FROM EXPERIENCING SOCIAL DISGUST TO PASSING AS NORMAL:

SELF-CARE PROCESSES AMONG THAI PEOPLE SUFFERING FROM AIDS

A thesis presented in fulfillment of the requirements for the degree of
Doctor of Philosophy
In
Nursing
At Massey University, Palmerston North, New Zealand

Jirapa Siriwatanamethanon
2008

ABSTRACT

AIDS is a chronic disease that seriously affects health, emotions, social relations and household economy. People living with HIV/AIDS experience great suffering, stigmatisation and discrimination from other people around them because they know that it is incurable, contagious, evokes social disgust and is a complex disease requiring life-long self-care. This researcher explored ways people with HIV/AIDS take care of their health and manage their lives in the context of stigma and discrimination. A grounded theory study was conducted with 30 participants with HIV/AIDS, in Mahasarakham Province, Thailand. Participants were recruited from an HIV/AIDS day care clinic and by snowball sampling. Data were gathered through in-depth interviews, participant observations and field notes made during home visits. Interviews were tape recorded, then transcribed verbatim.

"*From experiencing social disgust to passing as normal*" was generated inductively from the data as the basic social psychological process of Thai people living with HIV/AIDS. From experiencing social disgust to passing as normal comprised four categories: being HIV/AIDS, making choices, keeping well and feeling empowered. The category "being HIV/AIDS"- discovering the meaning of having HIV/AIDS, comprises four concepts: being diagnosed with HIV/AIDS, being stigmatised, suffering, and learning about HIV/AIDS. The category "making choices"- to live a normal life, involves three concepts: avoiding unhappy situations, getting remarried and seeking support. The category "keeping well"- maintaining emotional and physical health, includes eight concepts: religious practices, keeping a cheerful mind, self-treatment, taking care of the body, keeping the environment clean to prevent getting germs, healthy behaviours, getting healthcare services, and attention to, and concern about, medication. The last category "feeling empowered"- personal and social acceptance of illness, includes eight concepts: being encouraged, acknowledging the disease, social acceptance, tamjai, feeling proud of self, feeling good about life, feeling lucky and having hope.

In the context of northeastern Thailand, successful management of HIV/AIDS was underpinned by participants making a transition from “experiencing social disgust” to “passing as normal” within their communities. The desire to live a normal life despite having HIV/AIDS motivated participants to undertake effective self-care in order to remain symptom free (thus avoiding visible signs of the disease), and to selectively disclose their illness to avoid the ongoing risk of stigma and discrimination.

The findings of this study are useful in that they will provide Thai health professionals with a clearer conceptualisation of self-care among the Thai population. An inductively derived theory of self-care among Thai with HIV/AIDS can be applied and integrated by health professionals into the self-care models for people living with HIV/AIDS including models used in nursing education, research and practice.

ACKNOWLEDGEMENTS

I would like to acknowledge first, the participants and their families who shared their experiences with me and gave insights regarding their self-care managing of their lives with HIV/AIDS. I would like to thank the health professionals, especially the nurses at the HIV/AIDS day care clinic, Mahasarakham hospital, particularly, Ms. Kasemukda Chansiri, the head nurse in this clinic, who helped recruit the participants and facilitated access to health records and other information during this study. Thanks to Mahasarakham hospital for allowing me to conduct this study. Without the participants and Mahasarakham hospital this research could not have been completed. I hope that the results from this study will benefit people living with HIV/AIDS in managing and living with the disease; also that the model can be used in nursing education in Thailand.

I would like to express my deepest gratitude to Professors Julie Boddy, and Denise Dignam, and Associate Professor Khanitta Nuntaboot–my supervisors–for their understanding, guidance, encouragement, great help and support throughout the process of study and completion of this dissertation. This study would not have been successful if I had not received all of their effort. I appreciate Dr. Denise Wilson and Lecturer Lesley Batten, for their expert advice, and support at the time I analysed the data. I especially thank all staff of the Nursing School of Massey University who supported me during the study.

I am indebted to my colleagues and others: Kuephan Klankaradi, for her help typing the information sheet and consent form; Supatra Buatee, for her help with data collection and verbatim transcription; Piyaporn Boonphadh, for her help with solving computer problems and Mr. Norman Mangnall, for his help with English excerpt correction after I translated from Thai to English. I particularly want to acknowledge all my Thai friends for their support and sharing during the time of my PhD study at the School of Health and Social Services, Massey University.

My deepest gratitude is extended to Ms. Gay Eustace, whom I considered to be my mum in Palmerston North, for her love and support. Her help and sharing of New Zealand culture with international students are highly appreciated.

I would like to acknowledge the Royal Thai Government for providing financial support for my PhD study. Thanks also go to my faculty, who allowed me time to study, especially Associate Professor Dr. Darunee Rujkorakarn and Associate Professor Walaiporn Nuntsupawat, and Massey University for giving me the chance to study, which enabled me to complete this thesis.

LIST OF ACRONYMS AND GLOSSARY

ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ARC	Aids-Related Complex
ARV	Antiretroviral
AZT	Zidovudine
CD4+	T-Lymphocyte Count
FAO	Food and Agriculture Organization
GPO-vir	A single tablet 3 drug combination regimen (d4T +3TC+Nevirapine) produced by the Government Pharmaceutical Organization (GPO)
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
MOH	Ministry of Health
MOPH	Ministry of Public Health
NGO	Non Government Organization
NIAID	National Institute of Allergy and Infectious Diseases
PCP	Pneumocystis Carinii Pneumonia
PLWHA	People Living with HIV/AIDS
SARS	Severe Acute Respiratory Syndrome
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
VDRL	Venereal Disease Research Laboratory
WHO	World Health Organization

GLOSSARY

Thai

A

Ahan salang or kha- lum: Taboo food or forbidden food

Amphur: District

Arsaraha bucha day: Buddhist activity day (worship on the full-moon day of the 8th lunar month-July, It is the anniversary of the first sermon given by the Buddha after his enlightenment)

B

Baan rom yen: Cool shade house

Baht: Currency unit (NZ$ 1=27 baht)

Bai nard: The name of a leaf

Bai yuow: The name of a leaf

Bouw waan: Diabetes mellitus

C

Cham: An old man chosen as a spirit medium

Chan: I, myself, oneself

Changwat: Province

Chue ra nai parg: Oral fungus

D

Dakie: The name of toothpaste (a particular brand)

E

Ethon: Pity

F

Faa tha laai jone: Name of plant

Fab: The name of detergent powder (a particular brand)

G

Gue sawat: Herpes

H

Hiet-kong: The norms, rituals, tradition, customs, practices, rule of Isaan

Hue jai: Heart

I

Isaan: Northeast

J

Jai berk ban: Cheerful mind

K

Karma: The law of karma (belief in rebirth according to merit)

Karma khow: Old karma

Ka ra oo kae: Sing a song

Khon leaw: Bad person

Khum lung jai: Encouragement

King amphur: Minor district

Kin poa: Enough eating

Kuam done lo hid sung: Hypertension

Kun: Itchy

M

Makha bucha day: Buddhist activity day (worship on the full-moon day of the 3rd lunar month-February, in commemoration of the day that 1,250 monks gathered to listen to the Buddha's preaching)

Matahayom seuksa: Secondary school

Mee kah: Valuable

Mor: Health care providers (nurse, doctor, pharmacist and others)

Mor duu: Fortune teller

Mor nguu: Snake healer

Mor naam man: Oil healer

Mor pern ethon chan: Nurse took pity on me

Mor paw: Blow healer

Mor tham: Magic healer

Muang: City

Mubaan: Village

Muu dip: Raw pork

N

Nah klua: Fearful

Nah la ay: Shameful

Namjai: Spirit

Nam ya buan parg: Antiseptic solution

Nok-heit-nok-kong: Out of, tradition, custom, practice, rule of Isaan

Norn poa: Enough sleeping

Nue dip: Raw beef

O

Orkpunsaa day: Buddhist activity day (the full moon of the 11th lunar month-October) (the end of the Lenten period for the Buddhist monks. Monks can leave the temple to go anywhere after Lent)

P

Pah pan phae: Bandage

Phii: Spirit ghost

Phii paa: The spirit of the forest

Phu ying ha gin: Sex worker or prostitute

Plong: Accepting situation

Ploy mun pai: Let it go

Prathom seuksa: Primary school

Puad tong: Abdominal pain

R

Roke AIDS: AIDS disease

Roke tid tor: Communicable disease

Roke tid chue chuey oo gard: Opportunistic disease

Ron nai: Glossitis

Ruk sa bor souw: Incurable

Rungkiat: Disgust

S

Sa aad: Clean

Sabai jai: Easy mind, healthy mind

Samoon prai: Herbal medicine

Samson: Promiscuous or promiscuity

Samson tang pase: Promiscuous sex

Sa tha nee a na mai: Health centre

Shampoo: Hair cleaning

Sok ka pok: Dirty

Suad mon: Praying

Sungkom rungkiat: Social disgust

T

Tad: The four elements includes earth (din), water (naam), wind (lom) and fire (fai)

Taay wai: Expect to die (die soon)

Tambon: Sub-district

Tam boon: Making merit

Tam jai: Make mind up

Tiffy: The name of medicine (anti-cold)

Tod pah pa: Robe-giving ceremony to the monks

Tong kin suk: Eating cooked food

Tong taay nae: Must die for sure

Ton ta krai hom: The name of a tree

Tum: Papulae

Tum chua dai chua: Do evil will receive evil

Tum dee dai dee: Do good will receive good

U

Ugsape: Inflammation

V

Visakha bucha day: Buddhist activity day (worship on the full-moon day of the 6th lunar month-May-in commemoration of the birth, enlightment, and death of the Buddha that are all believed to have occurred on the same date)

W

Wan na rok pord: Pulmonary tuberculosis

Wat: Temple

Y

Yaan taay: Afraid to die

Ya: Medicine

Ya hark mai: Herb medicine (including roots and leaves of trees)

Ya nuad gaee puad: Anti-ache by rubbing

Ya pa ra: Paracetamol medicine

Ya pong guun laee ruk sa: Preventive and curative medicine

Ya samoon prai Thai: Thai traditional herb medicine

Ya taan virus: Antiretroviral medicine

Yay: Grandmother

Z

Zap Zap: Very delicious

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

PART ONE

CHAPTER ONE

BACKGROUND TO THE STUDY

1.1 INTRODUCTION

This grounded theory study explores the ways in which Thai people with HIV/AIDS take care of their health and manage their lives in the context of stigma and discrimination (Nilmanart, Street, & Blackford, 2006; Paxton et al., 2005; Parker & Aggleton, 2003; Phengjard, Brown, Swansen, & Schepp, 2002; Singhanetra-Renard, Chongsatitmun, & Aggleton, 2001; Sringernyuang, Thaweesit, & Nakapiew, 2005; UNAIDS, 2004; UNAIDS; 2005b; UNDP, 2004).

My interest in the topic stemmed from my involvement with people with HIV/AIDS in my work as a lecturer in community nursing at the Faculty of Nursing, Khon Kaen University for 12 years, and concurrently at the Northeast Center for AIDS Prevention and Care, Khon Kaen University for 5 years. I then worked as a lecturer in community nursing at the Faculty of Nursing, Mahasarakham University for 10 years. I noticed that despite my providing nursing care and health education for people living with HIV/AIDS in rural Northeast Thailand to assist them to maintain their life and achieve well-being, it was difficult for people with HIV/AIDS to follow that advice because of having low education and being very poor. They needed to earn money day-by-day for daily living expenses. Most of them kept their HIV/AIDS status secret because of fear of stigmatisation and discrimination. These impressions focussed my desire to learn more about how Thai people living with HIV/AIDS take care of their health and manage their situation.

HIV/AIDS is currently an important worldwide health problem; AIDS remains the leading infectious cause of adult death in the world (Merson, 2006; Rhucharoenpornpanich & Chamratrithirong, 2001; UNAIDS, 2006; UNDP, 2004; WHO, 2003). Complex medical, social, economic, political and ethical issues surrounding HIV/AIDS challenge those who are involved with the problem.

Moreover, treatment requirements are increasing the demand worldwide on health resources (Danziger, 1994; Li et al., 2007; UNAIDS, 2004). People living with HIV/AIDS and their families confront additional challenges due to the social context and stigma of HIV/AIDS (Alonzo & Reynolds, 1995; Lee, Kochman, & Sikkema, 2002; Mak et al., 2007; Phengjard et al., 2002; SaeTang & Nantachaipan, 2001; Songwathana, 1998; UNAIDS, 2005a).

The HIV/AIDS epidemic in Thailand has affected all sectors of Thai society, although the number of new HIV cases per year decreased from more than 130,000 in the early 1990s to fewer than 20,000 cases in 2003 (Sunthrajarn, Wongkongkathep, Onnom, & Amornwichet, 2005). Currently, the number of new HIV infections is estimated to be about 17,000 cases a year (MOPH, 2007a). There are many people living with HIV/AIDS, an increasing number of whom are beginning to show symptoms from opportunistic infectious diseases associated with AIDS, and need care and treatment to maintain their lives at a time when Government health budgets are limited and expenses for treatment are very high (MOPH, 2006a; MOPH & World Bank, 2006; Nilmanat & Street, 2004; Thongsa-aad, 2003). As a result, AIDS is seriously affecting health, emotions, social relations and both household and government economies (Boom & Sherr, 2004; Kulsomboon, Thanaviriyakul, & Pinyowiwat, 2004).

A number of changes in healthcare policy and provision in Thailand over the past five years have impacted on people's experience of living with HIV/AIDS. Prior to 2002, people living with AIDS suffered from a comparatively short illness with symptomatic disease and death. The majority of people with AIDS could not access health care because they were poor (MOPH, 2006a; MOPH, 2007a). Thailand has several health insurance schemes; however about 20% of Thai people are not in any scheme (MOPH, 2006b). The introduction of the "30 baht[1] universal coverage scheme" in 2001 enabled universal access to health care. However, only medications that were included on the national basic medicine list were permitted to be prescribed under that scheme. This list included preventive and curative care (treatment of all opportunistic infections), but excluded antiretroviral drugs[2] and costs associated with testing and monitoring. This situation changed following the July 2004 Bangkok

---

[1] 27 Thai baht is approximately equivalent to one NZ dollar
[2] Antiretroviral drugs refer to medications for the treatment of infection by retroviruses, primarily HIV.

International AIDS Conference, where the Thai Prime Minister announced that antiretroviral therapy would be included under the 30 baht universal coverage scheme.

Thus, during the period of the inception, data collection and writing up of this study, changes in health policy have enabled Thai people with AIDS to live longer because they can now more readily access healthcare service and antiretroviral therapy (MOPH, 2007a, 2007b; MOPH & World Bank, 2006). However, in addition to healthcare and medication, people living with HIV/AIDS need a wide range of self-management strategies to deal with the condition and life events in their home environment. It is the latter strategies that are the focus of this study.

This introductory chapter provides background information about the etiology of HIV/AIDS and the HIV/AIDS situation in Thailand, outlines the significance of the study, presents the research questions and provides an overview of the structure of the thesis.

1.2 BACKGROUND INFORMATION ABOUT HIV/AIDS

AIDS was first formally recognised as a new disease in 1981 in the United States of America (Barnett & Whiteside, 2002; Merson, 2006; Pratt, 1995; Smith, 1996; Stine, 2003; WHO, 2003), in young homosexual men who were presenting with Kaposi's sarcoma and serious infections, mainly pneumocystis carinii pneumonia, that were unusual in men of this age group with no underlying disease. AIDS is characterised as the breakdown of the body's immune system, which then allows "opportunistic" infections to occur (Barnett & Whiteside, 2002; Bartlett & Finkbeiner, 1998; Jonson, 1988; McMillan, 1992; Pratt, 1995).

1.2.1 Etiology

Only two years after AIDS was first described, scientists in France isolated its causative agent which they called *lymphodenopathy-associated virus* (LAV) (Pratt, 1995). The virus was independently isolated by two groups of research workers in the USA, who called it *human T-cell lymphotropic virus type III* (HLTV-III) and *AIDS-*

associated retrovirus (ARV). The virus is now generally known as the *human immunodeficiency virus* (HIV) (McMillan, 1992; Pratt, 1995).

Viruses are extremely small life forms that are composed of a piece of nucleic acid (either DNA or RNA, but not both). The Human Immunodeficiency Virus (HIV) belongs to a group of retroviruses, more specifically called *Retroviridae*, subfamily *Lentivirinae*. Retroviruses are viruses that have a ribonucleic acid (RNA) genome and a lipid-containing membrane surrounding their capsid[3] (McMillan, 1992; Pratt, 1995). Two serotypes of HIV are currently recognised, namely HIV-1 and HIV-2. Worldwide, the predominant virus is HIV-1. However, HIV-2 appears to have spread in most West African countries, although sporadic infections with this serotype have now been reported from Europe, Central and East Africa, as well as North America. The modes of transmission of HIV-2 are similar to those for HIV-1, however, HIV-2 may be less easily transmitted, less pathogenic and the spread between initial infection and illness may be longer in the case of HIV-2 (Pratt, 1995; Smith, 1996). Evidence of HIV-2 infections has been demonstrated in the sera from two foreigners who were admitted to hospitals in Bangkok. The first case came from West Africa and the other from India. Up to the end of 2000, no HIV-2 infection had been found in Thai serum samples (Chanbancherd et al., 2000; Wasi, 1995). However, differing subtypes of HIV-1 (subtype E and B strains) have been identified in Thailand (Subbarao, et al., 2000; Xiridou, et al., 2007), with the majority of cases being subtype E (Srisuphanunt, Sukeepaisarnchareon, Kucherer, & Pauli, 2004).

HIV is a retrovirus that primarily infects vital components of the human immune system. Most notably, CD4+ T lymphocyte counts are destroyed during the typical course of infection. These cells play a central role in the immune response, signalling other cells in the immune system to perform their special functions. A healthy, uninfected person usually has 500-1,600 CD4+ T lymphocyte counts per microlitre of blood. During HIV infection, the number of these cells progressively declines. When a person's CD4+ T lymphocyte count falls below 200 cells per microlitre, he or she becomes particularly vulnerable to the opportunistic infections and the syndromes that signal AIDS, the end stage of HIV disease (Barnett & Whiteside, 2002; Pratt, 1995).

---

[3] Capsid is the protein shell of a virus (Pratt, 1995)

People with AIDS often suffer infections of the intestinal tract, lungs, brain, eyes and other organs, as well as debilitating weight loss, diarrhoea, neurological conditions and cancers such as Kaposi's sarcoma and lymphomas. It is believed that once an individual has become infected with HIV, he or she remains infected for life (NIAID, 2003).

1.2.2 Mode of Transmission

HIV is transmitted through three primary routes; sexual contact with an infected person, significant exposure to infected blood or blood products (including needles shared among intravenous drug users) and perinatally from an infected mother to her child (Barnett & Whiteside, 2002; Bartlett & Finkbeiner, 1998; WHO, 2001). Laboratory and epidemiological studies have, however, shown that HIV is not transmitted by everyday contact, by touching, hugging or kissing, sneezing, through food or water or by mosquitoes and other biting insects (McMillan, 1992; WHO, 2001).

1.2.2.1 Sexual relations

Transmission through sexual intercourse between men occurs in most parts of the world, although in the developed countries it has become far less common as a result of the adoption of safer sex practices by homosexual men (Barnett & Whiteside, 2002; CDC, 2007; WHO, 2001). The majority of the world's HIV infections have, in fact, been acquired through heterosexual intercourse (Barnett & Whiteside, 2002; CDC, 2007; WHO, 2001). The most common way of exchanging bodily fluids and spreading the infection is unprotected penetrative sexual intercourse. In these situations, HIV-infected semen, vaginal fluid or blood from one person can pass into the other person's body through tiny cuts or sores in the vagina, anus or penis. This mode of transmission continues to grow in importance worldwide, and is on the rise in both the developed and developing world (Barnett & Whiteside, 2002; CDC, 2007; WHO, 2001). Prevention of sexual transmission of HIV and other sexually transmitted diseases can be achieved by 100 % condom use by persons whose sexual behaviours place them at risk.

1.2.2.2 Exposure to infected blood or blood products

HIV infection is also transmitted through transfusion of infected blood or blood products. In many parts of the world, progress towards a safer supply of blood and blood products is being achieved through the appropriate selection of donors, the screening of donated blood, and through more rational use of blood aimed at decreasing the number of people receiving transfusions. As a result, HIV infection resulting from contaminated blood transfusions has been controlled in developed countries and is declining elsewhere. Occupational exposure can be reduced through applying universal precautions, especially for medical and nursing staff. Routine use of gloves and sterilising equipment will protect them against HIV transmission from patients (Barnett & Whiteside, 2002). However, illegal drug users who share unsterile injecting equipment have very high risks of contracting the virus (Barnett & Whiteside, 2002; WHO, 2001). The provision of sterilised needles and syringes is effective in preventing transmission in this group.

1.2.2.3 Mother-to-child transmission

Mother-to-child transmission depends on the condition of HIV positive mothers' immune systems during pregnancy, delivery and breastfeeding (AIDSNet, 1998; Barnett & Whiteside, 2002). Much of the mother-to-child transmission of the virus occurs during pregnancy and delivery, although about 30% of all HIV infections transmitted from an infected mother to an uninfected child are reported to occur through breastfeeding (UNAIDS, 2002a). The progression of AIDS in perinatally infected children is rapid, with death occurring usually before the age of five years. An antiretroviral drugs regimen can reduce the risk of an HIV-infected mother transmitting the disease to her child by about 40% (WHO, 2001). For example, an HIV positive mother may take an antiretroviral drug such as Zidovudine-AZT during the last four weeks of pregnancy, and then take a single dose of Nevirapine at the onset of delivery (Barnett & Whiteside, 2002). Antiretroviral drugs are given to the infant within 72 hours of birth. When medications are not available, caesarean section is recommended instead of vaginal delivery, but this may not be available or practical in developing countries where many women lack access to healthcare services (Barnett & Whiteside, 2002; WHO, 2001).

In developed countries, including Thailand, HIV infected mothers are advised to use infant formula milk feeding, instead of breastfeeding, from birth. Formula milk feeding has been reported to reduce perinatal HIV infection in Thailand from 25-30 % to 18-20 % (AIDSNet, 1998). Nevertheless, formula milk feeding is not always available or appropriate, especially in poor families, where lack of affordability of formula products and risks accruing from poor housing conditions may result in babies dying from deficiency disease, or diarrhoea caused by dirty milk container equipment (AIDSNet, 1998; Barnett & Whiteside, 2002).

1.2.3 Stages of infection

Nearly all infected persons remain well for several years after infection. However, most will develop AIDS within eight to ten years without treatment after infection. The shortest time for development of AIDS–two years or less from infection–is very unusual as most people are asymptomatic for at least five years (Bartlett & Finkbeiner, 1998). There are three stages of development of HIV infection:

1.2.3.1 Asymptomatic HIV infection

The first stage of HIV infection is asymptomatic. People may look and feel healthy for many years. However, even when they appear well they can pass the virus to others, especially through semen and vaginal secretions (Bartlett & Finkbeiner, 1998; Jonson, 1988).

1.2.3.2 AIDS–related complex

The second stage is called *AIDS-related complex* (ARC). In this stage, people with HIV infection will experience minor symptoms lasting more than one month such as fever, night sweats, enlarged lymph nodes in neck, armpits and groin, weight loss, diarrhoea, cough, oral thrush, oral hairy leukoplakia, fatigue and loss of appetite. Although AIDS-related complex may be serious, it is not necessarily fatal. Those who have it do not suffer from the opportunistic infections related to AIDS (Bartlett & Finkbeiner, 1998; Jonson, 1988).

1.2.3.3 AIDS

The last stage of HIV infection is AIDS, which is diagnosed only when the immune system has been damaged by the HIV virus (CD4+T lymphocyte counts less than 200 cells per microlitre of blood) (Bartlett & Finkbeiner, 1998; Jonson, 1988; Stine, 1996, 2003). People with AIDS are vulnerable to opportunistic infections and malignancies because of their weakened immune systems. Common opportunistic infections and diseases include: 1) bacterial diseases such as tuberculosis, mycobacterium avium complex (MAC), bacterial pneumonia and septicaemia (blood poisoning). 2) protozoal diseases such as pneumocystis carinii pneumonia (PCP), toxoplasmosis, microsporidiasis, cryptosporidiosis, isopsoriasis and leishmaniasis. 3) fungal diseases such as candidiasis, crytococcosis and penicilliosis. 4) viral diseases such as those caused by cytomegalovirus, herpes simplex and herpes zoster virus. 5) HIV-related malignancies such as Kaposi's sarcoma, lymphoma and squamous cell carcinoma (Bartlett & Finkbeiner, 1998; Pratt, 1995; Stine, 1996, 2003). In addition, the natural history of HIV infection in the average patient without antiretroviral therapy from the time of HIV transmission to death is 10-11 years (Bartlett & Gallant, 2000).

1.2.4 Treatment

Since the discovery of HIV as the virus responsible for AIDS, investigations have focused on the identification and clinical testing of agents that are capable of inactivating this virus. Most of these drugs function as inhibitors of reverse transcriptase (an enzyme unique to retroviruses), although some have other modes of action such as being inhibitors of protease (MOH, 2004). Antiretroviral drugs are recommended for all people infected with HIV who have symptoms regardless of CD4+T lymphocyte counts, and for all asymptomatic patients whose CD4+T lymphocyte counts are below 200 cells per microlitre (MOH, 2004; Supakankunti, Phetnoi, & Tsunekawa, 2004). When an asymptomatic patient has a CD4+T lymphocyte count between 200 and 300 cells per microlitre then antiretroviral therapy may be considered on the basis of development of the immunological parameters (CD4+T lymphocyte count) and viral loads as well as other characteristics shown by the patient (motivation, willingness to adhere to medication, co-infections) (Barnett & Whiteside, 2002; MOH, 2004).

Highly active antiretroviral therapy (HAART) is an antiretroviral regimen capable of suppressing HIV for many months, and perhaps years, in a significant number of persons. HAART consists of combinations of at least three drugs belonging to at least two types of antiretroviral agents. It usually involves the use of two reverse transcriptase inhibitors and one protease inhibitor. Although they do not cure, such treatments are effective in rapidly reducing the viral load, thereby improving health and quality of life, which has led to prolonged survival (Barnett & Whiteside, 2002; MOH, 2004).

1.3 THE HIV/AIDS SITUATION IN THAILAND

The history of the HIV/AIDS epidemic in Thailand and the government's response to the epidemic, are well described by Punpanich, Ungchusak, and Detels (2004) and are only briefly summarised in this section. The first case of AIDS in Thailand was diagnosed in 1984 in a homosexual man returning from overseas and receiving treatment in Bangkok (Phoolcharoen, Kunanusont, Pitisuttithum, & Bhamarapravati, 2004; Punpanich et al., 2004; Thongcharoen, 1990). During 1984 to 1987, new cases were largely confined to Thai homosexual males. This period was followed by an explosive spread of HIV infection among injecting drug users in 1987 and 1988, when HIV prevalence rates among injecting drug users in Bangkok rose from 0 to 40 % (World Bank, 2006). The HIV virus then spread to sex workers and their clients in 1989 and 1990, with the result that heterosexual transmission became an increasingly important route. By 1994, the HIV prevalence rate had reached 31% among brothel-based sex workers, 38% of whom were found in the Northern region of Thailand (World Bank, 2006). Consequently, HIV spread rapidly between sex workers and their clients. By 1994, one in ten clients was infected with the HIV virus. Those clients then infected their wives who, in turn, became pregnant and transmitted the HIV virus to their newborn. In 1991, the first perinatal cases were documented and the numbers of infected children increased in the following years (World Bank, 2006).

1.3.1 National response to the HIV/AIDS epidemic

After the first AIDS case was recognised, AIDS was declared a severe communicable disease (Poolchareon et al., 2004; Punpanich et al., 2004; Sunthrajarn et al., 2005). The responses of the government to HIV/AIDS prevention and control, including the care of people living with HIV/AIDS from the beginning of the HIV/AIDS era to the present in Thailand, can be divided into the following three phases:

1.3.1.1 Phase one

During the first phase, prior to 1991, both the government and private sectors were worried about the negative image of HIV/AIDS. They believed that the epidemic would remain concentrated in high-risk group behaviours, particularly injecting drug users and homosexual men (Poolchareon et al., 2004; Punpanich et al., 2004; Sunthrajarn et al., 2005). Thai government policy on HIV/AIDS control followed a standard public health approach that emphasised case reporting of AIDS through the medical system. However, the standard of reporting failed to detect the rapid spread of HIV infection, which can be asymptomatic for many years before the onset of AIDS, and there was limited information on high-risk groups. The public perception was that AIDS affected marginalised groups such as homosexual men, male sex workers and injecting drug users (Poolchareon et al., 2004; Punpanich et al., 2004; Sunthrajarn et al., 2005). The programme for prevention and control of AIDS included measures for programme management, health education, counselling, training, surveillance, employing universal precautions in health care and blood safety control. The strategy focused on individuals at high risk by providing information, raising awareness, and delivering fear-inducing messages (Poolchareon et al., 2004; Sunthrajarn et al., 2005). However, mandatory reporting of HIV infection was seen as creating stigmatisation and breaching human rights, and was abolished in 1991 (Punpanich et al., 2004).

1.3.1.2 Phase two

The second phase includes the period from 1991-1996. The turning point in fighting AIDS in Thailand came in 1991, when AIDS prevention and control became a national priority at the highest level; responsibility for coordinating AIDS policy was placed with the Office of the Prime Minster and a multi-sectoral National AIDS Prevention and Control Committee that was chaired by the Prime Minister. The programme benefited from strong political commitment from the Prime Minister's office and mobilisation of the public, private and Non-Government Organization (NGO) sectors in the policy dialogue to fight AIDS. The plan urged society and community participation in the prevention of HIV and the care of people living with HIV/AIDS who were sick, and a reduction of stigma and discrimination (Ainsworth, Beyrer, & Soucat, 2001; Poolchareon et al., 2004; World Bank, 2006).

The government strategy focussed on changing the risk behaviours among sex workers and their clients. Intensive public education on HIV/AIDS prevention was commenced through the mass media, including one-minute AIDS education spots every hour on television and radio. These messages stressed prevention by condom use. The "100% condom programme" was initiated to promote universal condom use in all commercial sex situations with the aim of preventing HIV transmission rather than suppressing commercial sex. The programme involved cooperation at provincial and local levels between public health officers, brothel owners, the local police, and sex workers to encourage all customers to use condoms when engaging in sex, with a slogan "use a condom with every client, in every sex act". If a client refused, he must be reported to the manager of the brothel. Under the programme, sex workers were screened for sexually transmitted diseases every week at the government sexually transmitted disease clinics, treated as required and provided with free condoms (Poolchareon et al., 2004; Punpanich et al., 2004; Sunthrajarn et al., 2005; Thanprasertsuk, 2007; UNAIDS, 2002a, 2002b). The government provided almost 60 million free condoms a year to support this programme (Rojanapithayakorn & Hanenberg, 1996). Subsequently, a 90% decline in the rate of sexually transmitted diseases was documented. Other evidence of success included a reduction in HIV infection among army conscripts in the Northern region of Thailand (Ainsworth et al., 2001; Sunthrajarn et al., 2005; UNAIDS, 2000).

Education on HIV/AIDS was introduced into all schools from primary level upwards and provided through religious institutions. The whole society was involved including the movie industry and mass media. AIDS was approached not only as a health problem but also as a social problem (Poolchareon et al., 2004; Punpanich et al., 2004; UNDP, 2004).

1.3.1.3 Phase three

The third phase included the period from 1997 to the present. In 1997 a financial crisis affected the country that forced profound budget cuts and a reorientation of social affairs including the AIDS programmes. For example, the Ministry of Education decided to drop its plan for life skills education in schools (Poolchareon et al., 2004; Punpanich et al., 2004; Sunthrajarn et al., 2005). However, multi-sectoral collaboration remained the weak point of implementation, demanding broader and deeper understanding among staff about social aspects. The plan emphasised efforts to mobilise communities and civil society to initiate their own activities in HIV/AIDS prevention, care and alleviation of the socioeconomic impact of AIDS. The plan included the main programmes such as empowerment of community and family, development of psychosocial care for HIV/AIDS sufferers, and health and medical care for HIV/AIDS, HIV/AIDS research (Poolchareon et al., 2004; Punpanich et al., 2004; Sunthrajarn et al., 2005). Besides the prevention strategy, Thailand has included antiretroviral therapy into the service package in the social and health security programmes since 2005 (MOPH, 2007a).

Although the HIV prevalence rates have decreased dramatically since the middle 1990s, the HIV/AIDS situation in Thailand is far from over. The last waves of new HIV infections among women and their children have started to decline, but the HIV prevalence rates among injecting drug users remain very high (Thanprasertsuk, 2004; World Bank, 2006). The HIV prevalence rate among commercial sex workers has decreased because of the 100% condom use programme. Nevertheless, sex workers remain a major risk group (Thanprasertsuk, 2004). With the large number of HIV infected persons (currently estimated to be more than 500,000), there is a potential for the epidemic to spread if prevention programmes are relaxed. At present, almost 80% of all HIV/AIDS cases occur among people aged 20-39 and heterosexual transmission remains the major route of transmission (MOPH, 2006c).

Alongside the continuing focus on prevention programmes to control the epidemic, there is a parallel requirement to address the health needs of people with HIV/AIDS. Thailand has struggled with health service provision, particularly in relation to fiscal resources and manpower (doctors and nurses) (MOPH, 2006a, 2006b). That challenge is potentiated by the more extensive services now available under the universal coverage scheme and the consequent availability of antiretroviral medication that transforms AIDS from a short fatal illness to a chronic illness requiring extended healthcare and treatment.

1. 4 SIGNIFICANCE OF THE STUDY

In this study, grounded theory was used as a method to gain new knowledge about self-care processes of Thai people suffering from AIDS. The study is significant for a number of reasons: the extent of suffering of the population group, the magnitude of the health problem, the economic implications of the age group that is predominantly affected, and–consequently–the need for effective self-care, and for inductively derived local knowledge for health professionals to underpin their support of self-care.

1.4.1 The extent of suffering

People living with HIV/AIDS experience physical and psychological suffering and economic hardship. As previously discussed, infection with HIV leads to a variety of clinical conditions, such as episodes of illness, fever, sweats, headache, loss of weight, weakness, exhaustion, diarrhoea, pain and opportunistic infection (Bartlett & Finkbeiner, 1998; Danziger, 1994). People living with HIV/AIDS and their families may also experience stigmatisation and discrimination from people around them, causing psychological and sociological problems such as depression, anxiety, fear, isolation and hopelessness (Danziger, 1994; UNAIDS, 2004). They are likely to lose their jobs due to their illness and experience a decrease in their physical capabilities (Yanwaree, 2002).

1.4.2 The magnitude of the problem

As previously stated, the HIV/AIDS epidemic in Thailand has affected all sectors of Thai society, although the number of new HIV cases per year decreased from more than 130,000 in the early 1990s to less than 20,000 cases in 2003 (Sunthrajarn et al., 2005). Currently, the number of new HIV infections is estimated to be about 17,000 cases a year (MOPH, 2007a). Although the HIV prevalence rates have decreased dramatically since the middle 1990s, the HIV/AIDS situation in Thailand is far from over. The maintenance of effective prevention programmes alongside extended healthcare provision for people with AIDS is a costly exercise for the government.

1.4.3 Economic implications

AIDS affects the economic state of people living with AIDS and their families, and their communities, at differing levels. Many family breadwinners, in the prime of their working lives, are falling sick and dying prematurely. A rising number of wives are infected by their husbands. The long-term effect is that the parents of people living with AIDS, who are often elderly people, must take care of their children and grand-children who are sick with AIDS (Danziger, 1994; Im-emm & Phuangsaichai, 1999; UNAIDS, 2004). This situation is made worse by the loss of earnings of the breadwinner. At government level, the high costs associated with treatment of large numbers of people with AIDS to maintain their lives at a time when Government health budgets are limited, are challenging (MOPH, 2006a, 2006b; Nilmanat & Street, 2004). As a result, AIDS is seriously affecting both the household and government economies (Boom & Sherr, 2004; Kulsomboon et al., 2004).

1.4.4 The need for effective self-care

A focus on self-care has become increasingly evident in healthcare, with the rise in chronic illnesses and the world economic crisis stimulating the need for health care reform in Thailand (Hanucharurnkul, 2000; MOPH, 2006a). In Thailand, the National Health Care Reform Committee has included self-care as one of the key elements in primary care that is integrated, continuous and holistic in nature.

Self-care has been defined as "*a process whereby a layperson functions on his/her own behalf in health promotion and prevention, and in disease detection and* *treatment at the level of the primary health resource in the health care system*" (Levin, Katz, & Holst, 1976, p. 11). Self-care is very important for people with HIV/AIDS since if they care for themselves competently, they may extend their life span and prevent opportunistic infections from taking hold (Allan, 1990; Nilvarangkul, 2002; WHO, 1996). Effective self-care also reduces health costs and the impact on families.

Self-care has been one of the key domain concepts in nursing since 1959, with the development of Orem's self-care model (Orem, 1995). Over the past 10 years, many graduate nursing students have used Orem's general theory of nursing, alone or in combination with other theories, as a conceptual framework for quantitative research studies related to self-care (Hanucharurnkul, 2000). However, it is not clear how Orem's theory which was developed within an individualist society (USA), fits with the collective identity of Thai people.

Most Thai healthcare providers, including nurses, are more familiar with the medical model than with the self-care model. Within the medical model, an ill person is defined as a *patient* and as a *care receiver* (Sritanyarat, 1996). Thus, a patient is expected to change his or her behaviour to follow medical advice. Such an approach does not necessarily foster self-care as defined above.

1.4.5 The need for inductively derived local knowledge for health professionals

Theories and models of self-care that were developed in other countries may not 'fit' and 'work' in the Thai context. Understanding the self-care processes and the resources that people living with HIV/AIDS use to control and manage their symptoms is crucial for healthcare providers seeking to help clients in performing effective care and sustaining best quality of life (Chou, Holzemer, Portillo, & Slaughter, 2004). Such knowledge may guide the development of healthcare plans, strategies and interventions to facilitate effective self-care. A grounded theory approach was therefore utilised in this study to inductively derive substantive theory that "fits" and "works" in the context of North Eastern Thailand.

1.5 RESEARCH QUESTIONS

The broad questions that framed the study were:

1) What are the experiences of Thai people suffering from AIDS, in managing and living with AIDS in the context of their environment in daily life?

2) What are the self-care processes of Thai people suffering from AIDS living in their own homes?

1.6 OVERVIEW OF THE STUDY

This thesis is divided into two parts. Part I includes the first three chapters that provide a background to the study, review relevant literature and detail the design and methods of the research. In Part II, Chapters Four to Seven present the findings in detail. Chapter Eight presents a theoretical model and concludes the study.

In Chapter One, background information about the etiology of HIV/AIDS, and the HIV/AIDS situation in Thailand are outlined as a basis for identifying the significance of the study and the research questions. An overview of the structure of the thesis is provided.

In Chapter Two, the literature pertaining to stigma and discrimination related to HIV/AIDS is examined, followed by an introduction to the health care context of the research. A broad review of self-care literature and the related literature on health-seeking behaviours and health beliefs in Western and Thai contexts is undertaken that is indicative of my existing familiarity with professional and popular literature around self-care prior to undertaking this study, but including literature located throughout the duration of the study.

