutritional, psychological and quality of life indicators (He and Ji, 2007). These effects were not present in Tanzania and Uganda, although it was found that girls were more likely to be affected by problems than boys (Makame *et al.*, 2002). Another study reported on health-related quality of life in Icelandic schoolchildren that girls had better perception of health -related quality of life than boys (Svavarsdottir and Orlygsdottir, 2006).

4.1.3 Family structure and Number of Caretaker

Families have been the primary source of all health-related behavior patterns including HIV. Pattern of family treatment and care was embedded in this wider kinship system. The AIDS epidemic has caused adverse psychosocial and economic consequences, leading to changes in the family structure and thus disturbed the capacity of the nuclear and extended family to respond to the needs of family members affected by HIV and AIDS (Ankran, 2005). In certain countries, those who are infected with HIV typically live their extended family networks (e.g. Uganda and china) (Rotheram-Borus *et al.*, 2005). A study in Namibia found that 52.5 percent of respondents stated that the family and communities should be responsible for the care of HIV-infected individuals. Another study in sub –Sahara Africa found that nearly all children orphaned by AIDS lived were living with their extended families (Sunpuwan, 2001).

When parents die, the extended family provides HIV infected children the emotional nurturing and socialization that is the primary role of the family. This allows HIV infected children to be well-adjusted. In Thai society, care of children by grandparents is common. Tayansin stated that extended family provided sufficient care to children and gave support such as emotional support, tangible support, information support, better than nuclear family (Tayansin, 1998).

4.1.4 Severity of illness

During the early stage of HIV epidemic in Thailand, it was found that 85% of children expressed symptom in the first 3 years of life. Mean incubation period was approximately 10 years, while the period of time since expression of AIDS-related illness to death was dependent on treatment and level of CD4 (Kunanuson, 2002). The proportion of children who displayed AIDS-defined symptoms were 23% and 40% at the age of one and four years, respectively. Lumpikanon stated that the mean age of children who expressed symptoms was 3 months and found association with high level of virus after the age of 1-2 years and progression of disease to AIDS or death. In addition, antiretroviral treatment reduced the level of virus and showed association with favorable improvement of clinical symptom (Kosaralak, 2002).

It had been reported that health-related quality of life in Icelandic school children that children with chronic health condition or illness had their health-related quality of life were significantly lower than children without chronic health condition (Svavarsdottir and Orlygsdottir, 2006).

4.1.5 Antiretroviral use

Lee studied perinatally HIV-exposed infants who were HIV-infected (N=1847) and Uninfected (N=712) on quality of life during childhood and adolescence. Impact of HIV infection and antiretroviral treatment was that children 5 to 11 years of age and adolescents 12 to 21 years of age in no-antiretroviral treatment group had worse health perceptions than those receiving antiretroviral agents. And those in the no-antiretroviral treatment group had significantly worse symptom, compared with those receiving antiretroviral agents in adolescents 12 to 21 years of age (Lee, 2007).

4.2 Socio-demographic characteristics of caretakers

4.2.1 Age

Age is a factor that implies the quantity and the type of help that a person wants and is related to the ability to provide care for other individuals and be responsible for other individuals. As an older person would be more experienced, the latency in a person's provision of care increases with age, which will peak in adulthood and slow down at old age (Orem, 1985).

A more matured person should be seek for their ability to consider good choices and make a good decision in taking care of AIDS orphans. This corresponds with Molly A. Rose, who said that old individuals had more experience and had learned to confront problems better than younger individuals (Rose, 1998). A study by Patunwan found that the age of caretakers had a positive relationship with the ability to care for their child with acute lymphoblast leukemia (Patoomwan.1991).

4.2.2 Gender

Mahal and Rao conducted a study in India in a review of economic research on AIDS, and stated that households belonging to the poor and less educated or unskilled groups, as well as female members of households, faced a proportionately greater economic burden due to AIDS (Mahal and Rao, 2005). Dolbin-MacNab studied American grandmothers and found that the grandmothers seemed very confident in their parenting abilities and did not question applying their parenting strategies to their grandchildren because their previous parenting mistakes improve their parenting (Dolbin-MacNab, 2006).

4.2.3 Education

Weingkaew stated that the relationship between quality of life of school-age children with asthma and educational of mothers who had vocational/diploma was more significant than mothers who not attended and primary school (Weingkeaw, 1997). In another study on the determinants of young children quality of life in children age 5-8 years indicated that the father's income and education were significant explanatory variables (Jirojanakul, 2003). Ji studied the impact of HIV/AIDS on families and children in China and reported that some children affected with HIV/AIDS had to repeat a grade level. Poor performance in school will in turn affect the children's future as adults in family setting of caregivers who have very low level of education, and were almost illiterate(Ji *et al.*, 2003).

4.2.4 Occupation and Family Income

HIV/AIDS changes the number of family members, and the structure of the family is significantly modified. The structural change is accompanied by significant losses of income, as HIV is the fastest way for a family to move from relative wealth to relative poverty (Rotheram-Borus, 2005). Poverty deprives people of access to health services, schooling information, and education more than depriving them of wealth. Sunpuwan found that the economic problem of households with orphans could be traced to the loss of the middle generation, with most household being made up of young children and their grandparents. The grandparents need to find money to pay for the basic needs of their grandchildren, while social discrimination restricted their employment opportunities. They were affected by losing family income from the death of a family member in their productive years (Sunpuwan, 2001). Sommarin studied the needs of caregivers who were relatives of HIV/AIDS-infected people and found that when the family of HIV/AIDS-infected people had less income that was inadequate to pay for the cost of living, then it was a problem to care for HIV/AIDS-infected people (Somnarin *et al.*, 1997). In Thailand's Chiang Mai province, a large proportion of children who had lost one or both parents to HIV-related illnesses were being cared for by grandparents and other extended family members. Many of these families that provided care suffered significant financial hardship, highlighting concerned about the children's long-term well-being, stability and educational opportunities (Safman, 2004).

4.2.5 Relationship between caretakers and children

Children with HIV/AIDS often lived with their biological mothers who were single female heads of households in lower socioeconomic strata. However, the mothers also had the additional emotional challenge of dealing with their own HIV/AIDS signs and symptoms, stigma issues, rejection by family and friends, fear of being sick, possible frequent hospitalizations, and concerns over their children's long-term guardianship (Rose, 1998). Different issues surfaced when Reidy interviewed 30 caregivers (13 biologic mothers and 5 biologic fathers and 12 grandmothers or foster parents) at a Canadian pediatric AIDS clinic. The psychosocial needs that the caregivers identified in this study were: to learn ways in which to protect the infected child from other types of infection, to be respected and supported by health providers and to obtain honest answers to their questions, to learn how to deal with stress, and to be useful and worthwhile (Reidy, 1991). Rose reported that perceived support from family and perceived support from friends were significantly higher in the alternative caregivers (relatives and family friends or social agencies) as compared to mother-caregivers ($p < .001$ and $p < .05$, respectively) (Rose, 1998). This might be related to the perceived or real stigma and fear of rejection associated with telling family and friends about their HIV-positive status. Makame studied orphans' internalizing problem scores and found that orphans who were living with a surviving parent or with adult relatives scored lowest, while the orphan who were living alone, or with a non-relative, scored highest and score of orphans with grandparents were intermediate (Makame,2002).

4.3 Knowledge, attitudes and practices toward HIV/AIDS of caretakers

The Health Belief Model (HBM) was proposed to explain the relationship between cognitive variables and health behavior among pediatric patient population (e.g. cancer, obesity, asthma). Parental cognitive variables outlined in the HBM have been associated with adherence to various prescribed health behaviors. It has been reported that maternal perception of vulnerability was predictive of health-related outcome variables such as appointment keeping, preparation of a prescribed diet, and weight change among children with obesity (Becker *et al.*, 1997). Similar results were found by Labay, who reported about the effect of caretakers who had good knowledge, positive attitude, and good level of practices on childhood diarrhea. There was water source and water storage for drinking, a latrine in the house, garbage collection, drainage system for domestic water waste, and housing sanitation that was characterized as hygienic (Labay *et al.*, 2007). Contradicting results were found in a study from Karnataka State in India, which revealed that 1669 participants aged 19-49 years had relatively good knowledge regarding HIV/AIDS and its modes of transmission (52%) and 80 percent correctly answered that AIDS could not be cured, but they agreed that people living with HIV/AIDS (PLWA) should be kept away from others and 40 percent were not willing to accept a family member with HIV/AIDS (Meundi *et al.*, 2008). 62 percent of the participants were willing to undergo an HIV testing. This willingness to opt for HIV testing increased significantly with better knowledge score, better attitude score, and higher education status.

4.4 Social support

Social support represents a significant factor which both directly and indirectly affects health of individuals as well as their behaviors in that the support of others requires interpersonal relationship, thus building a feeling of personal self-value while motivating them to achieve healthy behavior to maintain well-being and good health. Social support, therefore, is essential to the health status of individuals. There are several definitions of social support as follow:

Cobb (1976) defined social support as information leading the subject to believe that he or she is cared for and loved is esteemed and value and belongs to social network of community and have mutual obligation.

Kaplan, Cassel, and Gore (1977) noted that individuals in the network provided relationships and their support provided nourishment for self-esteem, normative affirmation, dependency relatedness, clarification of expectations (if needed), and the discharge of disturbing affects.

Schaefer et al. (1981) defined social support as something that nurtures individuals when they are facing with stress in their lives.

House (1981) asserted that social support is the interaction among individuals which consists of love, caring, trust, assistance in the form of money or labor, information sharing, and feedback for self-learning and self-assessment.

Thoits (1982) pointed out that social support exists when individuals in a social network receive help in the form of morale, material, or information, which enables them to encounter and respond to sickness of stress in a shorter time.

Pender (1987) defined social support as a person’s general perception of belief that people in their social network would provide assistance in times of need or, on the other hand, they would receive help if enacted.

In summary, social support refers to emotional, psychological, material, and information supports that help people live in the society.

Type of social support

Cobb (1976) classified the social support into 3 types as:

1. Emotional support, which is the information leading an individual to believe that he or she is cared for and loved.
2. Esteem support, which is the information leading an individual to believe that he or she is esteemed and valued.
3. Social support or network support, which is the information leading an individual to believe that he or she belongs to a network of communications and mutual obligation.

House (1981) classified the social support into 3 types as:

1. Emotional support, which refers to caring, empathy, love, and trust.
2. Appraisal support, which refers to affirmation, feedback, and social comparison that created self-confidence.
3. Information support, which refers to advice, suggestion, directives, and information that could be used to solve the existing problem.
4. Instrumental support, which refers to aid in kind of necessity such as finance, labor, tome, and services.

Schaefer et al. (1981) classified social support into 3 types as:

1. Emotional support, which refers to bonding, warmth, and trust.
2. Information support, which is defined as advice on solutions or feedback about behavior of actions of other people.
3. Tangible support, which refers to the help in the form of material, money or services.

In general, type of support may be divided into “emotional” and “practical” (or instrumental). Emotional support includes “information” support, where support sources provide information which may help the respondent in problem solving. A further important component of emotional support is related to self-appraisal. Practical support is manifest in many forms, including practical help and financial support (Biscoti and Bergerman, 1999).

Mechanisms for the action of social support for health

There are two types of mechanisms. The first type of mechanisms is that which has a direct effect on support for health. Direct effects of social support on health may result from increasing perception of control over environment, and immunity to disease (Stansfeld, 2006). In the second type of mechanism, support does not have direct effects on health but helps to moderate the impact of acute and chronic stressor on health (Figure 3). When there is a potential threat, a supportive person may help to reappraise the threat implicit in stressor, perhaps making it more manageable or even avoidable. Moreover, practical aid or emotional consolation may help to moderate the impact of the stressor and help the person deal with consequences of the stressor, which might otherwise be damaging of health (Stansfeld, 2006).