In Chapter Three, the theoretical underpinnings of grounded theory methodology and its application in this study are illustrated. A rationale is provided for selection of grounded theory methodology as an appropriate approach to explore the ways that Thai people with HIV/AIDS take care of their health and manage their lives in the context of stigma and discrimination. The methods of grounded theory are outlined and their implementation in this study is detailed.

In Chapter Four the category "**being HIV/AIDS**" is outlined, that explains the initial experiences of the participants. The category "**being HIV/AIDS**" was supported by four concepts including ***being diagnosed with HIV/AIDS, being stigmatised, suffering,*** and ***learning about HIV/AIDS***. These concepts were identified by exploring the meaning, to participants, of having HIV/AIDS and their early experiences in managing and living with their HIV/AIDS.

In Chapter Five the category "**making choices**" is presented. The action of making choices became important when people with HIV/AIDS revised their understanding of what it means to have HIV/AIDS. Participants made choices in order to live a "normal" life, learning how to manage their life situation to live as satisfying a life as possible with HIV/AIDS. Consistent with living in a collective society, managing relationships with others was a key element in the choices made by participants; the category **"making choices"** was supported by the three concepts, including ***avoiding unhappy situations, seeking support,*** and ***getting remarried.***

In Chapter Six the category "**keeping well**" is described and illustrated. Keeping well describes the process by which the participants adjusted their daily activities in order to promote their physical well-being and maintain their lives. Participants were motivated to take good care of their physical and mental health because they now believed HIV/AIDS was a chronic disease rather than a rapidly fatal illness; and that they could face the future with HIV/AIDS. The category **"keeping well"** comprises eight concepts that include ***religious practices***, ***keeping a cheerful mind, self-treatment, taking care of the body, keeping the environment clean to prevent getting germs, healthy behaviours, getting healthcare services*** and ***attention to, and concern about, medication.***

In Chapter Seven the category **"feeling empowered"** is presented. Feeling empowered refers to the positive energy that drives one to maintain and move forward with one's life, which arises from having the will to live and the ability to cope with life's problems. Although they were confronting significant health and social problems, the participants made the decision to live and not quit. They took strength from people in society who were accepting of their illness. **"feeing empowered"** includes the concepts ***being encouraged, acknowledging the disease, social acceptance, tamjai, feeling proud of self, feeling good about life, feeling lucky*** and ***having hope.***

Chapter Eight presents a detailed description of the theoretical findings about the experiences of Thai people living with HIV/AIDS that are encapsulated within the basic social psychological process **"from experiencing social disgust to passing as normal"**. The relationship of the findings of this study to those of other comparable studies is discussed, followed by the implications, recommendations and limitations of the study.

1.7 CONCLUSION

This study is very important because appropriate self-care management while being HIV/AIDS depends on many factors such as physical, psychological, economical, political and social, which can cause major impacts on health conditions. Thus, this study is focused on the self-care processes of Thai people living with HIV/AIDS and the aim is to provide increased understanding of self-care processes which will lead them to develop their ability to manage their lives, based on the Thai Isaan perspective. By using grounded theory study, I hope that the process of the self-care model by which the study participants interpreted their experience of living with HIV/AIDS, and their interaction with others, will be useful for making recommendations to motivate people living with HIV/AIDS to practise self-care management appropriately. The next chapter will present a review of selected literature that is relevant to this study.

CHAPTER TWO

REVIEW OF THE LITERATURE

2.1 INTRODUCTION

There is some debate about the place of a literature review in a grounded theory study. Glaser (1978, p.31) argues that the researcher should read “in a substantive field different from the research” in order to avoid shaping the analysis of the data to conform with known concepts and theories. Schreiber (2001), however, acknowledges that in the world of nursing the researcher often brings to the study an existing background familiarity with the field of study (as I have outlined on page one), and with the professional and popular literature. In the context of doctoral research, some familiarity with existing literature is required to demonstrate the importance of the problem or its significance in the broader field of knowledge (as outlined in the previous chapter), and to ensure that the proposed research is likely to answer the question of interest and provide an original contribution to knowledge.

In this grounded theory study I explored the ways in which Thai people with HIV/AIDS take care of their health and manage their lives in the context of stigma and discrimination (Paxton et al., 2005; Phengjard et al., 2002; Phongphit, 2004; UNAIDS, 2004). In this chapter, the literature pertaining to stigma and discrimination related to HIV/AIDS is examined, followed by an introduction to the health care context of the research. A broad review of self-care literature and the related literature on health-seeking behaviours and health beliefs in Western and Thai contexts is undertaken that is indicative of my existing familiarity with professional and popular literature around self-care prior to undertaking this study, but including literature located throughout the duration of the study.

2.2. THE STIGMA AND DISCRIMINATION OF HIV/AIDS

AIDS is now widely accepted as a chronic illness (Lee et al., 2002; Mak et al., 2007). People living with HIV/AIDS experience social stigma and discrimination (Boer &

Emons, 2004; Lee et al., 2002; Mak et al., 2007; Parker & Aggleton, 2003; Phengjard et al., 2002). HIV/AIDS has been recognised as a stigmatised disease since the early cases of AIDS appeared among gay men and intravenous drug users in the United States in 1981 (Alonzo & Reynolds, 1995; Lee et al., 2002). The stigma of HIV/AIDS is reported to be greater than that of other stigmatised illnesses, such as cancer, leukemia and herpes (Lee et al., 2002), tuberculosis (TB) and severe acute respiratory syndrome (SARS) (Mak et al., 2006). HIV-related stigma results in people living with HIV/AIDS experiencing shame, fear of disclosure, social rejection, lack of social support, social isolation and suicidal thoughts (Hudson, Lee, Miramontes, & Portillo, 2001; Lee et al., 2002; Nilmanat et al., 2006). Alonzo and Reynolds (1995) consider that AIDS is stigmatised because it is:

> 1) associated with deviant behavior, both as a product and as a producer of deviant behavior; 2) viewed as the responsibility of the individual; 3) tainted by a religious belief as to its immorality and/or thought to be contracted via a morally sanctionable behavior and therefore thought to represent a character blemish; 4) perceived as contagious and threatening to the community; 5) associated with an undesirable and an unaesthetic form of death; and 6) not well understood by the lay community and viewed negatively by health care providers (p. 305).

In addition, a major reason why people living with HIV/AIDS are stigmatised is that the stigma of HIV/AIDS is “layered” up on the stigmas related to homosexuality, drug users and sexual promiscuity (Lee et al., 2002, p. 310). This finding is confirmed by other studies (Ford & Koetsawang, 1991; Parker & Aggleton, 2003; Songwathana & Manderson, 1998; Sringernyuang et al., 2005). A stigma is a social construction which affects the life experiences of HIV-infected people and their partners, families and friends (Alonzo & Reynolds, 1995).

There are many reasons for rejection and discrimination; in the Thai context the fear of contracting the virus from contact with people living with HIV/AIDS has been a major issue for Thai people (Nilvarangkul, 2002; Rujkorakarn, Siriwatanamethanon, Kiewying, Sukmak et al., 2000; Songwathana & Manderson, 1998). This fear arose from the first public media campaign on HIV/AIDS that the Thai government produced which was aimed at arousing fear of contracting HIV/AIDS, as a means of preventing and controlling HIV/AIDS in high-risk groups, such as intravenous drug users, prostitutes and homosexual men. Thus, the media portrayed the infection as lethal, incurable, a very severe disease that could be contracted by drug users or the sexually promiscuous, especially prostitutes (Lyttleton, 1994, 1996; Songwathana & Manderson, 1998). The perceptions of HIV/AIDS were influenced by the public image of AIDS with pictures of patients who had ulcers and thrush in the mouth, and were very thin with unsightly skin lesions covered with discharge. This media approach contributed to negative attitudes toward AIDS patients rather than focusing on controlling and preventing the disease (Songwathana & Manderson, 1998). The impact of any government media campaign is significant in Thailand because of the lack of any other sources of information. In addition, Thai people feel that information about HIV/AIDS from the government is reliable (Songwathana & Manderson, 1998).

Social rejection and stigmatisation are associated with the relative visibility of a disease. For example, diabetes mellitus is an invisible condition while a physical disability, such as paraplegia, is visible. Some diseases have both visible and invisible symptoms (Joachim & Acorn, 2000), such as leprosy, and HIV/AIDS. When people who have chronic illness including HIV/AIDS have visible signs, they tend to experience greater rejection than when they do not have any visible signs (Songwathana & Manderson, 1998).

Rejection and discrimination happen at both an individual and a societal level. The severity of rejection and discrimination is reported to vary from one village to another (Rujkorakarn et al., 2000). Research has shown that community, family, and caregivers have grown in confidence to care for people with HIV/AIDS (Nilvarangkul, 2002; Phengjard et al., 2002; Rujkorakarn, Sangsuwan, Nuntaboot, Nantsupawat et al., 1997); and that people with HIV/AIDS are more confident and able to care for themselves with a better means to carry on living and promoting their quality of life (Nilvarangkul, 2002; Rujkorakarn et al., 1997). However, recent research continues to report prejudicial responses to people with HIV/AIDS in

Thailand (Nilmanat et al., 2006). The negative image of AIDS is deep rooted in Thai society. In the following section the health care context of the research is outlined.

2.3 THE HEALTH CARE SYSTEM IN THAILAND

The advance of modern medicine in the Western world has led to the decline of the practice of traditional medicine in many countries in the world including Thailand, where modern medicine has become the major health care system and Thai traditional medicine is viewed as a branch of nonconventional medicine (Chokevivat, Chuthaputti, & Khumtrakul, 2005). The Thai health care system has gone through many reforms, having evolved from the self-reliance which prevailed in the past (that is, the use of local wisdom for curative care and health promotion), to the system of modern medical and public health services (MOPH, 1998; MOPH, 2006a, 2006b).

The health care system in Thailand comprises two sectors: the government and private sectors. In the government sector, the Ministry of Public Health has the responsibility for promoting, supporting, controlling and coordinating all public health service activities for the well-being of the Thai people. Medical and health services are provided to people through the state’s regional and general hospitals (Provincial Hospitals), community hospitals (District hospitals), health centres and community health service stations. In addition, the Ministry of Education, the Ministry of Interior, the Ministry of Defence, and the Bangkok Metropolitan Administration also carry out health-related activities or provide medical or health services. The private sector plays some part in providing curative care services for people who can afford the more expensive services. In 2003, there were about 436 private hospitals, 10,819 clinics, 11,094 drugstores and 2,106 traditional medicine drugstores in Thailand (MOPH, 2006a).

In the new health care system, several levels of health care have been organised, beginning with self-care at the family level to the highest level of medical care provided by medical specialists. Numerous health personnel in various health disciplines have been produced under the new system, which also requires the purchase and development of health technologies. Despite the advance of medical technologies, they cannot successfully cure chronic diseases related to lifestyle, which are major health problems in the world (Chokevivat et al., 2005).

Thailand has struggled with the provision of health care services; inadequacies in resources and a lack of manpower are major issues confronting the health care system in Thailand (MOPH, 2006a, 2006b), especially, physicians and nurses. At present, the proportion of physicians to the population is 1: 3,295 and staff-nurses to the population is 1: 2,185 for the whole country (MOPH, 2006a, 2006b). Moreover, as the current estimated number of people with HIV/AIDS is more than half a million, the burden of health care will increase in the future. Given the Thai national policy on universal coverage of health care, the provision of adequate manpower in the hospitals will be a critical challenge.

As previously stated, a focus on self-care has become increasingly evident in health care, with the rise in chronic illnesses and the world economic crisis stimulating the need for health care reform in Thailand (Hanucharurnkul, 2000; MOPH, 2006a, 2006b). For these reasons, self-care is emphasised and promoted as a strategy of primary health care in Thailand (MOPH, 2006a, 2006b). Effective self-care reduces both the burden of illness and the burden on healthcare systems (Thorne, Paterson, & Russell, 2003).

2.4 CONCEPTUALISATIONS OF SELF-CARE

Self-care has always been one of the key domain concepts in nursing (Hanucharurnkul, 2000), however there is no commonly agreed-upon term and scope of self-care. The frequently cited World Health Organisation (1983) of self-care is as follows:

> Self-care refers to the activities individuals, families and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health. These activities are derived from knowledge and skills from the pool of both professional and lay

> experience. They are undertaken by lay people on their own behalf, either separately or in participative collaboration with professionals.

The WHO definition of self-care places emphasis on the responsibility of the individual or family to make decisions and take actions to promote or restore their own health. However, the self-care concept commonly understood and utilised in nursing in Thai universities was influenced by Orem's self-care theory and definitions (Hanucharurnkul, 2000). In this theory, self-care is conceptualised as a goal and as a strategy in relation to the promotion of self-care for the individual, families, and communities, as elaborated below.

According to Orem (1995, p. 103) "self-care is an action taken by mature and maturing individuals who have developed the capabilities to take care of themselves in their environmental situations". Consistent with the WHO definition above, Orem also states that "self-care is the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being" (Orem, 1995, p. 104). Self-care actions are directed toward meeting three different types of self-care requirements including: 1) universal self-care requisites, which are the basic needs of human beings. The universal self-care requisites are related to many factors, such as age, development, and environment, 2) developmental self-care requisites, which are needs relevant during developmental periods, and 3) health-deviation self-care requisites, which relate to taking care of oneself while being ill (Orem, 1995, pp. 108-109). Orem suggests that effective performance in response to the three types of requisites identified above will produce environmental and personal conditions that 1) support life processes, 2) maintain human structures and human functioning within a normal range, 3) support development in accordance with human potential, 4) prevent injury and pathologic states, 5) contribute to the regulation or control of the effects of injury and pathology, 6) contribute to the cure or regulation of pathologic processes, and 7) promote general well-being (Orem, 1995, p. 109).

According to Orem, when the needs of self-care exceed the self-care ability of an individual, a self-care deficit occurs. The reasons for insufficient self-care abilities include a lack of ability to perform the required self-care, or health related or situational circumstances which preclude self-care actions. Orem's theory is designed to identify the situations in which there is justification for nursing input to care (where there is a self-care deficit), or for support and promotion of individual self-care.

Orem (1995) describes two phases of self-care action; the first phase of self-care action is intentional acts; decision making to perform self-care is an important step to enacting self-care. Productive action is the second phase of action that is able to be observed; external and internal conditions and circumstances can stop the action at any phase. It is important to understand what makes people decide to initiate self-care, particularly as it has been suggested that once people decide to manage their disease, they will do so at all times and in a consistent manner (Paterson, Russell, & Thorne, 2001).

2.5 INFLUENCES ON DECISION MAKING ABOUT SELF-CARE

Several factors help people to make a decision to undertake self-care action. People take action based on the meaning of situations to them. Meaning-making behaviours are an important part of human experience and understanding (Sarangi & Candlin, 2003). For example, Crossley (2004) suggested the importance of understanding subjective meaning to facilitating change in unsafe sex behaviours in gay men, while Pretorius, Goldstein, and Stuart (2005) reported that rediscovery of spirituality, religious beliefs and compassion helped individuals with HIV/AIDS have an appreciation for life, a need for belongingness, community and positive experience of living with this disease.

Cultural beliefs play an important role in decision making to initiate self-care. The ways people living with HIV/AIDS manage illness are likely to be shaped by interaction with society. In this way, the self-care actions of human beings can be derived through the meanings that they share with others. This construction of social understanding is evidenced by the way beliefs and culture strongly influences self-care during illness. For example, a study of health beliefs in Hmong found that traditional ceremonies for healing were important because of beliefs in spirits and ghosts (Johnson, 2002). Shared meanings about health and health care may also contribute to negative self-care behaviours. According to Papadopoulos (2000) the belief that God always protects human beings, held by Greek Cypriots, “almost encourages Greek people to take too many chances with their health” (Papadopoulos, 2000, p. 185).

Information plays an important role in the development of appropriate self-care strategies in people living with HIV/AIDS (Chou et al., 2004). Huber and Cruz (2000) suggested that it is important to understand information seeking behaviors in order to manage information. Hogan and Palmer (2005) reported that individuals living with HIV/AIDS were easily overwhelmed by information, and preferred to seek information from health professionals rather than from print or media sources. Chou et al. (2004) reported self, healthcare providers, personal networks, and the community as sources of self-care information for people living with HIV/AIDS.

Harris, Bausell, Scott, Hetherington, and Kavanagh (1998) found that instilling a sense of inner control and motivation were the factors required to empower HIV/AIDS people to improve self-esteem, which fostered self-care. Taking control of the illness situation can empower people living with HIV/AIDS to initiate and maintain self-care (Cote & Pepler, 2005; Makhubela, 1999). Adamsen (2002) indicated that self-help groups helped people living with HIV/AIDS to increase their self-confidence, which had a positive impact on their ability to cope with the psychological and social consequences of living with a life-threatening disease.

Antiretroviral therapy has a key role in treatment for persons with HIV/AIDS. Recent evidence shows the impact of social support on the management of treatment adherence. For example, Simoni, Frick, and Huang (2006) found a correlation between social support and self-efficacy which predicted self-reported adherence with antiretroviral therapy; Campero, Herrera, Kendall, and Caballero (2007) suggested that social support is one factor that affects adherence to antiretroviral therapy in Mexico. Strong social support is also important for development of self-care in people living with a life-threatening condition such as HIV/AIDS. People living with this condition face many challenges, both within and outside themselves. Hand, Phillips, and Dudgeon (2006) state that social support is an elementary mediator of perceived stress and can reduce feelings of emotional distress and depressive symptoms in people living with HIV/AIDS. Social support can help people living with HIV/AIDS to manage the uncertainty about HIV illness experience by assisting with information seeking and providing instrumental support (Brashers, Neidig, & Goldsmith, 2004).

2.6 HEALTH-SEEKING BEHAVIOURS

Health-seeking behaviour refers to the sequence of remedial actions that individuals undertake to rectify perceived ill health (Ahmed, Adams, Chowdhury, & Bhuiya, 2000). Health-seeking behaviour is initiated by symptom identification and definition, whereupon a strategy for treatment action is devised. However, the symptoms will not necessarily be identified in biomedical terms nor will their recognition necessarily result in the kind health action expected by scientific medicine. Treatment choice involves a myriad of factors related to illness type and severity, preexisting lay beliefs about illness causation, the range and accessibility of therapeutic options available, and their perceived efficacy (Ahmed et al., 2000).

People in both developing and developed countries may seek help from both traditional healers and healthcare facilities. Plummer et al. (2006) found that home remedies and visiting traditional healers and/or health facilities were used by people living with AIDS in sub-Saharan Africa. Similarly in Korea, Cho (2004), in a study of the health-seeking behaviour of Korean women with Lymphodema, found that professional, folk and popular sectors of health care were utilised; and that informants presented differing patterns of behaviour appropriate to each sector as they sought assistance.

In the Thai context, family environment, cultural background, and personal experience influence illness behaviours (Sangchart, 1997). Treatment is chosen according to the cultural meaning of the illness symptoms, which directs the selection of healthcare. Individuals seek help when they become aware of the illness. They are likely to discuss their symptoms with family members, cousins, friends, or neighbours before seeking help from healthcare services (Nadee, Intarasombat, & Hanucharurnkul, 1999; Sangchart, 1997). Consistent with the findings of Plummer et al. (2006) in sub-Saharan Africa, Thai people usually seek help from both indigenous healers and healthcare authorities (Sangchart, 1997).

A number of researchers have studied the healthcare seeking behaviours of Isaan people[1]. Charurnyut (1979) found that, initially, people who live in Isaan choose to treat themselves; secondly, they choose the local healthcare authorities, private health care and indigenous health care. Preedasawadi, Pradubmook, and Puranan (1987) demonstrated the influence of family and social networks on decisions about diagnosis and treatment that underpinned healthcare seeking behaviour. They identified three levels from which advice and treatment were sought among Isaan people: 1) Family: health decisions were usually made by the father and mother although all members of the multigenerational household may be involved in the discussion of symptoms and decision making. The usual outcome was the purchase of over-the-counter drugs from grocery stores in the villages. 2). Relatives (extended kin networks): family would consult extended kin networks including aunts and uncles and their kin networks according to their experiences of treating similar symptoms; decisions were based on the advice of people senior in the kin network and mostly the strategies of senior people-such as using herbal medicines-were implemented. 3) Community level: people in the community who were not kin but had experience of treating similar symptoms may recommend treatment that worked for them, including indigenous healers, using herbal medicines and fortune tellers to tell about prognosis. Moreover, this researcher found that 93% of illness was cured by self-care. People in rural areas used multiple strategies to treat symptoms, for example taking antifever medication and resting, avoiding taboo food (Kha-lum) such as chicken, beef, bamboo shoot, pickled vegetables and ice (Preedasawadi et al., 1987).

The findings in the latter study are consistent with those of Thanasetaungkul et al. (1992) who reported that people experiencing fever, cold, cough, diarrhoea, constipation and other symptoms firstly practised self-care by taking a rest, avoiding some taboo foods and giving a tepid sponge. Some took medications relevant to their illness**.**

---

[1] Isaan people: people of Northeastern region of Thailand.

Budsadee (2000) undertook an ethnographic study of health-seeking behaviour among people living with HIV/AIDS in Mahasarakham province. She found that patterns of health-seeking behaviour incorporated two processes: perception of AIDS and trialling healthcare. Health-seeking behaviour incorporated phases of self-care, folk care and professional care with choices of care influenced by the perceived cause of sickness, the perceived efficacy of healing of differing treatments, the availability and cost of healthcare, and the fear of others finding out about the disease.

Thus, choice of healthcare is influenced by prior knowledge or experience of symptoms, perceptions of efficacy of particular treatments or forms of healthcare and also beliefs about cause and other conditions. Family members, relatives and neighbours are usually involved in the process, however there are obstacles to seeking help when there is a possibility of stigma and discrimination. For example, Wong, Gray, Ling, and Holroyd (2006) found that street sex workers were likely to self-medicate and delay in seeking healthcare.

The literature on health-seeking behaviour cited above is consistent with the health belief model briefly described in the following section.

2.7 HEALTH BELIEF MODEL

The health belief model was originally developed by Rosenstock in the 1950s and is based on the hypotheses that health behaviours depend mainly on the desire to avoid illness (or to get well) and the belief that a particular action will prevent or relieve illness (Malcolm, Ng, Rosen, & Stone, 2003). The Model’s key components are:

- Perceived susceptibility (an individual's assessment of his/her risk of getting the condition)
- Perceived severity (an individual's assessment of the seriousness of the condition, and its potential consequences)
- Perceived barriers (an individual's assessment of the influences that facilitate or discourage adoption of the promoted behaviour)
- Perceived benefits (an individual's assessment of the positive consequences of

adopting the behaviour).

- Perceived efficacy (an individual's self-assessment of ability to successfully adopt the desired behaviour)
- Cues to action (external influences promoting the desired behaviour)

The key components in the health belief model may be useful for understanding individual health behaviours. The health beliefs held by individuals are likely to influence individual health prevention knowledge, behaviours and practices. Both social and cultural aspects influence the health belief model of individuals (Redding, Rossi, Rossi, Velicer, & Prochaska, 2000; Malcolm et al., 2003).

Gillespie (2005) found that religious beliefs strongly influence health practices both in the prevention of, and in dealing with, illness. The study by Schroeder et al. (2001) found that belief in the efficacy of medications make people who live with HIV/AIDS feel healthier. Morrison-Beedy (1993) also reported perception of susceptibility to HIV was influenced by peers/partners and by knowledge about HIV. There has been very little Thai research in relation to the Health Belief model and its impact on health practices. In the following sections what has been reported about the health beliefs of Isaan people is summarised.

2.8 HEALTH BELIEFS OF ISAAN PEOPLE

People in Isaan–especially in rural communities–usually live in small houses, which have only one room; the houses are built within a small area in close proximity to their neighbours, facilitating the development of close relationships. Such relationships follow the *norms (Hiet-kong)* and rituals of society, leading to the social norm to achieve peaceful living (Ruengsuwan, 1977; Sangchart, 1997).

Traditional farmers believe that human beings depend on, and live in the natural world both with in and outside its control. Nature has rules that must be followed in order to have safety and a good life. If people do not follow the rules, they believe they will be punished by nature. The prohibited behaviours, which are called *“Kha-lum”*, are the rules that guide Isaan people in their daily living. The rules are passed from generation to generation. As society changes, some Kha-lum rules are no longer followed and some Kha-lum rules remain in practice in relation to health and illness (Sangchart, 1997).

2.8.1 Beliefs about health, illness and treatment modality of traditional healers among Isaan people

Beliefs among Isaan people underpinning health, illness and the treatment modality of traditional healers can be categorised into three types of medical system (Chirawatkul, 1993).

2.8.1.1 Supernatural medical system

Belief that illness is effected by a spirit underpins the utilisation of a *Mor tham (magic healer)* and *cham (an old man chosen as a spirit medium).* Villagers who behave against social rules, such as cutting a big tree without permission from the *Phii paa (the spirit of the forest),* treat the elderly badly, fail to recognise the ancestors, or make trouble with neighbours, risk punishment by a spirit (Chirawatkul, 1993). A range of symptoms can be experienced by a person who is believed to be punished by a spirit, such as headache, stomach ache and loss of mind.

Belief in the supernatural as respect to *Phii (spirit-ghost)* is based on the belief in the relationships between humans, nature and the environment. This reflects human views that a human being is a unit of nature. Spirits live everywhere in nature or holy things to protect nature. There are believed to be two kinds of Spirit, good spirits which protect good humans, and bad spirits which cause people to get ill (Preedasawadi et al., 1987). According to Suwanaleid (1973), belief in the supernatural cause of illness and treatment from this power guides people to choose indigenous healthcare instead of seeking help from healthcare authorities, especially where the disease is without known cause or incurable by present treatment.

2.8.1.2 Astrological medical system

Belief that human life is associated with the zodiac cycle movement underpins the choice of *Mor duu (the fortune teller).* Illness is regarded as bad luck that cannot be avoided, but can be cured by sprinkling holy water on the body or performing a ceremony. According to Chirawatkul (1993), the treatment modalities of *mor duu* are designed to make the clients release their emotional tension and strengthen their souls.

2.8.1.3 Medical system based on the humoral theory

The healers within this system include *mor yaasamoon prai, mor nguu, mor paw, and mor naan man.* They have a common belief that the human body is composed of four *elements (tard); earth (din), water (naam), wind (lom) and fire (fai).* Each element has its nature and function that relate to each other. When the four elements of the body are in equilibrium, the person will be healthy. In contrast, if an imbalance in these elements happens, a person will become ill. Moreover, the imbalance in the four internal elements and illness can also be due to an imbalance in the four external elements. Thus, illness is caused by abnormal elements and imbalance among elements (Chirawatkul, 1993; Chokevivat & Chuthaputti, 2005).

2.8.2. Belief in religion among Isaan people

Belief in religion is important to Isaan people. The temple is the centre for many activities. Buddhism has been part of the life of Isaan people. People have adopted parts of these belief systems into their way of life. They believe the force of Dhamma is the most powerful force, able to destroy the force of evil and spirits (Nuntaboot, 1994).

Moreover, the rule of Buddhism is a strong influence on perspectives of life among Isaan people. *Boon-karma* is the key rule, 1) *boon* is the result of good practices which follow the *norms or "Hiet-kong" (the tradition, custom, practice, rule of Isaan)*; 2) *karma* is bad practices or behaviours against the norm or *" Nok-hiet-nok-kong"(out of tradition, custom, practice, rule of Issan)* (Sangchart, 1997). These rules lead Isaan people to believe that illness is caused by the law of karma, which enables them to accept what is occurring without question or complaint. The present life situation is always determined by one's previous karma. People have to select to react morally or positively to what has occurred. This generates positive karmic consequences for a better present and future life. It is believed that anything that happens which cannot be solved occurs because of the previous karma of that person. This belief has particularly applied to long or chronic illness and incurable disease

(Nuntaboot, 1994). Modernisation and adoption of Western healthcare models and the migration of many young people to the cities for work has weakened adherence to religious tradition. However, the challenge of experiencing a life-threatening illness and the need to find meaning (as outlined in section 2.5) are likely to support revisiting of religious beliefs and practices.

As previously stated, there has been very little Thai research in relation to the Health Belief model and its impact on health practices; in Thai nursing research the focus has been on health-seeking behaviour and self-care using Orem's model as a theoretical framework. Self-care research in Thailand based on Orem's theory includes exploratory surveys, theory testing studies, nursing intervention studies, and self-care outcome studies (Hanucharurnkul, 2000). These studies are focused on helping individuals and their families participate in self-care. Nurses facilitate individuals' learning and developing skills to care for themselves. However, the questions of what is appropriate self-care and who should decide remain problematic issues in the self-care project.

Another framework, which has been influential in nursing research in relation to chronic illness such as, HIV/AIDS is the trajectory framework outlined by Corbin and Strauss (1992).

2.9 THE TRAJECTORY FRAMEWORK

Corbin and Strauss (1992) argue that "nursing care is first directed at assisting with the prevention of illness and, should illness occur, with the proper management of the chronic condition, while giving consideration to biographical needs and the performance of everyday living activities" (p. 21). The major contribution of Corbin and Strauss to chronic illness management evolves around a nursing model for illness management based upon the "Trajectory Framework", that is built around the idea that chronic conditions have a course that changes and varies over time (Corbin & Strauss, 1992). The trajectory framework consists of eight phases: 1) *pretrajectory* refers to before the illness course begins; 2) *trajectory onset* refers to when signs and symptoms are present, and includes a diagnostic period; 3) *crisis* refers to a life-threatening situation; 4) *acute* refers to active illness or complications that require hospitalisation for management; 5) *stable* refers to illness course/ symptoms controlled by regimen; 6) *unstable* refers to illness course/symptoms not controlled by regimen, but not requiring hospitalisation; 7) *downward* refers to progressive deterioration in physical/mental status characterised by increasing disability/symptoms and 8) *dying* refers to immediate weeks, days, hours preceding death (Corbin & Strauss, 1992, p. 17). The combined efforts of the individual, family, and healthcare providers are required to shape the illness course. The shaping process results in physical well-being and the performance of everyday life activities.

The trajectory framework has been examined (Nokes, 1991, 1998) in relation to its applicability to HIV/AIDS as a chronic illness; and applied (Alonzo & Reynolds, 1995; Brashers, Neidig, Reynolds, & Haas, 1998) as a framework for analysis in HIV/AIDS.

2.10 NURSING CARE FOR PEOPLE LIVING WITH HIV/AIDS

By providing care during illness to maintain physical, psychological and spiritual health, nursing also aims at improving the quality of life of persons with chronic illnesses. As previously stated, when the person experiences a self-care deficit (Orem, 1995), nursing assistance is required. The nurse plays a key role in assessing the individual’s self-care ability and helping the individual in the development of necessary illnesss-related self-care tasks and their behaviours (Anastasio, McMahan, Daniels, Nicholas, & Paul-Simon, 1995). The role for nurses in supporting people living with HIV/AIDS is varied and potentially wide-reaching, including education, support, referrals for resources and ongoing assessment, planning, implementing and evaluating the individual’s physical, mental and spiritual health. This process requires the nurse to understand the individual: not only her/his physical, psychological and spiritual needs and abilities, but the social context in which she or he lives (Anastasio et al., 1995). In order to give real assistance, nurses need to understand more about the experiences and responses of people living with HIV/AIDS, their perceptions and their context. With this understanding, nurses can more effectively intervene during the process of people’s management and self-care of HIV/AIDS.

2.11 CONCLUSION

In this chapter, the literature pertaining to stigma and discrimination related to HIV/AIDS was reviewed, followed by an introduction to the healthcare context of the research. An overview of self-care literature and the related literature on health-seeking behaviours and health beliefs in Western and Thai contexts was undertaken that reflected my existing familiarity with professional and popular literature around self-care prior to undertaking this study, but included literature located throughout the duration of the study.

Self-care has always been integral to the lifestyle of Thai people as an action to promote their health, prevent disease and to maintain their survival. Traditionally, people have performed a range of forms of self-care and relied on their own beliefs and knowledge, and those of friends, family, neighbours, lay healers, and social networks, to handle common illnesses (Donkaewbua, 2005; Hanucharurnkul, 1994; MOPH, 2006a). Taking over-the-counter drugs, avoiding taboo foods, using herbs, massage and magic were the main strategies of healthcare. Improved access to modern healthcare has increased the opportunities for people living with HIV/AIDS to live an extended life with a chronic illness. However, traditional approaches to managing illness co-exist with Western healthcare.

Health professionals in Thailand receive a Western health education, however, as previously stated, theories and models of self-care and the illness trajectory that were developed in other countries may not ‘fit’ and ‘work’ in the Thai context. Understanding the self-care processes and the resources that Thai people living with HIV/AIDS use to control and manage their symptoms is crucial for healthcare providers such as nurses seeking to help patients in performing effective care and sustaining best quality of life. A grounded theory approach was therefore utilised in this study to inductively derive substantive theory that ‘fits’ and works’ in the context of North Eastern Thailand. The research design and methods of the study are described in the next chapter.

CHAPTER THREE
RESEARCH METHODS

3.1 INTRODUCTION

In this chapter, the theoretical underpinnings of grounded theory methodology and its application in this study are illustrated. A rationale is provided for selection of grounded theory methodology as an appropriate approach to explore the ways that Thai people with HIV/AIDS take care of their health and manage their lives in the context of stigma and discrimination. The methods of grounded theory are outlined and their implementation in this study is detailed. In particular, the processes of obtaining ethics approval, selection of the study site and participants, demographics of the participants, data collection and analysis are detailed. Measures by which the trustworthiness of the study may be assessed are articulated.

3.2 GROUNDED THEORY

Grounded theory, a systematic qualitative research approach, is aimed at developing an explanatory theory about a phenomenon of interest existing in a specific situation (Chenitz & Swanson, 1986, pp. 3-4). Grounded theory methodology was originally developed by two sociologists, Barney Glaser and Anselm Strauss, at the University of California, San Francisco Medical Centre, while they were studying the interactions of hospital personnel with dying patients. Their first book *The Discovery of Grounded Theory, Strategies for Qualitative Research* was published in 1967. In 1978, Glaser produced a second book *Theoretical Sensitivity: Advances in the Methodology of Grounded Theory* that elaborated new methods of generating grounded theory that were not clearly explained in the first book. Strauss (1987), and Strauss and Corbin (1990, 1994, 1998) followed with an elaboration of techniques and procedures for developing grounded theory with which Glaser (1992) took issue, resulting in a methodological split between the original authors. The divergence in approaches has been reviewed by a number of authors (e.g., Duchscher & Morgan, 2004; Heath & Cowley, 2004; Walker & Myrick, 2006). This study follows Glaser's interpretation of grounded theory methodology, sometimes referred to as *classic grounded theory*.

According to Glaser and Strauss (1967), a grounded theory is inductively generated from the data of social research through the process of comparative analysis. Grounded theory methods involve simultaneous data collection, coding, and analysis of data in order to identify a core category and related categories and concepts that underpin a substantive or formal theory about the phenomenon (Charmaz, 2006; Chenitz & Swanson, 1986; Dey, 1999; Finlay & Ballinger, 2006; Glaser, 1978; Glaser & Strauss, 1967). That theory must be grounded in the reality of life experiences. That is, the theory must “fit the situation being researched and work when put into use” (Glaser & Strauss, 1967, p. 3). Glaser (1978, p. 57) suggests that three questions are important in maintaining a research focus; “What is the data a study of? What category does the incident indicate? What is really happening in the data?” Grounded theory methodology also allows for exploration of the interaction between subjective experience and social structure.

The theoretical perspective that underpins grounded theory, as espoused by Glaser, is *symbolic interactionism,* which is a framework for understanding human behavior (Beck, 2004; Finlay & Ballinger, 2006; Glaser, 1978; Hutchinson, 1993; Mead, 1934, Wuest, 2007).

3.3 SYMBOLIC INTERACTIONISM

The notion of symbolic interaction–that is, the interaction that takes place between people through the use of symbols such as spoken language, gestures or facial expressions–was first articulated by Mead (1934). Mead, a pragmatist philosopher, argued that the individual is a product of society; the *self* arising out of social experience as an object of socially symbolic gestures and interactions, and the experience of role taking. Through “taking the role of other” the individual develops an ability to look back at self, and thus to develop a concept of self. Through interaction between the object and one’s self, the object is defined and meaning is attributed to it (Chenitz & Swanson, 1986).

Social interactionists view human behaviour as the result of process rather than structure (Chenitz & Swanson, 1986). All human behaviour or actions, individually or collectively, may therefore be viewed as the result of “a vast interpretive process in which people, singly and collectively, guide themselves by defining the objects, events and situations they encounter” (Blumer, 1969, p. 132).

Blumer, a student of Mead, defines symbolic interactionism as “a label for a relatively distinctive approach to the study of human group life and human conduct” (1969, p. 1). In a much cited formulation, Blumer describes three basic premises on which symbolic interactionism rests. These are: 1) “human beings act toward things on the basis of the meanings that the things have for them”. These things may be objects, human beings, institutions, activities of others and situations, 2) “the meaning of such things is derived from, or arises out of, the social interaction that one has with others”, and 3) “these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he [or she] encounters” (p. 2).

Chenitz and Swanson (1986, pp. 6-7) suggest that the symbolic interactionist perspective has three implications for research activity. Firstly, human behaviour must be examined in interaction; moreover, the setting, the implications, and the social forces are analysed. Secondly, the researcher needs to learn the participants’ world and understand their behaviour as the participants understand it. The researcher has to “take the role of the other” and understand the world from the participants’ point of view. Lastly, the researcher has to translate the meaning derived from the participants into the language of the research discipline in order for the knowledge to be understood and accepted. While the research disciplines of Mead and Blumer were social psychology and sociology respectively, social interactionism and grounded theory methodology have been utilised by a range of disciplines including nursing.

3.4 USEFULNESS OF GROUNDED THEORY TO NURSING

Grounded theory is useful for nursing practice because it enables the development of a substantive theory of human behaviour within a particular social context. The methodology is useful for exploring the richness and diversity of human experience and contributes to the development of middle-range theories in nursing (Carpenter, 1995; Morse, 1991; Streubert & Carpenter, 1995; Wuest, 2007). By using a grounded theory approach, researchers of nursing can identify the bases of informants' experiences, and incorporate the findings as a basis for action **(**Wuest, 1995). Thus, grounded theory methodology was considered to be an appropriate approach to explore the ways that Thai people with HIV/AIDS take care of their health and manage their lives in the context of stigma and discrimination.

3.5 ETHICAL CONSIDERATIONS

This study involved human lives. Thus, the research proposal for this study, including the information sheet and participant consent form, was approved by Massey University Human Ethics Committee (MUHEC: PN Application 04/ 186) and the research committee of Mahasarakham Hospital, Mahasarakham province, Thailand (Application MHA: MK 0027.2/ 9079) before data were collected. A permission letter to conduct the study in Mahasarakham Hospital was also obtained from the Hospital Director (Appendix A).

Protection of human subjects is essential in the conduct of research. Individuals have the right to self-determination. This means that they have the right to be informed about research in which they participate (Streubert & Carpenter, 1995). In this study, a complete explanation and written description about the purpose, the method, the potential risks and benefits of participation and the protection of confidentiality were given to each participant who met the criteria for participation (Appendix B). The participants were given opportunities to ask questions and decline, or agree, to participate in this study. Participants who agreed to participate were asked to sign a consent form (Appendix C). Both the information sheet and consent form were translated into the Thai language for participants.

Interviews were conducted at sites that protected each participant's confidentiality and were convenient for participants. All data, held in the form of audiotape recordings, transcripts, field notes and computer disks, were coded to protect participants' identities and to record the date of the interaction. For example, the code (A:

13/02/05) indicated the name (A) of a participant who was interviewed on 13th February 2005. Codes have been used in the writing up of the data chapters. No real names have been used in any publications or reports of this study. Data are stored anonymously in a locked file cabinet at the Faculty of Nursing, Mahasarakham University, Mahasarakham Province, Thailand, and retained for five years from completion of the study. Then, all interview tapes and information will be erased. As a result, ethical considerations should ensure that participants and their families are not physically or emotionally harmed as a result of their participation in this research.

3.6 SELECTION OF THE STUDY SITE

Mahasarakham province was selected as the site for this study primarily because of ease of access, and my work experience, outlined in Chapter One, with people living with HIV/AIDS in rural Northeast Thailand who struggled to follow health advice because of low education and poverty.

3.6.1 Mahasarakham province

Mahasarakham province is located in the heart of Northeastern Thailand. The northeast region is the poorest of the four regions of Thailand because it does not attract rich businesses or industries (Mahasarakham Hospital, 2006a). Mahasarakham province covers an area of approximately 5,291 square kilometres. It shares boundaries with five provinces, is located on the Korat Plain just above sea level and is without major hills or mountains (Figure: 3-1). Mahasarakham province remains primarily a farming region; approximately 75% of the land is used for growing rice and other crops including cassava, sugarcane, tobacco, peanuts, soybeans, jute, vegetable plants and fruits.

The distance from the capital, Bangkok, to the main centre in Mahasarakham province is 470 kilometres by air-conditioned bus; a trip that takes about 7.5 hours. It is also possible to reach Mahasarakham by train or plane via Khon Kaen, then travelling one hour on a bus. The weather in Mahasarakham is subtropical and semiarid with three seasons: hot, rainy, and cold.

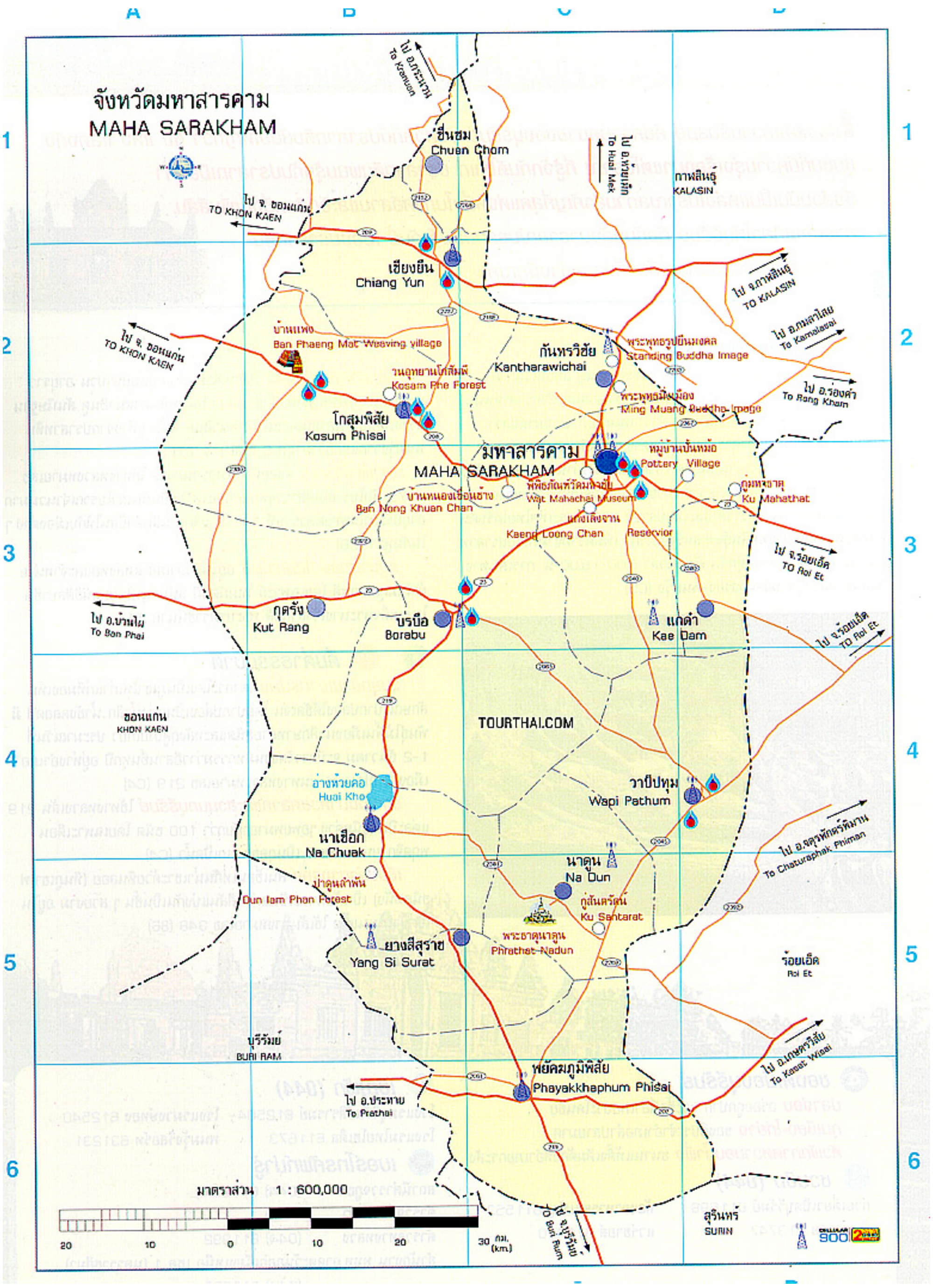


Figure 3-1: Map of Mahasarakham Province

Mahasarakham's population of 947,313 is composed of 466,700 males, and 480,613 females (Mahasarakham Hospital, 2006a). The province is divided into 11 districts (*Amphur*) and two minor districts (*King Amphur*), 133 sub-districts (*Tambon*), 1,934 villages (*Mubaan*) and 228,659 households.

Many young people migrate to larger cities in Thailand for work. Urbanisation and modernisation result in separation of people from their families when they seek work in large cities because of poverty. This results in a potential for more sexual activity with commercial sex workers. Migration is seen as an important factor in the spread of HIV/AIDS across the nation. Migrant workers are at increased risk of contracting HIV/AIDS because of inaccessibility to information and health services (Phoolcharoen, 2005; UNAIDS, 2004). Furthermore, in order to ensure their economic survival, some women become involved in sex work (Caballero, Dreser, Leyva, Rueda, & Bronfman, 2002). This finding has held true in several provinces of the Northeast including Mahasarakham.

HIV/AIDS is a significant issue in Mahasarakham province. From the year 1990 to 31 December 2006, the cumulative number of people living with HIV/AIDS in Mahasarakham province was 2,624 cases and the number that died from AIDS was 324 cases. Males with HIV/AIDS outnumbered females at a ratio of 2 to 1. Eighty-two percent of cases of HIV/AIDS were in the age range 20-39 years. Heterosexual transmission accounted for 86% of cases, 6% were newborn babies infected from their mothers, and 4% were intravenous drug users. The highest prevalence of people with HIV/AIDS was found in *Amphur Muang* (22%), the main urban area of the province (Mahasarakham Provincial Public Health Office, 2007).

3.6.2 Mahasarakham Hospital

Mahasarakham Hospital was selected as a site from which to recruit participants because it is a large public healthcare institution that provides services to clients from both urban and rural areas of Mahasarakham province and the nearby provinces. The hospital provides healthcare services for people living with HIV/AIDS at an HIV/AIDS day care clinic **(***Ban Rom Yen-Cool Shade House***)** which provides services between Monday and Friday from 08.00 a.m. to 4.00 p.m.

The services consist of a counseling service, medical service, socioeconomic service, and a psychosocial service for supporting people with HIV/AIDS to confront their problems and take care of themselves. People with HIV/AIDS are more likely to go to the general hospital than to other community hospitals because this hospital provides easy access to individuals from every part of the province, especially since they can access the HIV/AIDS health care service directly.

Figure 3-2: Mahasarakham Hospital

There were approximately 700 patients using services at the HIV/AIDS day care clinic in the fiscal year 2005 (Mahasarakham Hospital, 2006b). Moreover, the clinic keeps HIV/AIDS health records separate from other patient health records; this protection of privacy is regarded as important by people with HIV/AIDS.

People with HIV/AIDS normally come to the HIV/AIDS day care clinic on Monday by appointment in order to have a physical check up from the physicians, and to obtain prescriptions for antiretroviral and/or other medications. They also seek and receive advice about other problems from a range of healthcare providers (doctors, nurses, pharmacists and laboratory technicians) and their friends. Some participants join in activity groups such as exercise groups, or counselling groups. Furthermore, they can share their experiences with their friends who are in the same situation in order to learn alternative strategies to apply in their daily lives**.**

3.7 PARTICIPANT SELECTION

The participants in this study were 30 Thai people with HIV/AIDS (twelve males and eighteen females) selected from patients who lived at home and attended the HIV/AIDS day care clinic at Mahasarakham Hospital. Initially three participants were recruited purposively from the HIV/AIDS day care clinic. The criteria for selecting participants included people who: 1) were diagnosed with HIV infection by having a HIV-seropositive test, 2) accepted that they were HIV infected persons, 3) were able to communicate in–and understand–the Thai language, and 4) were willing to participate in the study. Subsequent participants were selected by snowball sampling, or by theoretical sampling that was based on questions arising from earlier data collection and analysis, in order to add further understanding of the phenomenon.

3.7.*1 Recruitment process*

After receiving ethics approval and permission from the hospital director to access participants and health records from the HIV/AIDS day care clinic, I contacted, and provided information about the study to, the health professionals who worked at the clinic. A head nurse who had worked with people with HIV/AIDS for more than 10 years assisted with making the study known to potential participants. I approached patients with HIV/AIDS directly, introduced myself and talked generally about the study, then asked whether they would be willing to discuss participation in it. I explained the information sheet and participant consent forms (see Appendices B and C) to potential participants who expressed interest, and I answered questions about the study until they were satisfied. When patients with HIV/AIDS agreed to participate in the study, I asked them for permission to visit them and their family members in their own homes. Participants were asked to sign a written consent form and appointments were scheduled for interviews at a time and place that was convenient for each participant. Participants were asked for directions to their homes. Snowball recruitment occurred when I met friends of participants, who were visiting from other villages, and they asked why I was not interviewing them.

3.7.2 Demographic characteristics of the participants

In this study, all of the participants were Buddhist. The participants ranged in age from 27 to 48 years with an average age of 36 years. Twenty participants were married with HIV/AIDS (10 couples), six participants were widowed, two were divorced and two were single. Twenty-three participants had children, none of whom were HIV positive.

The education level of the participants was low. Twenty-six participants had completed primary school (grades 1 to 6), while four participants had completed secondary school (grades 7 to 9). In the past, only primary education was compulsory (grades 1 to 6). Since 2004, attending school through grades 1 to 9 has been compulsory.

All of the male participants, and four women who accompanied their husbands, had previously moved away from Mahasarakham province to a large Thai city to find work. Once they contracted HIV/AIDS and were unable to retain their work in the city, they returned to their home villages in Mahasarakham province. Twenty-nine participants reported being infected with HIV by sexual transmission. Only one participant reported being infected with HIV by intravenous drug use.

At the time of participation in the study, 14 participants were unemployed. Sixteen participants were employed, the majority of these as employees in unskilled work in construction, cleaning, and sewing. Some participants were employed by the HIV/AIDS day care clinic as “volunteers”. Four participants were self-employed as farmers or barbers. Eleven participants had a total monthly income of 1,000 to 2,000 baht, ten participants earned more than 2,100 to 4,000 baht, while five participants had a total monthly income over 4,100 to 5,000 baht, and four participants had no income. Twenty participants had a total household monthly income over 5,100 baht, whereas ten participants had a total household monthly income of less than 5,000 baht (an exchange rate of 27 baht equal to NZ $ 1).

Most participants (24 cases) lived in extended families that included spouses, parents, sisters, brothers, and other family members, while four participants were in a nuclear family. Two participants lived alone, although both reported they had support from their sisters, brothers or neighbours who lived nearby. Twenty-six participants lived in rural villages spread across seven districts (Amphur), while four participants (two couples) lived in the city (Amphur Muang).

3.8 DATA COLLECTION

In grounded theory methodology, the collection of data does not finish until the end of the research because ideas, concepts and new questions continually happen which guide the researcher to new data sources. The researcher gathers data from first interviews or observations and then uses the initial emerging ideas to develop further interviews and observations. This means that the gathering of data becomes more focused and specific as the process develops (Holloway & Wheeler, 1996, p. 102). Data collection ends when no new information is forthcoming about a category or group. Data collection and data analysis are conducted simultaneously until theoretical saturation is achieved (Stanley, 2006). That is, no new categories of data emerge from the sample (Glaser, 1978; Glaser & Strauss, 1967).

3.8.1 Data collection methods

In this study, data collection methods included in-depth interviews, participant observations, field notes made during home visits, reviewing health records in the clinic and theoretical sampling. All participants preferred to be interviewed at their own homes because they wanted me to visit them at home, and they did not want to travel since it was not convenient for them. In this study, the data collection period lasted approximately eleven months, from February, 2005 to December, 2005. The following sections detail these processes.

3.8.1.1 In-depth interviews

In-depth interviews were used in the study to collect data from people with HIV/AIDS and their family members who cared for them. The in-depth interview technique was suitable when I knew most of the questions to ask but I could not predict answers from the participants. Additionally, in-depth interviews were very helpful to me in gaining all the information that I required. This interview technique also enabled participants to answer the questions freely (Morse & Field, 1996).

At the beginning of this study, the interview questions were designed to first seek general information. For example, about the participants' daily activities such as *"what are you doing?"* and then move on to the specific topics about their self-care perceptions and practices that the participants themselves may have initiated. For instance, *"Tell me about your disease". "How do you feel about living with HIV/AIDS?" "How do you manage yourself in your daily life?"* and *"How do you care for yourself"?* The interviews were audio-recorded, with the participant's permission, to capture the participant's interview word-for-word.

The most common type of interview is the individual face-to-face interview (Denzin & Lincoln, 2003; Fain, 1999; Grbich, 1999). For the most part, participants were interviewed alone, and appeared to feel comfortable and relaxed. Some women participants had their spouses sit near them so that it made them feel comfortable and able to answer the questions more freely. Only one man and one woman showed discomfort when I interviewed them, because they thought this disease made them suffer from their physical symptoms, social disgust and stigmatisation. Thus they did not want to talk about the disease in the first interview, but in the second interview both participants felt comfortable with my questions and enjoyed talking with me.

Morse and Field (1996) suggest that conducting short interviews many times is more effective than conducting a long one once. In this study, each participant was interviewed in the Isaan language at least twice, approximately 45 to 90 minutes each time. However, I spent approximately between one and three hours each time with participants and their families in order to establish and maintain rapport and mutual relationships with the participants. It was relatively easy to establish mutual interaction as I had supervised nursing students in many villages in the community and was, therefore, known to people in the villages.

3.8.1.2 Participant observation

The key element in participant observation is involvement with participants in their natural setting and participating in their lifestyle activities (Fain, 1999). During the data collection phase I sometimes participated with people in the community activities such as a wedding ceremony, religious activity and the New Year festival. When I visited participants in their own homes or their fields, I brought food, fruit, milk and clothes to them. Moreover, I helped them by cooking food and collecting vegetables and having lunch or dinner with them in their houses to gain rapport. After I had lunch or dinner with participants or with the participants' families they felt comfortable and happy because they felt that I was not disgusted by them. In return, people with HIV/AIDS and their family members gave me vegetables and fruits. This meant that participants and I displayed *spirit (namjai)* for each other. Spirit is an important element in the Thai cultural context.

Participant observation was also used to collect data during the interviews and home visits. I would observe social interactions between people living with HIV/AIDS and their families, self-care actions/interactions, behaviours, feelings, events, and surrounding participants, during interviews. For example, I interviewed one woman participant at her house. I observed the events:

> *When she talked about her husband, she kept quiet and bent her head for 3 minutes and started crying. She cried and cried because she feared the symptoms would happen with her. She said her life is uncertain, she feared of death like her husband. She knew this disease cannot be cured. May be she would not live longer. I stopped the interview because she was crying. Her face looked sad, serious, and unhappy. After she cried she looked at me then I touched her and persuaded her to go outside and talked about the weather until she was okay. After that we walked back to her home… (C: 15/02/05).*

3.8.1.3 Field notes

In qualitative research, field notes are a necessary database (Yin, 1989). Field notes are used to record information of observations, interactions, short conversations or descriptions of events after every trip into the field (Glaser, 1978; Morse & Field, 1996). In this study, field notes were used to record general information about participant observations, in-depth interviews, home visits and other activities throughout the study. For example, I took notes about the family members' interaction with people living with HIV/AIDS and their behaviours.

> *The participant and his family (mother, father, sister, and brother in-law) are having the evening meal. They sit in a circle around sticky rice containers and dishes of fish, vegetables, fermented fish and chilli sauce. Small balls of sticky rice are kneaded between the fingers and then dipped into the dishes and they use their fingers to catch the fish and vegetables, then put these in their mouths. After they have finished the meal, they wash their hands and drink water. Everyone enjoys eating the evening meal. They said to me that these meals are very delicious (zap zap)… (A: 13/03/05).*

As a result, I used field notes to formulate a context for analysis and interpretation of this study.

3.8.1.4 A review of health records

With the permission of participants, I reviewed their health records at the hospital clinic. This review provided data about CD4+ T lymphocyte counts, prescribed medications and body weight. The length of time that participants had been diagnosed with HIV/AIDS ranged from less than 1 year to 15 years. The mean length of time since they were first informed that they were HIV-sero-positive was 7.1 years. The CD4+ T lymphocyte counts, when participants first presented at the hospital and were diagnosed with HIV/AIDS, ranged from 0 to 643. Ten participants had CD4+ T lymphocyte counts of more than 200 cells /µl whereas 20 had a CD4+ T lymphocyte count of fewer than 200 cells /µl. I noted that the level of CD4+ T lymphocyte counts of most participants (20 cases) tended to rise after access to the healthcare service and antiretroviral medications, and their body weight increased. As a result, most participants viewed this healthcare as important to their self-care management. Nine participants were able to maintain their CD4+ T lymphocyte level higher than 200 without antiretroviral medication, because they took good care of their health. One participant with a CD4+ T lymphocyte count of less than 200 did not want antiretroviral medication, but was healthy because he took good care of himself and avoided risky behaviour such as smoking cigarettes, drinking alcohol and having unprotected sexual relations.

3.8.1.5 Theoretical sampling

Glaser (1978, p. 36) stated that “theoretical sampling is the process of data gathering for generating theory whereby the analyst jointly gathers, codes, and analyzes his data and decides what data to gather next and where to find them, in order to develop his theory as it emerges”. In the grounded theory approach, the theoretical sampling technique is used to guide the investigator to look for categories or concepts and relationships of concepts, rather than checking distributions of the concepts (Glaser & Strauss, 1967; Glaser, 1978, 1992). As the study progressed, categories emerged and HIV/AIDS people were recruited, who could give data on events or examples of each category and its properties. For example, in thinking about sources of social support and its impact on self-care, I noted that two participants, who worked as HIV/AIDS volunteers, received care of a high quality and funding support for their primary school-aged children (about 6,000 baht per year from the Thai government) because a nurse offered the project to them. Theoretical sampling was used to locate participants who had children but who were not eligible to receive funding from the Thai government to support their children in order to further understand the concept of seeking support.

3.9 DATA ANALYSIS

In this study, the goal of data analysis was the discovery of basic social psychological processes, not a description of phenomena. The process of data analysis includes first coding substantively. Each field note, transcription, or document is read line by line with the questions, and the coding, analysis of data and theorising would take place simultaneously (Glaser & Strauss, 1967). The audiotaped Isaan language interviews were transcribed verbatim, then I translated them into standard Thai language with the help of a colleague who could speak both Thai and the Isaan language, and had experience in qualitative research. I later translated the Thai transcripts into the English language. In order to ensure the accuracy of the English translated version, I also discussed and improved the content and meaning with a New Zealander who has been in Northeastern Thailand. Printouts were used for coding of categories which reflected the meanings of what was happening in the data.

In grounded theory, data collection and analysis occur concurrently and are based on constant comparative analysis (Glaser & Strauss, 1967). This method involves comparing incidents, participants or segments of data within and between groups in order to generate categories, concepts or hypotheses relevant to the study area. This is intended to promote the identification of the properties of categories and also of the links and relationships between categories (Glaser, 1978).

I conducted the preliminary data analysis in the field. On my return to New Zealand, that analysis was reviewed with the help of my supervisors, another visiting lecturer and a doctoral student who was also using the Glaserian grounded theory method. This group met a number of times over a period of months to discuss the interview data and draft analysis. Each member proposed her own idea about concepts, and categories that overlapped, and some concepts and categories were collapsed. In this process, concepts were renamed, additionally collapsed, or linked differently (Wuest, 2007) until revised categories and a core category, or basic social psychological process, were identified.

3.9.1 Coding process

Coding in grounded theory involves conceptualising data by constant comparison of incident with incident, and incident with category to generate many categories, and their properties (Glaser, 1992). In Glaserian grounded theory, there are three significant types of coding: 1) open coding or substantive coding; 2) selective coding and 3) theoretical coding (Glaser, 1992). In grounded theory, coding means to conceptualise the data by analysing it and identifying patterns or events in the data. Coding initiates the process of theory development (Charmaz, 2000; Glaser, 1978).

3.9.1.1 Open coding

Open coding is the process of breaking down, examining, comparing, conceptualizing, and categorising data (Glaser, 1992). Open coding, also called *substantive coding*, was done to fracture the data so that categories, along with their properties and dimensions, could be identified. An example of open coding is shown in Table 3.1. The following (translated) transcript excerpt shows both the open coded data which I generated, and those I generated from the substance of the data of one woman participant, who was a housewife and believed in religious practices.

Table 3.1: Open Coding

Transcript excerpt from data	**Open coding**
I know that the Buddhist religion teaches people how to be good, so I like to make merit. I go to the temple every holy day to offer food to the monks and to listen to them teaching from the scriptures.	*Buddhist religion teaches people to be good* *Making merit, Temple activities* *Offer food to the monks* *Listen to monks teaching from scriptures*
I practise ancestral worship and the maxim which my mother taught me – "tum dee, dai dee; tum chua, dai chua" (do good and you will receive good; do evil and you will receive evil). Buddhist religious teaching is like this.	*Practising worship* *Do good and you will receive good* *Do evil and you will receive evil* *Buddhist teaching*
I pray before the Buddha image every night for well-being, no pain or sickness and for a long life with my family. After making merit and praying, I feel well in my mind and I sleep well. I believe that in the next life I will be rich, healthy and happy… (Q: 06/05/05).	*Pray to Buddha image for well-being* *No pain, no sickness* *After making merit and praying* *Feeling well in mind and sleeping well* *Belief in the next life* *Will be rich, healthy and happy*

Open coding is later recoded at a more analytic level termed *theoretical coding.*

3.9.1.2 Theoretical coding

Theoretical codes conceptualise how the open codes and categories associated with each other are developed as an hypothesis to be integrated into a theory (Glaser, 1978, p. 72). Glaser (1978) presents a series of 18 theoretical coding families that include analytic categories such as his "six Cs: Causes, Contexts, Contingencies, Consequences, Covariances, and Conditions" (p.74). Glaser's coding families indicate a specific analytic category, but merge conceptual distinctions. For example, I labelled (coded) these actions as "religious practices" and "attention to, and concern about, medications". The following example describes open coding and theoretical coding in Table 3.2.

Table 3.2: Theoretical Coding

Open coding (substantive coding)	Theoretical coding
Making merit *Temple activities* *Praying to Buddha image*	Religious practices
Concerning the time of medicines *Concerning the amount of medicines* *Concerning the side effects of medicines*	Attention to, and concern about, medications

Coding is the first part of analysis which encourages insight and theoretical possibilities. Coding gives a primary set of ideas encouraging the exploration and examination of theory.

3.9.2 Theoretical memoing

Theoretical memos are the way of preserving emerging ideas and hypotheses about data analysis (Stanley, 2006). Researchers keep track of theoretical ideas and continuously link and build on the formulation of theory (Glaser, 1978, 1998; Strauss & Corbin, 1998). Memoing is used to raise the data to a level of conceptualisation (Grbich, 1999, 2007) and to locate the emerging theory within existing relevant theoretical frameworks. Writing memos is a crucial part of the process for developing grounded theory that begins when first coding data, and continues through the reading of memos or literature, sorting and writing papers until the end, in order to organise the ideas about self-care in HIV/AIDS (Glaser, 1978; Grbich, 1999, 2007; Stanley, 2006).

An example of an early memo about participants who had not disclosed their situation to others that I wrote to identify the major concept of ‘being HIV/AIDS’ is outlined below:

Excerpt from memos:

> *At first, when he knew he and his wife had HIV/AIDS. He and his wife did not tell other people that they had HIV/AIDS (e.g. ref: D, R). They said to me that nobody knew about them - only their lecturer (researcher-me) knew. They have not disclosed their situation to their neighbours and community. They are afraid and do not know what disaster could happen to their family. They keep it secret in order to protect themselves and maintain a living. They keep the front door shut but open the back door. The ventilation is poor and it is quite dark inside and untidy. But they look happy with their family and said that this is normal for them (e.g. ref: D, R).*

In addition, writing a memo can help the researcher to explore ideas about categories. Theoretical memos serve to firm up the data and final analysis.

3.9.3 Basic social process

The basic social process (BSP) is only one type of core category considered to emerge or to be discovered in grounded theory study (Glaser, 1978, 1996). A process is something that occurs over time and involves change. “BSPs are theoretical reflections and summarizations of the patterned, systematic … flows of social life …

which can be conceptually "captured" and further understood through construction of BSP theories" (Glaser, 1978, p. 100).

Glaser (1978) describes two types of basic social processes: a basic social psychological process (BSPP) and a basic social structural process (BSSP). A "BSPP" refers to a social psychological process such as becoming, highlighting, personalising, health optimising, giving the feeling of process, change, and movement over time. A "BSSP" refers to a social structure in the process of growth or deterioration processes such as bureaucratisation, debureaucratisation, centralisation, routinisation, admitting, or recruiting procedures, and succession. A BSSP is the social structure within which the BSPP process occurs. To understand the basic social process involved in a grounded theory study, it is helpful to first view it as a core category (Fagerhaugh, 1986, p. 135). As Glaser (1978, p. 93) states "the goal of grounded theory is to generate a theory that accounts for a pattern of behaviour, which is relevant and problematic for those involved". A core category is called a core variable, and explains a wide range of behaviour and interaction. In this study, "from experiencing social disgust to passing as normal" was viewed as a progressive movement process involving four phases; 1) being HIV/AIDS; 2) making choices; 3) keeping well; and 4) feeling empowered.

Figure 3-3 outlines the detailed four phases of the theory (BSPP). It is shown to illustrate interactive dynamic processes.

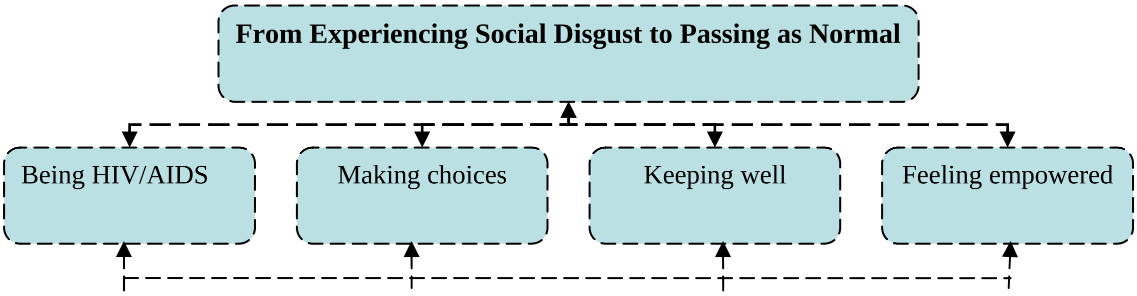


Figure 3-3: Basic Social Psychological Process and Core Categories

3.10 TRUSTWORTHINESS

The researcher is concerned to preserve trustworthiness through the process of gathering and analysing data. As qualitative research methods are essentially subjective in nature and local in scope, procedures for assessing the validity of research are quite different from those used for experimental study. Lincoln and Guba (1985) have provided a common set of criteria for establishing the validity of qualitative research. They suggest that because there can be known objective measures of validity, the underlying issue is to identify ways of establishing trustworthiness, the extent to which we can trust the truthfulness or adequacy of a research project. They propose that establishing trustworthiness involves procedures of credibility, transferability, dependability, and confirmability. These criteria were used as guidelines to assess the trustworthiness of this research study.

3.10.1 Credibility

Credibility relates to the trustworthiness of the findings (Carpenter, 1995) and credibility of qualitative research is achieved when it reveals accurate descriptions of individuals' experiences, and when the people having that experience would immediately recognise it from those descriptions as their own (Sandelowski, 1986). Lincoln and Guba (1985) identified credibility as an overriding goal of qualitative research, reflecting the relativistic nature of truth claims in the interpretivist tradition. Credibility includes activities which increase the probability that credible findings were produced (Lincoln & Guba, 1985). One of the best ways to establish credibility is through prolonged engagement with the subject matter. Another way to confirm the credibility of the findings is to return to the participants and see whether or not they recognise the findings to be true to their experience. Lincoln and Guba call this activity *member checks.*

In this study, the four methods; prolonged engagement, triangulation, peer debriefing, and member checks were used to enhance the credibility of the data gathering and analysing. Firstly, I established good rapport with participants by prolonged engagement with them until trust was built before gathering data. The participants were interviewed at least twice; some participants were interviewed more than twice.

As the participants felt acquainted with me, they felt more comfortable to share with me their experiences of managing and living with HIV/AIDS.

Secondly, triangulation of different data collection modes was carried out in this study. Interviews, observations, field notes, and a review of health records taken by me were used to cross-check and verify the emerging interpretation and to increase the credibility of the findings. I concluded the findings in accord with the empirical data, not pre-existing theory, by collecting adequate data and using the triangulation approach across different data sources (participants, family members, health records, head nurses), data settings (HIV/AIDS day care clinic and participants' home) data gathering methods (interviews, observations, field notes, review of health records), and data analysis (researcher, supervisors, PhD students).

Thirdly, peer debriefing refers to an activity that provided an external check on the inquiry process. In this study, peer debriefing involved three university professors who were experienced in the qualitative research method. They read the findings and confirmed or questioned the codes, concepts and categories. This peer review occurred many times during the data analysis process and provided me with opportunities to reflect on, and explore other interpretations.

Finally, I implemented informal member checking for data and preliminary findings by re-interviewing three participants. During the data collection phase, a summary of each previous interview was described to the participants during their next interview. I corrected any errors in the interview data after discussing them with these participants.

During a return visit to Thailand, I described the analytic categories in the self-care process of Thai people living with HIV/AIDS: being HIV/AIDS, making choices, keeping well, feeling empowered and the basic social psychological process of moving from experiencing social disgust to passing as normal, to some participants. These participants agreed that these categories and the basic social psychological process were consistent with their thoughts about their situation.

3.10.2 Transferability

Transferability, the alternative term for external validity and generalisability, means that the findings in one context can be transferred to similar situations or participants. Lincoln and Guba (1985) also suggest that researchers use thick description and that they describe accurately and in detail the data in their context so that peers and readers have a clear picture of what is going on. Through purposeful sampling, rich and specific information is obtained. In grounded theory the notion that the substantive theory must "fit" and "work" and be modifiable is consistent with the notion of transferability.

3.10.3 Dependability

Trustworthiness also depends on the extent to which observers are able to ascertain whether or not research procedures are adequate for the purposes of the study. Where insufficient information is available, or available information indicates the likelihood of superficial and/or limited inquiry, they will not feel that the study is dependable. The dependability of research is achieved through an *inquiry audit* whereby details of the research process are revealed (Lincoln & Guba, 1985; Stringer & Genat, 2004). The detailed description of the study design and methods in this chapter enables the reader to assess the adequacy of the research procedures.

3.10.4 Confirmability

Confirmability is achieved through an audit trail, the inquirer having retained recorded information that can be made available for review. These include raw data such as field notes, photographs, diary entries, original and annotated documents, copies of letters, and materials generated at meetings. They also include data reduction, analysis products, and plans and reports derived from the study. They enable participants or other observers to confirm that the research accurately and adequately represents the perspectives presented in the study. This means that they enhance the trustworthiness of the study (Lincoln & Guba, 1985; Stringer & Genat, 2004). In this study, data are stored anonymously and securely for five years to allow for audit. Quotations of the participants' statements are reported appropriately and adequately to demonstrate that the findings were grounded in events rather than being the researcher's personal constructions.

3.11 CONCLUSION

In this chapter, grounded theory methodology was reviewed as one qualitative research methodology that has been used in researching situations of social interaction in nursing, leading to theory development in nursing (Chiovitti & Piran, 2003). The process of this research, and methods used to analyse the data have been described. The inductive nature of the method is supported by the attention given to allowing theory to emerge from the data. In the following chapters, the analysis of the findings is reported, beginning with the category: **Being HIV/AIDS**.

PART TWO
CHAPTER FOUR
BEING HIV/AIDS

4.1 INTRODUCTION

This Chapter is the first of four data Chapters in Part Two, which construct the model of self-care captured in the basic social psychological process (BSPP) "from experiencing social disgust to passing as normal". **"Being HIV/AIDS"** is the first of the four core categories derived from the data that explains the initial experiences of the participants, and is introduced in this chapter. The other three core categories that contribute to the model are **"making choices", "keeping well" and "feeling empowered".** These categories are addressed in Chapters Five, Six and Seven respectively. Figure 3-3 shows the four core categories and the relationship between these core categories and the basic social psychological process, generated from the grounded theory analysis.

In this chapter, I present the core category **"being HIV/AIDS"**. The stage of being HIV/AIDS occurred as all participants living with HIV/AIDS first experienced their new identity as a person with HIV/AIDS. The perspectives of being HIV/AIDS varied. Most of the participants had heard the words HIV and AIDS from radio, television and from people in their community talking about the disease. Some had personal experiences of people with HIV/AIDS because their husband or wife had died from the disease. Moreover, most of the participants understood HIV/AIDS as a disease that is *roke tid tor (communicable), nah klua (fearful), nah la ay (shameful), ruk sa bor souw (incurable), and taay wai (expect to die soon).* In addition, it was *rungkiat* – a disease of *social disgust*. All participants reported that these words hurt their feelings and affected their life.

In this study, the category **"being HIV/AIDS"** was supported by four concepts including **being diagnosed with HIV/AIDS, being stigmatised, suffering,** and **learning about HIV/AIDS**. These concepts were identified by exploring the meaning, to participants, of having HIV/AIDS and their early experiences in managing and living with their HIV/AIDS (Figure 4-1). Each concept and code will be presented as separate, even though–in fact–they are related.

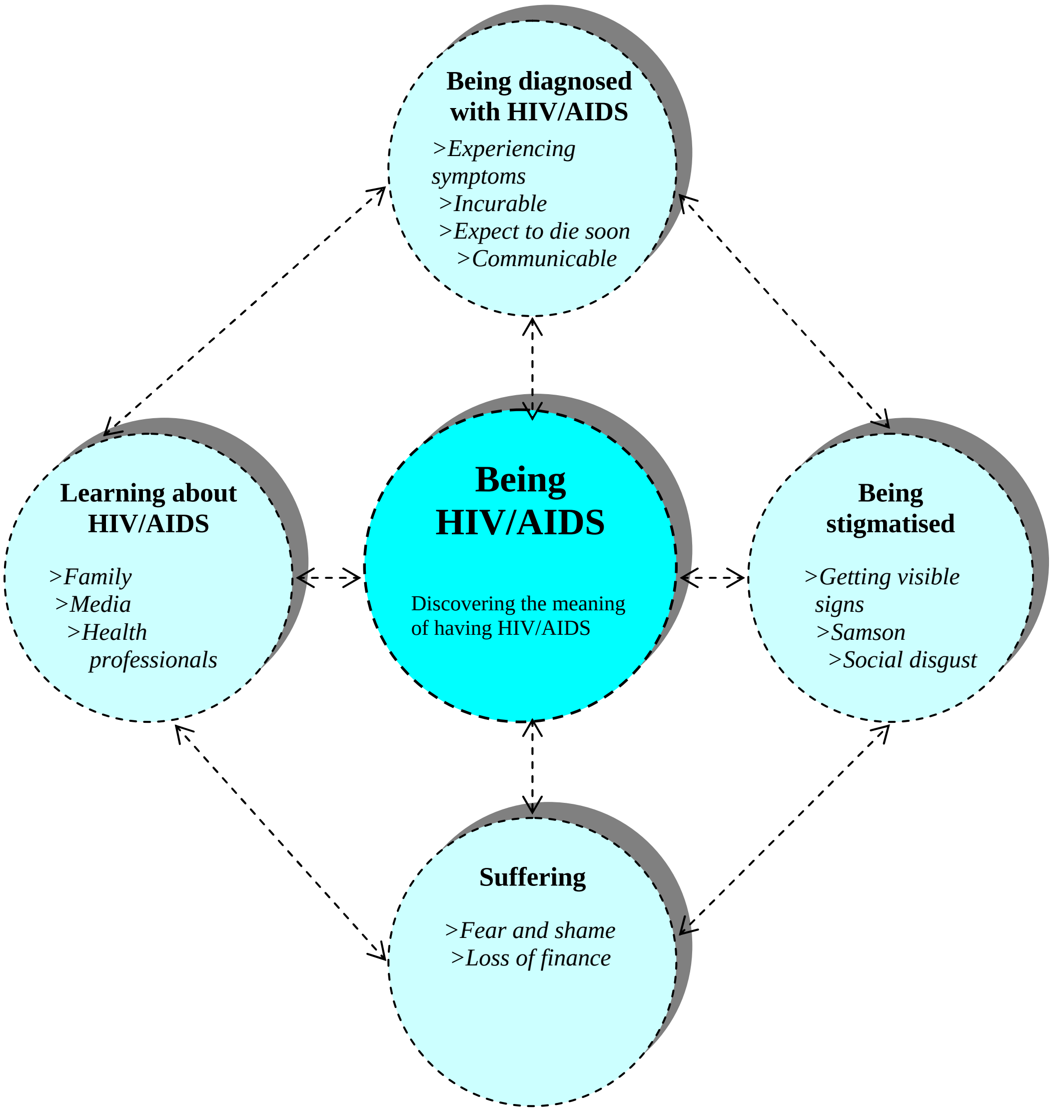


Figure 4-1: Core Category-Being HIV/AIDS, Concepts and Codes.