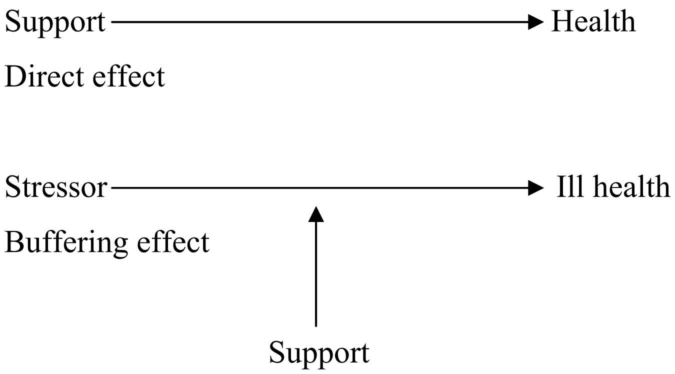

Figure 3 Direct and buffering effects of social support

Several study showed the effects of social support on health, in analyses, adjusted for age on the severity of myocardial infraction and other morbidities, subjects who reported no resources of emotional support experienced a nearly three fold higher mortality rate at six months than those reporting one or more sources of support (Bekman *et al.*, 1992). It might be possible that social support was operating here to strengthen the immune response to illness. It was stated that in the case of AIDS, the bereavement of AIDS patients has been associated with fall in the CD4 lymphocyte count, while increase in social support has been associated with an improvement in this index of immune function (Kiecolt-Glaser, 1995). In Henderson's community study in Canberra, measurement of perceived adequacy of support showed a much stronger negative relationship with neurotic symptoms: those who viewed their social relationships as inadequate were substantially more at risk of developing neurotic symptoms (Stansfeld, 2006).

5. Related study

There are not many numbers of studies in quality of life of HIV infected children, only few attempts have been made on the quality of life, in many areas of factor influences the quality of life of HIV infected children widely in 5-15 years of ages.

He and Ji studied the quality of life of AIDS orphans among 8-15 years of 186 children (93 orphans, 93 non-orphans) from a rural area of Henan province, China, by using the Inventory of Subjective Life quality for Children and Adolescents (ISQL), and reported that AIDS children orphans had depression, low self-esteem and lower quality of life. These differences mainly existed in boys in scoring of four ISQL dimensions of family life, school life, living environment and self-awareness. In the orphans' group main problem of living conditions focused on economical support, skill to earn money, and equal treatment by others (He and Ji, 2007).

Makame studied some of the possible stressors among orphans and non-orphans children aged 10-14 years whose parent had died from AIDS in Dar Es Salaan, Tanzania. It was demonstrated that going to bed hungry and not attending school were associated with increased internalizing problem which the scale comprised 21 items concerning mood, pessimism, somatic symptom, sense of failure, anxiety, positive effect, and emotional ties. Moreover, they found orphans both boys and girls had remarkedly increased internalizing problem compared with non-orphans ($p<0.0001$). There was a tendency for girls to have the most problems (Makame *et al.*, 2002).

Aeamlaor studied the quality of life of HIV-infected orphaned children in northern Thailand. Children aged 5-9 years and their caregivers were interviewed regarding the responsiveness to basic human needs and services for children in 7 dimensions, health evaluation, and life satisfaction. The result was that 96.2 % of HIV-infected children subjects had good quality of life. Therefore, they did not feel that they were neglected, which may contribute to their mental well-being and had good level of life satisfaction (Aemlaor, 2001).

Kie assessed the quality of life of HIV/AIDS-affected children in 90 children aged 9-12 years who received support from one particular non-governmental organization in northern Thailand. The study investigated the quality of life in 5 dimension: physical functioning, emotional functioning, social functioning, school function, and life satisfaction and found that 41.1% of the children were at a good level of quality of life, while only 25.6% and 33.3% were at a good level of school functioning and mental health. If support from the non-governmental organization were excluded, 74.7% of the children would need improvement on the level of social support. This study found that only monthly income of household members was significantly associated with level of quality of life (p=0.026)(Kanda, 2004).

As mentioned above, the results of all articles mentioned had covered many aspects of quality of life, including physical, emotional, social well-being and factors which influence quality of life such as age, gender, income, and social support. In conclusion, the measurement of quality of life is associated with socio-economic, psychological, and physical health. To increase understanding of the meaning of quality of life for children living with HIV, this study would use the quality of life concept of Zhan, which includes 5 dimensions: physical functioning, emotional functioning, social functioning, school functioning, and life satisfaction.

CHAPTER III
METHODOLOGY

Research design

A cross-sectional descriptive study was conducted to investigate social and behavioral factors related to the quality of life among HIV infected children who have received medical care from Infectious disease pediatric clinic of Sappasithiprasong Hospital, Ubonrachathani province.

Site of study

The pediatric infectious disease clinic of Sappasithiprasong Hospital, Ubonrachathani province provides medical care services for HIV infected children as follow: 1) HIV infected children are cared by Patient Comprehensive Treatment Team which are composed to Medicine, Pediatric, Obstetrics and Gynaecology staff, 2) HIV infected children and their caretakers received medical services at one-stop services 3) HIV infected children and their caretakers are empowered knowledge toward HIV/AIDS by health care providers to take care of themselves 4 times/year and organized a skill life camp 2 times/year, which result in improving adherences of children from 85% to 90%, 4) HIV infected children and their caretakers received home visit from PLWA(Sappasithiprasong hospital, 2007).

Population and sample

Study population

The study population was HIV infected children from mother to child transmission who had received medical care from the pediatric infectious disease clinic of Sappasithiprasong Hospital and their respective caretakers. 82% of these populations lived in rural area(Sappasithiprasong hospital, 2007). There were 94 HIV infected children and their respective caretakers, children age 8-15 years old, both sex.

Sampling procedure and sample size

Purposive sampling was used for the selection of participants.

Inclusion criteria for children

- HIV infected children 8 -15 years old;
- had received medical care from the pediatric infectious disease clinic of Sappasithiprasong Hospital for at least 1 year (registered before February, 2007, caretakers and children obtained completely education package from the pediatric infectious disease clinic of Sappasithiprasong Hospital for caring people living with HIV/AIDS within one years.).
- singed the consent informed (assent informed)

Inclusion criteria for caretakers

- Caretaker was a person who had gives a full time or part time to care a child for at least 6 months.
- singed the consent inform

Exclusion criteria for children

- A child who could not communicate because of severe symptoms related to AIDS or opportunistic infection.

Exclusion criteria for caretakers

- A caretaker who did not take care for HIV infected child for at least 6 months.

Sample size

Sample size of the study was calculated by using the following formula (Yamane, 1973)

$$n = \frac{N}{1 + N(e)^2}$$

$$n = \frac{N}{1 + N(0.05)^2}$$

$$= \frac{114}{1 + 114(0.05)^2}$$

= 89

Where; n = number of sample size

N = total number of population of children who have received medical care from Infectious disease pediatric clinic of Sappasithiprasong Hospital

e = probability of error (5%, 95 percent confidence)

To prevent the data error from sample size population increased 5% that total number was 94.

Research instruments

The structured questionnaire was used which composed of two parts:

Part 1 was the questionnaire for caretakers including; socio-demographic characteristics of children, socio-demographic characteristics of caretakers, knowledge, attitudes and practices toward HIV/AIDS of caretakers, and social support.

Part 2 was a quality of life responded by children and caretakers.

Part 2 was an information collection from the children medical records.

The details of each part were as follow:

Part 1 including:

Socio-demographic characteristics of children's interview were developed by the investigator for collecting general information about the subject, included education, extended or nuclear family, antiretroviral use, number of caretakers, parents being alive and caring their child.

Socio-demographic characteristics of caretaker's interview were developed by the investigator for collecting general information about the subject , included age, gender, education, occupation, income, relationship between caretakers and children.

Knowledge, attitudes and practices toward HIV/AIDS of caretakers' questionnaires, the investigator developed the questionnaire from the literature review. It assessed understanding of caretakers' knowledge, attitudes and practices toward HIV/AIDS manifestation, treatment, prevention, and caring people living with HIV/AIDS included 3 components:

1. Knowledge of caregivers; there were 12 questions (item 14-25); the score was a total score of all sub-item ranging from 0-23 scores. Item 14 was an introduction item exclude from scoring.

Criteria for scoring:

Correct answer in each sub-item scored 1.

Incorrect answer in each sub-item scored 1.

Then total score of all sub-items are summed up. Knowledge of caregivers was categorized to 2 levels:

More than $\overline{X}$ + 1SD was good.

Less than $\overline{X}$ +1SD was needed for improvement.

2. Attitudes of caretakers; the questionnaire composed 10 questions. There were 2 types of statements which were positive (item 30,32,33,34,35) and negative (item 26,27,28,29,31) with 5-level rating scale, a total score of all questionnaire ranging from 10-50 scores.

Criteria for scoring:

	Positive statement score	Negative statement score
Strongly agree	5	1
Agree	4	2
Neutral	3	3
Disagree	2	4
Strongly disagree	1	5

Then, total score of all questionnaires were summed up. Attitude of caretakers, categorized to 2 levels:

More than $\overline{X}$ + 1SD was a good attitude.

Less than $\overline{X}$ +1SD was a moderate attitude.

3. Caregivers’ practices about caring HIV/AIDS person. There were 9 questions (item 36-44). The score was a total score of all questions, ranging from 0-18 scores. It was categorized to 3 scales: always, sometime, never.

Criteria for scoring:

Always, the score was 2.

Sometimes, the score was 1.

Never, the score was 0.

It was categorized to 2 levels:

More than $\overline{X}$ + 1SD was good.

Less than $\overline{X}$ +SD was needed for improvement.

Social support questionnaire were developed by the investigator from the literature review. It assessed level of social support for HIV infected children and family in 5 types of support food, clothes, financial, consultation, information. From 5 sources of social support as follow: family (item 45-49), neighbors (item 50-54), community (item 55-59), government (item 60-64), and NGOs (item 65-69).

The total number of types of support was summed up for all five sources. It was categorized to 2 levels:

More than $\overline{X}$ + 1SD was good.

Less than $\overline{X}$ +SD was needed for improvement.

Then quality of social support was classified into 3 groups: adequate, moderate, and inadequate.

Part 2: quality of life questionnaires

This questionnaire was based on the quality of life concept of Zhan (Zhan, 1992) to describe the meaning of quality of life for children**.** Each dimension was developed from literature review in previous study as follow: physical functioning and school functioning used items of the Pediatrics Quality of life Interventory™ version 4.0 Generic Core Scales in healthy and Patient Population (PedsQL™) and did not modified items (Vani *et al.*, 2001). Emotional functioning, investigator modified original items " I am un happy, also crying" to 2 items due to its differences action. The original social functioning items separated to 2 dimensions which were relationship with peer and social. This study was combined it due both of its related to social development of children. Both emotional and social function used items of the School Children Behavioral Check list for parent(Manual for caring Mental Health for Teacher, Ministry of Public Health, Thailand) (Department of Mental, 2003). Life satisfaction were modified from 40 original items in 5 domain, this study used 8 items in 5 domain of Multidimensional students' Life satisfaction Scale (Manual for the Multidimensional students' Life satisfaction Scale) (Huebner, 2001)

The investigator modified some the original items so that they were appropriate to be used with caregivers and HIV infected children. There are composed of 5 dimension.

1) physical functioning	item 70-75
2) school functioning	item 76-80
3) emotional functioning	item 81-86
4) social functioning	item 87-96
5) life satisfaction	item 97-104

There were 2 types of statements which were positive (item 88, 89, 91-104) and negative (item 70-86, 87, 90) with in 3-level scale.

Criteria for scoring item:

	positive statements score	negative statements score
Never	0	2
Sometimes	1	1
Always	2	0

The criteria items can be used this definition in a negative statement.

Always = children can not do daily or normal activities.

Sometimes = children can do daily or normal activities less than 70%.

Never = children can do daily or normal activities more than 70 %.

And in a positive statement;

Never = children can not do daily or normal activities.

Sometimes = children can do daily or normal activities less than 70%.

Always = children can do daily or normal activities more than 70 %.

Criteria for scoring item 97-104: all of items are positive statements

Disagree	0	score
Neutral	1	score
Agree	2	score

There were 35 items; the total score of quality of life was categorized into 2 levels:

More than $\overline{X}$ + 1SD was good.

Less than $\overline{X}$ +SD was needed for improvement.

Emotional functioning, social functioning and life satisfaction were responded by children. Every question did not relate to HIV wording. Physical and school functioning was answered by caretakers.

Part 3: an information collection from children medical records.

The questionnaires were developed by the investigator for collecting secondary information from children's medical record included gender, and age, date of birth, severity of illness classified by CDC, antiretroviral use, and duration of antiretroviral use.

Validity and Reliability

1. **Validity**. Three experts were asked to assure the content validity of the research instruments with included: socio-demographic characteristics of children's interview, socio-demographic characteristics of caretakers' interview, knowledge, attitude and practice toward HIV/AIDS of caretakers questionnaire, social support questionnaire, quality of life questionnaires, an information collection from children's medical record. The experts also considered the research objectives, appropriate content and language used. List of experts were in Appendix A. they were:

Nurse	2	persons
Psychologist	1	person

After the experts reviewed the interviewed and questionnaire, the investigator would modify items according to their comments and suggestions.