4.2 BEING HIV/AIDS: Being diagnosed with HIV/AIDS

Being diagnosed with HIV/AIDS referred to the participants' experiences of learning from their healthcare provider, following a blood test, that they had HIV/AIDS. The blood test accurately gauges CD4+ levels and viral load levels, thus it reveals the most important criteria used to confirm HIV/AIDS (Bartlett & Finkbeiner, 1998; Stine, 1996). After participants received the diagnosis, they began to accept the fact that they really had HIV/AIDS. Some participants had initially suspected they had HIV/AIDS when they observed signs and symptoms that appeared on their body. Others were diagnosed when they were admitted to hospital for treatment of opportunistic diseases such as pulmonary tuberculosis (TB), fungal meningitis, or pnuemocystic carinii pneumonia (PCP). The concept of **"being diagnosed with HIV/AIDS"** was supported by codes including ***experiencing symptoms, incurable, expect to die soon, and communicable.***

4.2.1 Experiencing symptoms

When HIV infected persons changed from asymptomatic to symptomatic illness, they experienced distress and discomfort and sought help from the physician and others to maintain their health. For example, one participant stated:

> *I got white patches in my mouth, I couldn't eat, and it hurt my mouth. I lost weight, was thin and fatigued and couldn't walk. My friend took me to the community hospital; I was admitted for 2 weeks with AIDS-related symptoms…. My immunity was low, (CD4+ was 1)…. I had to take antiretroviral drugs…to control the HIV virus… (P: 17/02/05).*

The majority of the participants (20 cases) recognised the symptoms of HIV/AIDS by themselves. However, some participants did not recognise the relationship of their symptoms to HIV/AIDS until they became seriously ill and were admitted to the hospital for treatment of other opportunistic illnesses; eventually the diagnosis of AIDS was confirmed as illustrated below.

> *I got lymph node tuberculosis with an abscess at the neck area.* **.** *When I was discharged, I took antipulmonary tuberculosis and paracetamol medications to treat the symptoms but I did not feel better…. I got serious headaches, I could not sleep and was unable to eat, I was very thin, I lost 15 kilograms since I got sick, I felt hopeless and distressed, and I was scared of dying. I was*

> *admitted again, and had a blood test (CD4+ was 6). I was diagnosed with AIDS with fungal meningitis… (H: 18/02/05).*

Some participants were depressed and shocked after they received the diagnosis of AIDS. As one participant explained:

> *When I knew I had AIDS. I cried, was confused and lost consciousness. I could not sleep for a week. I could not explain. I did not know why I had AIDS… (AA: 26/ 05/06).*

On the other hand, some participants (9 cases) knew that they were susceptible when others in their families developed HIV/AIDS, and some loved ones had already passed away. They were concerned and suspected themselves because they knew that HIV infection and AIDS were communicable disease without a cure, could be transmitted by sexual intercourse, and that they had had unsafe sex relations with their spouse; as one participant said:

> *I got HIV from my first wife; I stayed living with her for 5 years until she passed away in 2002 with AIDS-related pulmonary tuberculosis. After she died I went to have a blood test at the hospital and (was diagnosed) HIV positive… (F: 17/02/05).*

One woman participant was asymptomatic, but learnt that she had an HIV infection because of a blood test during pregnancy for routine VDRL and HIV testing. She said she got the HIV infection from her first husband who passed away with AIDS and her second husband was not infected with HIV at the time of her pregnancy.

> *I knew I got HIV infection because of my pregnancy. I attended the antenatal care clinic, I had a blood test and a nurse told me about the result of the blood test, that I was HIV positive (B: 16/02/05).*

As outlined in Chapter One, HIV/AIDS is characterised by a variety of disturbing symptoms such as fever, diarrhoea, fatigue, weight loss, pharyngitis, headache, herpes zoster, oral thrush, cough, wasting, skin lesion, meningitis, pneumonia, tuberculosis, and depression. These symptoms vary in their degree of control, duration, and effects (Chapman, 1998; Corless et al., 2002; Deschamps, Fitzgerald, Pape, & Johnson Jr, 2000; Spirig, Moody, Battegay, & Geest, 2005). Anxiety and depression are the most common psychological symptoms of HIV-infected persons and are reported to be associated with raised symptom frequency and increased progression to AIDS (Cabaj, 1996; Hand et al., 2006; Ickovics et al., 2001). Thus, the experience of symptoms plays a key role in patients' illness representation.

4.2.2 Incurable (ruksa bor souw)

Most participants learned from the media, health professionals and their own experience that HIV infection and AIDS were disease that had no vaccine or medicine for a cure.

> *I knew AIDS was not curable; many people in the village talked about people who had AIDS must die. I would become sick and die … (F: 17/02/05).*

> *AIDS is not curable, I knew from my experience and when my husband got AIDS, I saw how he suffered from many symptoms until he died in front of my face… (I: 19/02/05).*

4.2.3 Expect to die soon (taay wai)

Most participants believed not only that AIDS was a fatal disease, but also that people who were infected would die soon. Most of the participants had seen people with AIDS die after a relatively short and severe illness. Thus, after the participants had been diagnosed with AIDS they felt hopeless because of the severity of the AIDS disease. Most of the participants expressed the fear that they would "*taay wai" (die soon), "tong taay nae" (must die for sure)* or were "*yaan taay" (afraid to die)* when they were describing coming to terms with being HIV/AIDS. Some participants stated that:

> *After I knew I got AIDS, in the first year, I was very afraid…afraid… to die because my condition was very severe, my*

> *friends said that I must die and I saw that of the people who had AIDS around 5-6 people were already dead after they got serious conditions in my village. My friends who got AIDS at the same time have died already… (K: 20/02/05).*

> *When I got serious illness, I was admitted at the hospital. I thought I must die for sure. I knew my disease is serious and death comes quickly, I have heard from the radio about AIDS patients who must die for sure and I was afraid to die… (H: 18 /02/05).*

Moreover, some participants lacked knowledge about the disease. They also suffered from rejection by their families, community and society, who left them alone. As one participant woman described her husband's illness:

> *My husband got AIDS. I thought that he had to die for sure, because he did nothing. He just slept and waited to die…He was very skinny and he could not walk… (C: 15/02/05).*

In addition, when participants became sick they were no longer able to work, they had to leave their job and did not have any money. They could not get treatment in order to live longer because of poverty and misunderstanding about the disease. Nelson, Suriyanon, and Taylor (1994) reported that an adult dying of AIDS is ill for an average of eight months in Thailand. Untreated, AIDS is a highly fatal acute illness (Siegel & Lekas, 2002; Vithayachockitikhun, 2006).

4.2.4 Communicable (roke tid tor)

People living with HIV/AIDS learned the etiology of HIV/AIDS from multiple sources, including both healthcare providers and public media. Most of the participants received HIV/AIDS counselling from health professionals after they confirmed the diagnosis that they were HIV positive. They learnt that HIV/AIDS was caused by the HIV virus, and that it was transmitted through sexual relations, sharing needles with an infected person, blood transfusion, or from mother to child when an HIV/AIDS mother became pregnant, if they had not received antiretroviral medication during their pregnancy to prevent the spread of the virus. While aware of the range of routes of transmission, most of the participants identified that AIDS was a disease associated with sexual contacts by having experiences with prostitutes.

> *The doctor told me AIDS is directly transmitted by sexual relations, needle sharing with HIV/AIDS persons and from mother-to-child in a pregnant woman with HIV infection… (P: 06/03/05).*

> *AIDS is a "roke tid tor" (communicable disease) and it is transmitted by sexual intercourse with females who are bad persons or females who sell sex… (R: 24/02/05).*

While participants learnt how transmission of HIV virus occurred and how to prevent its transmission family caregivers, and Thai people in general, feared that AIDS could be spread to other people by close association. One participant said that:

> *My mum did not eat meals with me because she feared contracting AIDS from me. She also left me alone (V: 17/05/05).*

This finding is supported by another Thai study, that suggests that some family caregivers recognised HIV/AIDS as very scary, dangerous, and a communicable disease (Maneesriwongul et al., 2004).

4.3 BEING HIV/AIDS: Being stigmatised

Because HIV/AIDS is a serious disease and easily transmitted by sexual contact, people living with HIV/AIDS have to confront the stigma related to their social lifestyle. Thus, in this study, people with HIV/AIDS had to hide their status due to fear of bringing trouble upon their families and being socially unacceptable.

The stigma of HIV/AIDS is a social construction, which seriously affects the life experience of a person living with HIV/AIDS and his/her family and community

(Bhattacharya, Cleland, & Holland, 2000). A major reason why people living with HIV/AIDS are stigmatised is the association of HIV/AIDS with the underlying stigmatisation of homosexual sex, and intravenous drug use (UNAIDS, 2005b).

From this study, the concept of **"being stigmatised"** was supported by codes including ***getting visible signs, "Samson" (promiscuity), and "sungkom rungkiat" (social disgust)*** which were affected by the stigma.

4.3.1 Getting visible signs

HIV/AIDS has recognisable signs and symptoms which are related to the illness, especially skin lesions, and oral fungal infections. Moreover, other visible physical symptoms such as thinness, weakness, pale appearance, and weight loss may also indicate AIDS. Some participants were afraid that visible signs of HIV/AIDS would alert others to their condition. As a result, they might get into trouble because other people would be disgusted and refuse contact with them and their family. Especially, in the Isaan community HIV/AIDS was socially stigmatised.

> *Before I got AIDS I feared AIDS patients because their body had skin lesions, facial rashes, weight loss, thin, dark skin, dry skin, oral fungus and they were unable to eat because it hurt their mouth and they were sleeping to die… (K: 06/03/05).*

Villagers often discussed with each other if they noticed their neighbours had an appearance of HIV infection, such as dry and dark skin, a rash or blister on any part of the body, or being skinny. Then they would avoid relating to those who had the look of an HIV infection (Rujkorakarn et al. 2000).

4.3.2 Samson (promiscuity)

When a person contracts HIV, his image becomes influenced by the common belief that AIDS is the result of promiscuity (samson). Thai people in general, and most participants in this study, perceived that HIV/AIDS comes from samson (promiscuity) although they knew of modes of HIV/AIDS transmission by sexual relations, exposure to infected blood, and perinatal transmission. Some participants explained that:

> *I view that other people still refused people with AIDS because they think people with HIV/AIDS are samson …like having sex with phu ying ha gin (sex workers and prostitutes) especially old people who have a bad attitude with people living with HIV/AIDS, I cannot change their belief… it is difficult to say but they view HIV/AIDS persons as bad persons, because of…samson (promiscuity)…People just think only this way… (F: 27/02/05).*

> *When I got AIDS I did not want to tell any one except my family. I fear they hate me, I know people think that AIDS is fear and shame. Especially, I am a woman I should not get AIDS……I fear people look down on me and blame me that I am promiscuous or a prostitute. I am a housewife. I just stay home and sleep with my husband… (O: 17:04/05).*

The findings of this study in Northeast Thailand are consistent with reported findings from Southern Thailand, that AIDS was recognised as a disease without cure and a disease associated with promiscuity *(rok sam son tang pate), mua pase* (promiscuous sex) and *mua kem* (needle sharing), reflecting the social and moral approval of risky behaviours (Songwatana & Manderson, 1998). Generally, people in Thai society assume that people who contract AIDS are promiscuous. Women with AIDS were usually blamed as agents of transmission and were marked as *samson* (promiscuous). On the other hand, most HIV-infected men were socially perceived as victims of prostitutes, while women who had contracted AIDS from their husbands carried the shameful label of “bad woman” (Nilmanat et al., 2006; Songwatana & Manderson, 1998).

In fact, most of the women participants in this study contracted HIV/AIDS from their husbands. But they were marked as *samson* and bad people by others in the community, as another woman participant commented:

> *I am not a bad person… I am not samson tang pase…I rely on myself…. I am a good person; I stop thinking to get a new husband (laughing) because I do not like to be hurt again, I do*

> *not want people to look down on me and blame me as bad person… or… samson…again…I did not do anything wrong…*
> *(C: 16/02/05).*

Most participants perceived that from the Thai society point of view a person who visits prostitutes is a *khon leaw (bad person)* and practises immoral behaviours as one male participant said:

> *I accepted myself that I am a bad person because I usually liked to have sex with prostitutes when I worked in Bangkok until I got AIDS….Then my big brother took me back to my hometown to live with my mum and my sister's family, I had a big problem with my health and I got more serious symptoms, I felt uncomfortable…. When I reached home I told my mum and my sister…. My mum was angry with me and blamed me that I was a bad person and was not responsible but my sister kept quiet, did not say anything…I accepted myself…I am a bad person (N: 17/05/05).*

Some participants described other families where their son and their daughter-in-law developed AIDS and stayed lonely without care and forgiveness from them. Moreover, the parents always complained about their son and daughter-in-law to others as being bad people.

> *Their family didn't understand and hated them, they viewed their son and daughter-in-law as bad people, mua pase…sok ka pok…(Promiscuous, dirty) (R: 24/02/05).*

4.3.3 Sungkom rungkiat (social disgust)

Several of the participants expressed their view that HIV/AIDS is a disease of *sungkom rungkiat (social disgust)* especially if an AIDS person has visible signs on the body. This meaning of HIV/AIDS was built from their own experience of living with HIV/AIDS in the Thai context.

> *AIDS is a disgusting disease as compared to other incurable diseases, such as Diabetes mellitus and Heart disease because those diseases had no nodules, pus and maculae on the body……but AIDS had…pus, nodules…on the body…and skinny it is disgusting… (C: 16/02/05).*

Most of the participants described rejection from many people around them. Fear of contamination was found to be a factor that led to discrimination, despite scientific evidence that AIDS cannot be transmitted via casual contact such as sitting next to people with HIV/AIDS, sharing a meal with people living with HIV/AIDS and using the same toilet.

> *I knew that some people don't accept me, especially my employer and his family. When they knew that I got sick from AIDS they didn't come close to me. They told my sister to tell me not come to work with them … (A: 13 /02 /05).*

Some participants protected themselves from social disgust by hiding signs of disease, as one woman participant stated:

> *I wear a long-sleeve shirt to hide my dark skin spots from other people, if they know I have it, perhaps they do not come close to me… (CC: 17/06/05).*

However, people still believe that there is the possibility of transmission from HIV/AIDS persons if they are close together. The negative perception of AIDS leads to substantial rejection and discrimination against people living with HIV/AIDS and their families (Kilmarx et al., 2000; Phengjard et al., 2002).

4.4 BEING HIV/AIDS: Suffering

Participants suffered when being diagnosed with HIV/AIDS because they perceived that HIV/AIDS is communicable, incurable and a fatal disease. Furthermore, it is noted that the psychological suffering of HIV/AIDS persons might also result from mass media information which is displayed in negative ways. Some participants look healthy and they did not disclose their HIV/AIDS status because they feared rejection and discrimination. Moreover, they were afraid of disappointing other people. Two participants stayed indoors, unwilling to meet other people in their village. As a result, participants found that the concept of **"suffering"** was supported by codes including ***fear and shame and loss of finance.***

4.4.1 Fear and shame

Although the Thai media campaign has recently begun to carry more positive messages about HIV/AIDS, many people in Thai society are still afraid of AIDS. Thus, the knowledge that Thai people rejected and stigmatised people with HIV/AIDS because they fear contracting the HIV virus, led to the participants feeling a variety of fearful apprehensions about the disease and shame about themselves. Some participants explained that:

> *Before I got AIDS, I was a restaurant worker. I myself got a salary every month. Now I stop working because I was afraid someone would know that I have AIDS. I did not want the owner of the restaurant to know I had AIDS, I was ashamed. I feared that it would affect their business. I resigned from work and helped my family doing some chores at home… (C: 16/02/05).*

> *During the early stage, when I got AIDS, my parents and my sister were normally close to me but after I had nodules and maculae on the body, my mother and my sister were afraid. They didn't take a meal with me, but they separated a meal for me because they were afraid to get a disease from me, via having food together… (K: 20/02/05).*

Some participants believed that AIDS disease could cause people to go blind. One woman participant said:

> *This disease could make people with AIDS blind. I do not know why? But I think the virus spread to their eyes…...Umm…it is fearful and severe…Now my husband has blindness due to the virus spread to his eyes…a doctor told me… (C: 16/02/05).*

Moreover, the participants felt anxious that others may learn that they were HIV/AIDS sufferers. They did not dare to tell anyone about their HIV/AIDS status because they feared stigmatisation, rejection and discrimination by people in the community. One participant described how she and her husband, both of whom had AIDS, managed their situation.

> *Since I got AIDS… I just stay indoors in the city; I did not join with people in the community. Around my house had a lot of food shops. I did not want somebody to know I had AIDS because I was afraid of them looking down on me and my family…Might be it can affect my family, especially I am concerned about my daughter as she is young and doesn't know every thing about me and her father……I feared getting stigmatized and being discriminated against from others……. I feared my husband must lack a job if other people knew he got HIV because of the social disgust…an AIDS person… (D: 26/02/05).*

When participants have visible signs on their bodies they have increased risk of being rejected and experiencing shame. Thus participants with visible signs protected themselves by getting dressed in long-sleeved shirts.

> *I saw AIDS patients in a village who had many symptoms such as dark skin, thin, headache, stiff neck, white patches in their mouth and fatigue. It is fearful and I felt disgusted with AIDS patients before…… I was afraid of contracting from them…At present; I get AIDS and had black skin lesions on my body. I fear the rejection and disgust of people in the community. I normally dress with long sleeve T-shirt to protect myself because I feel*

> *fearful and shamed…I don’t want other people to blame me……(L: 26/05/05).*

Many women participants reported feeling shame because of societal beliefs that they must have done something wrong or something immoral in order to be HIV infected, even though they knew that they had caught the disease from their husbands.

4.4.2 Loss of finance

Participants who were sick could no longer work and that led to a role change for them and their family members. They experienced loss of finance and also experienced loss of self-worth. Some participants stated that:

> *Before I got AIDS, I was a truck driver and drove to Bangkok every fortnight and back home for a few days. I earned money about 6,000 baht per month for family living. When I got sick, I stopped work and went back to my hometown with a lack of money…. I felt devalued… (G: 04/03/05).*
>
> *When I got AIDS and was sick, I lost a job, I had no money. I could not spend money like before I just stayed home… and watched television…. I would like to go back to work as before if I am healthy…but now I have nothing to do…I feel worthless… (N: 18/ 03 /05).*

Loss of jobs or inability to work because of visible signs of illness affected participants’ family life. Most participants and their families faced economic problems because of the expense related to HIV/AIDS treatment, which caused economic hardship. High rates of HIV infection and high mortality rates resulted in substantial social and economic cost. In another Thai study, Kilmarx et al. (2000) reported that many families were devastated by loss of young working people and consequent reduced family income.

4.5 BEING HIV/AIDS: Learning about HIV/AIDS

The participants tried to learn as much as possible regarding HIV/AIDS such as the nature of HIV/AIDS, the factors affecting health and the disease progression, prevention and care and the appropriate management of the disease, by devising learning experiences for themselves. Thus, participants would develop self-care skills to maintain their health or manage their illness. They hoped that they would be healthy and live for a long period of time. Although, previously they obtained information about HIV/AIDS in a negative way from television and radio, once diagnosed with AIDS they tried to learn the facts about the disease as it pertained to themselves. Participants focused more on how to be healthy and live as long as possible. The concept of **"learning about HIV/AIDS"** was supported by codes including ***family, media and health professionals.***

4.5.1 Family

Some participants had learned about HIV infection and AIDS disease and strategies to help them survive, from their husbands or wives who had HIV/AIDS**.** Some participants stated that:

> *I had experienced AIDS from my husband when he developed serious illness with TB and had many symptoms such as cough, headache, inability to eat, fatigue and weight loss which gave him suffering (took tor ra man) including my family. I had to look after him in order to help him to survive until I got sick with AIDS, I took good care of myself to prevent getting a serious illness, so I learned from my family experience…(V: 07/04/05).*
>
> *When I got AIDS I learned to stay alive from the experiences of my ex-husband and the present husband to cope with the problem to maintain life although AIDS is not cured, but if I take good care of myself I can live longer…I know because a doctor told me… (CC: 10/06/05).*

The participants learned about the disease from their own experiences with their family member's illness. Consequently, participants could understand and had more knowledge of AIDS disease, and this led them to change their perceptions about HIV/AIDS. As a result, participants found ways to adjust themselves to deal with the situation and maintain their daily life.

4.5.2 Media

The participants had learned about the disease when they tried seeking health information from differing media about HIV/AIDS. This learning taught them how they could perform self-management in order to live longer with their disease.

> *I liked watching television and listening to the radio about HIV/AIDS disease as it would help to really understand the disease in order to maintain life to live longer and look after my child until he grows up…(Q: 06/05/05).*

> *I sought knowledge about HIV/AIDS from the book I got from the hospital; it was useful for me to improve my quality of life because I needed to live longer and be healthier with my family. I avoided taking risks, I had appropriate food and enough sleep (S: 02/05/05).*

Knowledge about the disease from the media is needed to cope with the multiple problems that result, from HIV/AIDS, including medical, psychological, social and economic problems (Thaineua, 2007).

4.5.3 Health professionals

All participants learned about the disease from healthcare providers at the hospital when they had a regular health follow-up after they developed the illness. They gained knowledge about the disease and self-care practice and used it in their daily lives in order to reduce stress and manage their problems to maintain their lives.

> *I always saw AIDS patients in a village and nearby my village; many cases got serious symptoms and death so it is severe and*

> *fearful. I do not want to die because I am concerned about my children and my mother if I die, who would look after them? I try to make power and tam jai and went to baan rom yen to observe other HIV/AIDS patients, what are they doing? What about their health? I saw most patients are more serious than me. I stood near the door and looked around the HIV/AIDS patients until a nurse came to ask me, what am I doing here? I told her I got AIDS and she took me to sit in front of her desk and ask me how long since I had blood test. I said one week. How do you think? I was afraid of dying. She said to me do not fear death, it was not easy to die. Not only I had AIDS but also people around me got AIDS…. After I met her I felt my will-power increase and I am now healthy… (I: 19/02/05).*

> *The doctor told me this disease was not easy to die from…. If I took good care of myself I can live longer with my family so it depended on me. Thus, I went to baan rom yen to join the project activities such as counselling, and exercise. I joined in exercise groups about 3 times. After that, I felt physical strength… (H: 18/02/05).*

Participants learnt about their disease from a variety of sources including the media, families, peers, social support networks and healthcare providers. This is because they need to be knowledgeable about HIV/AIDS, understand their personal medical histories and treatment plan, and interact comfortably with their healthcare providers, in order to assist them in managing and living with their chronic condition (Nokes & Nwakeze, 2005).

4.6 CONCLUSION

The category **"being HIV/AIDS"** represents the first stage of the basic social psychological process: ***"from experiencing social disgust to passing as normal"*****.** The category includes the concepts, **"being diagnosed with HIV/AIDS", "being**

stigmatised", "suffering", and **"learning about HIV/AIDS"**. These substantive concepts are in turn composed of in vivo codes, which detail the experiences of suffering, rejection and discrimination that comprise "being HIV/AIDS".

The participants initially understood HIV/AIDS as an incurable, communicable disease that was survivable only for a short time period. Furthermore, they realised that the responses of family, community and society to people living with HIV/AIDS were likely to be rejection and disgust, both because they feared contracting the disease from social contact with people with HIV/AIDS, and because of the association of the disease with homosexual behaviour, promiscuity and illegal drug use. Being HIV/AIDS meant potential loss of health, friends, employment, financial independence, physical intimacy, and the support of one's family members (Friedland, Renwick, & McColl, 1996; Plattner & Meiring, 2006).

The initial shock, loss of hope and fear of stigmatisation that arose from being diagnosed with HIV/AIDS gradually abated as the participants learnt more about living with HIV/AIDS from health professionals and others who were living with AIDS. As participants came to accept being HIV/AIDS and learnt of the possibilities for living with HIV/AIDS as a chronic disease rather than as a rapidly fatal illness, they turned their attention to learning how to maintain their health and manage their situation to live as satisfying a life as possible with HIV/AIDS.

CHAPTER FIVE

MAKING CHOICES

5.1 INTRODUCTION

In the previous Chapter, I presented the category **"being HIV/AIDS"**. In this Chapter I describe the category **"making choices"**. The action of making choices became important when people with HIV/AIDS revised their understanding of what it means to have HIV/AIDS. Participants made choices in order to live a "normal" life, learning how to maintain their health and manage their life situation to live as satisfying a life as possible with HIV/AIDS. Consistent with living in a collective society, managing and rebuilding relationships with others was a key element in the choices made by participants. The category **"making choices"** was supported by the three concepts, including **avoiding unhappy situations, seeking support, and getting remarried** (Figure 5-1).

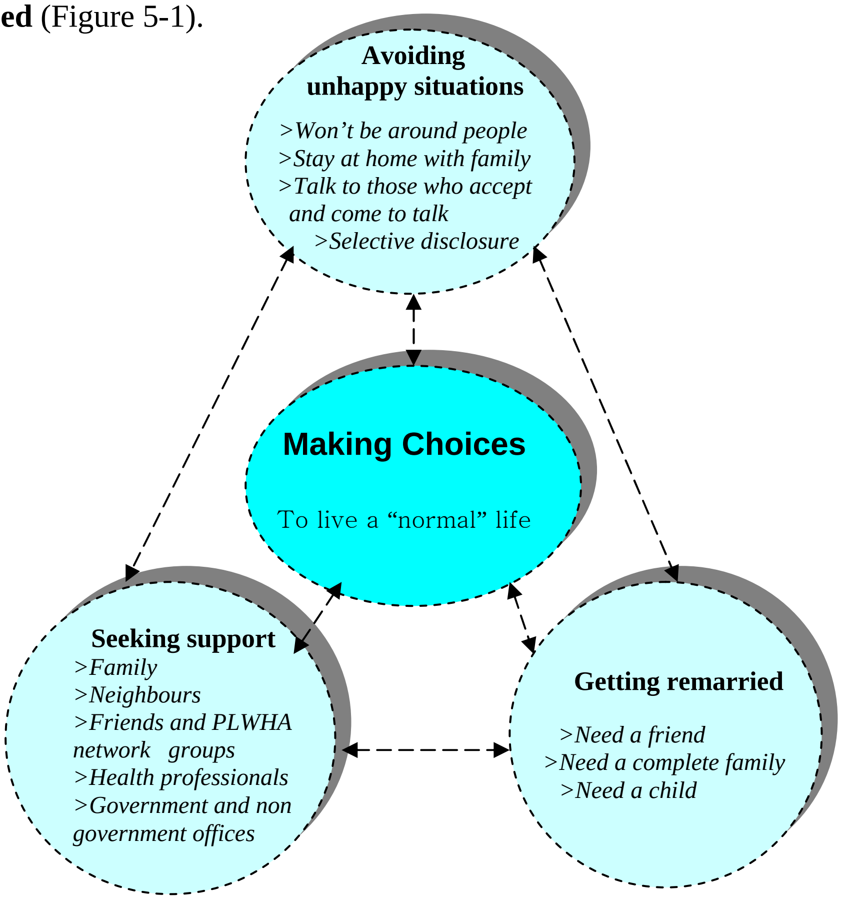


Figure 5-1: Core Category-Making Choices, Concepts and Codes

5.2 MAKING CHOICES: Avoiding unhappy situations

Participants kept themselves from harmful things and discrimination, by “avoiding unhappy situations” with people who looked down on them and made them feel uncomfortable. Thus, participants saved themselves from upset by limiting their activities in their villages. “**Avoiding unhappy situations**” was a way to enable them to have happiness in their life; the concept was represented by the codes: ***won’t be around people, stay at home with family, talk to those who accept and come to talk, and selective disclosure***.

5.2.1. Won’t be around people

Most participants said they kept themselves away from other people because they thought that others knew they were living with HIV/AIDS. The participants chose not be around other people, including avoiding participating in group activities with other people in the community, because they did not want to be hurt by others who might retain negative attitudes toward them. Avoiding being around people in public was a way of controlling fear of rejection.

> *I did not want to be around people, and I did not want people to know that I had AIDS. I knew that AIDS would stigmatise me. I did not want people to be revolted by me and I did not want to be hurt…. I did not want others to look down on me… (K: 20/02/05).*
>
> *When I joined in religious activities at the temple, the village people stared at me when I walked or stood there and whispered to each other about me. But they did not ask after me or chat with me as before…. I avoided them and walked back home because I was hurt and unhappy… (I: 19/03/05).*

Thus, participants did not want to be in a public place around people who may reject them because that caused them stress and unhappiness. This choice by some participants, to withdraw almost entirely from village life to protect themselves from hurtful rejection, is consistent with the findings of Klunklin (2001) and Ichikawa and Natpratan (2006).

5.2.2 Stay at home with family

Although most participants have disclosed their HIV/AIDS status to some others in their community and many have experienced some acceptance by others, they preferred to stay at home with their family rather than going to meet other people outside the family home. As one participant stated:

> *I have revealed myself. Now my friends and even other village people accept me, invite me to their homes and ask me to their parties but I do not want to join in. I am afraid of their hurtful words. I prefer to stay home and talk with family members, and if others drop in to see me it makes me so happy… (A: 13 /02 /05).*

Although the participants have revealed the truth about their HIV/AIDS status, they prefer to stay home because they know some people are insincere towards them– talking about them with others, and rejecting them. Some participants experienced social disgust rather than acceptance by others, thus staying at home or spending time with others with AIDS was a way to avoid unhappy situations.

> *I have disclosed myself to the community but they are disgusted by me. I feel that they are not being fair with me or my family. Nobody understands me. It was not me who did wrong and I feel unhappy. So I just stay home or go and talk with friends who are in the same situation …as me… I have to be strong and try to manage my life for normality… (I: 19 /03 /05).*

5.2.3 Talk to those who accept and come to talk

Participants who had disclosed their disease were happy to talk with neighbours and other people who showed that they accepted them by coming to visit them at home. Participants thought that other people came to talk to them at home because they understood that the disease could not be caught by social contact.

> *I am lucky because my neighbours are very good to me. They understand that my disease is not transmitted by talking. They do not hate me but come to talk with me at home. They have never shown that they are disgusted with me. Sometimes I go round to their house for a chat. Presently I am happy and content with my life and my family. I do not think much about my disease – if I do it makes me unhappy and it affects my health… (C: 19/02/05).*

> *Neighbours and others in the village come and talk with me, asking how I am. They are very friendly. They do not hate me as my father does. They understand me and my family. I feel better and happier with them than I do with my father… (H: 11/03/05).*

Staying at home with supportive family members, and restricting interaction to those people who demonstrated acceptance and some understanding of the disease by visiting the participant at home, are effective ways for participants to screen out those villagers who may rebuff or despise them.

5.2.4 Selective disclosure

Some participants chose not to disclose their HIV/AIDS status, or to selectively disclose it, because they did not want to be hurt by rejection and/or they did not want their families or their job to be affected. They chose to keep their health status secret in order to live a “normal” life and to earn money for living expenses for their families. A female participant said:

> *While staying at home I did not tell my mother or relatives that I had AIDS because they reject and hate people with HIV/AIDS, saying that people with HIV/AIDS are bad people and filthy. My new husband, daughter and I moved to the city to live with my husband’s grandmother. She does not know I have AIDS, nor do the neighbours around me because I did not tell them. I am afraid of being rejected and despised. I just stay home with my husband, daughter and husband’s grandmother… (D: 16/02/05).*

Another couple, both with HIV/AIDS, have a small barber shop in another village about 30 kilometres from their house. They have maintained this barber shop for three years and enjoy their work. They earn small amounts of money about 200- 400 baht (1$NZ= 27 baht) a day and they work every day from 9.00 a.m.-5.00 p.m. They keep their HIV/AIDS situation secret from others in order to earn a living from their job, but they chose to disclose their illness to people in their home town.

> *I have not revealed the fact that I have HIV. Sometimes I am afraid that people who live near my business will know that I am infected with HIV. I am afraid of the customers finding out that I have HIV, and then telling others so that my livelihood is affected. I am a barber, and perhaps some will decide not to get a haircut at my shop – especially uninformed people who do not understand the disease, but have a negative attitude to AIDS and HIV-infected people…(F: 27/02/05).*

Another participant disclosed his HIV-status only to his family because he feared social rejection and the impact disclosure would have on his job. He said:

> *If I reveal the truth about myself, I do not know what adversity will come to me and my family, because people do not tolerate this disease. Maybe it will affect my livelihood. I am a muffin vendor…(R: 24/02/05).*

One participant chose to disclose to family and the community because he needed support from, and to live with, family in the community. But he kept his AIDS status secret from his friends and his employer in other places because if he got better from his illness he would go back to work at the same place. He explained that:

> *At first, I did not tell other people that I had AIDS, but just told my mum, brother and sister. But village people suspected that I had AIDS because I had the same physical symptoms as an AIDS patient. I heard them say to each other that I surely had AIDS*

> *because they had seen other AIDS sufferers in the village with the same symptoms as me. Now I have told them the truth, but I told my friends and boss in Bangkok that I had pulmonary tuberculosis (TB). I really do have it, and I take anti-TB medicines. But I lied to my friends because I was afraid that they would be revolted by me, and if I got better, I could return to work in Bangkok again… (N: 18/ 03 /05).*

Disclosing HIV/AIDS status could bring shame on their family and the community. HIV-infected people needed coping strategies based on the concept of saving face (Bhattacharya, 2004). Some participants kept their status secret for many reasons. Some were afraid that their families and friends could not accept them. Some did not want to make their parents or families worry about them. Keeping their HIV/AIDS status secret made them feel safe in their life. In contrast, self-disclosure enabled participants to seek social support and new information about the disease. Participants' fears about disclosure of their illness are supported by other studies. For example, Viddhanaphuti (1999) reported that disclosure to the general public often has negative effects, particularly on people's work, and may lead to prejudice from society.

5.3 MAKING CHOICES: Seeking support

The participants were suffering with distressed feelings about their disease and people around them, so they needed to seek support from others in whom they had faith to accept them, and listen to them. Others could make them feel better and comfortable. The concept **"seeking support"** included the codes ***family, neighbours, friends and PLWHA network groups, health professionals, government and non-government offices.***

5.3.1 Family

Participants needed help from the family members around them for financial assistance and emotional and practical support. Thus they disclosed their HIV/AIDS status to family members on whom they felt they could rely. The participants could tell their feelings to family members and receive support from them, including acceptance, care and comfort. The participants stated:

> *When I stay home, my husband and daughter help with the household chores and support me with a little money for everyday living expenses. Especially, my son sends me about 2,000 baht every month because they love me. I am his wife and their mother (laughs…and looks at her daughter) … (B: 17/02/05).*

> *When I become ill and have no money, my elder brother helps me. He gives me money, supports me and takes me to hospital with my husband. He does not recoil from me but instead looks after me… (D: 26/02/05).*

Families provided care and sympathy including financial and emotional support to the HIV/AIDS member. However, the nature of care provided to HIV/AIDS people depended on household types (extended or nuclear family) and available family income (Singhanetra-Renard et al., 2001)

5.3.2 Neighbours

Most participants would disclose their HIV/AIDS status to their neighbours because they sought help, support and advice about their life, what to do next in daily life. Neighbours could help people living with HIV/AIDS in a variety of practical ways. For example:

> *My neighbours give me tap water to use, let my nephew play with their children and give me food. They are very sympathetic towards me and my family, and are not hurtful. They made me feel better after I talked to them… (G: 04/03/05).*

> *When I was working in the rice fields, they helped me look after the children. They understand and sympathise with me because*

> *they know it is not my fault that I developed AIDS. I got AIDS from my husband…. I just stayed home doing the housework….I was not a sex worker… (G: 11/04/05).*

> *The neighbours came to visit me at home when I was sick, and also provided food for me…. They told me do not worry about the disease, and I must fight the disease to stay alive… (O: 12/14/05).*

The participants hoped that they would receive help from neighbours because they knew some neighbours understood their disease and had pity for them.

5.3.3 Friends and PLWHA network groups

Friends, in this context, referred primarily to people who were not infected with HIV or AIDS, and were known to the participants from their home villages or work-places. Both friends and people living with HIV/AIDS (PLWHA) network groups, were sources of emotional, informational and financial support to participants.

> *I receive support from friends – they bring money and milk when they come to visit me at home. They feel sorry for my family and pity my nephew. PLWHA are also providing me with emotional support. They talk with me and persuaded me to join a vocational training group to get a job. They understand that I need to earn money to lift myself and live well… (F: 23/05/05).*

> *My friends who have AIDS come to visit me at home. The knowledge and experience they share with me helps in daily living and in improving my health… (B: 17/02/05).*

In addition, most participants joined in shared activities and shared experiences and feelings in the HIV/AIDS day care clinic at the hospital or in other places.

5.3.4 Health professionals

Participants most often sought help and support from health professionals at the health care services after they knew their diagnosis of HIV/AIDS. Some participants explained that:

> *Following a blood test I knew I had AIDS with TB in 2003 (CD4+ about 106). I felt sad. I did not want to contract it, and others did not want to get it either. But it happened to me. Later, I went to House of the Cool Shade (HIV/AIDS day care clinic) to receive counselling. I felt better because the nurses conveyed lots of advice about the disease, how to prevent it, how to lower the risk of infection, and the medical treatment of opportunistic diseases. They also gave me psychological support. In particular, when coughing, I was told to cover my mouth with my hand to prevent the spread of germs, and also to separate personal articles… from other people… (G: 18/02/05).*

> *When I went to hospital, nurses gave me emotional support to help me cope with stress. I also joined in an exercise group there and I talked and shared feelings with other HIV/AIDS patients about our life experiences with AIDS. I was able to relax more and …feel comfortable… (A: 13 /02 /05).*

> *I received good support from doctors and nurses in terms of AIDS information and funding. A nurse sought funding for me and succeeded in getting 2,000 baht per year for me. It is not much money but it is important for me to use money to obtain milk and food for our family needs. The nurses support me emotionally as well, asking how my symptoms are, and how the family is. They talk with me as if I was their cousin. They are very friendly with HIV/AIDS sufferers, refusing to look down on us… (B: 17/02/05).*

All participants usually went to see a doctor every health follow-up and before regular physical check-ups when they got sick. They also sought funding help from health care providers so the healthcare providers could help them to obtain funding from social welfare or government.

5.3.5 Government and non-government offices

Both the government and non-government offices in Thailand provide support and funding for people living with HIV/AIDS or for HIV/AIDS education programmes.

> *I cannot earn money, but I receive a benefit of 2,000 baht per year from the provincial social welfare fund, for living expenses… (D: 26/02/05).*
>
> *I received a grant of 12,000 baht ($NZ450) from an NGO to set up my business. I have a barber's shop and I am happy because I enjoy doing that work… (F: 17/02/05).*
>
> *I have 2 children – a girl aged 10 and a boy aged 8. Both of them look healthy and are not infected with HIV. They attend primary school in the village. The school provides free lunch for them and the government meets all tuition costs. They also receive 6,000 baht per child per year from the government. This support for my children began just this year after a nurse offered the proposal to me. I also receive 2,000 baht per year from social welfare which a nurse also arranged for me. …So Mor pern ethon chan (the nurse took pity on me)… (Q: 06/05/05).*

Seeking government and non-government support are ways to get an income through claiming HIV/AIDS benefits and via vocational training to replace the loss of income after being diagnosed with HIV/AIDS and losing employment.

5.4 MAKING CHOICES: Getting remarried

Most participants decided to remarry after their husband or wife died. Two participants married men who did not have HIV/AIDS. Ten participants married people who were also infected with HIV/AIDS. Participants remarried because they needed someone to take care of them and their families after their loved ones had passed away from them. In this study, the concept of **"getting remarried"** included the codes ***need a friend, need a complete family and need a child.***

5.4.1 Need a friend.

Six participants stated that they remarried because they needed friends to consult when they had a problem. Moreover, participants wanted someone to understand and to take care of them and their children. Remarriage was often supported by the participant's parents, who hoped that the new spouse would provide additional emotional and financial support and thus reduce the burden on the family. The following extracts illustrate the perspectives of one couple that married after meeting at the HIV/AIDS clinic:

> *My parents wanted me to remarry. They wanted me to have a friend to consult with when I have a problem. Now that I have married again, I do not feel lonely. I married an HIV-infected person whom I met at House of the Cool Shade (The HIV/AIDS daycare clinic). My new husband understands and takes care of me, helping me to raise my family. He gives me courage and love which make my life so much happier. I help my husband earn money for family living expenses… (E: 17/02/05).*
>
> *I remarried with an AIDS person. I needed someone to take care of me. Being in the same situation as me, my new wife understands and we love each other. I am happy because I am not lonely any more. After getting married, I moved to live with my wife's family. My wife's parents love me because they wanted*

> *their daughter to have a friend who would look after their daughter… (F: 17/02/05).*

5.4.2 Need a complete family

In addition to friendship and financial support, the notion of having a complete family was important to some participants, who had been left to live alone or with children, following the death of a spouse. Thus, participants remarried because they needed someone to replace their spouse (to be a father or mother) in order to be a complete family again.

> *I remarried because I want to have a complete family – father, mother and children. I wanted someone to come and look after me and the children who were born to my previous husband. Now I feel happy, my new husband earns money for the family, he loves my children and we live together in a good relationship (E: 24/03/05).*

> *When my wife died, I felt lonely so I lived with my mother and brother. But mum is old and I needed someone who understands me to come and take care of me and my family. I did not know what would happen to me or the family if I got sick…..so I remarried, to an AIDS person who looks healthy…and has two children. We live together and I help her raise the children. I am now happy with a family… (DD: 25/04/05).*

Many participants had lost a spouse, and had lost jobs. They did know what to do until they met someone who understood them. Then they tried to reconstruct their family in order to live a “normal” life by remarriage with an individual who also had HIV/AIDS, thus meeting the needs of both partners for a complete family. The family is the basic unit of society. Consistent with living in a collective society, managing and rebuilding relationships with others was a key element in the choices made by participants.

5.4.3 Need a child

Four participants chose to have a child after they were diagnosed with HIV/AIDS because they wanted to maintain the continuity of their family line. They knew that the HIV infection could be transmitted from mother to child when the women got pregnant but relied on the women taking good care of themselves during their pregnancy and following the doctor's advice about taking antiretroviral medicine.

> *I remarried because I want to have children to continue the family line. My family has only one child, but now my wife is pregnant and if she has a son, he will bear my surname. If she has a daughter, she will have my wife's surname (laughs…laughs)…. I say it like that because a son is very important to me in keeping the family line going. Really, and I do not worry about the children becoming infected. I have found that lots of babies are free of infection….I pray every night before bed, asking Lord Buddha for a normal child for my family. And during my wife's pregnancy I abstained from having sex with her because I did not want the baby to be infected with HIV. I am 100 % sure the baby does not have HIV (laughs…and …boasts)… (K: 20/02/05).*

> *I needed a child in the same way my husband needed a child. I knew how to avoid passing the virus to my baby during the pregnancy. I took AZT medication until I gave birth. My son is OK – he looks healthy… (J: 20/07/05).*

During pregnancy, women were routinely tested for HIV infection before delivery, and HIV-infected women were provided with infant formula and advised to avoid breast feeding. It is recommended that antiretroviral treatment (zidovudine) be given for 3 months during pregnancy, controlled intravenously during labour, and be given for 6 weeks to newborn infants to reduce the transmission of HIV infection from mother-child (Kanshana & Simonds, 2002).

The findings of this study are consistent with those of Klunklin and Greenwood (2005a) who found that people living with HIV/AIDS remarried to make sure that they and their children would be cared for when they got sick or that their children would be cared for after their mother died. They also remarried to be normal.

5.5 CONCLUSION

The category **“making choices”** represents the second stage of the basic social psychological process: ***“from experiencing social disgust to passing as normal*”.** The category includes the concepts, **“avoiding unhappy situations”, “seeking support”, and “getting remarried”.** These substantive concepts are in turn composed of in vivo codes, which demonstrate how participants made choices in order to live a “normal” life, learning how to manage their life situation to live as satisfying a life as possible with HIV/AIDS. Consistent with living in a collective society, managing and rebuilding relationships with others was a key element in the choices made by participants. With these relationships settled, participants had the emotional and financial support and the reason for living that motivated them to focus on “**keeping well”.** This category is addressed in the next chapter.

CHAPTER SIX

KEEPING WELL

6.1 INTRODUCTION

In the previous chapter, I presented the category **“making choices”.** Participants made choices in order to live a “normal” life, learning how to manage their new life situation, in particular managing and rebuilding relationships with others. In this chapter, I describe and illustrate the category **“keeping well”.** Keeping well was the process by which the participants adjusted their daily activities in order to promote their well-being and maintain their lives. Participants were motivated to take good care of their physical and mental health because they believed, having learnt of the possibilities for living with HIV/AIDS as a chronic disease rather than as a rapidly fatal illness, that they could face the future with HIV/AIDS. Although they had developed a serious illness, they could recover and live longer.

Most of the participants looked as healthy as other people in their communities. However, many had experienced some minor illnesses or severe illness from AIDS-related opportunistic infections. Only a few participants had visible signs of disease, such as skin diseases, oral candidiasis, cough and diarrhoea. All participants had to manage their conditions to sustain their health and recover from their illness by “keeping well” to maintain their physical and mental health.

The category **“keeping well”** was supported by the eight concepts that include **religious practices**, **keeping a cheerful mind, self-treatment, taking care of the body, keeping the environment clean to prevent getting germs, healthy behaviours, getting healthcare services** and **attention to, and concern about, medication.** These concepts, and the codes that are included in each concept, are illustrated in Figure 6-1.

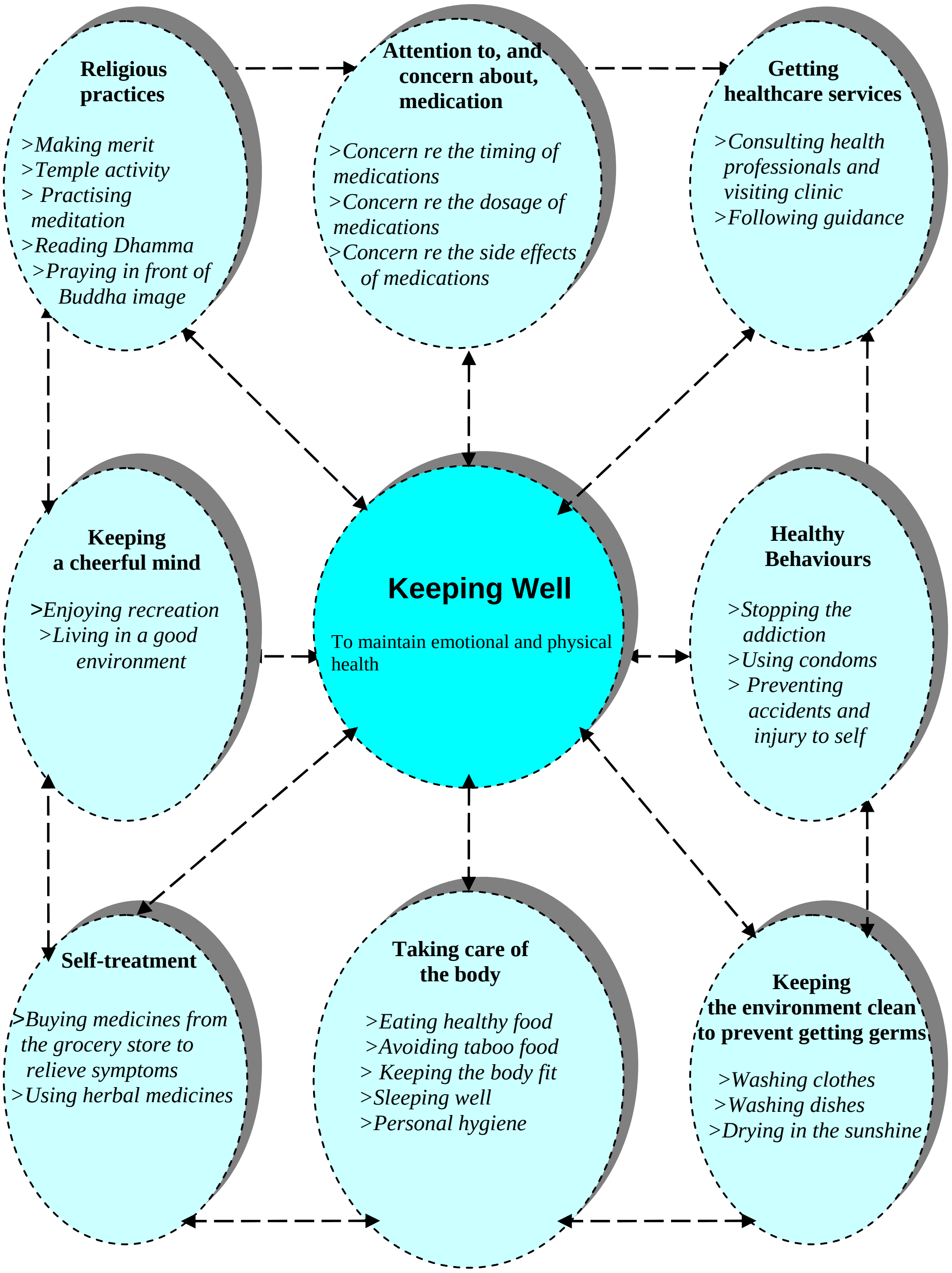


Figure 6-1: Core Category-Keeping Well, Concepts and Codes.

6.2 KEEPING WELL: Religious practices

A religious practice occurred when people living with HIV/AIDS made a decision to take actions of self-management to face distress brought on by illness. All participants in this study were Buddhist; they believed in, and performed, religious practices to help them confront their situation and to reduce their stress. Most participants increased their attention to religious practices after becoming ill; women participants were more likely to perform these activities than men were. Religious practices helped them to maintain their perspective on life and to experience comfort, peace and happiness in life. In addition, practising religious activities could help participants to feel better and adjust well to face their problems and to have hope for better outcomes in the future or in the next life. The concept of **"religious practices"** included the codes ***making merit, temple activities, meditation, reading Dhamma book (Buddha's scriptures), and praying in front of Buddha image*** for help when the illness became severe or life threatening.

6.2.1 Making merit

Making merit (tam boon) is normally practised to promote the present and the next life. For Thai Isaan cultures, making merit usually involved going to the temple, praying to the Buddha images, meditating, joining in temple activities on Buddhist holy days, donating articles or money to the monks and helping others to do work. Most of the participants performed *"tam boon" (making merit)* by offering food and listening to monks' sermons because they believed that religion was good for people and could make them have *"sabai jai" (an easy mind or healthy mind)* and be good persons after they made merit. They thought making merit could help them to be healthy, free from sickness, have a peaceful mind, and be happy in their lives. Participants said that:

> *Whenever there are traditional merit-making events in the community, I like playing the drum in the procession, then I pray and attend the monks' sermon in the temple. I feel encouraged and contented because I participate with the people of the community and I also make merit to the monks. I am not weary of it all, but rather I have peace of mind and a sense of contentedness with my life… (keeps smiling…) (F: 27/02/05).*

> *I like to make merit. I offer glutinous rice and boiled eggs to monks every morning in front of my house. I pray for peace, happiness, health and wealth for me and my family both now and in the next life. I believe that if I do good things, I will have good things returning to me, but I do not know when … the good will come back. I try to do …good things… (I: 05/03/05).*

Most Thai people and participants in this study believed that effects in the present day originated from a cause in the past, or even in the previous life. People make merit and virtue *(tam boon)* in order to eliminate selfishness and greed. Buddhism teaches people that practising good deeds affects their karma and that they should make merit by performing morality *(sila)*, mental discipline *(samadhi)*, and wisdom *(panya)* (Klunklin & Greenwood, 2005b).

6.2.2 Temple activity

The participants visited the temple on Buddhist holy days to perform religious activities, including making merit, paying respect to Buddha’s image, worshipping and listening to sermons from the monks. Participants explained that:

> *Today is Makha Bucha Day, and my mother and I went to the temple to make merit, by offering food and alms to the monks there. I venerated the Buddha to take my sins away. My mother believes that after making merit, suffering and misfortune will be sent away… (A: 23 /02 /05).*

> *On holy days, I visit the temple to offer food and alms to the monks and listen to their sermons. These days include Makha Bucha Day, Visakha Bucha Day, Arsaraha Bucha Day and Orkpunsaa Day. After making merit, I feel at peace with myself, with calmness of mind too. My parents taught me to make merit on behalf of my ancestors by offering food and giving alms to the monks, who then send them to my ancestors. I believe Buddhism is the best part of my life… (T: 03/05/05).*

Most Buddhists believed that by donations of things, food, and money to the monks, or sponsoring temple activities, they would obtain merit (Klunklin, 2001; Songwathana, 1998). In addition, participants believed that when they went to practice temple activities that made them healthy in their life.

6.2.3 Practising meditation

Meditation may be used as a self-care management strategy by people living with HIV/AIDS. Meditation helped to increase the participants' awareness of their stream of consciousness. Thus, performing meditation practices could lead them to better health and assist them to stay well. When they felt worried and stressed they would practise meditation for reducing anxiety. A participant explained that:

> *I practise meditation by sitting and doing breathing exercises. On breathing in I say "phut" and when breathing out I say "tho". After about 20 minutes I have peace of mind and I sleep well until morning. I believe that having peace can result in better health. I have heard the monks teach this when they preach at the temple on holy days… (S: 02/05/05).*

Most women participants performed meditation before sleeping because they perceived that if they had a calm mind and could sleep well, that helped them to improve their health and stay well. Meditation practises can positively influence the experience of HIV/AIDS or other chronic illness (Bonadonna, 2003). There are many forms of meditation practice.

6.2.4 Reading Dhamma (Buddhist scriptures)

Most participants read *Dhamma (Buddhist scriptures)* because they wanted to know what Buddha taught people by speaking via the book. Some participants reported that reading Buddhist scriptures in Thai and *Pali (the language of Buddhist scriptures)* reduced their feelings of boredom or guilt and anxiety and helped them to have calm minds, while others looked for answers about the meaning of life. Participants said that:

> *I seldom go out. I just stay home and look after my grandmother. Sometimes I feel bored and anxious but I manage these feelings and learn to survive by reading Dhamma … (D: 26/02/05).*
>
> *When I read Dhamma I understand what life is about and it gives me peace of mind. I stop worrying about the disease because the teaching states that humans will experience birth, ageing, sickness and death, so everyone has to face it… (Z: 17/04/05).*

Participants reported that reading *Dhamma* taught them to be good people, to adapt themselves to live in society and to be free from stress. Sritanyarat (1996) reported that people living with diabetes performed religious practices when the illnesses were severe or life-threatening by practicing *Dhamma* because they believed that performed religious practices seem to adapt well to their problem.

6.2.5 Praying in front of Buddha image

The participants connected with the Buddhist religion by praying in front of Buddha's image. They believed that worshipping and *"suad mon" (praying)* could help them and their families to be healthy, with peaceful minds and be free from diseases. Participants said that:

> *I worship the Buddha image every night before going to bed. I believe that worship stills my mind, preventing it darting from thought to thought, and I sleep well… (G: 25/02/05).*
>
> *I sleep well because I chant and bow down before the Buddha's image. Lord Buddha protects me and my family from disease and imparts well-being to us. After praying, I feel happy… (T: 03/05/05).*

Thus, people with HIV/AIDS believed that reciting chants before sleeping would help to protect them from evil. HIV/AIDS was a life-threatening condition. It was important for people living with HIV/AIDS to have inner strength. Religion helped them to have that strength. Chinouya and O' Keefe (2005) reported that finding inner strength by religion helped Africans living with HIV to cope with the disease, while Chammas (1999) suggested that an increase in hope may improve quality of life. Thus, participants tried to maintain or reestablish religious practices in their life. These religious practices helped them to not dwell anxiously on their HIV/AIDS condition and they were able to sustain their life in society.

6.3 KEEPING WELL: Keeping a cheerful mind

Participants stated that keeping a *cheerful mind (jai berk ban)* is an activity important for maintaining their well-being and staying healthy. Participants believed that they could forget their health problems while enjoying recreation because they focussed on another activity instead of their disease. When participants lived in a good environment, they felt comfortable and stayed well. The concept of "**keeping a cheerful mind"** includes codes ***enjoying recreation,*** and ***living in a good environment.***

6.3.1 Enjoying recreation

Most participants engaged in recreation activities more than was usual because they had more free time after they had HIV/AIDS. Many participants had no permanent job and just stayed home. Thus, they were able enjoy activities which made them more comfortable in their physical and mental states such as listening to music, playing karaoke, watching television, watching cockfights, chatting with friends, shopping with friends and playing cards. Such activities distracted them from thinking too much about their illness. Some participants said that:

> *I have free time. Some days I will play cards with my friends nearby, other times I will sleep, watch television and chat with my friends at home. I am happy, have an easy life and feel at peace… (G: 25/02/05).*

> *In the weekends I like to watch cockfighting in the village, and watch Thai boxing on television. So I talk, laugh and shout along*

> *with other people. It is fun, and gives me relaxation and mental health. Since I was young I have loved to watch cockfighting and my father loves it too. I am raising 5 fighting cocks as a hobby. I love them. After handling them, I always wash my hands to avoid getting a virus from them. I know how to care for myself… (K: 20/02/05).*

> *I watch television, listen to music and chat with my wife. At the market I chat with friends. These things keep me free of stress – laughing and talking, and knowing I am not alone. I do not remind myself that I have a disease, but that I can live with anything. I imagine that I am normal…my weight is OK… If I think (too much)… I am not happy, and become irritable… (R: 24/02/05).*

Participants believed that these activities were fun and helped them to feel relaxed, and happy and to forget their disease or their problems for a while.

6.3.2 Living in a good environment

Participants identified living in a good environment as important to keeping a cheerful mind and keeping well. A good environment included both physical and emotional aspects. They identified fresh air, a clean household and good ventilation as important to their health and happiness. One participant explained that she cared about the environment around her, because she knew that HIV-infected persons and AIDS patients have low immunity and could get germs that make them ill if they were not concerned about the environment.

> *As a housewife, I stay at home. But I care about the environment around so I try to protect it by cleaning the house, and things such as floor, crockery and food utensils, and clothes. I do not leave cooking and eating utensils around, but clean them immediately I have finished with them to prevent flies coming… (B: 14/02/05).*

Some participants did not want to live in a crowded situation, as they would be exposed to people who may reject them, because of their disease.

> *On the farm the environment is good, with clean fresh air whether I sleep in the hut or whether I sit under a tree. Ventilation is good, and the air is not hot. By the way, people who reject me create a bad environment for me and I do not like being around them. I get stressed and unhappy with them… (A: 13/02/05).*

In contrast, some participants who had fully disclosed their illness to others in their village felt happy to engage with others in activities in public places as normal people.

> *I like going out to talk with others and join in their activities, rather than staying at home… (Z: 11/04/05).*

When they engaged in public environments with others they said they felt happy, not bored like staying at home. Thus, a good living environment was one that met the needs of participants for mental and physical well-being; it contributed to their ability to keep a cheerful mind.

6.4 KEEPING WELL: Self-treatment

The concept of **"self-treatment**" referred to the actions that participants took to take care of themselves when they got sick, but perceived that the illness was not serious. They preferred to buy medicines from a grocery store to treat themselves without a prescription from doctors. Moreover, they believed that they could take care of themselves when they developed symptoms by taking medicine in order to maintain their health and recover from illness. Only if the symptoms did not improve would they go to see a doctor in the hospital. The concept of **"self-treatment"** included the codes: ***buying medicines from the grocery store to relieve symptoms*** and ***using herbal medicine.***

6.4.1 Buying medicines from the grocery store to relieve symptoms

In Thailand, people are able to buy medicine from a grocery or drug store without prescription. Most participants would buy medicine from a grocery store to treat themselves, because they were confident that they knew how to treat themselves when the symptoms were not serious. Participants explained that:

> *Sometimes I get mild sickness like a cold or a headache and I buy some paracetamol or tiffy (cold relief drug) at the drug store to treat myself. I drink warm water and take a rest as well. If I do not get better, I go to the doctor. I try to take care of myself first when it is not a serious illness… (D: 16/02/05).*

> *I got muscle pain, back pain and headache I then took ya pa ra (paracetamol) 2 tablets, when my symptoms disappear, I stop taking it… (T: 03/05/05).*

Some participants said that when they got sick, they took medicines immediately (rather than rest) in order to relieve their symptoms and to go back to work again.

> *I walked long hours because of working in the noodle shop, I got a leg pain then I used bandages to support the legs to relieve the pain…. I had a headache, my friend gave me four white tablets of medicine, after I took it, I felt better … (L: 26/02/05).*

6.4.2 Using herbal medicines

After being diagnosed with HIV/AIDS, some participants and their family members tried to seek herbal medicines to cure their illness based on the recommendation of others. The herbal medicines used by participants included *faa tha laai jone (name of plant), ya hark mai (herb medicines including root and leaf of trees)* and other kinds of herbal medicine plants. Participants explained that when their mothers needed them to be cured from the disease, they tried to find *ya samoon prai Thai (Thai traditional herb)* for their loved ones. There were many kinds of roots of trees and leaves and there was a good smell after boiling them. They took herbs sometimes.

> *I drink about one cup of herbal medicine every morning to cure my disease…. I believe my mother, who used it before without harmful effects…. After I take it, I feel like eating a lot…*
> *(E: 27/02/05).*

One participant developed symptoms such as *gue sawat (herpes),* itchiness and an abscess in her genital area. She then went to see a doctor at a private clinic and the doctor told her that she had gonorrhea and herpes. The doctor gave her an injection and medicine to cure the diseases at home, but her symptoms did not improve. Thus, she sought other ways than modern treatment, and bought herbal medicines from the *wat (temple)* to treat herself. Once she had no symptoms, she stopped using it.

> *I bought 4 bags of herbal medicine for 400 baht, made up of mixed tree roots and leaves. I boil it in a pot with water. Instead of water, I drank 4 pots of this for about a month. I felt much better. My symptoms disappeared, I was not itchy, had no herpes or abscess problems. I consider herbal medicine to be better than modern medicine. It also made me eat a lot, and I felt strong and energetic for work… (I: 19/03/05).*

Another participant said that he always used herbal medicines when he got *papulae (tum kun, ugsape)* over his body that he scratched because they were itchy. His grandmother boiled many kinds of leaf with water *(yay tom bai nard, bai yuow, plurg ma tum and ton ta krai hom)* for him to take a bath 2-3 times a day; then she painted the papulae on his body with *kha min (curcuma longa-kind of herb)* after bathing**.**

> *After I had bathed in herb water for about a month I felt better. The papulae disappeared and I was not itchy. Although I got calamine lotion from the hospital I did not use it because it has not helped in the past… (P: 06/03/05).*

Herbal medicine was cheaper, and considered better than modern medicine by some participants, who believed that after they used herbal medicines they could eat well and some symptoms disappeared.

6.5 KEEPING WELL: Taking care of the body

The concept of "**taking care of the body**" referred to the daily practices carried out by participants to maintain their physical health. Participants understood that taking care of the body in terms of nutrition, fitness, sleep and personal hygiene would support their immune systems and would make it difficult for infections (germs) to attack the body. The concept of **"taking care of the body"** included the codes: ***eating healthy food, avoiding taboo food, keeping the body fit, sleeping well and personal hygiene.***

6.5.1 Eating healthy food

Food choices for people with HIV/AIDS are very important. All participants received advice from healthcare providers that they should be careful to avoid eating contaminated food or raw food and they had to obtain enough food to promote their health. Most participants would say *"tong kin suk, sa aard" (cooked food and cleaned)* to prevent getting germs. Therefore, most of the participants would cook their own food.

> *I eat 3 meals per day and always on time. I still eat everything that I used to eat before such as noodles with beef or pork, papaya salad, pork salad, fried fish and vegetable soup. It is a good diet for me and my family and we can vary it each day depending on what we feel like eating. I never feel ill after eating. I also eat fruit- especially jackfruit, guava and mango for the vitamins and fibre content. I never buy fruit because my brother grows these near my parents' rice fields… (E: 17/02/05).*

> *I have 3 meals per day. In the morning I like roasted pork or fried fish with glutinous rice and for lunch I prefer noodles*

> *because it is both a good food and easy to buy. In the evening I have a big meal with a variety of dishes such as steamed chicken, bamboo shoot salad, mushroom salad and steamed fish with vegetables. This is Northeastern food, and with the herbs I keep a good nutrient balance and enjoy good health… (F: 17/02/05).*

One participant said she could not restrict her diet; she ate many kinds of food, just as she did before developing HIV. She could eat *"nue dip"and "muu dip" (raw meats)* because she thought that raw meat had a good taste and made her strong. This participant knew the disadvantages of eating raw meat, and she said if she got sick she would stop eating raw meats. She liked to buy cooked food from the market; she did not want to cook by herself because she needed to relax and rest after working hard and prepared food was very cheap. She could get enough food included in the five food groups to keep her alive and healthy.

> *I eat many kinds of food. If I want to eat raw beef or pork then I do. They are delicious, make me strong and I do not suffer allergies after eating. I have a big meal 3 times a day because I work hard on construction sites carrying bricks and sand. Sticky rice, meat and vegetables are very important to me because they give me the energy I need. I eat a lot each meal time and I also drink lots of water- about 3-4 litres per day- because of the heavy work and hot temperatures. I cook sometimes but mostly I buy prepared food from the market. It is cheap and for 10 baht I can get a bag containing a complete meal of meat, vegetables, oil, vitamins and mineral salt. I prefer not to cook because I save both time and money. I work hard over a long day for rather low pay and I need to relax and rest too… (I: 05/03/05).*

Participants and their family members knew how to prepare and cook foods for HIV/AIDS persons when they were sick and when they were healthy. Normally, women prepared the food, paying attention to cleanliness and healthy food choices. They demonstrated good knowledge of food groups, understood the importance of good nutrition to the health of their immune system, and to their ability to live a “normal” life. Good food can help to extend the period when the person living with HIV/AIDS is healthy and working.

> *I have 3 meals per day which I normally eat with my family. (I actually need 5 meals per day to get a complete nutrient diet). I clean my hands and the kitchen utensils before preparing food and cooking it. Every meal consists of plain or glutinous rice, meat, fish, chilli paste and fresh vegetables. I make sure I get good food. I also drink about 10 glasses of water every day, eat bananas to avoid constipation and I drink milk before going to bed. I think that I get adequate nutrients to maintain good health. When my sister buys ready-to-eat-food, I will reheat it to prevent infection in case it is not hygienic… (Q: 06/05/05).*

Most participants or their family members prepared and cooked food by themselves. They bought some items from the market and obtained rice from their rice fields, or their house garden. Most of the participants did not eat out because they were of a lower economic status; they were predominantly farmers or labourers who were dependent on daily earnings for living expenses.

> *My wife does most of the cooking and she likes to cook the fresh-water frog, fried fish, fried egg, fried dried meat (or chilli with fish sauce instead) and soft boiled vegetables. It is common food for us but it is nutritious…. We do not spend much money on food because we can catch it in the rice fields or in the ponds around the house… (K: 20/02/05).*

Nutritional status is an important factor for quality of life of people with HIV/AIDS. Nutrition management strategies contribute to long-term survival and nutrition also plays a crucial role in improving oral health (Brown & Batterham, 2001; Patel & Hansen, 2005).

6.5.2 Avoiding taboo food

The participants modified their eating habits by avoiding *"ahan salaeng or kha-lum" (taboo food or forbidden food)* and consuming the foods that were recommended by healthcare providers, friends and books, as participants explained:

> *I do not eat chicken or eggs because they cause me to itch. I stopped because I am concerned for my health. I can have pork, seafood and fish which are richer in proteins. I do not eat raw food because of the parasites and the doubtful value they have for healthy living… (D: 16/02/05).*
>
> *I have had allergic reactions to seafood after eating them. I get an itchy rash over my body. I stopped eating seafood such as squid and shellfish… (P: 17/02/05)***.**
>
> *My taboo food is pickled bamboo shoots. My eyes swell after eating it so I have now stopped taking it for my health's sake… (Q: 06/05/05).*

Participants selected foods that they believed would be useful for their health such as protein from meat, vitamins from vegetables and fruits that they ate to promote their health and to improve their immunity to prevent getting sick. Participants avoided taboo foods such as raw foods, seafood and pickled foods, which made them ill. This finding is consistent with that of Klunklin and Greenwood (2005a) who found that people with HIV/AIDS chose foods that were not spicy or pickled and avoided taboo foods because they needed to stay as healthy as possible.

6.5.3 Keeping the body fit

Some participants kept their body fit by regular exercise such as jogging, bicycling, playing badminton, walking, or doing aerobic dance. Other participants undertook housework at home, and some helped with farm work and in the rice fields. Exercise was normally associated with increased immunity and reduced mental stress.

Participants perceived that exercise and work caused them to have strong muscles and a healthy mind, and prevented diseases.

> *I get up early and go jogging along the street in front of my house for about 30 minutes. By that time I am soaked with perspiration. I think this is good exercise because it strengthens my muscles and gives me feelings of both relaxation and renewal (A: 23/02/05).*

> *I do aerobic dance with others for about 30 minutes while my daughter joins other children at a playground until about 5.00 p.m. The aerobic dance strengthens my body and refreshes my mind… (C: 16/02/05).*

Exercising was viewed as a formal type of increased physical activity; therefore, some participants gave the reason for not exercising as not having time. However, they thought that working in the construction industry or on the farm or rice field and collecting firewood and carrying water provided enough exercise for them. Participants said that:

> *I do not do exercise because I do heavy physical work all day carrying bricks, sand and cement. My body moves, and blood circulation is good. This is my exercise. I do get tired but I am strong and healthy… (I: 05/03/05).*

> *I am physically active, doing heavy work such as drawing water from the well and carrying it, chopping fire wood in the field and carrying heavy loads of it back home… (M: 17/02/05).*

> *I do not have an exercise regime but I work hard physically every day. I do the housework, herd the cattle 4 km per day to the paddy fields, and grow vegetables for the table. I feel that this is my exercise which keeps me strong and healthy because I move*

> *my body, my feet and hands, my joints and the blood circulates well, especially when I have to run to catch up with the cattle… (T: 03/05/05).*

Regular exercise has been reported to strengthen the muscles, make people living with HIV/AIDS feel energetic, help to reduce stress and improve their appetite (WHO and FAO, 2002). The participants chose to increase physical activity depending on their daily lifestyle and their perceptions about the usefulness of exercise in their HIV/AIDS self-care management.

6.5.4 Sleeping well

Sleeping well at night is very important for human well-being. In this study, most participants focused on sleeping well to maintain their physical and mental health. They understood that lack of sleep would affect their immune system, and enough sleep would improve their well-being. They had a range of strategies to relax themselves in order to sleep, and most had enough sleep, around 7-8 hours per night.

> *Normally I go to bed immediately after watching television, and I sleep for 7-8 hours each night. I think it is enough for me. Once I joined with other hospital members playing music but then I did not get enough sleep that night and felt out-of-sorts the following day so I slept then. I slept well and felt well enough to work. I know how to take care of myself and prevent sickness. I am concerned for my health… (F: 17/02/05).*

> *I sleep 8 hours per day and sleep well. I go to bed after watching television news and drama. The news gives me knowledge, the drama entertains me and I relax from work. Before sleeping I sometimes read the Buddhist scriptures or meditate and that relaxes me further for a good sleep. I also open a window for good ventilation during the night …(S: 02/05/05).*

6.5.5 Personal hygiene

Participants reported paying particular attention to personal hygiene in order to stay well. Many undertook hard work in a hot environment and reported getting dirty and sweaty from their housework and work in the fields. All participants took care of their personal hygiene by brushing teeth, bathing, washing hair, washing hands and cutting their finger and toe nails. People living with HIV/AIDS have low immunity and are easily infected. Therefore, the participants practised personal hygiene care to prevent infection.

Brushing teeth and mouth care are very important for people living with HIV/AIDS. Brushing teeth can prevent fungus or bacteria from causing oral infection or tooth decay.

> *I brush my teeth twice daily–after waking and before going to bed–to prevent germs build-up…. I understand that this disease causes weak immunity, and if I do not clean my mouth I can get infected with oral fungus…(C: 16/02/05).*

Participants reported taking regular baths because bathing made the body clean, look fresh and encouraged blood flow. Participants normally used soap to clean their body because they believed that soap could kill germs and get rid of dirt. In contrast, if participants did not bathe they felt uncomfortable and worried that germs could invade their body. Most of the participants washed their hair once a day; some participants washed their hair 3 times a week, depending on their work.

> *I bathe twice each day…. I always wash before going out to work in the morning, and again in the evening after getting home…. If I do not bathe, I feel uncomfortable and itchy all over… (E: 17/02/05).*

> *I am a farmer and I have to keep the body clean to prevent germs and skin disease. Most of my time is spent in the rice fields and I get very dirty and sweaty and it makes me feel uncomfortable. I*

> *wash twice daily with soap, which can kill germs on the skin before they can cause disease… (T: 17/05/05).*

> *I also wash my hair with shampoo every day in the evening because I work hard and perspire a lot. After I have cleaned the body, I feel comfortable and fresh- not tired… (S: 02/05/05).*

Washing hands was recognised as very necessary and important for people with HIV/AIDS to prevent infection because they have low immunity and easily get infections.

> *I use my hands to seize things when I work and so I have to wash my hands before and after having a meal because I use my fingers in eating. If my hands are not clean, I would bring germs to my mouth. I am careful. My disease causes insufficient immunity and I can easily pick up infection… (S: 02/05/05).*

From the researcher's observation, not all participants used soap when washing their hands, before and after serving meals to their children or to themselves. However, some participants reported much concern about washing their hands with soap to prevent infection and smells.

Most participants would cut and clean their finger and toe nails to prevent infection. Some participants used their hands to prepare food for sale or to work with other people and recognised the importance of keeping nails short and clean.

> *I cut my nails and keep my body clean to prevent myself and my loved ones getting infected. I do not want to get sick but to live for a long time so that I can raise my youngest son to adulthood (B: 14/02/05).*

> *I take good care of myself to prevent infection. I usually cut and clean my finger and toe nails by using soap and a scrubbing*

> *brush. I am a barber and I deal with people every day. I do not want people to suspect that I am infected with HIV (F: 17/02/05).*

As well as paying attention to taking care of the body in order to keep well, participants valued a clean environment to prevent infection.

6.6 KEEPING WELL: Keeping the environment clean to prevent getting germs

The concept "**Keeping the environment clean to prevent getting germs**" refers to managing the surrounding environment by cleaning things and keeping the equipment around people clean to prevent infections. This concept included the codes: ***washing clothes, washing dishes*** and ***drying in the sunshine*** because household articles were seen as a source of bacteria and fungi that made the participants and their family members vulnerable to infections.

6.6.1 Washing clothes

The participants described washing their clothes regularly with washing powder to kill the germs and prevent smells.

> *I change my clothes every day. It is hot. If I do not change, I fear getting skin disease. I always wash my clothes with Fab (cold water detergent powder) in order to kill the germs and dry them in the sun at the back of the house… (R: 24/02/05).*

6.6.2 Washing dishes

Participants would wash dishes with liquid solution after having a meal to prevent smells, avoid attracting ants and other insects and avoid infection.

> *I eat with the family and when we have finished, I gather and wash the dishes immediately. I do not leave them about because ants and other insects soon come. I want to keep them clean and avoid infection…(C: 16/02/05).*

6.6.3 Drying in the sunshine

Participants would dry washing and air things such as mattresses, pillows, blankets and mosquito nets in the sun in order to kill germs and insects and prevent smells. As one woman participant said:

> *My house is well ventilated with a lot of windows. When I open these, it is not hot. It is also clean because I clean and wipe every day so that I can even lie on the floor. There are no ants or other insects to trouble me. I wash the pillow-case, sheets and blanket every 3 weeks and air the mattress and pillow in the sunshine to kill germs and insects and prevent smells… (T: 17/05/05)*

6.7 KEEPING WELL: Healthy behaviours

Participants received advice from healthcare professionals and from family and friends about changing unhealthy habits or addictions and introducing healthy behaviours to maintain their well-being and prevent getting sick. After receiving knowledge and advice about their disease, they tried to do their best in order to be healthy and live a normal life. The concept of "**healthy behaviours**" included the codes: ***stopping the addiction, using condoms, preventing accidents and injury to self.***

6.7.1 Stopping the addiction

Most participants smoked, and drank alcohol before they were diagnosed with HIV/AIDS; and one participant used to take drugs and shared needles. Families and friends strongly encouraged participants to quit, or reduce, their smoking and alcohol usage in order to avoid getting sick again.

> *My family does not want me to get sick again, they need me to have good behaviour. Quitting alcohol has been good for my health… (H: 11/03/05).*

> *I revealed to the community that I have AIDS and my friends don't encourage me to drink and smoke as before. My cousins even tell me to stop drinking and smoking to change my life. They are concerned about my health, they do not want me to get sick and I think they are very kind to me. Being a young man, I feel it is not too late to change my habits. I feel sorry for grandpa and grandma who are concerned for my life and wonder why I do not do anything good for them. Now I have given up the vices like drinking, smoking and drug-taking, maybe I can help them with some work… (P: 23/04/05).*

Some participants still drank alcohol and smoked cigarettes, but they reduced the amount and tried to stop.

> *Sometimes I drink beer with my wife and friends when they visit to improve my appetite. I do not drink an excessive amount because I know it will lower my immunity and I will lose my health and get sick… (R: 24/02/05).*

Most participants stopped smoking and drinking because they knew that these habits were not useful for their health. They wanted to be healthy and live longer with their family.

6.7.2 Using condoms (cide thung yang)

Most participants were concerned about sexual relations and used condoms when they had sex with their partner because they did not want to infect their partner with their virus. Some expressed awareness of differing strains (subtypes) of the HIV virus, others thought that the HIV virus was different from that of AIDS.

> *When I have sex with my husband I use a condom. If I do not I will infect my husband with germs. I do not want to do this because he only has the HIV infection but I am living with fully-*

> *developed AIDS. I think my virus is more serious than his, and I do not want him to get AIDS… (E: 17/02/05).*

Some participants did not use condoms when they had sex, arguing that they already both had HIV/AIDS so what will happen will happen; although the decision was not necessarily a mutual one as illustrated below:

> *I am concerned about our sex life. I want my husband to use a condom when we have sexual relations but he does not like doing it because he said it is not natural. The cap over his penis robs him of the feeling and he is not happy about it. He said it is not real. I cannot do anything about it because he gets what he wants. I am a woman and I dare not refuse him. He said we are husband and wife together. Whatever is about to happen will surely take place… (B: 14/02/05).*

> *When I have sex with my husband, we sometimes use a condom, but mostly we do not, because we are both HIV/AIDS patients and my husband refuses to use it anyway. We are not concerned about the virus but just concerned about our life at the time so it makes us happy and we can forget everything. So we know what will happen but we do not care … (D: 16/02/05).*

6.7.3 Preventing accidents and injury to self

Preventing accidents and injury to self referred to participants' awareness of risks of injury with sharp instruments that may harm them and jeopardize their future work opportunities.