2. **Reliability**. The investigator used the interview and questionnaires with 20 caregivers and children who had similar characteristics as those in the study. Cronbach Alpha coefficient was used for calculation of reliability of knowledge, attitudes toward HIV/AIDS of caretakers' questionnaires**,** social support questionnaires and quality of life questionnaires**.** The reliabilities were 0.78, 0.61, 0.91, and 0.78 respectively.

Data collection

The study site was the pediatric infectious disease clinic of Sappasithiprasong Hospital. All 110 HIV infected children aged 8-15 years old visit the clinic who caretakers allowed to participants were recruited as study subject. The researcher excluded those caretakers who took care of HIV infected children less than 6 months. All caretakers and HIV infected children voluntarily participated and signed the consent form/assent form. The children and their caretakers were interviewed by trained interviewers. Oral interviewing was used by asking the children and caretakers.

Socio-demographic characteristics of children, socio-demographic characteristics of caretakers, knowledge, attitudes and practices toward HIV/AIDS of caretakers, and social support questionnaires were responded by caretakers.

The quality of life questionnaires separated for interviewing. Emotional functioning, social functioning and life satisfaction were responded by children. Physical and school functioning was answered by caretakers.

CD4 count, classification of illness, age and gender were collected from the children medical records with permission of the director of Sappasithiprasong Hospital.

Data analysis

SPSS 11.5 software was used for data analysis with the statistic level of significance at 0.05.

1. Descriptive statistics was utilized for analysis socio-demographic characteristics of children, socio-demographic characteristics of caretakers**,** knowledge, attitudes and practices toward HIV/AIDS, social support**,** and quality of life by the frequency, percentage, mean, and standard deviation.
2. Chi-square test was used to determine association of socio-demographic characteristics of children, socio-demographic characteristics of caretakers, knowledge, attitudes and practices toward HIV/AIDS, social support with quality of life of HIV infected children.
3. Multivariate using Multiple Logistic Regression for to adjusting confounding variables to determine independent variables were the predictor of quality of life of HIV infected children

Ethical considerations

The study proposal was approved by the Ethical Committee of Faculty of Tropical Medicine and the Ethical Committee of Sappasithiprasong Hospital. The participants were explained and asked to sign a consent form with voluntarily participation in the research project.

CHAPTER IV
RESULTS

This study was conducted to investigate the social and behavioral factors related to quality of life in HIV infected children.

The sample was 110 HIV infected children who were registrations before February 2007 and their respective caretakers. The number of the children was 114, but four of them did not participate in this study which resulted in the number of 110. Both children and caretakers had been receiving medical care services from the pediatric infectious disease clinic of Sappasithiprasong Hospital, Ubonrachathani province. Data were collected by interviewing and using structured questionnaires from October 2008 to November 2008. The study findings are presented as follow:

1. Socio-demographic characteristics of children
2. Socio-demographic characteristics of caretakers
3. Knowledge, attitudes and practices toward HIV/AIDS of caretakers
4. Social support for HIV infected families
5. Quality of life of HIV infected children
6. Socio-demographic characteristics of the children, socio-demographic characteristics of the caretakers and quality of life in HIV-infected children
7. Knowledge, attitudes, practices toward HIV/AIDS and social support for HIV infected children families and quality of life in HIV infected children
8. Socio-demographic characteristics of both and the quality of life in HIV infected children, analysis was performance by Multiple Logistic Regression

Table 4 Socio-demographic characteristics of the study children

Variable	Number n = 110	Percent
Gender		
Male	49	44.5
Female	61	55.5
Age (in years)		
8-12	70	63.6
13-15	40	36.4
(Range = 8-15, Mean = 11.75, SD = 1.94)		
Family structure		
Nuclear	40	36.4
Extended	70	63.6
Primary caretakers		
Biological parents	61	55.5
other	49	44.5
Main caretakers		
Mother/Farther	46	41.8
Grand mother/Grandfather	48	43.6
Relatives	13	11.8
Foster parent	1	0.9
Other	2	1.8
Number of assistance caretakers (persons)		
0	23	21.3
1	64	59.3
2	17	15.7
3	3	2.8
4	1	0.9

Table 4 Socio-demographic characteristics of the study children (continued)

Variable	Number n = 110	Percent
Parent being alive		
Yes	62	56.4
No	48	43.6
Caring their child by themselves (n=62)		
Yes	43	69.4
No	19	30.6
CD4% (Range = 2-38 , Mean = 23.36 , SD = 8.56)		
CD4 count (cell/µL.)		
< 200	10	9.3
200-499	26	24.0
≥500	72	66.7
(Range = 30-1802, Mean = 675.75, SD = 35.35)		
CDC classification		
N	6	5.6
A	36	33.3
B	48	44.4
C	18	16.7
Antiretroviral use		
No	3	2.7
Yes	107	97.3
Duration on treatment		
1-3 years	53	50.0
4-6 years	53	50.0
(Range = 13-82 months, Mean = 43.40 months, SD = 17.86 months)		

Table 4 showed that the proportions of female and male children were similar (55.5% and 44.5 %). Most of the children were 8-12 years old (63.6%); the mean age was 11.65 years with a standard deviation of 1.94 year. The majority of the children were living with extended families (63.6%), the primary caretakers after knowing the HIV status of the children were biological parents (55.5%) and grandparent or aunt (44.5%). The main caretakers of the children were mother/farther (41.8%) and relatives (11.8%). Only three children were cared by foster parents or other. More than half of the child had one assistant caretaker, 15.7 percent had two, but 21.3 percent did not have any assistant caretaker to help the main caretakers. For the parent being alive, 56.4 percent of children had a father or a mother or both, and 70 percent of the parents were able to take care of the child by themselves. By clinical categories, most of the HIV-infected children were in category B (moderately symptomatic) (44.4%), and only 5.6 percent were not symptomatic. Almost 70 percent of the children had CD4 count $\geq$ 500 cell/µL.and 9 percent had CD4 count < 200 cell/µL. CD percentage ranged from 2 to 38, mean CD percentage was 23.36 and standard deviation was 8.56. The majority of the children used antiretroviral drugs and the duration of treatment was 13 to 82 months, the mean was 43.40 and the standard deviation was 17.86.

Table 5 Socio-demographic characteristics of caretakers

Variable	Number n = 110	Percent
Gender		
Male	25	22.7
Female	85	77.3
Age (in years)		
20-39	34	30.9
40-59	49	44.5
≥60	27	24.5
(Range = 23-80, Mean = 48.95, SD = 13.81)		
Education		
Primary school	74	67.3
Secondary school	22	20.0
Diploma/ vocational	4	3.6
Not attend school	10	9.1
Occupation		
Civil services/state enterprise	1	0.9
Agriculturalist	52	47.3
Employee	18	16.4
Merchants	19	17.3
Other	2	1.8
No work	18	16.4
Family income/month (Baht)		
≤1,999	38	34.9
2,000-4,999	41	37.6
5,000-9,999	29	26.6
≥10,000	1	0.9
(Range = 400-20000 , Mean = 3130, SD = 2748.56)		

Table 5 Socio-demographic characteristics of caretakers (continued)

Variable	Number n = 110	Percent
Relationship between caretakers and children		
Biological parents	44	40.0
Relatives	64	58.2
Other	2	1.8

Table 5 presented frequency and percentage of socio-demographic characteristics of the caretakers. More than one-third of the caretakers (77.3%) were female, and approximately 22 percent were male. The age of caretakers varied from 23 to 80 years with the mean age being 48.95 years, while the standard deviation was 13.81 years. Most of the caretakers (67.3%) completed primary school, 20 percent completed secondary school, 3.6 percent completed diploma/vocational and 9.1 percent had not attended school. Almost 50 percent of the caretakers were agriculturalist, followed by merchants, employee (17.3% and16.4%), 16.4 percent of them were unemployed.

Monthly family income varied from 400-20,000 baht (mean = 3,130, SD = 2,748.56), most of the families had monthly family income between 2,000-4,999 baht (37.6%), followed by ≤1,999 baht (34.9%), and 5,000-9,999 baht (26.6%). More than half of the caretakers were relatives. 11.8 percent of caretakers were foster parents who took their child to visit the physician at the day interviewing.

Table 6 Knowledge, attitudes, practices toward HIV/AIDS of caretakers and social support for HIV infected children families

Variable	Number n = 110	Percent
Knowledge		
good	32	29.1
needed for improvement	78	70.9
(Range = 4-23 , Mean = 16.25, SD = 4.36)		
Attitudes		
good	45	40.9
moderate	65	59.1
(Range = 24-50 , Mean = 37.70, SD = 5.38)		
Practices		
good	53	48.2
needed for improvement	57	51.8
(Range = 11-18 , Mean = 16.69, SD = 1.70)		
Social support		
good	17	15.5
needed for improvement	93	84.5
(Range = 0-25 , Mean = 11.70, SD = 4.68)		

Table 6 showed the frequencies and percentages about the knowledge, attitudes, and practices toward HIV/AIDS of caretakers and social support for families of HIV infected children. More than 70 percent of caretakers showed a need for improvement in their knowledge (Mean = 16.25, SD = 4.36) and social support (Mean = 11.70, SD = 4.68). Only 15.5 percent of them had a good score for social support. The proportion of caretakers with moderate attitudes scores (Mean = 37.70, SD = 5.38) was 59 percent. The proportion of caretakers with practices score in need of improvement (Mean = 16.69, SD = 1.70) was 51.8 percent.

Table 7 Percent of knowledge in caretakers regarding HIV/AIDS

Statements	Number n = 110	Percent
Knowledge of HIV cause		
HIV	94	85.45
Devemon virus (represented HIV virus in the cartoon to teach children)*	16	14.55
Knowledge of symptom		
Weight loss	75	68.18
Chronic diarrhea	67	60.90
Prolong Fever	91	82.72
Knowledge of transmission		
Sexual intercourse	100	90.90
Transplacental	87	79.09
Sharing injection needle	70	63.63
Blood transfusion	62	56.36
Others	23	20.90
How do you prevent from HIV?		
Do not have sexual intercourse	54	49.09
Use condom	94	85.45
Do not sharing injection needle	69	62.72
Others	15	13.63
Knowledge of treatment and caring children with HIV		
AIDS can be treated or not		
Treatment with modern medicine*	76	69.09
Can not cure now	30	27.27
There are an opportunistic infections or not		
Tuberculosis	87	79.09
Pneumonia	82	74.54
Candidiasis	63	57.27

Table 7 Percent of knowledge in caretakers regarding HIV/AIDS (continued)

Statements	Number n = 110	Percent
What caretakers should do for caring for children diarrhea?		
Taking antibiotic drugs*	51	46.36
Drinking ORS water	65	59.09
Taking to physician	102	92.72
Do not thing*	1	0.90
What caretakers should do for caring the child when had TB patient in their house?		
Taking to physician for screening TB	80	72.72
Not allow children closing TB patient	88	80.00
Do not thing*	4	3.63

* incorrect statement

Table 7 showed knowledge regarding HIV/AIDS among 110 caretakers. Only 60% of the caretakers knew that chronic diarrhea was a symptom of AIDS, and only 63% and 56% knew that sharing injection needle and blood transfusion, respectively, were the routes of transmission of HIV. Only 27% knew that AIDS cannot be treated now, 58% knew that candidiasis was an opportunistic infection of AIDS, and 59% knew that drinking Oral Rehydration Salts solution (ORS) was appropriate.

Table 8 Percent of social support for HIV infected children's families (n=110)

Type of support\Source (percent)	Family	Neighbor	Community	Government	NGOs
Food	95.5	56.4	8.2	31.8	12.7
Clothes	95.5	48.2	10.9	30.9	14.5
Financial	92.7	33.1	8.2	57.3	15.5
consultation	92.7	60.0	15.5	67.2	51.8
Information	90.9	51.0	19.1	66.3	52.7

Table 8 showed that more than 90 percent of the families of HIV infected children received all types of social support from their family, followed by their neighbors who provided support in terms of food, clothes, and consultation (56.4%, 48.2%, and 60.0% respectively), followed by the government which provided support in terms of finance, consultation, and information (57.3%, 67.2%, and 66.3% respectively). The communities provided small amount of all types of social support for the families. Furthermore, approximately 50 percents of the families received consultation and information support from NGOs.

Table 9 Adequacy and needs of social support from five sources for HIV infected children families (n=110)

Sources/types	Don't received %	Received %			Don't needs %	Needs %		
		adequate	moderate	inadequate		great	moderate	least
Family								
food	4.5	44.5	38.2	12.7	21.8	23.6	48.2	6.4
clothes	4.5	41.8	40.0	13.6	20.9	18.2	49.1	11.8
finance	7.3	27.3	41.8	23.6	16.4	**40.0**	38.2	5.5
consultation	7.3	**53.6**	30.0	9.1	21.8	26.4	41.8	10.0
information	9.1	**45.4**	39.1	5.5	23.6	27.3	40.0	9.1
Neighbor								
food	43.6	1.8	42.7	11.8	43.6	4.5	41.8	10.0
clothes	51.8	3.6	31.8	12.7	49.1	2.7	38.2	10.0
finance	67.3	0.9	13.6	18.2	41.8	10.0	37.3	10.9
consultation	40.0	12.7	28.2	19.1	41.8	12.7	30.9	14.5
information	49.0	5.5	26.4	19.1	43.6	10.0	30.0	16.4
Community								
food	91.8	0.9	4.5	2.7	**54.5**	8.2	27.3	10.0
clothes	89.1	0.9	5.5	4.5	**57.3**	8.2	23.6	10.9
finance	91.8	1.8	2.7	3.6	**44.5**	22.7	27.3	5.5
consultation	84.5	8.2	4.5	2.7	**52.7**	12.7	22.7	11.8
information	80.9	6.4	9.1	3.6	**50.0**	14.5	24.5	10.9
Government								
food	68.2	6.4	15.5	10.0	21.8	29.1	40.0	9.1
clothes	69.1	3.6	15.5	11.8	21.8	22.7	33.6	21.8
finance	42.7	4.5	26.4	26.4	14.5	**50.0**	32.7	2.7
consultation	32.8	**41.8**	23.6	1.8	11.8	49.1	32.7	6.4
information	33.7	**44.5**	19.1	2.7	11.8	50.0	32.7	5.5
Non-government								
food	87.3	4.5	4.5	3.6	46.4	12.7	35.5	5.5
clothes	85.5	2.7	9.1	2.7	49.1	11.8	30.0	9.1
finance	84.5	0.9	9.1	5.5	40.0	16.4	39.1	4.5
consultation	48.2	18.2	28.2	5.5	29.1	28.2	34.5	8.2
information	47.3	20.0	26.4	6.4	29.1	28.2	36.4	6.4

Table 9 showed that HIV infected children's family received adequate social support for consultation and information from family sources (53.6%, 45.4%) and governmental organization (41.5%, 44.5%). However, the proportion of families which needed financial support from family sources and governmental organization were 40% and 50%, respectively. Almost 50% of the family did not need all types of social support from the community.

Table 10 Quality of life in HIV infected children

Variable	Number n = 108	Percent
Quality of life		
good	23	21.3
needed for improvement	85	78.7

Table 10 showed frequency and percentage of quality of life in HIV infected. The majority of the children needed improvement in their quality of life, while 21.3 percent had a good level of quality of life. Two children were excluded from analysis because of incomplete data due to the fact that they did not attend school.

Table 11 Distribution of quality of life scores in HIV infected children

Variable	Possible range	Actual range	Mean	SD
Overall Quality of life	0-70	34-68	50.87	8.24
Physical Functioning	0-12	1-12	7.92	3.33
School Functioning	0-10	3-10	6.35	1.70
Emotional Functioning	0-12	1-12	8.49	2.57
Social Functioning	0-20	6-20	14.40	3.82
Life Satisfaction	0-16	3-16	13.57	2.89

Table1 11 showed both the overall (mean = 50.87, SD = 8.24) and individual dimension of quality of life. The mean scores were high. The mean scores of physical functioning was 7.92(ranged = 1-12, SD = 3.33), the mean scores school functioning was 6.35(ranged = 3-10, SD = 1.70), the mean scores of emotional functioning was 8.49(ranged = 1-12, SD = 2.57), the mean scores of social functioning was 14.40(ranged = 6-20, SD = 3.82), the mean scores of life satisfaction was 13.57(ranged = 3-16, SD = 2.89).

Table 12 Socio-demographic characteristics of children and their quality of life (n = 108)

Variable	Quality of life (%)		Crude Odds Ratio (95% CI)
	Good	Needed for improvement	
Gender			
Male	14.3	85.7	1.00
Female	27.1	72.9	2.23(0.83-5.97)
Age (in years)			
8-12	15.9	84.1	1.00
13-15	30.8	69.2	2.34(0.92-5.98)
Family structure			
Nuclear	15.0	85.0	1.00
Extended	25.0	75.0	1.88(0.67-5.27)
Main caretakers			
parents	8.7	91.3	1.00
other	30.6	69.4	**4.64(1.45-14.78)**
Number of assistance caretakers (persons)			
Zero	30.4	69.6	1.00
One or more	19.3	80.7	0.54(0.19-1.54)
Parent being alive			
Yes	11.3	88.7	1.00
No	34.8	65.2	**4.19(1.55-11.31)**
Caring child with biological parents			
Yes	9.3	90.7	1.00
No	15.8	84.2	1.82(0.36-9.11)

Table 12 Socio-demographic characteristics of children and their quality of life (n = 108) (continued)

Variable	Quality of life (%)		Crude Odds Ratio (95% CI)
	Good	Needed for improvement	
CDC classification			
Symptomatic (B,C)	18.8	81.2	1.00
Asymptomatic (N,A)	26.2	73.8	1.53(0.60-3.90)
CD4 count (cell/ µL.)			
≤ 200	30.0	70.0	1.00
200-499	32.0	68.0	1.09(0.22-5.39)
≥500	16.9	83.1	0.46(0.10-2.10)
CD4%			
<25	24.5	75.5	1.00
≥25	18.9	81.1	0.71(0.28-1.81)

Table 12 showed that children who were cared by others (grandparents, relatives, others) had better quality of life than those who cared by their biological parents (OR=4.64, 95% CI=1.45-14.78). Children who did not have parents had better quality of life more than those who have parent being alive (OR=4.19, 95% CI=1.55-11.31).

Table 13 Socio-demographic characteristics of caretakers and the quality of life of children (n = 108)

Variable	Quality of life (%)		Crude Odds Ratio (95% CI)
	Good	Needed for improvement	
Gender			
Male	28.0	72.0	1.00
Female	19.3	80.7	0.61(0.21-1.71)
Age(in years)			
20-45	5.7	94.3	1.00
>45	36.4	63.6	**9.52(2.62-34.53)**
Education			
Did not attend school	50.0	50.0	1.00
Primary school	20.3	79.7	0.25(0.05-1.13)
Secondary school	15.4	84.6	0.18(0.03-1.04)
Diploma/vocational			
Occupation			
No work	18.8	81.2	1.00
Agriculturalist	25.0	75.0	1.44(0.35-5.87)
Others	17.5	82.5	0.91(0.20-4.10)
Family income/month			
>5,000 Baht	6.7	93.3	1.00
≤5,000 Baht	27.3	72.7	**5.25(1.14-23.99)**
Relationship between caretakers and children			
Biological parents	9.1	90.9	1.00
Relatives	30.6	69.4	**4.41(1.38-14.10)**

Table 13 showed that children of caretakers over 45 years old had better the quality of life in the children compared to those caretakers 20-45 years old (OR=9.52, 95%CI=2.62-34.53). The children with family income per month of 5,000 baht and lower were 5.25 times had better the quality of life more than those with family income per month more than 5,000 baht. The children who were living with relatives had better the quality of life more than who were living with biological parents (OR=4.41, 95%CI=1.38-14.10).

Table 14 Knowledge, attitudes, practices toward HIV/AIDS and social support for HIV infected children families with the quality of life of children (n = 108)

Variable	Quality of life (%)		Crude Odds Ratio (95% CI)
	Good	Need for improvement	
Knowledge			
needed for improvement	18.4	81.6	1.00
good	28.1	71.9	1.73(0.66-4.54)
Attitude			
moderate	20.3	79.7	1.00
good	22.7	77.3	1.15(0.45-2.92)
Practices			
needed for improvement	21.8	78.2	1.00
good	20.8	79.2	0.93(0.37-2.36)
Social support			
needed for improvement	23.1	76.9	1.00
good	11.8	88.2	0.44(0.09-2.10)

Table 14 showed there was no a significant association of knowledge, attitudes, practices toward HIV/AIDS and social support with the quality of life in the children.

Table 15 Independent variables and the quality of life of children (n = 108)

Variable	Quality of life (%)		Ajusted Odds Ratio (95% CI)
	Good	Need for improvement	
Gender of child			
Male	14.3	85.7	1.00
Female	27.1	72.9	1.63(0.52-5.07)
Age of children (in years)			
8-12	15.9	84.1	1.00
13-15	30.8	69.2	1.76(0.55-5.60)
Main caretakers			
parents	8.7	91.3	1.00
other	30.6	69.4	0.51(0.06-3.82)
Parent being alive			
Yes	11.3	88.7	1.00
No	34.8	65.2	3.21(0.78-13.20)
Age of caretakers(in years)			
20-45	5.7	94.3	1.00
>45	36.4	63.6	**6.32(1.12-35.62)**
Education of caretakers			
Did not attend school	50.0	50.0	1.00
Primary school	20.3	79.7	0.37(0.06-2.02)
Secondary school Diploma/vocational	15.4	84.6	0.46(0.05-4.05)
Family income/month			
>5,000 Baht	6.7	93.3	1.00
≤5,000 Baht	27.3	72.7	3.01(0.56-16.28)

Table 15 showed multiple logistic regression analysis, after adjusting for socio-demographic characteristics of children (gender, age, main caretakers, parent being alive), and socio-demographic characteristics of caretakers (age, education, family income) revealed that the age of caretakers was a predictor for the quality of life of the children. The caretakers who were older than 45 years of age had a positive association with the quality of life of the children (OR=6.32, 95%CI=1.12-35.62).

CHAPTER V

DISCUSSION

The discussion is presented as follows as the objectives of the study.

1. Quality of life in HIV infected children.

Results of this study showed that the quality of life in HIV infected children needed improvement (78.7 %). Only 21.3 percent of HIV infected children had a good level of quality of life. This study contrasted a previous study by Aeamlaor, who investigated the quality of life regarding the basic human needs and services in 7 dimensions in HIV infected orphans children aged 5 to 9 years in the northern part of Thailand. In the mentioned study, 92.2 percent of the children, who were cared for by social welfare organizations, had a good level of quality of life (Aeamlaor, 2001). It may explain that 82 percent of HIV infected children in this study were living in rural areas (Sappasithiprasong hospital, 2007). They were living in their community, so the quality of life was different from children who were cared for by social welfare organizations and received appropriate caring, treatment, and adequate financial support.

This study was consistent with that of Kanda. The mentioned study was conducted on the quality of life in HIV-affected children aged 9 to 15 years who received support by particular non-governmental organizations and were living in communities in Chaing Mai and Lampoon provinces. 41.1 percent of the children had a good level of quality of life (Kanda, 2004). This study also showed that more girls had a better good quality of life (27.1%) than boys (14.3%), which was consistent with a previous study that girls in Icelandic school perceived better health-related quality of life than boys (Svavarsdotti and Orlygsdottir, 2006). Children aged 13-15 years old had a good level of quality of life more than those children aged 8-15 years old (30.8% and 15.9%, respectively). A possible explanation could be that children would have more development of intelligence, maturity of thought, reason of concrete thinking, ability to evaluate situation and make decision, and self-responsibility when they became older (Orem, 1985).

2. Socio-economic characteristics of children and their quality of life.

This study, the main caretakers and parent being alive was significantly associated with the quality of life at $p<0.05$. Those children who were not parent being alive were 4.19 times better quality of life than those who were parent being alive. Those children who were cared for by others (grandparent, relatives, foster parent, others) were 4.64 times better quality of life than those who were cared for by parents. It may explain that a parents were unable cared for his/her child because they had a health problem related to HIV infection and were unemployed or going to work in another province. It showed that 30 percent of parents who were parent being alive did not care for their child by themselves.

This study, there was no significant association between family structure and quality of life. It contradicted the results of a previous study that extended families had a positive relationship with the basic caring of AIDS orphans within family, and that extended families were able to care for the child better than nuclear family (Wiboonchai, 2001). In this study, 63 percent of HIV infected children were living in extended families similar to study in sub – Sahara Africa found that nearly all children orphan by AIDS lived in extended families (Sunpuwan, 2001). In the study area, the number of caretakers who provided assistance were similar to a previous study in the northern part of Thailand, which found that the children had one or more person who took care them, but there was no significant association with the quality of life (Kanda, 2004). This may be related to the strength of the kinship system in rural of Thailand, in some cases the family structure is nuclear but the family would be surrounded by households of relatives.

In Bivariate analysis, the CDC classification was combined into 2 groups: asymptomatic (stage N and stage A) and symptomatic (stage B and stage C). It showed that asymptomatic group had a higher percentage of those with good quality of life (26.2%) than the symptomatic group (18.8%). It could be explained that most children who were treated with antiretroviral drugs (97%) reduced their viral loads and increased their CD4 counts, but those children still had health risk and psychological risk because of the chronic nature of their illness. It has been reported that there was significantly higher quality of life in HIV infected children who had no immune suppression comparing to that in children with immune suppression (Oberdofer, 2008).