> *I am a barber; I cut hair. I do not worry about my job; I just make sure that I do not have any accidents with the instruments of my trade. I do not wear gloves but I take particular preventive care… (F: 17/02/05).*

> *I work in the health centre; I am a cleaner. I clean everything such as cleaning the floor, beds, and washing the medical instruments by hand. I sometimes wear gloves to prevent the infection, sometimes do not wear gloves ……umm I take special care not to injure myself on the syringes, needles, blades and scissors… (U: 07/06/05).*

> *I take care of myself. When I work I use a machete to cut the wood and during the cutting and also the carrying I have to take special care to prevent injury. I do not want to get ill and when I use a machete I would increase the level of caution…*
> *(Y: 01/07/05).*

Participants appeared to be more concerned about risks to their own health from work-related injuries, than about the transmission of the disease by exposure of others to their blood.

6.8 KEEPING WELL: Getting healthcare services

After being diagnosed with HIV/AIDS, participants continued to seek healthcare services for their condition from the hospital. They believed that healthcare professionals in the hospital, such as doctors and nurses, could help them to get better from their condition, because they know about their problem. Participants expected that they could receive quality care from the hospital because of the progress of technology and medication at present, or in the future. The concept of "**getting health care services**" includes the codes: ***consulting health professionals and visiting the clinic*** and ***following guidance.***

6.8.1 Consulting health professionals and visiting the clinic

When participants were concerned about their health and illness, they went to the hospital to consult healthcare providers and visited the HIV/AIDS day care clinic, in order to receive quality care and health education about HIV/AIDS. They believed that visiting the clinic could help them learn more about their physical health, self-care and prevention of further illness.

> *When I went to the hospital, I attended counselling about HIV/AIDS disease, and nurses taught me about its cause, its transmission and prevention, as well as self-care and prevention of illness from it. The nurses spoke politely without showing revulsion, and told me to take good care of myself, and to avoid sickness, that I have to face the disease head-on. And if I get abnormal symptoms, to hurry to see the doctor at the hospital. They recommended a check every 6 months, and for me to take the children there for a blood test. All this information is helpful to me in my daily life to prevent sickness… (Q: 07/05/05).*

> *I do not take any medicine. The doctor told me that my white blood cell count was high (CD4+ greater than 500). I am healthy with no sickness or abnormal symptoms. I have never taken herbal medicine. The doctor told me that there is no herbal medicine to cure HIV/AIDS but there are herbal medicines to relieve some symptoms like fever, coughs and diarrhoea…… but I have never taken any … I go for a check-up at the hospital every 3 months and a blood cell count check (CD4+) every 6 months according to the doctor's recommendation. I have never missed a check-up. I am concerned for my health. I do not want to get ill. If I get sick I don't know who will bring money in for the family needs…(R: 24/02/05).*

6.8.2 Following guidance

Following their visits to the hospital clinic, participants strictly followed the guidance and recommendations of the health professionals because they believed that following the advice would enable them to maintain their life and have hope for the future.

> *I went to the hospital and was admitted for 10 days with AIDS-related symptoms. Before I was discharged I joined up with a group of HIV/AIDS patients at Cool Shade House for counselling and healh-promoting activities. I obtained many kinds of medicine to take home to treat opportunistic diseases and control the spread of the virus. The doctor told me my immunity was low (CD4+ of 1) and I had to take many kinds of medicine following his recommendations. I cannot remember the names of them all. I thought that I would surely die if I did not continue going to the hospital and taking the medicines. I am alive today because of the medicines. I think I can be cured in the future sometime…*
> *(H: 03/04/05).*

> *I have never taken antiretroviral or other medicine because I have good immunity with my CD4+ at 315. The doctor urged me to take good care of myself regarding eating, exercising and having enough sleep. In that way, I could survive for a longer time comparable with the life expectancy of people with diabetes, cancer and heart disease. So it was my choice whether to take good care of myself or not. I chose to take good care of myself following the nurse's guidance and here I am today normal and healthy… (Q: 20/05/05).*

6.9 KEEPING WELL: Attention to, and concern about, medication

Participants mentioned that attention to, and concern about, medication was very important for them to control their diseases. The participants searched for the "right" medicines to cure their illness. Most participants used medicines to help them control the spread of the virus and to treat opportunistic infections. They used modern medicines that they got from the hospital because they believed that modern medicine would help them to get better after taking it. The participants strictly followed their healthcare provider's instructions about taking antiretroviral medications and medication for opportunistic infections because they needed to be cured of the disease. The concept of **“attention to, and concern about, medication”** includes the codes: ***concern re the timing of medications, concern re the dosage of medications*** and ***concern re the side effects of medications.***

6.9.1 Concern re the time of medications

Participants managed their disease by being concerned about the timing of medication. When they got serious symptoms they went to hospital to consult a doctor and the nurse advised them how to manage the medication to prevent getting sick again. They would take medicines on time because they did not want to get sick and suffer from drug resistance, and they wanted to be healthy and live longer with their family. Participants in this study learnt about the natural history of HIV infection and the association between the CD4+ T lymphocyte count and illness, from healthcare providers who gave them information about the disease and medication. Participants understood that if their CD4+ T lymphocyte counts was less than 200 cells they had to get *“ya taan virus” (antiretroviral drugs)* medication to control the spread of the virus and also get *“ya pong guun laee ruk sa rok tid chue chuey oo gard” (co-trimoxazole prophylaxis drug for preventable and treatable opportunistic infections).* Therefore, participants would have to take medicines according to a regular timetable, and they adhered to it very strictly because it was very important to them.

> *I have AIDS and I have to continue taking drugs. The doctor prescribed antiretroviral (GPO-vir) medicine for me in order to control the spread of the virus. I take it every day at 8.00 a.m. and 8.00 p.m. according to the doctor’s advice. If I stop or forget to take it, I will suffer from pathogen resistance and become sick again. So medicine is a necessity for me. It keeps me alive and strong enough to live long with my family… (C: 16/02/05).*

> *Although I know that everyone has to die someday, I do not know when. My wife insisted that I take drugs but I did not take them. Then I found out that everyone who takes the drugs gets well, so I dared to get some for myself. Presently, I take medicine on time at 7.00 a.m. and 7.00 p.m. every day. I never forget to take it*

> *because I do not want to get sick again. I want to continue taking medication because my health is gradually improving, with no fever, and no cough. I can work for my family, and some days, I visit others with HIV/AIDS at their home. We share our experiences of the disease, and I encourage them to face the disease squarely because some are in despair (K: 20/02/05).*

6.9.2 Concern re the dosage of medications

Participants managed their medication by being concerned about the dosage of medicines in order to prevent the symptoms' recurrence and drug resistance. Although they took many kinds of medicine each time, they continued taking them following the treatment regimen that healthcare providers gave them. After they took medicine at the correct dosage, they felt better. Participants believed that medicines were good for helping them survive and to live with their family through to their old age. Therefore, participants would not forget even one dose of medicine because they needed to stay physically healthy. Moreover, participants knew that their CD4+ T lymphocyte counts affected their body's immune status and it was an index of the disease progression. As a result, the participants tried to observe the association between their conditions and the level of their CD 4+ T lymphocyte counts.

> *The doctor told me that I had AIDS and that it was incurable. He gave me Fluconazole (a fungicide) to treat oral fungus and antiretroviral drugs to control the spread of the virus because my CD4+ count was below 200. He made a monthly follow-up appointment as well. When I returned home, I took seriously the doctor's recommended drug dosages and followed them strictly. I am receiving good treatment and am encouraged by my parents and brother to face up to the disease… (E: 17/02/05).*

> *I first knew when I got AIDS-related TB on my lungs. The doctor gave me anti-TB medication for 6 months (I forget the name of the drug), and also medication to prevent opportunistic diseases (Bactrim) and an antiretroviral drug, GPO-vir to control the*

> *spread of the virus. Now I am on only GPO-vir medication because my CD4+ count is more than 200, it is 226. I have stopped taking Bactrim and have no complications from that… I am serious about taking the medicine because I do not want to promote resistance in the pathogens or to get sick, but I want to live with my family (husband, daughter and nephew) until my old age…(G: 18/02/05).*

6.9.3 Concern re the side effects of medications

Participants mentioned that they developed some side effects of antiretroviral medicines such as fatigue, nausea, vomiting, confusion, blurred vision, tiredness and inability to eat. Some participants took care of themselves by drinking lemon juice, sleeping, eating bananas and drinking water; after that they felt well and could eat more. Some participants went to see a doctor after experiencing side effects from the medicine and the doctor changed the drug regimen for them enabling them to continue taking the drugs without side effects.

> *In the first week, I had some side effects after taking the medicine such as nausea and vomiting but I tried to treat myself by drinking lime juice and resting, and I felt better. Now I am normal and have no side effects (D: 16/02/05).*

> *The first time I took the drug, I experienced confusion, with blurred vision and lassitude. My thinking was dull and I looked like a deranged person. Once I woke at 2.00 a.m. and began cooking because I did not know what to do with myself. When I went to see the doctor at the hospital and told him my symptoms, he changed the drug to GPO-vir regimen. I take one tab at 7.00 a.m. and another at 7.00 p.m. After the doctor changed the medication, I have no reaction and continue taking it…*
> *(E: 27/02/05).*

People living with AIDS who take an antiretroviral drug must continue to take it on time and regularly in order to maintain a constant drug level in the blood, to ensure such effectiveness as CD4+, a higher immunity level, weight increase, the absence of opportunistic diseases and reduction of HIV. In contrast, a lack of discipline in taking the antiretroviral drugs may result in the virus becoming resistant to the drugs. Most of the side effects due to taking antiretroviral drugs are not severe to the point of causing death. In the first period of taking the drug, the patients may suffer such symptoms as headache, nausea and diarrhoea. Severe side effects that may result in death unless treatment is given are inflammation of the liver, numbness around the hands and feet, and kidney stones, which may occur at any period during the medication. Other long-lasting side effects that occur after a protracted period of medication (3-4 years) are a breakdown of fatty tissue and elevated blood sugar (Bartlett & Gallant, 2000; Thongsa-aad, 2004).

6.10 CONCLUSION

The category “**keeping well**” represents the third stage of the basic social psychological process: ***“from experiencing social disgust to passing as normal”.*** The category includes the concepts, **religious practices**, **keeping a cheerful mind, self-treatment, taking care of the body, keeping the environment clean to prevent getting germs, healthy behaviours, getting healthcare services** and **attention to, and concern about, medication.** These substantive concepts are in turn composed of in vivo codes, which detail the ways in which the participants adjusted their daily activities in order to promote their physical and emotional health and maintain their lives.

All participants had to actively manage their conditions to sustain their health and recover from their illness. **Keeping well** resulted in many participants feeling and looking comparatively healthy, being able to work around the home or in positions that contributed to family income and being able to partake in activities that enabled them to define themselves as living a “normal” life. Living with HIV/AIDS in this manner enables the participants to feel empowered. The category of **feeling empowered** is addressed in the next chapter.

CHAPTER SEVEN

FEELING EMPOWERED

7.1 INTRODUCTION

Feeling empowered for living refers to the positive energy that drives one to maintain and move forward with one’s life, which arises from having the will to live and the ability to cope with life’s problems. Although they were confronting significant health and social problems, the participants made the decision to live and not quit. They took strength from people in society who were accepting of their illness and drew motivation for living and hope for the future from their families. **“Feeling empowered”** could be seen through the concepts **being encouraged, acknowledging the disease, social acceptance, tamjai (make mind up), feeling proud of self, feeling good about life, feeling lucky and having hope** (Figure 7-1). People living with HIV/AIDS became self-empowered to face difficulties in their current and future life. They used various strategies and social interaction processes to achieve self-empowerment.

7.2 FEELING EMPOWERED: Being encouraged

Being encouraged (khum lang jai) refers to the strength of mind that drives one to live. The participants said that encouragement was important for them to survive, and that if they did not have encouragement they could not survive. Participants also said that encouragement came from within themselves and from other sources. The concept of **“being encouraged”** included the codes ***self*** and ***family, neighbours, friends and PLWHA network groups***, and ***health professionals***: all people who knew them and encouraged them to have a positive attitude toward life.

7.2.1 Self encouraged

Some of the positive energy that drove participants to maintain and move forward with their lives arose from having the will to live for their children’s sake; participants thus encouraged themselves to think positively, to calm down and feel courage, to look after themselves and to do what was necessary in their situation to survive.

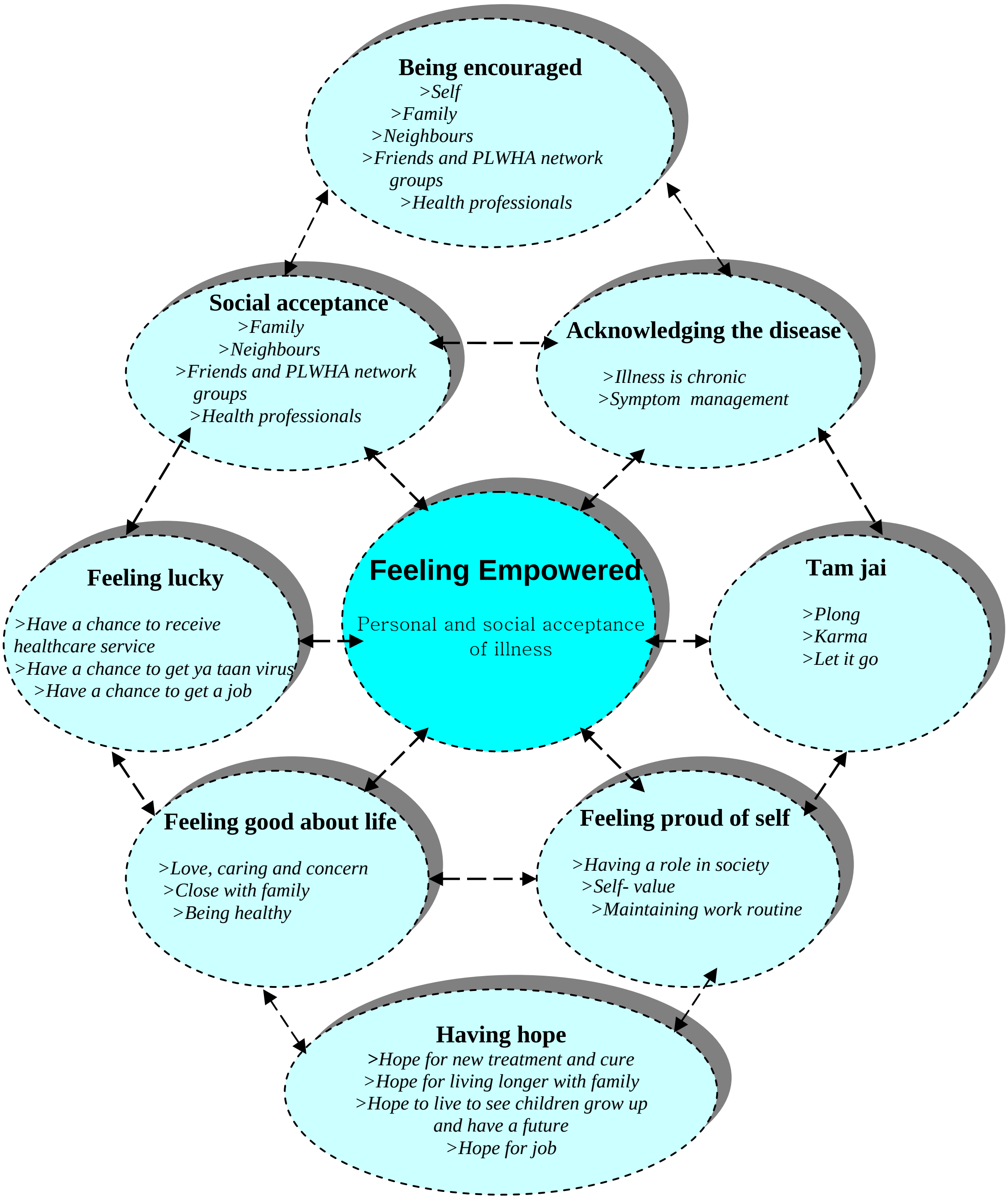


Figure 7-1: Core Category-Feeling Empowered, Concepts and Codes.

> *When my husband died from AIDS I had to encourage myself to face the situation I was in. I had to help my mother rather than my husband in the rice fields. I had to stand on my own two feet and do everything to earn money for the family to live. I never feel hopeless if I am alive, and I never expect anyone else to help me. To stay alive I try to take good care of myself and do not think about my disease. I need to stay living with my mother and daughter, my daughter is only 13 years old… (I: 05/05/05).*

> *I am energised to fight the disease because I am now healthy, with no symptoms. I do not dwell on it in my mind too much. I need to stay alive to look after my children. My children are my life and if I die I have no idea who will look after them. So I have to rouse myself and do the best things to keep alive… (U: 17/05/05).*

7.2.2 Family encouraged

The participants said family members–including husbands, children, mothers, brothers, sisters and other relatives–were important sources of encouragement. Their families encouraged them to have courage to face the disease and pushed them to take care of themselves to maintain their own health and for the sake of their families.

> *I was depressed because of my disease. I wanted to die, but my wife and daughter rallied me to stand against the disease and they encouraged me to take medicine to stay alive. They have done everything to maintain life. They told me not to be afraid to die, but that I would live with them because they would look after me forever… (H: 18/03/05).*

> *My family (dad, mum, sister, brother, brother-in-law and cousins) helped me and my husband until he died. After my husband died, they let me and our children live with them, gave me power and encouraged me to fight the disease…They did not*

> *leave me alone, they support me in everything I want…they encouraged me to stay alive with them, although AIDS was not cured… I don't think too much. I am healthy and can survive for a long time like other AIDS patients who have lived for 10 years and still look healthy… (Q: 20/05/05).*

7.2.3 Neighbours encouraged

The participants said neighbours were another source of encouragement because some neighbours understood them and were willing to listen, to comfort and to give advice about their problems, in addition to their practical help described in Chapter Five (section 5.2.3). Neighbours also encouraged them to face the situation to sustain their life.

> *My neighbours gave encouragement to me to stand against the disease because I felt despairing over it. They supported me in such a way that their words may have cured me. They came to talk and advise me. I did not feel lonely because they were friendly and showed concern for me… (E: 27/02/05).*

> *Some neighbours came to visit me and my family at home even though we are a poor family… they said to look after myself and do not think too much about it. Then my condition would be better. I had the willpower to do it because they were not disgusted with me…After that I felt better because the neighbours understood me and I stopped doing the bad things I used to do before, and I began to take good care of myself and to live a settled and normal life with my wife… (Y: 1/07/05).*

7.2.4 Friends and PLWHA network group encouraged

The participants said that their friends came to ask them about their problem, and other people living with HIV/AIDS also visited them at home to talk, and shared their feelings and experience about the disease and gave them comfort and made them feel better about their life, as earlier discussed (section 5.3.3). In addition, friends and PLWHA reinforced the need to stay alive because of their family.

> *When I first knew that I was infected with the HIV/AIDS virus, I felt discouraged, depressed and did not know what I should do. My friends, who were in the same situation, came to visit me at home and advised me to fight the disease and urged me to join them at the Cool Shade House- Baan rom yen (HIV/AIDS day care clinic). We had to participate in many activities there. I have a lot of friends who understand me; I am now not discouraged and indeed am happily living with the family (DD: 25/04/05).*

> *I knew AIDS was a severe disease and those who got AIDS would die soon. I felt hopeless and did not take care of myself until a friend came to visit me at home and they said to me, do not fear death, it was not always death. Many with AIDS could live longer. They encouraged me to take care of myself and continue taking the medications…Then I would get better and be strong…They always came visiting me at home… They wanted me to stay alive with the family…because they pitied my mother (W: 3/06/05).*

7.2.5 Health professionals encouraged

The participants said that health professionals gave them encouragement to face the disease and other problems in addition to giving information and advice (section 5.3.4). They particularly valued the home visits by nurses who did not look down on them, but showed concern about their life and their families, listened to their problems and gave them advice about their disease.

> *I think when the nurses came visiting my family, I dared to talk and consult them about my condition. I felt better to talk with them. They also asked about, and listened to, my problems. They*

> *gave me the advice about disease and warned me to go to follow-up every time. I felt happy with them because they were good conversations with concern about me and my family life… (K: 06/03/05).*

Receiving encouragement from others helped people with HIV/AIDS to feel better about themselves, to find meaning in their lives and gain a sense of control and restore their self-esteem. Encouragement increases the ability of people with HIV/AIDS to confront their situation in their everyday life (Ciambrone, 2002; Junda, 2004; Phengjard et al., 2002).

7.3 FEELING EMPOWERED: Acknowledging the disease

The concept of **"acknowledging the disease"** as a part of their lives took place after the participants learnt that the disease could not be cured, but was not quickly fatal (easy to die from) as they had earlier feared and despaired. The participants accepted that the illness had happened to them and that it was a chronic illness, like diabetes, hypertension, or cancer. The concept of **"acknowledging the disease"** included the codes ***illness is chronic*** and ***symptom management***.

7.3.1 Illness is chronic

The participants acknowledged that AIDS was a chronic illness when they learned from their experiences with AIDS that they were not able to get rid of their illness. However, medicines were available to cure the opportunistic infections that related to the AIDS disease, such as tuberculosis, meningitis and oral fungus, so that the participants could manage their illness if they had knowledge and took good care of themselves. Moreover, participants compared AIDS to other serious illnesses, such as diabetes mellitus, heart disease, hypertension and cancer; they believed that AIDS was one of the deadliest diseases and had long-term complications, which required life-long treatment.

> *I have learned that AIDS is one of the most deadly diseases, and if I take good care of myself, I can live longer because I saw*

> *some AIDS person live longer for 16 years and he looked healthy like normal people. Now I think that it is as chronic a disease as "bouw waan" (Diabetes mellitus) and "kuam done lo hid sung" (Hypertension), so there is no cure for the AIDS disease… (A: 13 /02 /05).*
>
> *Now I view this disease as a chronic disease, although HIV/AIDS is not curable, but "roke tid chue chuy oo gard" (opportunistic diseases), which happen with HIV/AIDS patients, are curable; HIV/AIDS patients can live longer like "bouw waan" (diabetes mellitus) patients. I learn about my disease from my experience and my friends who are in the same situation; I know how to take care of myself to prevent illness to maintain my life. I am now still able to work as well as engage in daily activities… (P: 06/03/05).*

The transition of HIV/AIDS from an acute terminal illness to a chronic illness (Vyavaharkar et al., 2007) enabled participants to think more positively about their illness because they recognised that the symptoms were treatable and, although HIV/AIDS was a serious disease, people with HIV/AIDS were not always sick.

7.3.2 Symptom management

Physical symptoms were more dominant and easily noticeable in people living with HIV/AIDS. Most of the participants looked physically healthy. However, many of them had had a serious illness associated with HIV/AIDS-related symptoms, so they had experienced admission to the hospital and learnt to take care of themselves when they had symptoms at home. They sometimes took care of their symptoms by using both modern medicines and herbal medicines as previously discussed (section 6.4). Most participants knew how to treat themselves because they had knowledge from their own experience, friends, and healthcare providers. Participants reported managing symptoms of fever and headache, diarrhoea, leg pain, cough, skin problems and oral fungus. The following examples of self-care strategies were effective in managing a range of symptoms. The participants based their actions on previous advice from nurses and acted in the knowledge that if the symptoms did not improve they were able to go to see the doctor at the hospital.

> *I had three times "tong sia" (diarrhoea), "hark" (vomiting) one time also "puad tong" (abdominal pain). I did not take medicine but I stopped eating food, except I mixed salt, and sugar in water and drank it a lot until my symptoms disappeared. I knew how to take care of myself because "mor" (nurse) told me how when I went to the hospital… (A: 13/03/05).*

> *When I had a cough, I did everything a nurse told me. I drank a lot of warm water. I drank lemon juice and anti-cough syrup. I stopped having oily food, it gave me an itchy throat and more cough. If I did not feel better I would go to see a doctor… (G: 04/03/05).*

A woman who had leg pain from her long days serving noodles in the noodle shop treated her symptoms with a non-steroidal anti-inflammatory drug bought from the drug store.

> *I had leg pain from working, I walked long days I used "ya nuad gaee puad" (diclofenac gel) to rub my legs and used "pah pan phae" (bandage) to support them when I slept. I always lifted up the legs, after that I felt better. If I got worse I would go to see a doctor… (L: 26/02/05).*

One participant had an allergic reaction from having seafood and treated himself with herbs and an antihistamine drug bought from the drug store before bed 1 tab per oral.

> *I got rash and itchy all over my body, I stopped having seafood, I took a bath with herb water and used "kha min luang" (herb) to paint on body and took anti-itching medicine for 10 days then the symptoms disappeared … (Y: 17/04/05).*

Some participants had complications from HIV/AIDS and they managed symptoms themselves, as one participant described:

> *I was concerned about my oral cavity because I often got "chue ra nai parg, ron nai" (oral fungus, glossitis). I had special mouth wash with" nam ya buan park" (antiseptic solution) 2 times a day in the morning and before going to bed, I always mix salt in water and gargle the mouth after having a meal, and I stopped having spicy food. Now I have no oral fungus and I continue to gargle my mouth with salt water every day to prevent getting fungus… (P: 06/03/05).*

Most people living with HIV/AIDS perceived that in the future they would confront numerous symptoms associated with the disease or the side effects from medication. Symptom management for people living with HIV/AIDS includes prevention, promotion, assessment and treatment of symptoms (Bunch, 2004). Enhancing the self-care knowledge of people with HIV/AIDS has been reported to improve their abilities to deal with their symptoms (Chiou et al., 2004).

7.4 FEELING EMPOWERED: Social acceptance

Social acceptance refers to the relationships between the participants and their families, their neighbours, their friends and people living with HIV/AIDS network groups and health professionals. Participants needed to find social acceptance and understanding from at least one source in order to move forward with their lives. Thus, receiving social acceptance, understanding and care from others, helped the participants to feel comfortable and happy in life. The concept of **"social acceptance"** included the codes ***family, neighbours, friends and PLWHA network groups*** and ***health professionals.***

7.4.1 Family

The majority of participants said that their families now accept and understand them, although as–outlined in Chapter Five (sections 5.2.4 and 5.3.1)–participants had to make choices about disclosing their illness to family in order to receive their support. They received security, comfort, and love from their families who made them feel safe and happy, and empowered to take care of themselves in order to survive.

> *I feel happy with my family because they understand me and my husband. They love us and let us live together with them. We have always talked about everything and have a meal together every day in the evening. I feel safe with life, I am not afraid of dying although I have lived with HIV/AIDS for 6 years, because I have warmth from my family, I can do everything. I am careful about myself I know this disease is uncertain, it depends on the symptoms, I now have no symptoms… (E: 17/02/05).*

7.4.2 Neighbours

Good relationships with their neighbours were important to participants. Neighbours demonstrated social acceptance of participants by coming to talk with them either at home or during activities in the community. Social acceptance by neighbours enabled participants to participate in community activities without fear of rejection and influenced their self-esteem. Social acceptance was a prerequisite for social support (section 5.3.2), the latter being expressed in ways that are more practical. When neighbours showed social acceptance they treated the participants as normal people; for example in the second quotation below, neighbours asked about the participant's work, not about his disease.

> *Today my neighbours and other people came to talk to me while the monk had breakfast. After the monk had had breakfast and finished praying, we enjoyed eating together at the temple. I felt better and happy because they accepted me, they did not show disgust with me…the next time I will go to the temple again (A: 13/02/05).*

> *When I stay at my wife's parents' house, my neighbours come to talk with me, and ask me about my work; they don't talk about*

> *my disease. I am not pained by neighbours, nobody hates me, and I feel good and dare to talk to them. They don’t hurt me, I feel happy and live actively, I can manage myself in my daily life (F: 17/02/05).*

7.4.3 Friends and PLWHA network groups

Participants said that their friends and PLWHA network groups had positive feelings toward them, and showed mutual understanding and acceptance. Participants reported receiving close attention from their friends and PLWHA networks groups, so that they never felt alone.

> *I have lots of friends in the same situation who come to see me at home and we understand that together we can share our experiences about the disease, the feelings, behaviours and everything that happens to us. This is useful for me. And I know how to manage myself to keep myself alive, I never feel alone (C: 16/02/05).*

> *When I get sick I feel hopeless and I do nothing. The PLWHA network groups come to visit and be near me at home. They take care of me and remind me to take medicine to prevent serious illness and they tell me about their experiences from AIDS, that they nearly died, but they don’t want to die-and therefore take care of themselves until they look good like normal people. They make me hopeful to fight for my life… (I: 06/03/05).*

7.4.4 Health professionals

The participants said they received power from the health professionals who showed that they accepted them by their style of communication, friendliness and accessibility and the absence of social disgust. Health professionals understood their problems and their feelings, and gave them advice to help them to stay alive.

> *When I went to hospital, nurses ask me and talk to me about my health problems and my daily activities; they also told me how I should take care of myself to survive. They accept me and told me if I have a problem, I can come to talk to them at the hospital or phone them at home. I am happy when I go to hospital, because they are friendly, have good communication, and do not look down or show disgust to me… (G: 18/02/05).*

Social acceptance of people living with HIV/AIDS is a necessity that influences the participants' actions in working and living in the community with complete disclosure (Namjantra, Hanucharurnkul, Panpakdee, Kompayak, & Sitthimongkol, 2003).

7.5 FEELING EMPOWERED: Tamjai

Tamjai (make one's mind up) is a method of dealing with one's own thoughts and feelings when facing uncomfortable circumstances so that people living with HIV/AIDS could accept the situation that was happening, which led to a temporary peace of mind. When the participants had problems, they faced up to them by accepting that they had problems and they looked for the best way to solve them. The concept of **"Tamjai"** included the codes ***plong***, ***karma*** and ***let it go.*** *Tamjai* (make one's mind up) is very important for Thai people living with HIV/AIDS.

7.5.1 Plong (accepting the situation)

The participants accept the situation, and can manage their lives and lifestyle so that they can face and solve their problems by using reasons to explain the circumstances that have occurred. So the participants used *plong* to get rid of negative feelings or thinking.

> *When I first knew I got HIV infection I felt sad and hopeless but I try to "plong" (accepting the situation). I accept myself and have to be strong. I am lucky because I have no children, I do not worry and do not care…I just care about my life; I must take*

> *good care of myself. Now I live with my father, I help my father do work because he is older… (S: 02/05/05).*

> *I accept myself and can live with HIV. I live normally in a village because I have no symptoms. I can work hard and I am happy with my family, I do not think about my disease because when the time comes, all people must die, including me…I plong already…I try to do the best for my children and my mother…*
> *(T: 17/05/05).*

All participants felt sad and unhappy when HIV/AIDS happened to them. They tried to make up their mind *(tamjai)* and to accept their situation *(plong)*. These strategies enabled them to forget about the disease, not think too much and accept themselves. People with HIV/AIDS can control their thoughts, their feelings and make the best of living with HIV/AIDS (Sangchart, 1997). According to Namjantra et al. (2003), *tamjai* is composed of four modes including trying not to think, thinking positively, accepting and *plong*, which was crucial in gaining control of themselves and their feelings in such an event that brought great harm and loss to them as being HIV/AIDS.

7.5.2 Karma

As briefly addressed in Chapter Six (section 6.2.1), most participants believed that illnesses are the outcome of karma and for some participants "making their mind up" may reflect an acceptance because of their belief in karma. Participants believed in the law of karma in the past life and the next life. If people do good things, more good will come back to them. If they do bad things, something bad will happen to them later. Participants found it useful to think of their disease as their karma, because it eased their minds and they felt better.

> *I felt sad when I knew I got HIV infection… my karma. My old karma (karma khow). I do not know what I did in the previous life. Now I can manage the problems which will occur in my life*

> *with a positive outlook. I have determined in my mind not to think about it… (I: 19/03/05).*

> *When I told my parents and sister that I had AIDS, they were very sad and upset with me. My mother said it was my karma which caused me to have sexual relations before I was married (A: 13 /02 /05).*

According to Sangchart (1997), Thai people believe in *karma* and may perceive that people living with HIV/AIDS have been infected with the virus because of their *karma*, which is the consequence of their own or other family members' actions. Moreover, most Thai people are Buddhists who believe in "*karma*" (the law of cause and effect) (Choowattanapakorn, 1999; Ford & Koetsawang, 1991; Thongprateep, 2000). Buddhism teaches that illness is caused by a "person's *karma* (action)" (Junda, 2004). Thus, the law of "*karma*" helps people to understand their own health situation (Klunklin, 2001, Klunklin & Greenwood, 2005a, 2005b).

7.5.3 Let it go (Ploy mun pai)

Participants described their belief in letting go by explaining that it is an important strategy to enable living without worry, concern, problems and conflicts, which will happen. Nobody can stop it, so they do not want to cling to anything. Letting it go can help them to feel a calm mind, comforted and happy in every condition.

> *I am not without hope, even though my husband's family (father, mother, brother and sister in-law) have rejected us and leave us alone. I fight for my family, I have put it out of my mind, and do not think about it. If I think about it, I become unhappy and tired. I have let it… go (G: 18/02/05).*

> *I have a good point, I do not ponder it too much, I don't think about my disease, I do not have concern about other people gossiping about me or rejecting me, I let it go…. I am just*

> *concerned about my family and working daily to earn a living for us… (I: 19/03/05).*

Participants stopped thinking and talking about HIV/AIDS because it was not good for their health. Most participants viewed their situation in a positive light. They kept positive thinking by letting go of thoughts about AIDS. They felt comfortable and could live with having AIDS. Consistent with the study by Namjantra et al. (2003), participants thought about life and death, followed by realising the reality of the uncertainty of life; that everybody must die some day when the time comes. After that realisation, participants made the decision to let it go; when they could accept their situation they tried to focus on the present rather than the past.

7.6 FEELING EMPOWERED: Feeling proud of self

Feeling proud of self refers to realising that one's life has meaning and this comes from perceiving one's self-esteem and having pride in oneself. The concept **"feeling proud of self"** includes the codes ***having a role in society, self-value, and maintaining work routines.***

7.6.1 Having a role in society

Having a role in society refers to the ability to do good things for other people or families and communities. Participants said that their role in society came from their knowledge, and their abilities which had led to accomplishment in work, so their knowledge and abilities helped the participants to feel proud of themselves.

> *I often participate in social activities, such as a temple fair or a New Year celebration with my friends; I play a drum, sing and dance….I like it. It lifts my spirits, mind, and also I get some money, 200 baht per time, to help with living. Next month I am booked to play the drum in a procession for robe-giving ceremony "tod pah pa" (Buddhist activity) at a temple in Loei Province. I am very proud of myself because I have a role in society. I sometimes I go with health personnel as a music-*

> *player. I have a role in society. I feel I have value because they accept me and I can bring enjoyment to their lives. I feel happy with my life and proud of myself… (F: 17/02/05).*
>
> *I have a role in society as a person living with AIDS volunteer. I visited AIDS patients at home, giving them information about AIDS and sharing my experiences with them. I was very proud of myself because I could help other AIDS patients both face their disease, and reduce stress by talking with them and encouraging them to survive as I have done. I go on home visits every Tuesday (K: 06/03/05).* ***Field note:*** *when he talks about other AIDS patients he looks proud and very confident (keeps smiling)…. He is sure that he contributes significantly to people living with AIDS… (K: 06/03/05).*

Finding new roles in society, following the loss of work and loss of self-worth that resulted from being diagnosed with HIV/AIDS (section 4.4.2), led to a renewed sense of self-value.

7.6.2 Self- value

Participants said that self-value came from making good use of their knowledge and competence to help themselves and their society. They realised that their families, friends and neighbours depend on them, and receive love and care from their families and friends, which made the participants feel that they had self-value.

> *Before I had AIDS, I could work outside and got money 4,500 baht per month, for a living for the family. But now I have to stay home or stroll out to the fields where there is not a lot to do. My daily tasks are light. But I am still very proud and feel valuable that I can work. Although I can not earn money for the family, I can help them do some work. My father said to me, “Don’t worry about work and money because your brother-in-law and I*

> *can earn the money for our families. You need to take care of yourself"… (A: 13 /02* /05).
>
> *I enjoy working, I own my own hair-cutting business, I earn small money between 200 and 400 baht per day working every day from 9.00 a.m. -5.00 p.m. Although I have the HIV infection yet I can still work and earn money. I am very proud that I do not depend on other people, except for my wife who cooks and washes the clothes for me. I stand on my own two feet; I have a sense of self-worth… (F: 17/03/05).*
>
> *I am very proud of myself. Although I have AIDS I join with a group of women in the village producing sticky rice containers, flowers and vases for sale in the village. I make about 1,000 to 1,500 baht per month to live on. I feel happy and feel self-valuable (mee khun kah) because I can work and earn money without depending on others… (T: 03/05/05).*

7.6.3 Maintaining work routines

Participants tried to maintain a work routine to promote themselves and their families. They felt proud of themselves because they can work and earn money. In contrast, some participants kept up a work routine at home although they could not go out to get a job because of the disease.

> *I do not worry about work, I can help my father carry bamboo woods to make kraae mai phi (the bamboo tables) at home. I think I work hard sometimes, but nothing is happening to me. I am still normal and continue working. I was proud of myself because I can work…better than nothing to do…(C: 16/02/05).*
>
> *I go to work in a noodle shop in the city every day from 7.00 a.m. to 5.00 p.m. I do everything from buying the ingredients, making the noodles and serving them, serving cold drinks, acting*

> *as cashier, washing up and closing the shop. I am so busy all day that I forget about my disease and am happy in my work, bringing home 150-180 baht each day. After work, I buy food and travel 12 km home where I rest up with my mother, son and husband. I feel I live a normal life. Even though I have AIDS, I can work. I am proud of myself because I can earn money for the family, I feel that I am the head of the family… (L: 26/05/05).*
>
> *I went to work at sa tha nee a na mai (health centre) in a village every day from 8.00 a.m. to 4.00 p.m. I helped a healthcare provider to do supplies, clean the health centre and the medical equipment, I felt proud of myself, although I have AIDS, but I had a chance to work… (U: 10/06/05).*

Most participants felt proud of themselves because they could stand on their own two feet and continue working to support themselves and their families. Some participants dedicated themselves to working for others who had HIV/AIDS by home visiting and giving advice about their experiences of living with HIV/AIDS. These findings confirm those of Namjantra et al. (2003), that people living with HIV/AIDS felt self-worth and were proud of themselves because they were dedicated and continued working for other infected persons, their community and their society. As identified in Chapter Six (section 6.3.1), participants who did not return to work engaged in recreation activities that provided interaction with others in their community and supported their sense of acceptance and self-worth.