3. Socio-demographic characteristics of caretakers with the quality of life in HIV infected children.

This study categorized age of caretakers into 3 groups. However, due to the small number of caretakers in each group, the age of the caretakers was then combined into 2 groups. The children who were cared by caretakers aged 45 years old and higher had better quality of life than those whose caretakers were 20-45 years old (OR=6.32, 95%CI=1.12-35.62)(table 15). It was contrast to Orem stated that the latency in caring for a person increase follow age which will be peak in adult age and be slow down at the old age (Orem, 1985). It may explain that caretakers aged 20-45 years old, most of them were parents and was HIV positive. They may have a health problem related to HIV infection which difficulty for them to keep up with their child.

The children with family income per month of 5,000 baht and lower were 5.25 times had better quality of life more than those with family income per month more than 5,000 baht. It may explain that 46 percent of caretakers who had monthly family income of more than 5,000 baht had an occupation in the “others” category (e.g. merchants, employee, other), the work obligation of which would restrict them from participating in empowerment activities provided by the clinic. It was revealed that 87.5 percent of the children who were cared by caretakers who were merchants, employees, and other professions needed more improvement in the social aspect of their quality of life comparing to other children. The results of this study contradicted a previous study, which showed that school-aged children with asthma with average monthly family income of 18,000-30,000 baht per month and higher had better quality of life than those living in families with income less than 6,000 baht per month (Weingkeaw, 1997). It may explain that caretakers who were aged 45 years old and higher may not earn much money which they had family income of 5,000 baht and lower.

In area of relationship between caretakers and children, the children who were living with relatives (grandparent, aunt, uncle, adult siblings)had better quality of life more than who were living with biological parents (OR=4.41, 95%CI=1.38-14.10). This contradicted with another study on HIV infected families, which found that mother and child had more bonding and found that the mother would stop working and provide exclusive care and sympathy to the child, especially when the child was sick and hospitalized (Lamchang, 1998).

4. Knowledge, attitudes and practices toward HIV/AIDS of caretakers with the quality of life in HIV infected children.

This study showed that there was no significant association between knowledge, attitudes, and practices towards HIV/AIDS and quality of life. More than 70 percent of caretakers needed improvement in their knowledge toward HIV/AIDS (Mean = 16.25, SD = 4.36). 59 percent of caretakers had a moderate level of attitudes toward HIV/AIDS (Mean = 37.70, SD = 5.38). It has been reported that 88.6% of caretakers had negative attitudes toward children diarrhea, and there was a negative (though non-significant) association between level of attitude and diarrhea occurrence (Labay, 2007). It was shown that 51 percent of caretakers needed improvement in practices in caring for HIV-infected children (Mean = 16.69, SD = 1.70).

The result of this study contradicted with a previous study from Karnataka State in India. 1669 participants aged 19-49 years had relatively good knowledge regarding HIV/AIDS and its modes of transmission (52%). 80 percent answered that AIDS could not be cured and they agreed that people living with HIV/AIDS (PLWA) should be kept away from others. Also, 40 percent were not willing to accept a family member with HIV/AIDS. 62 percent of the participants were willing to undergo HIV testing, and this willingness to opt for HIV testing increased significantly with better knowledge score, better attitudes scores, and higher education status (Meundi, 2008). Another study in Roi-et province, Thailand, showed that most of the family members of people living with HIV/AID had a good knowledge toward HIV/AIDS but two-thirds of them separated used utensils and toilet from people living with HIV/AIDS (Burirat, 2005).

This study was explained by Health Belief Model components. Ninety percent and 79.9% of the caretakers perceived susceptibility to HIV infection by sexual transmission, and transpalcental respectively. Caretakers perceived severity that AIDS could not be treated at the time, but they viewed that a person with HIV infection might have a long life if he or she were treated with antiretroviral (69.1%). Caretakers received health education regarding AIDS and caring for HIV person from health care providers. The life skill camps, empowerment activity, books, media, were used to provide the health education. Caretakers perceived barrier of financial support and their health problem. However, 49% of caretakers reported that they had a good practice to take the preventive health action. They advised their children to exercise, to clean their body, to take the drugs, and took the children to the physician when they became sick.

5. Social supports with the quality of life in HIV infected children.

This study showed that 84.5 percent of the children needed an improved level of social support for them and their families (Mean = 11.70, SD = 4.68). There was no significant association between social support for the children’s family with quality of life. The result of this study contrasted with a previous study, which showed that social support was a factor positively affecting the basic caring in families of AIDS orphans. It may be related to the fact that the families of HIV infected children limited themselves in term of belonging to their community (Wiboonchai, 2001). It presented a small amount of all types of support such as food (8.2%), clothes (10.9%), financial support (8.2%), consultation (15.5%), and information (19.1%) from community source the community leader was the largest supporter for information, finance, food, and clothes. It was reported that in the North of Thailand, the community provided little help to orphans and their families on three aspects of family provision of care to orphans, namely physical, psychological, social and educational support. Although the families received some help from governmental and non-governmental organizations, the help remained inadequate (Sunpuwan, 2001). This study showed that family source provided all types of social support, accounting for more than 90%. Most of neighbor source supported consultation (60%) and food (56%). The government source showed that among 35 HIV infected families, 28 of them received food support and 20 families received clothes from school. 84 percent of the families of HIV infected children received financial support from sub-district administrative organizations, which provided 500 baht per month. Most of the hospitals were the source of consultation and information (more than 80%). Non-governmental organizations, such as the Global Foundation, provided indirect support though the self-help group of people living with HIV/AIDS (PLWA), which provided more than 90 percent of consultation and information for the children’s families.

CHAPTER VI
CONCLUSION

Summary of the study

This cross-sectional study was conducted in Ubonratchathani province, Thailand to assess quality of life in HIV infected children and determine the association between socio-demographic characteristics of children, socio-demographic characteristics of caretakers, knowledge, attitudes and practices toward HIV/AIDS of caretakers, social support and quality of life. 110 HIV infected children and their respective caretakers were recruited in the study. Those children aged 8-15 years old had received medical care from the pediatric infectious disease clinic of Sappasithiprasong Hospital, Ubonratchathani province. They were interviewed by structured questionnaires from October 15 to November 30, 2008. Descriptive statistics, Chi-square test and Multiple Logistic Regression Analysis (multivariate analysis) were performed.

Findings of the study were summarized as follows:

1. 78.7 percent of the children needed to improve quality of life and 21.3 percent had a good level of quality of life.

2. This study found a significant association between age of caretakers, family income, main caretakers, parent being alive, relationship between caretakers and children with the quality of life of the children at $p < 0.05$.

3. Multiple regression analysis which adjusted for socio-demographic characteristics of children (gender, age, main caretakers, parent being alive), and socio-demographic characteristics of caretakers (age, education, family income) showed the children who were cared by caretakers aged 45 years old and higher had better quality of life than those whose caretakers were 20-45 years old (OR=6.32, 95%CI=1.12-35.62).

4. There were no significant association between knowledge, attitudes and practices toward HIV/AIDS of caretakers, social support with the quality of life at $p < 0.05$.

Recommendations for implementation

1. Family income has a significant association with the quality of life of HIV infected children; government and non-government organizations should focus on support of generating income programs for their families.
2. Providing the knowledge about HIV/AIDS should focus on including individual persons and group of caretakers. This knowledge should be provided continuously to promote their understanding about symptoms, prevention, treatment, and caring people living with HIV/AIDS.
3. Government, NGOs and communities should be co-operating to provide better knowledge of HIV/AIDS to community populations for greater understanding and supporting of those living with HIV/AIDS.

Recommendations for further study

1. In this study, most of the social support for HIV infected children's families was received from external sources. In further study, social support should focus on investigating internal community sources of all type of support, especially emotional support related to self appraisal of HIV infected children families.
2. This study found that the efficacy of social support services varied by the characteristics of the support services provided. Thus further studies should focus on the intervention that co-operates between local administrative organizations, health care centers, community hospitals, groups of PLWA, and communities to plan for caring for HIV infected children's families and to develop referral systems to receive support in communities which concern people living with HIV/AIDS, and treating them with dignity and respect.
3. This study showed that knowledge of caretakers needed for improving. Further study should find health education patterns that focus on old age volunteers to promote communication channels among these groups to enhance care for people living with HIV/AIDS.

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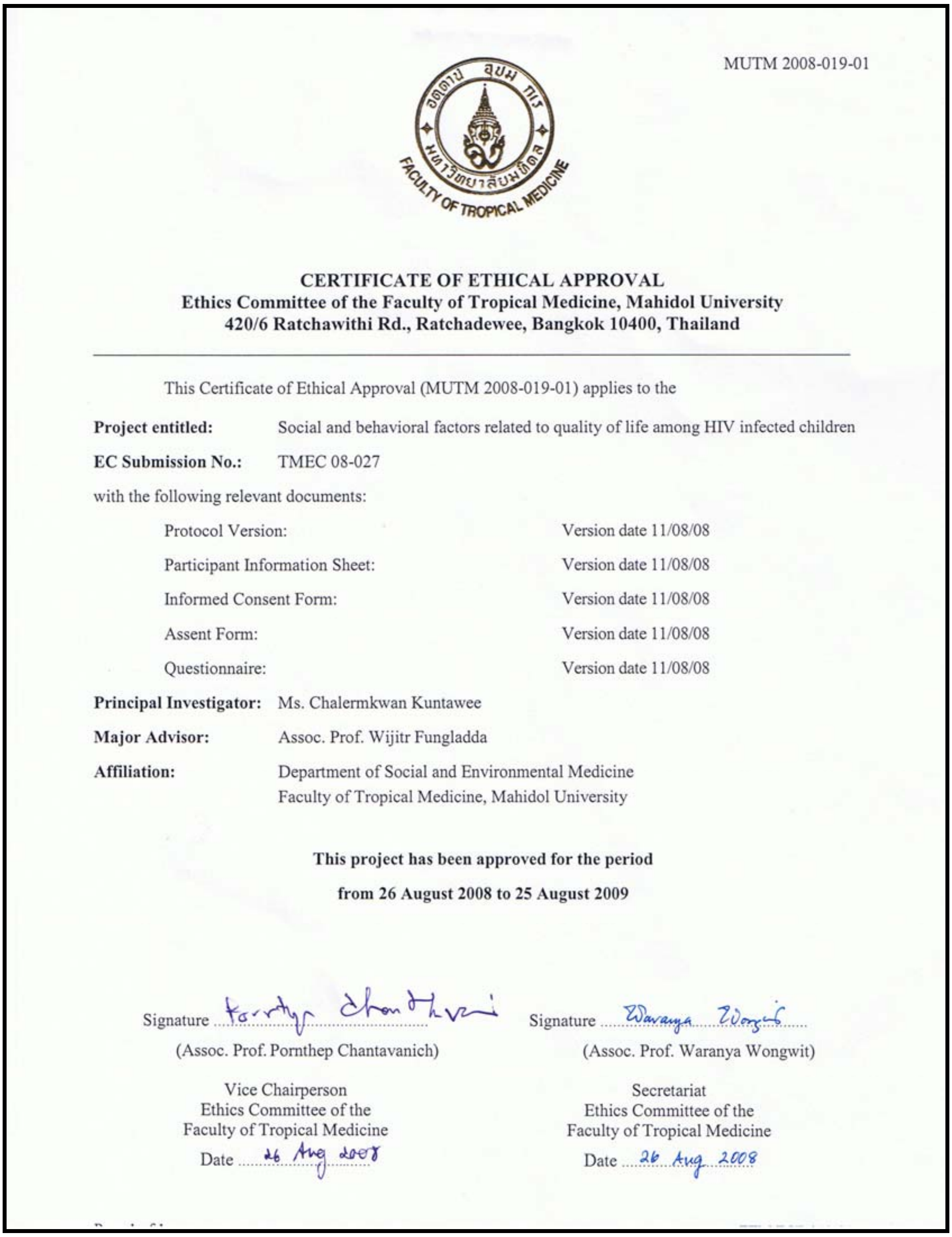
APPENDIX

APPENDIX A
LIST OF EXPERTS

The content validity of the interviews and questionnaires used in this study were assured by three expert persons. Name list of expert persons was as follow:

1. Mrs. Rattanaporn Tangyingyong, RN
   Pediatric infectious disease clinic of Sappasithiprasong Hospital
2. Miss Inthira Reungsith, Clinical Psychologist
   Mental health clinic of Sappasithiprasong Hospital
3. Mrs.Palidchat Jaisupab, RN, M.N.S. (Mental Health and Psychiatric Nursing)
   Mental health clinic of Sappasithiprasong Hospital

APPENDIX B
CERTIFICATE OF ETHICAL APPROVAL



MUTM 2008-019-01

CERTIFICATE OF ETHICAL APPROVAL
Ethics Committee of the Faculty of Tropical Medicine, Mahidol University
420/6 Ratchawithi Rd., Ratchadewee, Bangkok 10400, Thailand

This Certificate of Ethical Approval (MUTM 2008-019-01) applies to the

Project entitled: Social and behavioral factors related to quality of life among HIV infected children

EC Submission No.: TMEC 08-027

with the following relevant documents:

Protocol Version:	Version date 11/08/08
Participant Information Sheet:	Version date 11/08/08
Informed Consent Form:	Version date 11/08/08
Assent Form:	Version date 11/08/08
Questionnaire:	Version date 11/08/08

Principal Investigator: Ms. Chalermkwan Kuntawee

Major Advisor: Assoc. Prof. Wijitr Fungladda

Affiliation: Department of Social and Environmental Medicine
Faculty of Tropical Medicine, Mahidol University

This project has been approved for the period

from 26 August 2008 to 25 August 2009

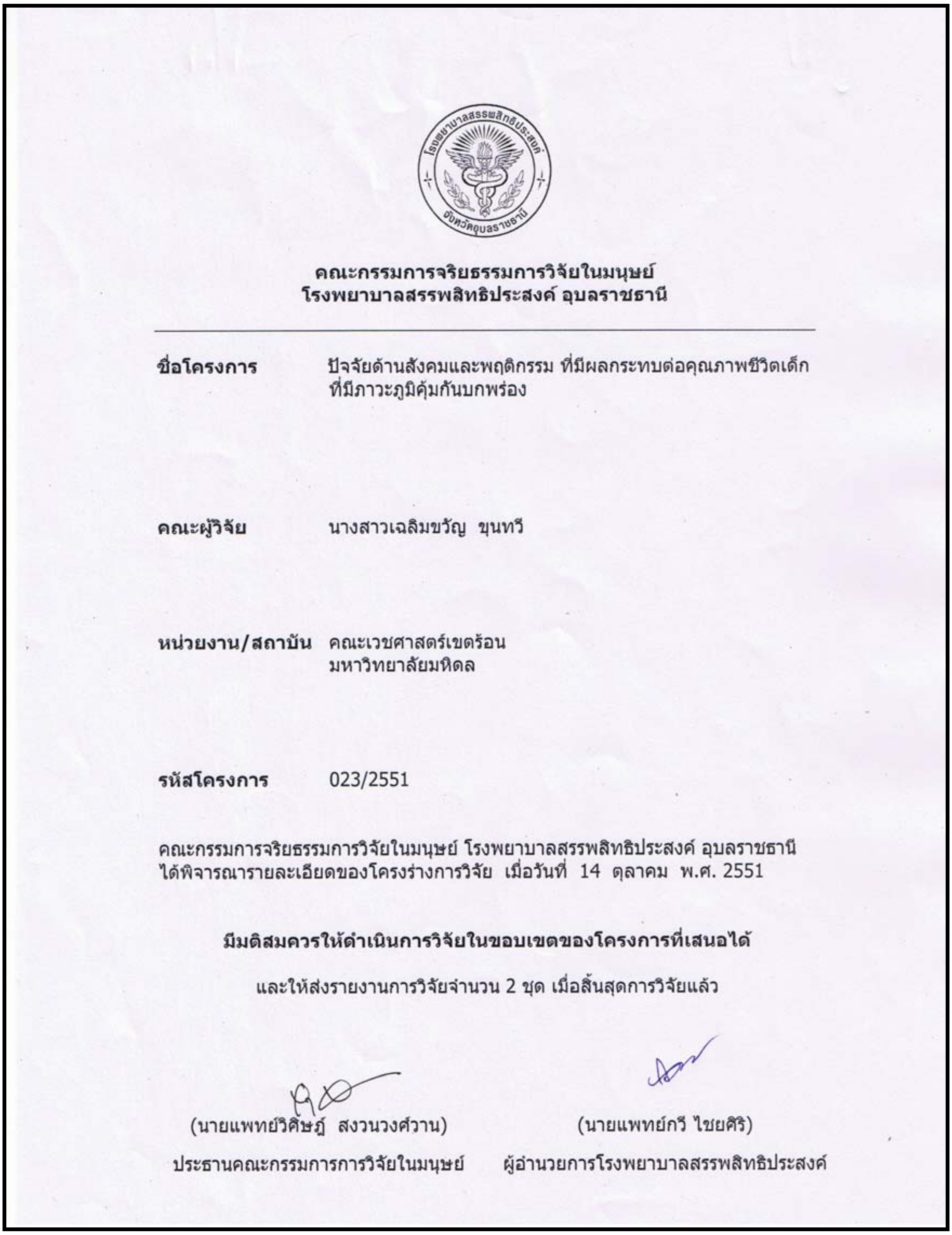
Signature ....
(Assoc. Prof. Pornthep Chantavanich)

Vice Chairperson
Ethics Committee of the
Faculty of Tropical Medicine
Date ....26 Aug 2008....

Signature ....Waranya Wongwit....
(Assoc. Prof. Waranya Wongwit)

Secretariat
Ethics Committee of the
Faculty of Tropical Medicine
Date ....26 Aug 2008....

Certificate of Ethical Approval from Ethics Committee of Sappasithiprasong Hospital



คณะกรรมการจริยธรรมการวิจัยในมนุษย์
โรงพยาบาลสรรพสิทธิประสงค์ อุบลราชธานี

ชื่อโครงการ ปัจจัยด้านสังคมและพฤติกรรม ที่มีผลกระทบต่อคุณภาพชีวิตเด็กที่มีภาวะภูมิคุ้มกันบกพร่อง

คณะผู้วิจัย นางสาวเฉลิมขวัญ ขุนทวี

หน่วยงาน/สถาบัน คณะเวชศาสตร์เขตร้อน
มหาวิทยาลัยมหิดล

รหัสโครงการ 023/2551

คณะกรรมการจริยธรรมการวิจัยในมนุษย์ โรงพยาบาลสรรพสิทธิประสงค์ อุบลราชธานี ได้พิจารณารายละเอียดของโครงร่างการวิจัย เมื่อวันที่ 14 ตุลาคม พ.ศ. 2551

มีมติสมควรให้ดำเนินการวิจัยในขอบเขตของโครงการที่เสนอได้

และให้ส่งรายงานการวิจัยจำนวน 2 ชุด เมื่อสิ้นสุดการวิจัยแล้ว

(นายแพทย์วิศิษฎ์ สงวนวงศ์วาน)
ประธานคณะกรรมการการวิจัยในมนุษย์

(นายแพทย์กวี ไชยศิริ)
ผู้อำนวยการโรงพยาบาลสรรพสิทธิประสงค์

APPENDIX C
PARTICIPANT INFORMATION SHEET AND INFORMED CONSENT FORM

ข้อมูลเกี่ยวกับโครงการวิจัย

โครงการวิจัยเรื่อง

"ปัจจัยด้านสังคมและพฤติกรรม ที่มีผลกระทบต่อคุณภาพชีวิตเด็กที่มีภาวะภูมิคุ้มกันบกพร่อง"

ข้าพเจ้านางสาวเฉลิมขวัญ ขุนทวี นักศึกษาหลักสูตรวิทยาศาสตรมหาบัณฑิต สาขาวิชาอายุรศาสตร์เขตร้อน คณะเวชศาสตร์เขตร้อน มหาวิทยาลัยมหิดล มีความประสงค์จะดำเนินการวิจัย โดยใคร่ขอความสมัครใจในการเข้าร่วมโครงการจากท่าน ดังนั้นผู้วิจัยจึงขอให้ท่านอ่านข้อมูลนี้ให้เข้าใจอย่างละเอียด ถ้าหากท่านไม่เข้าใจโปรดสอบถามผู้วิจัยก่อนที่จะตัดสินใจยินยอมเข้าร่วมโครงการนี้

โดยมีวัตถุประสงค์

1. ศึกษาระดับคุณภาพชีวิตของเด็กที่มีภาวะภูมิคุ้มกันบกพร่อง
2. ศึกษาปัจจัยที่มีผลกระทบต่อคุณภาพชีวิตเด็กที่มีภาวะภูมิคุ้มกันบกพร่อง

การเก็บข้อมูล

ผู้เข้าร่วมวิจัยและตอบแบบสอบถามจากการสัมภาษณ์จำนวน 2 คน คือ ผู้ดูแลและเด็ก การสอบถามใช้เวลาประมาณ 20 นาทีสำหรับผู้ดูแล และประมาณ 10 นาทีสำหรับเด็ก ผู้วิจัยจะเก็บข้อมูลจากเด็กจำนวน 94 คน และผู้ดูแลจำนวน 94 คนเด็ก

แบบสอบถามประกอบด้วย 2 ส่วนดังนี้

ส่วนที่ 1

1.1 คุณลักษณะทั่วไปของเด็ก, คุณลักษณะทั่วไปของผู้ดูแล, ความรู้ ทัศนคติ และการปฏิบัติของผู้ดูแลเด็ก, การสนับสนุนทางสังคม ส่วนนี้ใช้สัมภาษณ์ผู้ดูแล

1.2 คุณภาพชีวิต ประกอบด้วย แบบสัมภาษณ์ด้านสุขภาพกาย, เกี่ยวกับหน้าที่ตามบทบาทใช้สัมภาษณ์ผู้ดูแล และด้านสุขภาพจิต, การเข้าสังคม, ความพึงพอใจในชีวิตใช้สัมภาษณ์เด็ก

ส่วนที่ 2

ข้อมูลจากแบบบันทึกทางการแพทย์ เก็บโดยนักวิจัยและต้องได้รับการอนุญาตให้เก็บข้อมูลได้จากผู้อำนวยการโรงพยาบาลสรรพสิทธิประสงค์ เป็นที่เรียบร้อยก่อนทำการเก็บข้อมูล

ความเสี่ยงและประโยชน์ของการศึกษา

การตอบแบบสอบถามจะไม่ก่อให้เกิดผลเสียใดๆ ต่อท่านและเด็กในความดูแลของท่าน อย่างไรก็ตามท่านอาจจะรู้สึกอึดอัดบ้างจากคำถามที่ต้องใช้ความจำเกี่ยวกับตัวเด็กและชีวิตประจำวันของเด็ก คำถามบางคำถามอาจจะค่อนข้างเปิดเผยและเป็นสิ่งที่ไม่ได้คาดคิดมาก่อน ท่านจะไม่ได้รับประโยชน์โดยตรงจากการศึกษาแต่ข้อมูลที่ได้จากท่านจะเป็นประโยชน์ในการปรับปรุงคุณภาพชีวิตและพัฒนาการดูแลผู้ป่วยเด็กที่มีภาวะภูมิคุ้มกันบกพร่องต่อไปในอนาคต

การเก็บรักษาข้อมูลเป็นความลับ

ผู้วิจัยจะรักษาข้อมูลของท่านเป็นความลับจะไม่มีการระบุชื่อของท่านและเด็กในแบบสอบถาม ผลการวิจัยจะนำเสนอในภาพรวมของการศึกษาเท่านั้นโดยไม่มีการระบุเป็นรายบุคคล

การบอกกล่าวเพื่อขอความยินยอม

ผู้วิจัยต้องการศึกษาเกี่ยวกับ ปัจจัยด้านสังคมและพฤติกรรมที่มีผลต่อคุณภาพชีวิตเด็กที่มีภาวะภูมิคุ้มกันบกพร่องในฐานะที่ท่านเป็นผู้ดูแลเด็กให้ได้รับการการตอบสนองทั้งทางด้านร่างกาย ด้านอารมณ์ และด้านสังคม ให้สามารถดำเนินชีวิตได้อย่างปกติ ข้าพเจ้าจึงใคร่ขอความร่วมมือในการเข้าร่วมวิจัยครั้งนี้ โดยกรุณาตอบคำถามจากการสัมภาษณ์ ข้อมูลที่ได้จากท่านจึงมีความสำคัญและจำเป็นอย่างยิ่งในการวิจัยครั้งนี้

ข้อพิจารณาทางจริยธรรม

การยินยอมเข้าร่วมการศึกษาครั้งนี้ขึ้นอยู่กับความสมัครใจของท่าน โดยผู้เข้าร่วมมีสิทธิที่จะปฏิเสธการตอบคำถามหรือยุติการให้ข้อมูลทันทีที่ท่านต้องการ โดยจะไม่มีผลกระทบต่อการรับบริการทางการแพทย์ของเด็กในความดูแลท่านแต่อย่างใด