7.7 FEELING EMPOWERED: Feeling good about life

The majority of participants in this study were satisfied with their life at present. Perceived family support (as addressed in section 7.4.1), and the ability to manage the impact of HIV/AIDS on their health, played an important part in their feeling good about life. The concept of **“feeling good about life”** included the codes ***love, caring and concern, close with family and being healthy.***

7.7.1 Love, caring and concern

Love, caring and concern refer to the relationships within the family which are bound in love, concern, and caring. The participants described bonding with their family members. These persons were their support and were very protective of the participant. They were willing to do anything for each other. The family bond, as a result, provided security, comfort and happiness to the participants. Some participants received love, caring and concern from their families, for example:

> *Previously, my parents and relatives did not want me to go out. They did not want others to know that I had AIDS. They love me and are concerned about me because they thought this disease was socially unacceptable, and that the gossiping would make me unhappy. They did not want me to be hurt. When I was sick my sister took me to the hospital, she was concerned about me. And I know my parents' and sisters' concern about me comes from their love for me. When I am sick, they help me by washing my clothes, cooking for me and generally looking after me until I get better. They never leave me… (C: 16/02/05).*

> *My wife and daughter forbade my working hard because of their love and concern for me. They wanted me to stay alive and be with them for a long time. They knew this disease brings low immunity and I could become ill… (H: 18/02/05).*

7.7.2 Close with family

Participants said that they need to be close to their families; they do not want to be separated from their families. They need their families to treat them as normal. When participants have a health problem or other problems their families can look after them and they can talk and consult about everything with their families. Moreover the participants can join the families' activities as normal people can.

> *When my mother knew I had AIDS, she did not blame me and let me live together with them. Everybody in my family is not*

> *disgusted with me. We eat together and sometimes I cook for them. We are a close family and they all have a positive attitude toward me. In the evening, during dinner my family and I like to watch television news and drama until 9.30 p.m. we enjoy discussing the actors and actresses in the drama, especially the love stories…(C: 16/02/05).*

> *I feel good about life. When I have a problem, I can talk with mum, dad and other family members, I can consult with them all the time. We live together, are a big family and we have close relationships. I can talk about anything with them and they will help me. They have already told me not to worry about anything, that they will look after me and my children, that I am a part of their family. They will not leave me and my children to stand alone… (Q: 20/05/05).*

The desire to be part of a family and to be treated as normal was also evidenced by participants' choices to remarry and have a child in order to have a normal life (sections 5.4.1-5.4.3).

7.7.3 Being healthy

Participants said they are healthy; they have no signs or symptoms– a consequence of their attention to taking care of their body (section 6.5). They take care of themselves and they can do everything like normal people can. Being healthy makes them feel good about their life, forget the disease and they can also live longer.

> *Now I am not sick I have no symptoms, I have a normal life. I can do everything that other people can…. I look healthy and very strong… (K: 06/03/05).*

> *I am concerned that I am a good person. Normally I never drink alcohol, never smoke cigarettes and never have raw food, I am healthy like normal people… (Q: 20/05/05).*

Feeling good about life is particularly important for people living with HIV/AIDS. Most participants mentioned feeling satisfied and happy with their family members and other providers who expressed love, care and concern for them, because they can–and do–manage better with the stress of their disease and stay healthy and can live longer in society (Edwards, 2006: Rutledge & Abell, 2005). In Thai culture, most people living with HIV/AIDS are cared for by family members and others and are supported because of love, bonding and obligation (Chitwarakorn, 2003: Phengjard et al., 2002). Most people living with HIV/AIDS eventually end up living with parents at the terminal stage of their sickness and parents usually take care of, and support, them (Knodel & Saengtienchai, 2005).

7.8 FEELING EMPOWERED: Feeling lucky

Feeling lucky refers to participants' responses to receiving care and support from the healthcare system, or other places, to give them a chance to stay alive and reduce their suffering from physical, emotional and economic problems–although they are poor people. The concept of **"feeling lucky"** includes the codes ***have a chance to receive the healthcare services, have a chance to get ya taan virus (antiretroviral medicines), and have a chance to get a job***. They had an opportunity to obtain those things that make them feel good and can maintain their health to live in society.

7.8.1 Have a chance to receive the healthcare service

Participants said that they can use their rights to access the healthcare system because of the health policy scheme that covers the treatment and care for Thai people by using a 30 baht healthcare gold card per visit, which was the scheme that the Thai government offered for all Thai people who did not have physical access to any health or welfare services. The participants said they felt lucky because this welfare now provided healthcare expenses for every disease, including HIV/AIDS disease. Participants could utilise the healthcare service that covered the provision of prevention of illness from opportunistic infection and health promotion for HIV/AIDS. For example, their rights to most health welfare did cover blood tests and they could receive prophylactic medicines to prevent opportunistic infections. They thought the healthcare policy schemes gave a chance for them to maintain their lives, although they were poor people.

> *Now people with HIV/AIDS can access healthcare services because the government gives us the opportunity. Even me! I am lucky to stay alive… (D: 26/02/05).*

7.8.2 Have a chance to get ya taan virus (antiretroviral drugs)

Participants said that they were very lucky to be able to obtain ya taan virus (antiretroviral drugs) to control the spread of the virus and it made them feel better, because of the public healthcare scheme, or the 30 baht gold card which covered the treatment with anti retroviral medications. Participants knew that ya taan virus (antiretroviral drugs) are very expensive, they could not buy them, because they were poor. Participants said that if they didn't get ya taan virus they might die, or get a serious illness. They could stay alive although they were poor.

> *Present government policy is that treatment with ya taan virus (antiretroviral medicine) can be provided for poor AIDS patients like myself using the 30 baht health care card, I am now lucky even though I am a poor person, because I can access health care services and survive because of the medicine… (A: 13 /02 /05).*

Participants were at risk of HIV infection by sexual transmission between husband and wife. Two female participants got pregnant and attended the antenatal care clinic. They had a routine blood test for VDRL and HIV infection. They then knew, by the results of blood tests, that they had HIV infection transmitted from their husbands who had passed away from TB. During pregnancy they received antiretroviral therapy in order to prevent HIV transmission from the mother to the child, until they delivered. Moreover, female participants received powdered milk to feed their children for two years. They feel that they are lucky to receive treatment and care free from the hospital. If they did not receive treatment and care free from the hospital, they thought they and their children had to die for sure because they were poor and had no money to pay for the treatment.

> *During pregnancy I could get antiretroviral medicine from late pregnancy until birth. I fed the child with powdered milk for 2 years. I obtained the powdered milk from the hospital free. Now my daughter is normal... (D: 26/02/05).*

> *I was not afraid of dying because I was lucky. Although I was poor I could get the antiretroviral drug from the hospital and stay alive. In the past, my friends all died because they had no money for treatment, which was expensive and the government had no health policy scheme for AIDS people… (D: 17/03/05).*

As discussed in Chapter One, the availability of antiretroviral medication under the 30 baht healthcare policy scheme in Thailand since 2005 has transformed the treatment options and hope for the future for people with HIV/AIDS. Thus people living with HIV/AIDS are living longer due to recent advances in antiretroviral treatments (Stein & Rotheram-Borus, 2004).

7.8.3 Have a chance to get a job

Some participants secured a job in the hospital, or were supported by Non-Government Organisations and friends to help them have income to maintain their life. They were not without hope because they had a chance to get a job from healthcare providers to work in the hospital day by day and earned money, about 120 baht per day. They worked during the day time from 8.00 a.m. - 4.00 p.m.

> *When I go to the hospital, doctors and nurses help me, and educate me regarding my disease. In particular, they give me power and encourage me to stay alive and to face the disease. They also gave me a job as cleaner in the operation room, I earn 2,400 baht per month… (K: 06/03/05).*

One participant got support from a Non-Government Organisation (NGO) by training for a job and obtaining a loan, about 12,000 baht, to own a business to maintain his life.

> *I am lucky in having an opportunity to do a vocational training course with an NGO. I own my own hair-cutting business now, and earn a modest 200-400 baht per day. I work every day of the week from 9.00 a.m. to 5 p.m. Although I have the HIV infection, I can work and earn money. The NGO granted me 12,000 baht to fund my business set-up costs, and I have been operating 3 years now, in another village 30 kilometres from my home… (F: 17/02/05).*

One participant obtained support from his friend's cousin. He felt lucky to stay free in his friend's cousins house and be given a job by his friend.

> *When my wife got AIDS, I got HIV infection. My wife lacked a job because of illness and I could not work because I was caring for her. I did not have enough money to live on. I sold everything to stay alive. I looked for a job. In the end, I was lucky because a friend's cousin employed me to look after his house and invited me to sell puddings if I want to. I then began a new life selling puddings until now. Although it is not a permanent job, it provides a living of 200-300 baht per day. I cannot stop selling. If I did, I would have no money. It is a tough time. But I must be patient for the sake of my family (mother, wife and daughter), especially my daughter. It is essential for me that she gets a higher education and job before I die. I have to survive and earn money day by day for my daughter. With a bit of luck, I might win a lottery… (R: 24/02/05).*

In Thailand, people living with HIV/AIDS have a chance to work with some hospitals in the follow up, home visit, information distribution and counselling with other patients and those who are affected by AIDS (Thongsa-aad, 2004).

7.9 FEELING EMPOWERED: Having hope

All participants in this study lived with hope for positive changes and good things to happen in the future. Moreover, participants perceived that hope was essential to their life because having hope helps them to manage their disease and they can go on with life and living with HIV/AIDS. Participants described their hope for a better future for themselves and their families. The concept of **"having hope"** included the codes ***hope for new treatment and cure, hope for living longer with family, hope to live to see children grow up and have a future, and hope for job.***

7.9.1 Hope for new treatment and cure

All participants with HIV/AIDS hoped that in the future this disease will be curable. They reasoned that now there are medicines to treat other diseases related to AIDS, so why in the future should there not be medicine to cure AIDS?. Participants think that the doctors are clever and with new technology they may detect new drugs to treat HIV/AIDS disease in the future.

> *At first, when I knew I had AIDS, I must die for sure because AIDS was not curable. At the present, I receive treatment. I take three drugs, GPO-vir, Bactrim and Fuconazole to treat my symptoms. I make sure I can survive because my health has improved after I continued taking drugs and I think I may not die and in the future I will get a new drug that can cure (Y: 1/07/05).*

> *I have been infected since 1992 and developed to AIDS in 1997. I got chronic diarrhoea and headache. I was admitted to the hospital 3 times. My mother sought medical treatment information from others and bought "ya samoon prai" (herbal medicines) for me until money ran out. By 1999, I had enrolled with some herbal medicines project at the hospital and took mala khi nok (name of herb) about 6 months to improve my immunity… and my health was improved… Now I am taking GPO vir, my CD+4 has increased to about 345 cells…I think in*

> *the future we will have new medicine to cure AIDS… (W: 11/06/05).*

7.9.2 Hope for living longer with family

The motivation for living with HIV/AIDS and taking good care of themselves was to live longer with their families. Participants hoped and thought that at least, they may be alive for 15-20 years because AIDS can be controlled by taking care of themselves.

> *I must make myself get well. I don't think too much; if I think too much the CD4+ would be down. I think I can live longer, as long as possible with my family… (A: 13/02/05).*

> *I quit drinking alcohol but I eat good food, take medicine on time, observe myself and go to see a doctor every appointment because I want to be cured, and live with my family for my old age… (H: 18/02/05).*

7.9.3 Hope to live to see children grow up and have a future

Participants hoped to live long enough to see their children grow up and be successful in their lives. They wanted their children to complete their education and get a job before they died. Because they think that the prognosis of this disease is uncertain, fulfillment of that hope depends on the care they take of themselves. Some participants explained that:

> *If my immunity is good, I am strong, I will live longer. If my immunity is low, I may be sick, it is uncertain; I have to take better care of myself to nurture my children until they grow up and meet success in the future… (Q: 06/ 05/ 05).*

> *I have only one son. After my husband passed away I need to take care of him the best as I can. I will prepare everything for his future if he wants. I want him to be a good person, complete*

> *his education and get a job including success in his life before I die. If I die before, he can receive support from his aunt. But I think I can live with him for long time because I am healthy… (X: 14/06/05).*

7.9.4 Hope for a job

After being diagnosed with HIV/AIDS, most of the participants lacked a job due to their illness. When they recovered from their illness, they needed a job that did not affect their health. They did not want to be a burden on others. Many participants confronted problems in finding a job because having HIV/AIDS evoked social disgust and fear from potential employers or customers. These conditions made them suffer, feel depressed and discouraged.

> *If I recovered from my illness I thought I could get back to work in the same place. It was good money for me; I earned money about 5,000 baht per month. I was a delivery man to send the goods and collected money. I hoped my boss would understand me. He and my friends knew I had "wan na rok pord" (TB lung) before I came back to my home town… (N: 17/05/05).*

Some participants worked as construction labourers. They stopped work or moved to other places many times although the work was not finished because other workers mocked them when they knew the participants had AIDS. This situation hurt their feelings. They needed others to give them a chance to work in society and to give them sympathy as human beings. One participant moved to work in another province.

> *My friends didn't understand me I had AIDS because my husband infected me. It was not my wrong. I worked day to day for my family living, but I had to stop working and sought a new job. I didn't do other jobs except construction work…I had AIDS they feared contracting AIDS from me…I was shamed… I had to go…because they hurt me… (I: 20/07/05).*

Some participants needed to work at every job that gave them a chance to earn money for their own living expenses and those of their family such as being a cleaner, labourer, driver, doing housework, being a dressmaker or waitress.

> *I thought I could get a job as before. I was a dressmaker in a private company. I earned 4,000-5,000 baht per month. When I had AIDS I stopped work because of fatigue, cough, headache and lost weight. I now feel better and have gained weight 6 kilograms. I will go back to work, but I don't know which work I can get … I can work many jobs a woman can do…but I don't want to work far from my hometown; I hope I can get a job…(M: 17/03/05).*

> *I hope to recover as soon as possible, I hope to be healthy; I hope to get a job. I don't want to depend on others; I need to stand on my own two feet like before. Now I receive money about 1,000 baht a month from my boss; she pities me… (M: 5/04/05).*

Hope is one of the forces that motivated the participants to keep trying to reach their goals. Goals are key to purposive behaviour and effective management of their lives. Building hope has been described as part of psychosocial care of people with HIV/AIDS (Choksawadphinyo, 2005).

7.10 CONCLUSION

"Feeling empowered" enabled participants to move forward and to feel in control of their lives. Empowerment can help people to develop a critical thinking awareness of their situation and enable them to control their environment to achieve their goal and to live a normal life in society. In the context of this study, feeling empowered enabled participants to prioritise their own self-care. They realised their self-responsibility and their rights to protect themselves from deteriorating health and early death from HIV/AIDS. Personal and social acceptance and hope for the future underpinned that feeling of empowerment. In the next chapter the core variable or basic social psychological process **“from experiencing social disgust to passing as normal”** is illustrated.

CHAPTER EIGHT
FROM EXPERIENCING SOCIAL DISGUST TO PASSING AS NORMAL

8.1 INTRODUCTION

The purpose in this chapter is to present a detailed description of the theoretical findings about the experiences of Thai people living with HIV/AIDS that are encapsulated within the basic social psychological process “From experiencing social disgust to passing as normal”. The relationship of the findings of this study to those of other comparable studies is discussed, followed by the implications, recommendations and limitations of this study.

8.2 STUDY OVERVIEW

The broad questions that framed the study were:
1) What are the experiences of Thai people suffering from AIDS, in managing and living with AIDS in the context of their environment in daily life?
2) What are the self-care processes of Thai people suffering from AIDS living in their own homes? The key questions used to elaborate information about their self-care processes were: *tell me about how you manage your disease, and how you take care of yourself in your daily life?*

In order to understand how Thai people living with HIV/AIDS take care of their health and manage their lives in the context of stigma and discrimination, I used grounded theory methods to generate a substantive theory that describes their experiences in their world. As Glaser (1978, p. 93) states “the goal of grounded theory is to generate a theory that accounts for a pattern of behaviour which is relevant and problematic for those involved”. In this research study I have inductively developed a substantive theory which reflects the views of people living with HIV/AIDS and accounts for the patterns of behaviour that occur following diagnosis with HIV/AIDS. The substantive theory includes the codes, concepts, core categories, theoretical propositions and the basic social psychological process as summarised in Table 8.1. Arising out of this is a process-oriented model (Figure 8-1) around the basic social psychological process “from experiencing social disgust to passing as normal”. It provides a framework to understand how Thai people living with HIV/AIDS take care of their health and manage their lives in the context of stigma and discrimination.

The preceding four data chapters (Chapters 4-7) detailed the core categories that contribute to the basic social psychological process. In Chapter Four I presented the first core category “being HIV/AIDS” elaborating on the theoretical proposition that “discovering the meaning of having HIV/AIDS” comprises four concepts: being diagnosed with HIV/AIDS, being stigmatised, suffering, and learning about HIV/AIDS. In Chapter Five I presented the second core category “making choices” developing the theoretical proposition that “to live a ‘normal’ life” involves three concepts: avoiding unhappy situations, getting remarried, and seeking support. Next in Chapter Six, I presented the third core category “keeping well” developing the theoretical proposition that “to maintain emotional and physical health”, includes eight concepts: religious practices, keeping a cheerful mind, self-treatment, taking care of the body, keeping the environment clean to prevent getting germs, healthy behaviours, getting healthcare services, and attention to, and concern about, medication. In Chapter Seven I presented the fourth core category “feeling empowered” elaborating on the theoretical proposition that “personal and social acceptance of illness” includes eight concepts: being encouraged, acknowledging the disease, social acceptance, tamjai, feeling proud of self, feeling good about life, feeling lucky, and having hope.

The basic social psychological process “from experiencing social disgust to passing as normal”, discussed in this chapter, is the core variable that draws together the stages of the process reflected in the core categories and illuminates the strategies used by participants to resolve the ever present risk of stigma and discrimination and to “pass” as normal.

Table 8.1: The codes, concepts, core categories and theoretical propositions leading to the basic social psychological process

Codes	Concepts	Core Categories	Theoretical Proposition	BSPP
>Experiencing symptoms >Incurable >Expect to die soon >Communicable	1)Being diagnosed with HIV/AIDS	1) Being HIV/AIDS	Discovering the meaning of having HIV/AIDS	**FROM EXPERIENCING SOCIAL DISGUST TO PASSING AS NORMAL**
>Getting visible signs >Samson >Social disgust	2)Being stigmatised			
>Fear and shame >Loss of finance	3)Suffering			
>Family >Media >Health professionals	4)Learning about HIV/AIDS			
>Won't be around people, >Stay at home with family >Talk to those who accept and come to talk >Selective disclosure	1)Avoiding unhappy situations	2)Making choices	To live a "normal" life	
>Family >Neighbours >Friends and PLWHA network groups >Health professionals >Government and non-government offices	2)Seeking support			
>Need a friend > Need a complete family >Need a child	3)Getting remarried			
>Making merit >Temple activity >Practising meditation >Reading Dhamma >Praying in front of Buddha image	1)Religious practices	3)Keeping well	To maintain emotional and physical health	
>Enjoying recreation >Living in a good environment	2)Keeping a cheerful mind			
>Buying medicines from grocery store to relieve symptoms >Using herbal medicines	3)Self-treatment			
>Eating healthy food >Avoiding taboo food >Keeping the body fit >Sleeping well >Personal hygiene	4)Taking care of the body			
>Washing clothes >Washing dishes >Drying in the sunshine	5)Keeping the environment clean to prevent getting germs			
>Stopping the addiction >Using condoms >Preventing accidents and injury to self	6)Healthy behaviours			
>Consulting health professionals and visiting clinic >Following guidance	7)Getting healthcare services			
>Concern re the timing of medications >Concern re the dosage of medications >Concern re the side effects of medications	8)Attention to, and concern about, medication			
>Self >Family >Neighbours >Friends and PLWHA network groups >Health professionals	1) Being encouraged	4)Feeling empowered	Personal and social acceptance of illness	
>Illness is chronic >Symptoms management	2)Acknowledging the disease			
>Family >Neighbours >Friends and PLWHA network groups >Health professionals	3)Social acceptance			
>Plong >Karma >Let it go	4)Tamjai			
>Having a role in society >Self valuable >Maintaining work routine	5)Feeling proud of self			
>Love, caring and concern >Close with family >Being healthy	6)Felling good about life			
>Have a chance to receive healthcare service >Have a chance to get ya taan virus >Have a chance to get a job	7)Feeling lucky			
>Hope for new treatment and cure >Hope for living longer with family > Hope to live to see children grow up and future > Hope for job.	8)Having hope			

In order to explicate the basic social psychological process I explore the theoretical components of the model as illustrated in Figure 8.1, drawing on Stevens-Barnum's (1994) theoretical commonplaces as a framework. The components of the theory are illustrated as follows.

8.3 THE COMPONENTS OF THE THEORY

The person, act, other and environment are the functional components of any theory that are referred to as *commonplaces* by Stevens Barnum (1994) and Meleis (1991, 2005), and are utilised in work by Dignam (2001) and Wilson (2004). These commonplaces provide a structure in order to evaluate a theory. Before I explain the model's structural components and the interrelationship of the components, the concepts of person, act, other and environment, which relate to this substantive theory are defined as follows.

8.3.1 The "person" of concern for this theory refers to the participants who live with HIV/AIDS which causes suffering in the physical, psychological, and socioeconomic dimensions of the person.

8.3.2 The "other" in this theory includes the family members, neighbours, friends and PLWHA groups and healthcare professionals who interact with people living with HIV/AIDS. The interaction may have either a direct or an indirect influence on the self-care management of people living with HIV/AIDS.

8.3.3 The "act" is self-managing and living with HIV/AIDS which is the practice of activities that participants initiate and perform on their own behalf in maintaining life, health, and well-being. Self-management is encompassed in the basic social psychological process "from experiencing social disgust to passing as normal" for people living with HIV/AIDS. Self-management includes strategies that are identified within the four core categories to enable participants to avoid social disgust and pass as normal within Thai society.

8.3.4 The "environment" comprises sociocultural beliefs, including societal beliefs and responses toward those with HIV/AIDS, and the healthcare system that influence the self-care process of people living with HIV/AIDS. The sociocultural environment of people in Thai society is a very important influence on the ability of people living with HIV/AIDS to develop appropriate self-management strategies to achieve well-being and to live a 'normal' life in society.

8.4 FROM EXPERIENCING SOCIAL DISGUST TO PASSING AS NORMAL

Figure 8.1 illustrates the process by which people with HIV/AIDS learn to manage the problems in their life following their diagnosis with HIV/AIDS, which, as outlined in Chapter Two, occurs in a sociocultural environment in which HIV/AIDS is a highly stigmatised disease. "From experiencing social disgust to passing as normal" describes the process by which participants learn to manage not only the disease but the ongoing risk of social disgust.

8.4.1 Experiencing social disgust

In Thai, the words "sungkom rungkiat" mean social disgust (Kornsaku, 2003; Songwathana, 1998). Thus AIDS is not just a physical disease but it is also a disease that opens one to social loathing from within one's own family as well as friends, employers, neighbours and the wider community (Namjantra et al., 2003; Phengjard et al., 2002; Rujkorakarn et al., 2000). One participant clearly described that experience of social disgust from his family:

> *I had AIDS, I had many symptoms such as oral fungus, black spots on the body, dark skin and I was thin. I was tired and fatigued, I just sat, slept and watched television all day. I looked much older than my age. I lived at the same house with my mum and my sister's family but my sister and her family gave me a separate place from them…. I had wanna roke pord (Pulmonary*

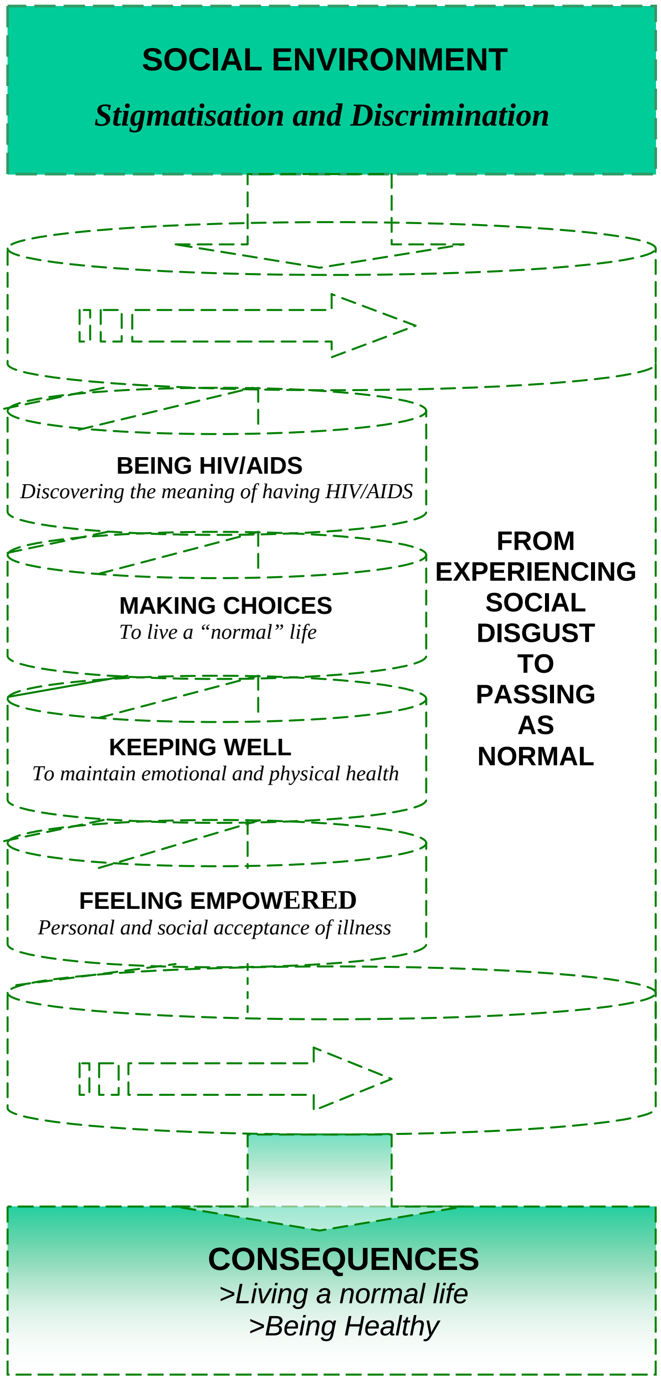


Figure 8-1: The Basic Social Psychological Process: "From Experiencing Social Disgust to Passing as Normal"

> *tuberculosis), it is as contagious as AIDS disease…. My mum and sister's family feared to contract germs from me. Sometimes I regret that they take care of me because of duty, not love. They didn't sit close to me and talked to me briefly, they did not talk too much to me because they were disgusted and hated me. I know when they came to see me they stood far away from me and asked me what I wanted to have then they walked away. They did not interact with me. Just sent in some foods and things and walked away. I tried to tamjai, positive thinking and accept my situation. If I were without them, I would have hardship, no one would look after me. I was afraid to die I knew AIDS can not be cured…and is disgusting… (N: 20/07/05).*

Chapter Four addressed the experiences of being HIV/AIDS, the initial shock, loss of hope, fear of stigmatisation, shame and suffering. The diagnosis of HIV or clinical AIDS leads to both the stigma of being contagious and the expectation of premature death (Dane, 2002). Beliefs about AIDS as a disease of social disgust were held by participants, as well as by those around them. As participants came to accept having HIV/AIDS and learnt of the possibilities for living with HIV/AIDS as a chronic disease rather than a rapidly fatal illness, they needed to develop strategies to deal with their internalised social disgust as well as the potentially discriminatory responses of others. As Goffman (1963, p. 18) commented: "shame becomes a central possibility, arising from the individual's perception of one of his attributes as being a defiling thing to possess". The strategies of acknowledging the disease and *Tamjai*, described in Chapter Seven, effectively addressed internalised shame and suffering, as illustrated by another participant.

> *I accept myself, I don't think about my disease, I let it go. I enjoy doing housework, chatting with family members and friends, watching television, listening to music and shopping with friends. It makes me forget my disease and have a cheerful mind. I can control myself and live a normal life (Q: 06/05/05).*

All participants tried to accept their disease although it was incurable. They learnt not to think about the disease and to “let it go” because if they thought too much about their disease and the shame of it, their health would suffer. In this study, *tamjai* improved the participants’ peace of mind. The findings of this study are consistent with those of Junda (2004) who found that *tamjai* provided a soothing/calming effect on the mind, increased happiness and will-power to cope, for people living with breast cancer. It is important for people living with HIV/AIDS to have hope for themselves and their families which leads them to initiate, develop, and maintain self-care to achieve their goals: having a normal life and well-being.

Therefore, the participants should try to confront their situation and tend to create self-care management strategies while having HIV/AIDS by understanding and learning about their disease. Then they change their feeling into positive ways in order to manage their stigma and discrimination in their social environment around them and move to seek the way to live a “normal” life (illustrated in Figure 8-1 with an arrow) through making choices, keeping well and feeling empowered in order to achieve their goal.

8.4.2 Living a normal life

As outlined in Chapter Five, participants made choices in order to live a “normal” life, learning how to maintain their health and manage their life situation to live as satisfying a life as possible with HIV/AIDS. Consistent with living in a collective society, managing and rebuilding relationships with others was a key element in the choices made by participants. Such relationships provided emotional and financial support, and a reason for living that both motivated and enabled participants to focus on getting well and keeping well.

For most participants living a normal life meant living with extended family and contributing to family life and family income.

> *I am now having a normal life. I am very happy because everything is normal and good for me. I can stay alive and live with my family (husband, my parents, my brother and my*

> *daughters) in my old age and I can do everything other people can. I have no symptoms on my body I look healthy… (E: 27/02/05).*

Participants asserted that they did not need to be treated by family members and the community as HIV/AIDS patients. They wanted to join the family activities and community as normal people. They wanted to help with the housework or other work-related activities such as going to the farm to feed animals, and to enjoy themselves. They could help themselves and wanted to live normal lives as normal people can.

> *Every day I live a normal life. I learn about my disease from my experience. I accept myself; I don't think about my disease, I have a normal life, I help myself, not trouble other people. I can do everything like normal people can…and can help my family earn money for living… (Q: 20/05/05).*

As outlined in Chapter Five, "normal life" for some participants included getting remarried and having a baby to continue the family line (section 5.4). Consistent with the findings of Klunkin and Greenwood (2005a), participants in this study remarried because they want to be a complete family and a "normal" family, the same as other families living in Thai society. Nanjantra (2003), in a grounded theory study of the coping process of people with long-term HIV infection, described that process as fighting to live normally with HIV infection.

The experience of living with HIV/AIDS unfolds in the context of stigma and discrimination. Thus, participants who wanted to have a normal life had to develop strategies either to pass as normal or to avoid contact with those who may pass judgement on them.

8.4.3 Avoiding potential discrimination

Participants kept themselves from potentially harmful situations and discrimination, by "avoiding unhappy situations" with people who looked down on them and made them feel uncomfortable. Thus, participants saved themselves from upset by limiting their activities in their villages. Avoiding being around people in public was a way of controlling fear of rejection. This choice by some participants, to withdraw almost entirely from village life to protect themselves from hurtful rejection, is consistent with the findings of Klunklin (2001) and Ichikawa and Natpratan (2006). However, avoiding social interaction in this manner is not consistent with "living a normal life".

8.4.4 Passing as normal

Passing is defined by Goffman (1963, p. 58) as "the management of undisclosed discrediting information about self". In the context of this study, "Passing" means that people living with HIV/AIDS try to ensure that they have no visible signs so that their disease is not noticeable to others; "the goal of passing is to become part of the 'normal' group" (Joachim & Acorn, 2000). Passing as normal is an attempt to protect their families and themselves (Dane, 2002) and enables them to go on with their lives with a lower level of distress. Participants who successfully pass may become part of the normal group and can live in society, as two participants explained:

> *If I have no symptoms I think I am not an AIDS patient because my body is as clean as normal people (keeps smiling) but if I have symptoms on my body I am afraid that I will die. I fear people would avoid me and would not understand me, it would hurt me…and I would feel shame… (G: 04/03/05).*
>
> *I am not sick; I have no symptoms, although I am an infected person… I feel normal and happy with life as other people… (U: 17/05/05).*

As previously stated, villagers often discussed with each other if they noticed their neighbours had any signs of HIV infection, such as dry or dark skin, a rash or blister on any part of the body, or being thin. Then they would avoid relating to those who had the look of an HIV infection (Rujkorakarn et al., 2000). Participants who had HIV/AIDS applied the same lens as "normal" people to identify others with the disease; as another participant stated:

> *I just look outside at the physical, I do not know who has AIDS … because they had nothing wrong happen to them, and they have no visible signs such as dark skin, rash or maculae on their body. If they don't tell me …they've got AIDS, I won't believe they have it… (F: 17/02/05).*

Attempting to conceal the illness is one way that people living with chronic conditions that are stigmatised and discredited by other people in society can avoid discrimination (Joachim & Acorn, 2000). In this study participants had many strategies for "passing" by concealing their HIV/AIDS status or symptoms from others, or by controlling information as to their status through selective disclosure.

8.4.5 Strategies to pass as normal

Keeping well, as detailed in Chapter Six, was the primary strategy to "pass as normal" by avoiding having visible signs of the disease. As previously stated, all participants had to actively manage their conditions to sustain their health and recover from their illness. Keeping well resulted in many participants feeling and looking comparatively healthy, being able to work around the home or in positions that contributed to family income and being able to partake in activities that enabled them to define themselves as living a "normal" life. Any visible signs such as dark spots on arms were covered with a long-sleeved garment. Living with HIV/AIDS in this manner enabled the participants to feel empowered.

Participants sought information about the disease and treatment from many sources, in order to prevent or treat opportunistic infections that left them overtly sick. Eating healthy food, avoiding taboo food, exercising, sleeping well, keeping personal hygiene, avoiding risky behaviours, taking medication regularly, and enjoying recreation were intentional actions of participants to restore their health and well-being. The findings are consistent with those of Corless et al. (2002) who reported that taking supplements, vitamins and nutrition, sleeping, doing exercise, taking rest and adjusting activities were used as self-care strategies in relieving fatigue in people living with HIV/AIDS. Looking and feeling healthy enabled participants to pass as normal.

The other strategy used to “pass as normal” was that of selective disclosure (detailed in section 5.2.4). Disclosure is an important issue among people living with HIV/AIDS. Keeping their HIV/AIDS status secret made some participants feel safe in their life. In contrast, self-disclosure enabled participants to seek social support and new information about–and treatment for–the disease. This dilemma is also reported by Greeff et al. (2008) in the context of Africa. The concept of disclosure is often categorised as disclosed or not disclosed (Greeff et al., 2008), however the notion of selective disclosure has more fit with the goal of passing as normal. In Thailand, as in Africa (Greeff et al., 2008), participants reported that disclosure is highly complex and risky because of the high degree of stigmatisation and discrimination by society, but they selectively disclosed to others because they needed support to maintain their lives.

Acceptance and social support were critical to participants to enable them to have hope and to maintain their health. Most participants sought support because when they were initially diagnosed with HIV/AIDS, they had both serious illnesses and were unable to work, resulting in loss of money to support themselves and emotional distress (section 5.3). Support included money, food, work, advice and medicines, good communication and good relationships. Ciambrone (2002) stated that social support is particularly important for people living with HIV/AIDS. For example, support can assist participants to find meaning in their life and gain a sense of control.

Disclosure was actively managed by the participants in this study; that is, participants maintained control over the decision to disclose, with disclosure ranging from full to selective (Greeff et al., 2008). Often, selective disclosure was used to obtain acceptance and support, while concealment was practised in order to be able to work. Working in a village distant from the participant’s home village was an example of the latter.

Keeping well and selective disclosure were effective strategies that enabled participants to move forward and to feel in control of their lives: that is, to feel empowered as detailed in Chapter Seven. Empowerment can help people to develop a critical thinking awareness of their situation and enable them to control their environment to achieve their goals and to live a normal life in society. In the context of the study, feeling empowered enabled participants to prioritise their own self-care. Personal and social acceptance and hope for the future underpinned that feeling of empowerment.

Hope was a powerful incentive for participants to maintain their lives. Moreover, having hope lifted participants' spirits and helped them manage their disease and promote their well-being; a finding consistent with that of McCormick, Holder, Wetsel and Cawthon (2001). The result of hope is the energy to work for the future (Holt & Reeves, 2001). Hope is influenced by the sociocultural environment and is dependent on managing the risk of stigma and discrimination within that environment.

8.4.5 Consequences of passing as normal

The consequences of passing as normal, for the participants in this study, were that they were able to live comparatively normal lives and to maintain their health like other people with a socially invisible chronic disease (Lonardi, 2007). Participants accepted themselves and went on with life as normal people in their local social environment context. Where participants had fully disclosed their illness they may have contributed to increasing the "social and moral space" (Viddhanaphuti, 1999, p.10) for people with HIV/AIDS in their local community. However, the focus of the majority of participants was on selective self-disclosure for social support, and finding new meaning in life (Viddhanaphuti, 1999).

The basic social psychological process "from experiencing social disgust to passing as normal" represents a dynamic process that Thai people living with HIV/AIDS used to manage their lives by using knowledge, skill and resources from their own perspectives in their natural circumstances.

8.5 IMPLICATIONS OF THE STUDY

This qualitative research using grounded theory generated a mid-range theory that focuses on a specific phenomenon, "the self-care processes among Thai people suffering from AIDS". The theory described how Thai people manage their self-care and living with their disease in their natural context. The theory reflects the views of people living with HIV/AIDS and accounts for the patterns of behaviour that occur following diagnosis with HIV/AIDS. The findings from this study will help healthcare professionals understand how Thai people living with HIV/AIDS learn about their disease and manage their HIV/AIDS within their natural circumstances. It is argued that, in the context of Northeastern Thailand, the basic social psychological process "from experiencing social disgust to passing as normal" underpins successful management of HIV/AIDS and enables and motivates people living with the disease to undertake effective self-care in order to remain symptom free.

The substantive theory developed in this study provides a differing perspective for healthcare providers and the potential to both develop more effective interventions for people living with HIV/AIDS and to better support the families in continuing to care for people living with HIV/AIDS at home. The findings from this study have implications for nursing practice and nursing theory and for nursing education. Recommendations are made for future research and for HIV/AIDS health policy in Thailand.

8.5.1 Implications for nursing practice and nursing theory

The basic social psychological process "from experiencing social disgust to passing as normal" is useful in understanding self-care processes of people living with HIV/AIDS from their own perspectives. This substantive theory can be used to guide practice and to provide a framework for self-care assessment activities. Table 8.2 outlines a series of questions based on the fundamental aspects of the self-care experiences of people living with HIV/AIDS. These questions might help healthcare providers to develop appropriate healthcare services, which encourage people living with HIV/AIDS to initiate, maintain and develop suitable self-care activities that can help them to reach well-being and to have a normal life in their society.

The findings can be used for developing the nursing practice programme to provide care for people living with HIV/AIDS at all levels of the healthcare service such as a University Hospital, Provincial Hospital, Community Hospital, Health centre and in the family and community. In order to provide the best care for people living with

HIV/AIDS, nurses and other healthcare providers should assess the strategies that are being used by people living with HIV/AIDS, to manage the risks of stigma and discrimination. Health professionals need to provide and promote social acceptance and hope so that people can live a normal life with HIV/AIDS, as well as providing information about the disease and effective self-care.