หากท่านมีข้อสงสัยประการใดโปรดติดต่อผู้วิจัยโดยตรงตามสถานที่และหมายเลขโทรศัพท์ข้างล่างนี้
นางสาวเฉลิมขวัญ ขุนทวี
เบอร์โทรศัพท์ที่ติดต่อได้ : 081-7892189, 045-264966
สถานที่ติดต่อ: 25/3 ถนนสมเด็จ ตำบลในเมือง อำเภอเมือง จังหวัดอุบลราชธานี 34000

หากอาสาสมัครได้รับการปฏิบัติไม่ตรงตามที่ระบุไว้จะติดต่อ คณะกรรมการจริยธรรมเกี่ยวกับการวิจัยในคน คณะเวชศาสตร์เขตร้อน มหาวิทยาลัยมหิดล ได้ที่ เบอร์โทรศัพท์ 02-3549100 ต่อ 1349, 1524, 1525เลขานุการ ชั้น 4 อาคารเฉลิมพระเกียรติฉลองสิริราชครบ 60 ปี

ใบยินยอมเข้าร่วมโครงการวิจัย

(สำหรับอาสาสมัครอายุตั้งแต่ 8-15 ปี)

โครงการวิจัยเรื่อง

“ปัจจัยด้านสังคมและพฤติกรรม ที่มีผลกระทบต่อคุณภาพชีวิตเด็กที่มีภาวะภูมิคุ้มกันบกพร่อง”

ข้าพเจ้าได้รับทราบข้อมูลเบื้องต้นเกี่ยวกับการวิจัย ตลอดจนวิธีและขั้นตอนในการศึกษา ข้าพเจ้าจะได้รับการสัมภาษณ์เพื่อตอบคำถามเกี่ยวกับคุณภาพชีวิตใช้เวลาประมาณ 10 นาที

ข้าพเจ้ามีสิทธิเข้าร่วมโครงการด้วยความสมัครใจหรือจะปฏิเสธไม่เข้าร่วมโครงการวิจัยนี้ แม้ว่าผู้ปกครองหรือพ่อแม่จะให้เข้าร่วมโครงการนี้ก็ตาม และหากข้าพเจ้าเข้าร่วมโครงการนี้ข้าพเจ้ามีสิทธิที่จะบอกเลิกการเข้าร่วมในโครงการนี้เมื่อใดก็ได้ ซึ่งการบอกเลิกการเข้าร่วมวิจัยจะไม่มีผลกระทบต่อการรักษาพยาบาลที่ข้าพเจ้าได้รับตามปกติ

การยินยอมของผู้ดูแลเด็ก

ข้าพเจ้า นาย/นาง/นางสาว...

ได้อ่านและเข้าใจเกี่ยวกับการเข้าร่วมโครงการวิจัยทั้งหมดตามใบยินยอมเข้าร่วมโครงการวิจัยและคำอธิบายข้างต้นแล้ว ข้าพเจ้า (กรุณาใส่เครื่องหมาย / ลงในช่องที่กำหนด)

☐ ยินยอมให้ เด็กชาย/เด็กหญิง/นาย/นางสาว.......................................เข้าร่วมโครงการวิจัย

ลงชื่อ...ผู้ดูแลเด็ก วันที่......./......./........

ลงชื่อ..พยาน วันที่......./......./........

การยินยอมของเด็ก

ข้าพเจ้า เด็กชาย/เด็กหญิง/นาย/นางสาว...

ได้อ่านและเข้าใจเกี่ยวกับการเข้าร่วมโครงการทั้งหมดตามใบยินยอมเข้าร่วมโครงการวิจัยและคำอธิบายข้างต้นแล้ว ข้าพเจ้า (กรุณาใส่เครื่องหมาย / ลงในช่องที่กำหนด)

☐ ยินยอม ☐ไม่ยินยอม เข้าร่วมโครงการวิจัยดังกล่าว

ลายมือชื่อ/ลายพิมพ์นิ้วหัวแม่มือ..........................ผู้เข้าร่วมการวิจัย วันที่......./......./........

ลงชื่อ..ผู้วิจัย วันที่......./......./........

ลงชื่อ..พยาน วันที่......./......./........

ใบยินยอมเข้าร่วมโครงการวิจัยของผู้ดูแลเด็ก

การวิจัยเรื่อง

“ปัจจัยด้านสังคมและพฤติกรรม ที่มีผลกระทบต่อคุณภาพชีวิตเด็กที่มีภาวะภูมิคุ้มกันบกพร่อง”

ก่อนที่จะลงนามในใบยินยอมเข้าร่วมโครงการวิจัยนี้ ข้าพเจ้าได้รับคำอธิบายวัตถุประสงค์ วิธีการศึกษา และประโยชน์ที่จะเกิดขึ้นจากการวิจัยอย่างละเอียดและมีความเข้าใจดีแล้ว

ข้าพเจ้ามีสิทธิเข้าร่วมโครงการวิจัยด้วยความสมัครใจและมีสิทธิที่จะบอกเลิกการเข้าร่วมโครงการวิจัยนี้เมื่อใดก็ได้ พร้อมทั้งยินยอมให้ผู้วิจัยใช้ข้อมูลส่วนตัวของข้าพเจ้าที่ได้รับจากการวิจัย แต่จะไม่เผยแพร่ต่อสาธารณะเป็นรายบุคคล โดยจะนำเสนอเป็นข้อมูลโดยรวมจากการวิจัย

หากข้าพเจ้าได้รับการปฏิบัติไม่ตรงตามที่ระบุไว้ในเอกสารชี้แจงผู้เข้าร่วมวิจัย ข้าพเจ้าสามารถติดต่อกับฝ่ายเวชศาสตร์เขตร้อน มหาวิทยาลัยมหิดล เบอร์โทร 02-3549100 ต่อ 1349, 1524, 1525เลขานุการคณะกรรมการจริยธรรมเกี่ยวกับการวิจัยในคน ชั้น 4 อาคารเฉลิมพระเกียรติฉลองสิริราชครบ 60 ปี

ข้าพเจ้าได้เข้าใจข้อความในเอกสารชี้แจงข้อมูลเกี่ยวกับโครงการวิจัย ใบยินยอมเข้าร่วมโครงการวิจัยของผู้ดูแลเด็ก นี้โดยตลอดแล้ว

ข้าพเจ้า (กรุณาใส่เครื่องหมาย / ลงในช่องที่กำหนด)

☐ ยินยอมเข้าร่วมโครงการวิจัย

จึงลงลายมือชื่อไว้

ลงชื่อ...ผู้เข้าร่วมการวิจัย วันที่...../......./......

(………………………..………….)

ลงชื่อ...ผู้วิจัย วันที่...../......./......

(………………………….……….)

ในกรณีผู้เข้าร่วมการวิจัยอ่านหนังสือไม่ออก ผู้อ่านข้อความทั้งหมดแทนผู้เข้าร่วมการวิจัยคือ

....

จึงได้ลงลายมือชื่อไว้เป็นพยาน

ลงชื่อ.....................................พยาน วันที่....../......../.......

(……………….…………….)

APPENDIX D

THE INTRUMENTS

ชื่อโครงการ : ปัจจัยด้านสังคม และพฤติกรรม ที่มีผลกระทบต่อคุณภาพชีวิตเด็กติดเชื้อเอชไอวี

เลขที่....................................

วันที่......../.........../............

แบบสอบถามคุณภาพชีวิตเด็ก

ผู้วิจัยต้องการทราบคุณภาพชีวิตของเด็ก คำถามที่ถามต่อไปนี้ไม่มีคำตอบที่ถูกหรือคำตอบที่ผิด แบบสอบถามนี้จะไม่มีการระบุชื่อ และข้อมูลที่ให้จะถูกเก็บไว้เป็นความลับ

ส่วนที่ 1 สำหรับถามผู้ดูแลเด็ก

โปรดทำเครื่องหมาย √ ในช่องสี่เหลี่ยม และเติมข้อความตามความเหมาะสม

คุณลักษณะทั่วไปของเด็ก

1. เด็กที่ท่านดูแลอยู่เรียนหนังสืออยู่ในระดับชั้นใด(ระบุ).....................
2. ลักษณะของครอบครัวเด็กเป็นแบบใด ☐ 1. ครอบครัวเดี่ยว ☐ 2. ครอบครัวขยาย
3. ใครเป็นผู้ดูแลเด็กตั้งแต่เริ่มแรก

   ☐ 1. แม่ ☐ 2. พ่อ ☐ 3. ยาย/ย่า ☐ 4. ตา/ปู่
   ☐ 5. ญาติ ☐ 6. บิดา/มารดาบุญธรรม ☐ 7. อื่น ๆ ระบุ...........
4. ใครเป็นผู้ดูแลเด็กมากที่สุด (ในรอบ 6 เดือน)

   ☐ 1. แม่ ☐ 2. พ่อ ☐ 3. ยาย/ย่า ☐ 4. ตา/ปู่
   ☐ 5. ญาติ ☐ 6. บิดา/มารดาบุญธรรม ☐ 7. อื่น ๆ ระบุ...........
5. มีคนอื่นที่ช่วยดูแลเด็กหรือไม่(ตอบได้หลายคำตอบ)

   ☐ 1. แม่ ☐ 2. พ่อ ☐ 3. ยาย/ย่า ☐ 4. ตา/ปู่
   ☐ 5. ญาติ ☐ 6. บิดา/มารดาบุญธรรม ☐ 7. อื่น ๆ ระบุ.........
6. บิดาหรือมารดาของเด็กยังมีชีวิตหรือไม่ ☐ 1. มี →ข้อ 7. ☐ 2. ไม่มี→ข้อ 8.
7. บิดาหรือมารดาของเด็กเป็นผู้ดูแลเด็กหรือไม่ ☐ 1. ใช่ ☐ 2. ไม่ใช่

คุณลักษณะทั่วไปของผู้ดูแลเด็ก

8. เพศ ☐ 1. ชาย ☐ 2. หญิง
9. อายุ................ปี
10. อาชีพ

    ☐ 1. ไม่ได้ประกอบอาชีพ ☐ 2. รับราชการ/รัฐวิสาหกิจ

☐ 3. เกษตรกร ☐ 4. รับจ้าง/แรงงาน

☐ 5. ค้าขาย ☐ 6. อื่น ๆ ระบุ.........................

11. การศึกษา

☐ 1. ไม่ได้เรียนหนังสือ ☐ 2. ประถมศึกษา

☐ 3. มัธยมศึกษาตอนต้น ☐ 4. มัธยมศึกษาตอนปลาย

☐ 5. อนุปริญญา/ประกาศนียบัตร ☐ 6. ปริญญาตรีหรือสูงกว่าปริญญาตรี

12. รายได้ของครอบครัว(บาทต่อเดือน) ระบุ.......................

13. ท่านมีความสัมพันธ์อย่างไรกับเด็กในความดูแล

☐ 1. เป็นบิดา/มารดาโดยกำเนิด ☐ 2. เป็นญาติทางฝ่ายบิดา/มารดา

☐ 3.ไม่ได้เป็นญาติ ☐ 5.อื่น ๆระบุ..................

ความรู้ ทัศนคติ และการปฏิบัติของผู้ดูแลเด็กติดเชื้อเอช ไอ วี ต่อโรคเอดส์

ความรู้เรื่องโรคเอดส์ กากบาท× ข้อที่เลือกตอบ

14. ท่านรู้จักโรคเอดส์หรือไม่ ☐ 1. รู้ ☐ 2. ไม่รู้

15. เชื้อที่ทำให้ป่วยเป็นโรคเอดส์คืออะไร ☐ 1. ไวรัสเอช ไอ วี ☐ 2. เดวีม่อน ☐ 3. ไม่ทราบ

16. โรคเอดส์คืออะไร(เลือกได้หลายคำตอบ)

1) เป็นโรคที่เกี่ยวกับภูมิคุ้มกันบกพร่อง
2) เป็นระยะหนึ่งของโรคที่เกิดจากการติดเชื้อไวรัสเอช ไอ วี
3) ไม่ทราบ
4) อื่นๆ ....

17. อะไรคืออาการของโรคเอดส์(เลือกได้หลายคำตอบ)

1) น้ำหนักลดอย่างรวดเร็ว
2) ท้องเสียเรื้อรัง
3) มีไข้เรื้อรัง
4) อื่นๆ ....

18. การติดเชื้อไวรัสเอดส์เกิดได้ทางใดบ้าง (เลือกได้หลายคำตอบ)

1) เพศสัมพันธ์
2) การได้รับเลือด
3) สัมผัส กอด จูบ ผู้ติดเชื้อเอดส์
4) การใช้เข็มฉีดยาร่วมกับผู้ติดเชื้อเอดส์
5) เป็นเรื่องของเวรกรรม
6) การถ่ายทอดเชื้อเอดส์จากแม่สู่ลูก
7) ถูกยุงหรือแมลงกัด

19. โรคเอดส์สามารถป้องกันได้หรือไม่ ☐ 1. ได้ →ข้อ 20. ☐ 2. ไม่ได้→ข้อ 21.

20. มีวิธีใดบ้างที่สามารถป้องกันการติดเชื้อเอดส์ได้ (เลือกตอบได้หลายคำตอบ)

1) งดเว้นการมีเพศสัมพันธ์

2) ใช้ถุงยางอนามัย
3) ไม่ใช้เข็มฉีดยาร่วมกับผู้ติดเชื้อ
4) ไม่ให้ยุงกัด
5) ไม่สัมผัส กอด จูบ ผู้ติดเชื้อ
6) ใช้ยาสมุนไพรโบราณ

21. คนทั่วไปที่ดูภายนอกสุขภาพดี อาจเป็นผู้ติดเชื้อไวรัสเอชไอวี ☐**1.**ใช่ ☐ **2.**ไม่ใช่

22. โรคเอดส์สามารถรักษาได้ด้วยวิธีใด(เลือกได้หลายคำตอบ)

1) รักษาด้วยยาสมุนไพร
2) รักษาด้วยการเปลี่ยนถ่ายเลือด
3) รักษาด้วยยาสมัยใหม่
4) ยังไม่มีทางรักษา

23. โรคติดเชื้อฉวยโอกาสในเด็กคือโรคอะไรบ้าง(เลือกได้หลายคำตอบ)

1) ปอดอักเสบ
2) วัณโรค
3) เชื้อราในปาก (ฝ้าขาวในปาก)
4) อื่นๆ ....

24. การดูแลเด็กติดเชื้อเอดส์ที่ท้องเสียควรทำอย่างไรบ้าง(เลือกได้หลายคำตอบ)

1) ให้กินยาแก้ท้องเสีย
2) ให้ดื่มน้ำเกลือแร่บ่อย ๆ
3) พาไปพบแพทย์
4) ไม่ทำอะไรเดียวอาการก็หายเอง

25. หากมีผู้ป่วยเป็นวัณโรคอาศัยอยู่ร่วมบ้านกับเด็กท่านควรทำอย่างไร(เลือกได้หลายคำตอบ)

1) พาเด็กไปตรวจร่างกายเพื่อทดสอบหาเชื้อวัณโรค
2) ไม่ให้เด็กใกล้ชิดกับผู้ป่วย
3) ไม่ต้องทำอะไร
4) อื่นๆ ....

ทัศนคติต่อโรคเอดส์ ทำเครื่องหมาย √ ข้อที่เลือกตอบ

ข้อความ	เห็นด้วยอย่างยิ่ง	เห็นด้วย	ไม่แน่ใจ	ไม่เห็นด้วย	ไม่เห็นด้วยอย่างยิ่ง
26. ท่านคิดว่าโรคเอดส์เป็นโรคที่น่ารังเกียจ					
27. ท่านคิดว่าโรคเอดส์รบกวนการดำเนินชีวิตของผู้ป่วยเอดส์/ผู้ติดเชื้อและครอบครัว					
28. ท่านคิดว่าการดูแลผู้ป่วยเอดส์ทำให้เพื่อนบ้านรังเกียจท่าน					
29. ท่านคิดว่าการแยกตัวจากสังคมเป็นการป้องกันไม่ให้สังคมรังเกียจท่าน					
30. ท่านคิดว่าการได้รับการช่วยเหลือจากชุมชนและเพื่อนบ้านทำให้ท่านดูแลเด็กได้ดีขึ้น					
31. ท่านคิดว่าการป้องกันการติดเชื้อจากผู้ป่วยเอดส์ที่ท่านดูแลเป็นเรื่องยาก					
32. ท่านคิดว่าการไปพบแพทย์ตามนัดจะทำให้เด็กที่ท่านดูแลมีร่างกายที่แข็งแรง					
33. ท่านคิดว่าการที่เด็กได้รับยาต้านไวรัสเอชไอวีจะทำให้เด็กมีภูมิคุ้มกันต่อโรคอื่นๆ มากขึ้น					
34. ท่านคิดว่าการที่เด็กได้รับยาต้านไวรัสเอชไอวีจะทำให้เด็กติดเชื้อเอดส์มีชีวิตยืนยาวขึ้น					
35. ท่านคิดว่าการดูแลเด็กติดเชื้อเอดส์เหมือนกับเด็กปกติทั่วไปจะทำให้เด็กมีสุขภาพที่ดีได้					

การปฏิบัติของผู้ดูแลเด็กติดเชื้อเอช ไอ วี ทำเครื่องหมาย √ ข้อที่เลือกตอบ

	ระดับการปฏิบัติ		
	ทุกครั้ง	บางครั้ง	ไม่เคย
36. ท่านพาเด็กไปพบแพทย์ตามนัดทุกครั้ง			
37. ท่านดูแลให้เด็กทานยาตามแพทย์สั่งทุกครั้ง			
38. ท่านปฏิบัติตามที่แพทย์พยาบาลบอกทุกเรื่อง			
39. ท่านล้างมือก่อนปรุงอาหารให้เด็กทุกครั้ง			
40. ท่านให้เด็กดื่มน้ำสะอาดทุกครั้ง			
41. ท่านทำความสะอาดเสื้อผ้าที่ไม่เปื้อนเลือดหรือน้ำเหลืองของผู้ติดเชื้อด้วยผงซักฟอก			
42. ท่านและ ผู้ติดเชื้อใช้เสื้อผ้าเครื่องนุ่งห่ม จานชาม แก้วน้ำ ที่ผ่านการทำความสะอาดแล้วร่วมกัน			
43. ท่านดูแลให้เด็กอาบน้ำอย่างน้อยวันละ 1 ครั้งเป็นประจำทุกวัน			
44. เมื่อเด็กไม่สบายท่านพาเด็กไปพบแพทย์ทุกครั้ง			

การได้รับการสนับสนุนทางสังคม

โปรดทำเครื่องหมาย √ ในช่องตามคำตอบของผู้ตอบแบบสอบถาม

การได้รับการสนับสนุนทางสังคม	ไม่ได้รับ	ได้รับ			ไม่ต้องการ	ต้องการ			
		พอเพียงมาก	พอเพียงปานกลาง	น้อย		มาก	ปานกลาง	น้อย	
การได้รับการสนับสนุนจากครอบครัว 45. ที่พัก/อาหาร									
46. เสื้อผ้า									
47. การเงิน									
48. การให้คำปรึกษา									
49. การให้ข้อมูลข่าวสาร									
การได้รับการสนับสนุนจากเพื่อนบ้าน 50. ที่พัก/อาหาร									
51. เสื้อผ้า									
52. การเงิน									
53. การให้คำปรึกษา									
54. การให้ข้อมูลข่าวสาร									
การได้รับการสนับสนุนจากองค์กรระดับชุมชน 55. ที่พัก/อาหาร									ระบุแหล่ง
56. เสื้อผ้า									
57. การเงิน									
58. การให้คำปรึกษา									
59. การให้ข้อมูลข่าวสาร									
การได้รับการสนับสนุนจากรัฐ 60. ที่พัก/อาหาร									ระบุแหล่ง
61. เสื้อผ้า									
62. การเงิน									
63. การให้คำปรึกษา									
64. การให้ข้อมูลข่าวสาร									
การได้รับการสนับสนุนจากองค์กรเอกชน 65. ที่พัก/อาหาร									ระบุแหล่ง
66. เสื้อผ้า									
67. การเงิน									
68. การให้คำปรึกษา									
69. การให้ข้อมูลข่าวสาร									

ส่วนที่ 2 คุณภาพชีวิต

สำหรับถามผู้ดูแล

ให้ผู้ปกครอง ตอบคำถามต่อไปนี้ตามสิ่งที่เกิดขึ้นไม่ว่ามากหรือน้อย <u>ในช่วง 1 เดือนที่ผ่านมา</u> โดยทำเครื่องหมาย √ ในช่องที่ถูกเลือก

เกี่ยวกับสุขภาพกาย	ไม่เคย	เคยบางครั้ง	ประจำ
เด็กที่ท่านดูแล มีความยากลำบากในการทำกิจกรรมเหล่านี้หรือไม่ 70. เดินจากบ้านตนเองไปบ้านข้างเคียงระยะ100 เมตร			
71. วิ่งเล่นกับเพื่อน			
72. ออกกำลังกายหรือเล่นตามวัยของเด็ก เช่นกระโดดยาง			
73. …………………………..			
74. …………………………..			
75. ………………………….....			

เกี่ยวกับโรงเรียน	ไม่เคย	เคยบางครั้ง	ประจำ
76. เด็กที่ท่านดูแลไม่สนใจเรียน			
77. เด็กที่ท่านดูแลมักลืมสิ่งของ เช่น สมุด ดินสอ ปากกา			
78. …………………...			
79. ……………………			
80. ……………………			

สำหรับถามเด็ก

ให้หนู ตอบคำถามต่อไปนี้ตามสิ่งที่เกิดขึ้นไม่ว่ามากหรือน้อย <u>ในช่วง 1 เดือนที่ผ่านมา</u> โดยทำเครื่องหมาย √ ในช่องที่ถูกเลือก

เกี่ยวกับสุขภาพจิต	ไม่เคย	เคยบางครั้ง	ประจำ
81. ฉันมักจะปวดหัว			
82. ฉันรู้สึกกังวลใจหลายเรื่อง และวิตกกังวลอยู่เสมอ			
83. …………………….			
84. …………………….			
85. …………………….			
86. …………………….....			

เกี่ยวกับการเข้าสังคม	ไม่เคย	เคยบางครั้ง	ประจำ
87. ฉันชอบเล่นคนเดียว			
88. ฉันมีเพื่อนสนิท			
89. ฉันเป็นที่ชื่นชอบของเพื่อนๆ			
90. …………………..			
91. …………………..			
92. …………………..			
93. …………………..			
94. …………………..			
95. …………………..			
96. …………………..			

ให้หนู ตอบคำถามต่อไปนี้ตามความรู้สึกที่เกิดขึ้น โดยทำเครื่องหมาย √ ในช่องที่ถูกเลือก

เกี่ยวกับความพึงพอใจในชีวิต	ไม่เห็นด้วย	เห็นด้วย	เฉย ๆ
97. ฉันรู้สึกมีความสุขเมื่ออยู่กับครอบครัว			
98. เพื่อน ๆ ให้การช่วยเหลือเมื่อฉันต้องการ			
99. ฉันรู้สึกมีความสุขกับเพื่อน ๆ			
100. ฉันชอบการเรียนหนังสือ			
101. ……………………			
102. ……………………			
103. ……………………			
104. ……………………			

“จบการสัมภาษณ์ ขอบคุณผู้ปกครองและเด็กเป็นอย่างมากที่ได้ให้ความร่วมมือในการตอบคำถามครั้งนี้”

ส่วนที่ 3 ข้อมูลจากแบบบันทึกทางการแพทย์

เฉพาะผู้วิจัยกรอก ข้อมูลส่วนนี้ได้จากแบบบันทึกทางการแพทย์ของผู้ป่วย

105. เพศของเด็กที่ได้รับการดูแล ☐ 1.ชาย ☐2. หญิง

106. อายุของเด็กที่ได้รับการดูแล..................ปี วัน/เดือน/ปี เกิด ..../........../.........

107. ภาวะโรค และระดับภูมิต้านทานโรคในปัจจุบัน(ผู้วิจัยเก็บข้อมูลการตรวจ 6 เดือนย้อนหลัง)

- ภาวะโรคปัจจุบัน (CDC stage) ระบุ…...................................

  (N - Asymptomatic, A – mildly symptomatic, B – moderately symptomatic, C – severely symptomatic)
- ระดับภูมิต้านทานโรค CD4 count ………cell/mm

  CD4 % ……………………

108. เด็กที่ท่านดูแลอยู่ได้รับการรักษาด้วยยาต้านไวรัสเอช ไอ วีหรือไม่

☐ 1. ได้ →ข้อ 109. ☐ 2. ไม่ได้

109. ระยะเวลาที่เด็กเริ่มได้รับการรักษาด้วยยาต้านไวรัสเอช ไอ วีจนถึงปัจจุบัน................เดือน

BIOGRAPHY

NAME	Miss. Chalermkwan Kuntawee
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