Table 8.2: Questions About Self-Care Management

Question	Category	Concept	Theoretical proposition
Could you please tell me about your disease?	Being HIV/AIDS	Being diagnosed with HIV/AIDS	Discovering the meaning of having HIV/AIDS
How do you think and feel about AIDS disease?	Being HIV/AIDS	Being stigmatized Suffering Learning about HIV/AIDS	Discovering the meaning of having HIV/AIDS
How do you view your disease?	Moving from social disgust to passing as normal	BSPP	Environmental context
How do you manage your disease in your daily life?	Keeping well	Religious practices Keeping a cheerful mind Keeping the environment clean to prevent getting germs	To maintain emotional and physical health
How do you take care of yourself?	Keeping well	Taking care of the body Healthy behaviour	To maintain emotional and physical health
When you get sick what do you do?	Keeping well	Self-treatment Getting healthcare services	To maintain emotional and physical health
How do you manage your medicine?	Keeping well	Attention to, and concern about, medication	To maintain emotional and physical health
Does anything make you feel better when living with HIV/AIDS?	Making choices	Avoiding unhappy situations Seeking support Getting remarried	To live a ‘normal’ life
Who helps you with your disease?	Feeling empowered	Social acceptance Being encouraged	Personal and social acceptance of illness
Is there anything else you would like to tell me about your experience of living with HIV/AIDS?	Feeling empowered	Feeling proud of self Having hope Feeling good about life Feeling lucky	Personal and social acceptance of illness
How do you manage your thoughts and feelings about living with HIV/AIDS?	Feeling empowered	Acknowledging the disease Tamjai	Personal and social acceptance of illness

Professional nurses are interested in developing nursing theory that can guide nursing practice. Findings in this study, as described in Chapters Four to Seven, support concepts within various models used in nursing, including Orem’s self-care model, the Health belief model and the health-seeking model. However, it can be argued that these models differ in their theoretical underpinnings, purposes and usefulness. Thus, integrative models and methods are needed to further develop nursing theories about the self-care phenomenon that can be used to guide Thai health professionals. Nursing theory that is too broad, even though valuable to guide overall intervention, is sometimes not practical for a specific condition or situation. In addition, a practical model for specific nursing interventions is needed when applying nursing theory to particular situations and contexts. In Thailand, health professionals, especially community nurses, play a key role in the delivery of primary care. This role includes facilitating and providing health education to the individual, family and community to improve their knowledge about self-care processes among Thai people with HIV/AIDS living at home in their natural context. So the results of the study provide empirical evidence to build scientific underpinning for home care nursing practice in Thailand and to help nursing administrators and policymakers understand the nature of home care provision and outcomes for care that are influenced by people living with HIV/AIDS.

8.5.2 Implications for nursing education

“From experiencing social disgust to passing as normal” also provides a practical framework for curriculum development and delivery of healthcare services, which influence the development of self-care among people living with HIV/AIDS. It is important to prepare healthcare providers to understand what enables and motivates people living with chronic life-threatening conditions such as HIV/AIDS to initiate, develop and maintain self-care behaviours.

The results of this study have implications for Thai nursing education in two aspects including the teaching of both nursing perspective and nursing care for people living with HIV/AIDS in order to further improve health outcomes.

8.5.2.1 A self-care process perspective of people living with HIV/AIDS should be introduced to students by nurse educators.

At present, education for nursing professionals in Thailand tends be directive, with the instructors providing the information to students who are playing a passive role rather than one in which they are integrally involved and share their views. It is important for community health professionals, particularly the community nurse educators who work in the family and community, to involve family members and community members to support and promote self-care in people living with HIV/AIDS because the family or home is the central point of concern. Community nurse educators must be able to model this involvement with students, both in the classroom and in their practice as a community instructor caring for people living with HIV/AIDS in their family. In this way, the community nurse educators could support and help shape the views and the values of nursing students about self-care nursing practice.

8.5.2.2 A culturally sensitive approach to nursing care of people living with HIV/AIDS is necessary

The outcomes of this study demonstrated that the processes of self-care associated with the beliefs and culture of Thai people in relation to health and illness should be addressed and emphasised in a nursing curriculum. Community nurse educators should prepare nursing students to think about the way Thai beliefs and culture impact healthcare situations in Thai people living with HIV/AIDS in contrast to Western literature.

8.6 RECOMMENDATIONS FOR NURSING RESEARCH

Grounded theory was used to discover the self-care process of Thai people suffering from AIDS. The findings in this study not only enhance knowledge and understanding about self-care experiences of Thai people suffering from AIDS in the context of Northeastern Thailand, but also the concept of self-care in nursing research in Thailand. The following recommendations for further research in nursing are derived from this study.

1) Based on the findings of this study, further study on life experiences relevant to the self-care of people with HIV/AIDS in different contexts such as orphans, youth, and pregnant women and drug addicts, those who live in prisons, and those who live in the temples should be explored in order to further develop formal theories about self-care processes of Thai people living with HIV/AIDS.

2) Based on the findings of this study, further research using quantitative methodology could be applied to measure concepts such as social support, health seeking, healthy behaviours, and others concepts in order to understand the factors that relate to self-care processes of Thai people living with HIV/AIDS.

3) The study should be replicated in people with other chronic illnesses, such as hypertension, heart disease, arthritis, chronic lung diseases, stroke, and other conditions in order to develop a substantive theory about the self-care process of Thai people living with chronic diseases that are not stigmatised.

4) Participatory action research could be conducted with key stakeholders such as monks, teachers, community leaders, village health volunteers, and health professionals in order to promote greater involvement of people living with HIV/AIDS in community life.

5) A prospective study could be undertaken to evaluate the symptoms and medication side effects that influence adherence to highly active antiretroviral therapy in people with AIDS in each regimen.

However, the grounded theory approach was very useful in this study. It helped me to understand the research problem and also discover possible interventions that can be used to address the problem in the Thai Isaan context.

8.7 RECOMMENDATIONS FOR HIV/AIDS HEALTH POLICY IN THAILAND

Although Thailand has achieved significant success in controlling the spread of HIV/AIDS, with new infections dropping from 130,000 in the early 1990s to 17,000 cases a year in 2005 (MOPH, 2007a; MOPH & WHO, 2005), there are signs that the HIV epidemic is threatening to rebound (Poolcharoen, 2005). The National Plan for the Prevention and alleviation of HIV/AIDS in Thailand 2007-2011 continues the work of the previous National Plan (2002-2006), however concepts and policy orientations have been modified to account not only for the rapidly changing HIV/AIDS situation but also for globally induced changes in the domestic economy, society and culture (Poolcharoen, 2005). The current National Plan is to be used as a tool for the national response to the current and future HIV/AIDS situation and its impact on the health, sociocultural and economic aspects of the life of the people living with HIV/AIDS in Thailand and neighbouring countries. The project has the following specific objectives;

1) To develop a strategic plan for all relevant sectors through a participatory approach.

2) To use the plan as a tool to ensure that policy and programme components are transformed into appropriate actions for each organisation and related national mechanism.

3) To integrate the next plan on HIV/AIDS prevention and alleviation in response to the needs from provincial strategic planning clusters facilitated by the provincial committee on HIV/AIDS prevention and alleviation.

At present, Thai people are increasingly well educated and share an improved level of collective well-being, but the incidence of illness and death from behavioural diseases remains a health problem (MOPH, 2006a). Stigma and discrimination are the major barriers to effective HIV/AIDS treatment and prevention; and are manifested in blame, loss of self-value and shame. Thus, the findings of this study could influence health policy in Thailand as follows.

1) National healthcare policy should have a specific section that focuses on health promotion and illness prevention in relation to HIV/AIDS. Information about HIV/AIDS should be available in every community and at every level of healthcare. Additionally, healthcare professionals at healthcare centres should be well trained to assist people with HIV/AIDS to resolve their restricted condition, providing new perspectives, and supplying information about all available alternatives. Some healthcare providers still hold negative attitudes toward people living with HIV/AIDS and their families (Wattradul, 2002). Thus, health policy should support continued training of health professionals in every level of the healthcare system to change their attitudes toward people living with HIV/AIDS.

2) Intersectoral collaboration among Government and Non-Government Organisations, and other private sector and community organisations should be included in national policies related to eradicating AIDS-associated stigma and discrimination, and promotion of care for people living with HIV/AIDS.

3) This study was focused on the experiences of people with HIV/AIDS who had low economic status and low education levels. The Government should continue assisting people with HIV/AIDS in terms of education, job training, and occupation. Access to government funds would assist people living with AIDS to improve their socio-economic status particularly for daily living.

4) The government should continue employing people with HIV/AIDS in government organisations and units especially in hospitals. Such employment would help people with HIV/AIDS to realise the value of their lives. It would also make them role models for persons newly diagnosed with HIV/AIDS, giving them hope for a better life.

5) The government should support formal education as well as vocational training. People with HIV/AIDS need access not only to vocational training like repairing

electronic instruments or making flowers. Those with intellectual capacity and who are still young should be supported to continue their studies such as computer training.

8.8 LIMITATIONS OF THE STUDY

The limitations of this study are related to the characteristics of the participants, methodological procedures and the researcher’s skill. In qualitative research, the researcher is the instrument. The quality of the data gathered and the subsequent conceptualisations that emerged during data analysis are limited by the researcher’s skills.

Data gathering and initial data analysis for the study were conducted in Thai, but the study findings are presented in English as my second language. There were difficulties in translation to generate accurate meanings between different languages regardless of my attempt to ensure a reliable translation by using several approaches.

Data generated from this study were gathered from thirty participants, who lived in the rural Isaan community in Thailand where common beliefs, and common social and cultural context influenced the strategies these persons used to manage their own health and their life experiences following diagnosis with HIV/AIDS. The intent of grounded theory study is to obtain an in-depth understanding of a phenomenon and not to generalise beyond the context of the study. Thus, further studies will be needed to assess whether or not the findings of this study hold in different sociocultural contexts.

I argue that despite these limitations, understanding the process by which people who have been diagnosed with HIV/AIDS move “from experiencing social disgust to passing as normal” which has emerged from this study is useful for people living with HIV/AIDS to manage their health, illness and other conditions and living in their own homes in the Isaan context.

8.9 CONCLUSION

As a result of this research study a substantive theory has been inductively developed which reflects the views of people living with HIV/AIDS in Northeastern Thailand and accounts for the patterns of behaviour that occur following diagnosis with HIV/AIDS. The study was conducted to gain a better understanding of how Thai people living with HIV/AIDS, take care of their health and manage their lives in the context of stigma and discrimination. A theoretical model, grounded in the perceptions and action/interaction strategies of thirty participants was developed that illustrates the basic social psychological process “from experiencing social disgust to passing as normal”. While other studies (for example, Nanjantra, 2003) have identified living normally as the goal for people living with HIV/AIDS, this study has illuminated the strategies used by participants to resolve the ever-present risk of stigma and discrimination and to “pass” as normal.

Implications for practice, and further research were derived from the findings of this study. The findings in this study not only enhance knowledge and understanding about the experiences of Thai people suffering from AIDS in the context of Northeastern Thailand, but also have relevance to research on the concept of self-care in Thailand. The national health policy can promote and protect the well-being of people living with HIV/AIDS and increase the potential human resource of the country. Limitations of this study are related to its sociocultural context and to my skill in carrying out the research.

REFERENCES

Adamsen, L. (2002). From victim to agent: The clinical and social significance of self-help group participation for people with life-threatening diseases. *Scandinavian Journal of Caring Sciences, 16*(3), 224-231.

Ahmed, S. M., Adams, A. M., Chowdhury, M., & Bhuiya, A. (2000). Gender, socioeconomic development and health seeking behaviour in Bangladesh. *Social Science & Medicine, 51*, 361-371.

AIDS Network Development Project (AidsNet). (1998). AIDS from mother to child. *AidsNet Newleter, 1*(1), 20-23.

Ainsworth, M., Beyrer, C., & Soucat, A. (2001). Success and new challenges for AIDS control in Thailand. *AIDScience, 1*(5). Pdf, Retrieved August 20, 2008, from http://aidscience.org/Aarticles/aidscience005.pdf.

Allan, J. D. (1990). Focusing on living, not dying: A naturalistic study of self-care among seropositive gay man. *Holistic Nursing Practice, 4*(2), 56-63.

Alonzo, A. A., & Reynolds, N. R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science & Medicine, 41*(3), 303-315.

Anastasio, C., McMahan, T., Daniels, A., Nicholas, P. K., & Paul-Simon, A. (1995). Self-care burden in women with human immunodeficiency virus. *JANAC, 6*(3), 31-42.

Barnett, T., & Whiteside, A. (2002). *AIDS in the twenty first century: Disease and globalization.* New York: Palgrave Macmillan.

Bartlett, J. G., & Finkbeiner, A. K. (1998). *The guide to living with HIV infection* (4th ed.). Baltimore: The Johns Hopkins University Press.

Bartlett, J. G., & Gallant, J. E. (2000). *2000-2001 Medical management of HIV infection*. Johns Hopkins University, Department of Infectious Diseases.

Beck, C.T. (2004). Grounded theory research. In J. A. Fain (Ed.). *Reading, understanding, and applying nursing research: A text and workbook* (pp. 266-268). Philadelphia: Davis Company.

Bhattacharya, G. (2004). Health care seeking for HIV/AIDS among South Asians in the United States. *Health & Social Work*, *29*(2), 106-115.

Bhattacharya, G., Cleland, C., & Holland, S. (2000). Knowledge about HIV/AIDS, the perceived risks of infection, and sources of infection by Asian-Indian adolescents born in the U S A. *AIDS Care*, *12*, 203-211.

Blumer, H. (1969). *Symbolic Interactionism: Perspective and method*. Englewood Cliffs, New Jersey: Prentice Hall.

Boer, H., & Emons, P. A. A. (2004). Accurate and inaccurate HIV transmission beliefs, stigmatizing and HIV protection motivation in northern Thailand. *AIDS Care*, *16*(2), 167-176.

Bonadonna, R. (2003). Meditation's impact on chronic illness. *Holistic Nursing Practice, 17*(6), 309-319.

Boom, F. V. D., & Sherr, L. (2004). AIDS impact. *AIDS Care, 16*(5), 547-549.

Brashers, D. E., Neidig, J. L., & Goldsmith, D. J. (2004). Social support and the management of uncertainty for people living with HIV or AIDS. *Health Communication, 16*(3), 305-331.

Brashers, D. E., Neidig, J. L., Reynolds, N. R., & Haas, S. M. (1998). Uncertainty in illness across the HIV/AIDS trajectory. *Journal of the Association of Nurses in AIDS Care, 9*(1), 66-77.

Brown, D., & Batterham, M. (2001). Nutritional management of HIV in the era of highly active antiretroviral therapy: A review of treatment strategies. *Australian Journal of Nutrition & Dietetics*, *58*(4), 224-235.

Budsadee, S. (2000). *Health care seeking behaviour among persons with HIV infection and AIDS*. Unpublished Master Thesis, Khon Kaen University, Thailand.

Bunch, E. H., (2004). Symptom management for HIV-positive persons in Norway. *International Nursing Review*, *51*, 167-175.

Cabaj, R. P. (1996). Management of anxiety and depression in HIV-infected patients. *Journal of the International Association of Physicians in AIDS Care*, *2*, 11-16.

Caballero, M., Dreser, A., Leyva, R., Rueda, C., & Bronfman, M. (2002, July 7-12). *Migration, gender and HIV/AIDS in Central America and Mexico*. XIV International AIDS Conference, Barcelona, Spain.

Campero, L., Herrera, C., Kendall, T., & Caballero, M. (2007). Bridging the gap between antiretroviral access and adherence in Mexico. *Qualitative Health Research*, *17*(5), 599-611.

Carpenter, D. R. (1995). Grounded theory research approach. In H. J. Streubert & D. R. Carpenter (Eds.). *Qualitative research in nursing*: *Advancing the humanistic imperative* (pp. 145-160). Philadelphia: J. B Lippincott Company.

Centers for Disease Control and Prevention (CDC). (2007). *Basic information of HIV/AIDS*. Retrieved June 25, 2007, from http://www.cdc.gov/hiv/topics/basic/

Chammas, G. Y. (1999). *Hope, functional status, and quality of life in hospitalized patients with human immunodeficiency virus infection and acquired immunodeficiency syndrome*. Abstract, Retrieved November 13, 2007, from http://web.ebscohost.com.ezproxy. massey.ac.nz/ehost/delivery?vid=7&hid=17&sid=e…

Chanbancherd, P., Limpairojn, N., Benenson, M., Jugsudee, A., Julananto, P., Tienamporn, P., et al. (2000). HIV-2 infection in Thailand. *Asia Pacific Journal Allergy Immunology, 18*(4), 245-248.

Chapman, L. (1998). Body image and HIV: Implications for support and care. *AIDS Care*, *10*(S2), S179-S189.

Charurnyut, C. (1979). *Factors determinating health services utilization of people in rural area*. Unpublished master thesis, Mahidol University, Thailand.

Charmaz, K. (2000). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative Research* (2nd ed., pp. 509-536). Thousand Oaks, CA: Sage Publications.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide though qualitative analysis*. London: Sage Publications.

Chenitz, W. C., & Swanson, J. M. (1986). Qualitative research using grounded theory. In W. C. Chenitz & J. M. Swanson (Eds.), *From practice to grounded theory: Qualitative research in nursing* (pp. 3-15). Menlo Park, CA: Addison-Wesley.

Chiou, P. Y., Kuo, B. I. T., Lee, M. B., Chen, Y. M., Wu, S. I., & Lin, L. C. (2004). A program of symptom management for improving self-care for patients with HIV/AIDS. *AIDS Patient Care and STDs, 18*(9), 539-547.

Chinouya, M., & O' Keefe, E. (2005). God will look after us: Africans, HIV and religion in Milton Keynes. *Diversity in Health & Social Care*, *2*(3), 177-186.

Chiovitti, R. F., & Piran, N. (2003). Rigour and grounded theory research. *Journal of Advanced Nursing*, *44*(4), 427-435.

Chirawatkul, S. (1993). *Sud lyad sud luuk: The social construction of menopause in northeastern Thailand.* Unpublished doctoral dissertation, The University of Queensland, Australia.

Chitwarakorn, A. (2003). HIV/AIDS and sexually-transmitted infections in Thailand: Lessons learned and challenges ahead. *Journal of Health Management*, *5*(2), 173-189.

Cho, M.O. (2004). Health care seeking behavior of Korean women with lymphedema. *Nursing and Health Sciences*, *6*, 149-159.

Choksawadphinyo, K. (2005). Behaviors and barriers to self-care in people with HIV/AIDS: Findings from a qualitative study in northern Thailand. *Asian Journal of Nursing Studies*, *8*(3), 31-38.

Chokevivat, V., & Chuthaputti, A. (2005). *The role of Thai traditional medicine in health promotion*. Department for Development of Thai Traditional and Alternative Medicine. Ministry of Public Health, Thailand.

Chokevivat, V., Chuthaputti, A., & Khumtrakul, P. (2005). *The use of traditional medicine in the Thai health care system*. Department for Development of Thai Traditional and Alternative Medicine. Ministry of Public Health, Thailand.

Choowattanapakorn, T. (1999). The social situation in Thailand: The impact on elderly people. *International Journal of Nursing Practice*, *5*, 95-99.

Chou, F., Holzemer, W. L., Portillo, C. J., & Slaughter, R. (2004). Self-care strategies and sources of information for HIV/AIDS symptom management. *Nursing Research, 53*(5), 332- 339.

Ciambrone, D. (2002). Informal networks among women with HIV/AIDS: Present support and future prospects. *Qualitative Health Research, 12*(7), 876-896.

Corbin, J. M., & Strauss, A. (1992). A nursing model for chronic illness: Management based upon the trajectory framework. In P. Woog (Ed.). *The chronic illness trajectory framework: The Corbin and Strauss Nursing Model* (pp. 9-28). New York: Springer Publishing Company.

Corless, I. B., Bunch, E. H., Kemppainen, J. K., Holzemer, W. L., Nokes, .K. M., Eller, L. S., et al. (2002). Self-care for fatigue in patients with HIV. *Oncology Nursing Forum, 29*(5), E 60- 68.

Cote, J. K., & Pepler, C. (2005). Cognitive coping intervention for acutely ill HIV-positive men. *Journal of Clinical Nursing, 14*(3), 321-326.

Crossley, M. L. (2004). Making sense of ‘barebacking’: Gay men’s narratives, unsafe sex and the ‘resistance habitus’. *British Journal of Social Psychology, 43*(Part 2), 225-244.

Dane, B. (2002). Disclosure: The voices of Thai women living with HIV/AIDS. *International Social Work, 45*(2), 185-204.

Danziger, R. (1994). The social impact of HIV/AIDS in developing countries. *Social Science & Medicine, 39*(7), 905-917.

Denzin, N. K., & Lincoln, Y. S. (2003). *Collecting and interpreting qualitative materials*. Thousand Oaks, CA: Sage Publications.

Deschamps, M. M., Fitzgerald, D. W., Pape, J. W., & Johnson Jr, W. D. (2000). HIV infection in Haiti: Natural history and disease progression. *AIDS*, *14*(16), 2515-2521.

Dey, I. (1999). *Grounding grounded theory: Guidelines for qualitative inquiry*. San Diego, CA: Academic Press.

Dignam, D. M. (2001). *'Linking as One': An intimate breastfeeding moment*. Unpublished doctoral dissertation, Massey University, New Zealand.

Donkaewbua, S. (2005). *Empowering women's self-care: A participatory approach to prevent HIV/AIDS for women and children in northeast Thailand*. Unpublished doctoral dissertation, The Robert Gordon University, Scotland.

Duchscher, J. E. B., & Morgan, D. (2004). Grounded theory: Reflections on the emergence vs. forcing debate. *Journal of Advanced Nursing*, *48*(6), 605-612.

Edwards, L. (2006). Perceived social support and HIV/AIDS medication Adherence among African American women. *Qualitative Health Research*, *16*(5), 679-691.

Fagerhaugh, S. Y. (1986). Analyzing data for basic social process. In W. C. chenitz & J. M. swanson (Eds.). *From practice to grounded theory: Qualitative research in nursing* (pp. 133-145). Menlo Park, CA: Addison-Wesley.

Fain, J. A. (1999). *Reading, understanding, and applying nursing research: A Text and workbook.* Philadelphia : F A Davis Company.

Finlay, L. & Ballinger, C. (2006). *Qualitative research for allied health professionals: Challenging choices.* England: John Wiley & Sons, Ltd.

Ford, N., & Koetsawang, S. (1991). The socio-cultural context of the transmission of HIV in Thailand. *Social Science & Medicine*, *33*(4), 405-414.

Friedland, J., Renwick, R., & McColl, M. (1996). Coping and social support as determinants of quality of life in HIV/AIDS. *AIDS Care*, *8*(I1), 15-32.

Gillespie M. M. (2005). HIV/AIDS-preventive behaviour in recent-immigrant Jamaican women. Abstract, Retrieved November 20, 2007, from http://web.ebscohost.com.ezproxy.massey.ac.nz/ehost/detail? vid=6&hid=6&sid=c375…

Glaser, B. G. (1978). *Advances in the methodology of grounded theory: Theoretical sensitivity*. Mill Valley, CA: Sociology Press.

Glaser, B. G. (1992). *Emergence vs forcing: Basics of grounded theory analysis*. Mill Valley, CA: Sociology Press.

Glaser, B. G. (1996). *Gerund grounded theory: The basic social process dissertation*. Mill Valley, CA: Sociology Press.

Glaser, B. G. (1998). *Doing grounded theory: Issues and discussions.* Mill Valley, CA: Sociology Press.

Glaser, B. G., & Strauss, A.L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine De Gruyter Publishing Company.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, New Jersey: Prentice-Hall.

Grbich, C. (1999). *Qualitative research in health: An introduction*. California: Sage Publications.

Grbich, C. (2007). *Qualitative data analysis: An introduction*. California: Sage Publications.

Greeff, M., Phetlhu, R., Makoae, L. N., Dlamini, P. S., Holzemer, W. L., Naidoo, J. R., et al. (2008). Disclosure of HIV status: Experiences and perceptions of persons living with HIV/AIDS and nurses involved in their care in Africa. *Qualitative Health research*, *18*(3), 311-324.

Hand, G. A., Phillips, K. D., & Dudgeon, W. D. (2006). Perceived stress in HIV-infected individuals: Physiological and psychological correlates. *AIDS Care*, *8*(8), 1011-1017.

Hanucharurnkul, S. (1994). *Self-care: Nursing science and art* (2nd ed.). Bangkok: V. J. Printing.

Hanucharurnkul, S. (2000). Ten years of self-care research in Thailand: What we have accomplished and where should we go?. *In abstract proceedings of the 6th International Self-Care Deficit Nursing Theory Conference.*11-13 February, 2000, (p. 25). The Emerald Hotel, Bangkok, Thailand,

Harris, R. M., Bausell, R. B., Scott, D. E., Hetherington, S. E., & Kavanagh, K. H. (1998). An intervention for changing high-risk HIV behaviors of African American drug-dependent women. *Research in Nursing & Health*, *21*(3), 239-250.

Heath, H. & Cowley, S. (2004). Developing a grounded theory approach: A Comparison of Glaser and Strauss. *International Journal of Nursing Studies*, *41*, 141-150.

Hogan, T. P., & Palmer, C. L. (2005). Information preferences and practices among people living with HIV/AIDS: Results from a nationwide survey. *Journal of the Medical Library Association, 93*(4), 431-439.

Holloway, I., & Wheeler, S. (1996). *Qualitative research for nurses*. Cornwall: Blackwell Science.

Holt, J., & Reeves, J. S. (2001). The meaning of hope and generic caring practices to nurture hope in a rural village in the Dominican Republic. *Journal of Transcultural Nursing, 12*(2), 123-131.

Huber, J. T., & Cruz, J. M. (2000). Information needs and information-seeking behaviors of HIV positive men and women. *Medical Reference Services Quarterly, 19*(3), 39-48.

Hudson, A. L., Lee, K. A., Miramontes, H., Portillo, C. J. (2001). Social interactions, perceived support, and level of distress in HIV-positive women. *Journal of The Association of Nurses in AIDS Care, 12*(4), 68-76.

Hutchinson, S. A. (1993). Grounded theory, the method. In P. L. Munhall, & C. O. Boyd, (Eds.). *Nursing research: A qualitative perspective* (2nd ed., pp. 180-212). New York, NY: National League for Nursing.

Ichikawa, M., & Natpratan, C. (2006). Perceived social environment and quality of life among people living with HIV/AIDS in northern Thailand. *AIDS Care, 18*(2), 128-132.

Ickovics, J. R., Hamburger, M. E., Vlahov, D., Schoenbaum, E. E., Schuman, P., Boland, R. J., et al. (2001). Mortality, CD4 cell count decline, and depressive symptoms among HIV-seropositive women: Longitudinal analysis from the HIV epidemiology research study. *Journal of the American Medical Association, 285*(11), 1466-1474.

Im-emm, W., & Phuangsaichai, S. (1999). *Household resources allocation and responses toward AIDS-related illness.* Institute for Population and Social Research, Mahidol University. Department of Economics, Chiang Mai University. Care Thailand. Northnet Foundation.

Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing*, *32*(1), 243-248.

Johnson, S. K. (2002). Hmong health beliefs and experiences in the Western health care system. *Journal of Transcultural Nursing, 13*(2), 126-132.

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2000). *Caring for carers: Managing stress in those who care for people with HIV/AIDS*. UNAIDS in Thailand.

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2002a). *2002 Thailand country profile, HIV/AIDS situation in Thailand and National response to the epidemic*. UNAIDS in Thailand.

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2002b). *Workshop report: Networking and partnership between young people and governments on HIV/AIDS prevention for East and South-East Asian Countries. Bangkok, 18-22 March 2002*. UNAIDS in Thailand.

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2004). *2004 Report on the global AIDS epidemic 4th global report*. NLM classification: WC 503.4.

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2005a). *A scaled-up response to AIDS in Asia and the Pacific*. NLM Classification: WC503.6.

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2005b). *HIV-related Stigma, discrimination and human rights violations: Cases studies of successful programmes.* NLM Classification: WC503.7.

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2006). *2006 report on the global AIDS epidemic*. A UNAIDS 10 th anniversary special edition.

Jonson, E. P. (1988). *AIDS: Myths, facts & ethics*. Singapore: Singapore National Printers Ltd.

Junda, T. (2004). Living with breast cancer: Thai women's perspective. *Thai Journal of Nursing Research, 8*(3), 208-221.

Kanshana, S., & Simonds, R. J. (2002). National program for preventing mother-child HIV transmission in Thailand: Successful implementation and lessons learned. *AIDS, 16*(7), 953-959.

Kilmarx, P. H., Supawitkul, S., Wankrairoj, M., Uthaivoravit, W., Limpakarnjanarat, K., Saisorn, S., et al. (2000). Explosive spread and effective control of human immunodeficiency virus in northernmost Thailand: The epidemic in Chiang Rai province, 1988-99. *AIDS, 14*(17), 2731-2740.

Klunklin, A. (2001). *Thai women's experiences of HIV/AIDS in the rural north: A grounded theory study*. Unpublished doctoral dissertation, University of Western Sydney, Australia.

Klunklin, A., & Greenwood, J. (2005a). "Hanging in" with HIV/AIDS in the rural north of Thailand: A grounded theory study. *Journal of the Association of Nurses in AIDS Care*, *16*(6), 24-32.

Klunklin, A., & Greenwood, J. (2005b). Buddhism, the status of women and the spread of HIV/AIDS in Thailand. *Health Care for Women International*, *26*, 46-61.

Knodel, J., & Saengtienchai, C. (2005). "Older aged parents: The final safety net for adults sons and daughters with AIDS in Thailand". *Journal of Family Issues, 26*(5), 665-698.

Kornsaku, N. (2003). *Wife caregiver's experiences in caring for AIDS patients.* In abstract proceedings of the 9th National AIDS Seminar, 7-9 July, 2003, (p. 158). Impact Muangthong thanee. Bangkok, Thailand.

Kulsomboon, V., Thanaviriyakul, S., & Pinyowiwat, V. (2004). Cost-benefit analysis of triple antiretroviral therapy as a benefit of universal health care coverage in Thailand. *Journal of Health Science, 13*(6), 1022-1033.

Lee, R. S., Kochman, A., & Sikkema, K. J. (2002). Internalized stigma among people living with HIV-AIDS. *AIDS and Behavior*, *6*(4), 309-319.

Levin, L. S., Katz, A. H., & Holst, E. (1976). *Self-care: Lay initiatives in health*. London: Croom Helm.

Li, L., Lin, C., Wu, Z., Wu, S., Rotheram-Borus, M. J., Detels, R., et al. (2007). Stigmatization and shame: Consequences of caring for HIV/AIDS patients in China. *AIDS Care*, *19*(2), 258-263.

Lincoln, Y. S., & Cuba, E. G. (1985). *Naturalistic inquiry*. Beverly Hill, CA: Sage Publications.

Lonardi, C. (2007). The passing dilemma in socially invisible diseases: Narratives on chronic headache. *Social Science & Medicine*, *65*, 1619-1629.

Lyttleton, C. (1994). Knowledge and meaning: The AIDS education campaign in rural northeast Thailand. *Social Science & Medicine*, *38*(1), 135-146.

Lyttleton, C. (1996). Message of distinction: The HIV/AIDS media campaign in Thailand. *Medical Anthropology*, *16*, 363-389.

Mahasarakham Hospital. (2006a). *Annual reports of Mahasarakham hospital in the fiscal year 2005*. Summary until, 31 December, 2005. Mahasarakham Province, Thailand. (Thai).

Mahasarakham Hospital. (2006b). *Medical records and statistics*, Mahasarakham province, Thailand. (Thai).

Mahasarakham Province Public Health Office. (2007). *AIDS and STDs control reports of Mahasarakham.* Summary until, 31 December, 2006. Mahasarakham Province, Thailand. (Thai).

Mak, W. W. S., Cheung, R. Y. M., Law, R. W., Woo, J., Li, P. C. K., & Chung, R. W. Y. (2007). Examining attribution model of self-stigma on social support and psychological well-being among people with HIV+/AIDS. *Social Science & Medicine, 64,* 1549-1559.

Mak, W. W. S., Mo, P. K. H., Cheung, R. Y. M., Woo, J., Cheung, F. M., & Lee, D. (2006). Comparative stigma of HIV/AIDS, SARS, and Tuberculosis in Hong Kong. *Social Science & Medicine, 63,* 1912-1922.

McCormick, D. P., Holder, B., Wetsel, M. A. & Cawthon, T. W. (2001). Spiritualty [sic] and HIV disease: An integrated perspective. *Journal of the Association of Nurses in AIDS Care, 12*(3), 58-65.

McMillan, A. (1992). The human immunodeficiency virus. In C. Anderson., & P. Wilkie (Eds.). *Reflective helping in HIV and AIDS* (pp.33-48). Open University Press, Milton Keynes: Philadelphia.

Makhubela, B. H. (1999). *Self-care practices of young adult married women in Swaziland.* Abstract, Retrieved November 21, 2007, from http://web.ebscohost.com.ezproxy. massey.ac.nz/ehost/detail?vid=11&hid=15&sid=4c…

Malcolm, S. E., Ng, J. J., Rosen, R. K., & Stone, V. E. (2003). An examination of HIV/AIDS patients who have excellent adherence to HAART. *AIDS Care, 15*(2), 251-261.

Maneesriwongul, W., Panutat, S., Putwatana, P., Srirapo-ngam,Y., Ounprasertpong, L., & Williams, A. B. (2004). Educational, needs of family caregivers of persons living with HIV/AIDS in Thailand. *Journal of the Association of Nurses in AIDS Care, 15*(3), 27-36.

Mead, G. H. (1934). *Mind, self and society*. Chicago: University of Chicago Press.

Meleis, A. I. (1991). *Theoretical nursing: Development & progress* (1st ed.). New York: J. B. Lippincott Company.

Meleis, A. I. (2005). *Theoretical nursing: Development & progress* (3rd ed.). New York: Lippincott Williams & Wilkins.

Merson, M. H. (2006). The HIV-AIDS pandemic at 25-the global response. *The New England Journal of Medicine*, *354*(23), 2414-2417.

Ministry of Health (MOH). (2004). *Recommendation on antiretroviral therapy in HIV-infected adults and adolescents*. Brazil: Brasilia/DF.

Ministry of Public Health (MOPH). (1998). *Thailand health profile*. Nonthaburi: Ministry of Public Health, Thailand.

Ministry of Public Health (MOPH). (2006a). *Thailand health profile 2001-2004*, Bureau of Policy and Strategy, Ministry of Public Health, Thailand.

Ministry of Public Health (MOPH). (2006b). *2006 Health policy in Thailand.* Bureau of Policy and Strategy, Ministry of Public Health, Thailand.

Ministry of Public Health (MOPH). (2006c). *HIV/AIDS analytical situation in Thailand (Data as of December 31, 2006).* AIDS Division Bureau of AIDS, TB and STIs Department Disease Control, Ministry of public Health, Thailand. Retrieved December 13, 2007, from http://www.aidsthai.org/aidsenglish/situation_03.html

Ministry of Public Health (MOPH). (2007a). *Towards universal access by 2010: Thailand national HIV and AIDS program*. Bureau of AIDS, TB and STIs Department of Disease Control. Ministry of Public Health, Thailand.

Ministry of Public Health (MOPH). (2007b). *Analysis of policy development on antiretroviral treatment (ART) services, its advocacy and integration into universal health insurance: Term reference.* Bureau of AIDS, TB and STDs, Department of Disease Control. Ministry of Public Health, Thailand.

Ministry of Public Health (MOPH) and World Bank. (2006). *Expanding access to ART in Thailand: Achieving treatment benefits while promoting effective prevention.* MOPH: Thailand.

Ministry of Public Health (MOPH) and World Health Organization (2005). *External review of the health sector response to HIV/AIDS in Thailand.* WHO Regional Office for South-East Asia. New Delhi: India.

Morrison-Beedy, D. C. (1993). *Self assessment of HIV risk in women: Functional and dysfunctional patterns of assessment.* Abstract, Retrieved November 20, 2007, from http://web.ebscohost.com.ezproxy.massey.ac.nz/ehost/detail? vid=6&hid=6&sid=c375…

Morse, J. M. (1991). *Qualitative nursing research: A contemporary dialogue.* Newbury Park, CA: Sage Publications.

Morse, J. M., & Field, P. A. (1996). *Nursing Research: The application of qualitative approach* (2nd ed.). London: Chapman & Hall.

Nadee, K., Intarasombat, P., & Hanucharurnkul, S. (1999). Health-seeking behaviour of the elderly receiving first service at King Mongkut Prachomklao Hospital, Petchaburi province. *Thai Journal of Nursing Research, 3*(1), 27-44.

Namjantra, R. (2003). *Coping process of persons with long-term HIV infection.* Unpublished doctoral dissertation, Mahidol University, Thailand.

Namjantra, R., Hanucharurnkul, S., Panpakdee, O., Kompayak, J., & Sitthimongkol, Y. (2003). The process of struggling to live normally among persons with long-term HIV infection. *Thai Journal of Nursing Research, 7*(2), 105-120.

National Institute of Allergy and Infectious Diseases (NIAID). (2003). *The evidence that HIV causes AIDS*. Retrieved June 28, 2007, from http://www.niaid.nih.gov/factsheets/evidhiv.htm.

Nelson, K. E., Suriyanon, V., & Taylor, E. (1994). The incidence of human immunodeficiency virus type-1 infections in village populations in northern Thailand. *AIDS, 8,* 951-955.

Nilmanat, K., & Street, A. (2004). Search for a cure: Narratives of Thai family caregivers living with a person with AIDS. *Social Science & Medicine, 59,* 1003-1010.

Nilmanat, K., Street, A. F., & Blackford, J. (2006). Managing shame and stigma: Case studies of female carers of people with AIDS in southern Thailand. *Qualitative Health Research, 16*(9), 1286-1301.

Nilvarangkul, K. (2002*). Development of a community-based care program for people with HIV/AIDS in rural Thailand.* Unpublished doctoral dissertation, The University of Newcastle, Australia.

Nokes, K. M. (1991). Applying the chronic illness trajectory model to HIV/AIDS. *Scholarly Inquiry for Nursing Practice: An International Journal, 5*, 197-204

Nokes, K. M. (1998). Revisiting how the chronic illness trajectory framework can be applied for persons living with HIV/AIDS. *Scholarly Inquiry for Nursing Practice, 12*(1), 27-31.

Nokes, K. M., & Nwakeze, P. C. (2005). Assessing self-management information needs of persons living with HIV/AIDS. *AIDS Patient Care & STDs, 19*(9), 607-613.

Nuntaboot, K. (1994). *Cultural perceptions of illness in rural northeastern Thailand*. Unpublished doctoral dissertation, Massey University, New Zealand.

Orem, D. E. (1995). *Nursing concepts of practice* (5th ed.). Missouri: Mosby.

Papadopoulos, I. (2000). An exploration of health beliefs, lifestyle behaviours, and health needs of the London-based Greek Cypriot Community, *Journal of Transcultural Nursing, 11*(3), 182-190.

Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science & Medicine, 57,* 13-24.

Patel, A. S. H., & Hansen, H. J. (2005). Oral health in human immunodeficiency virus patients. *Topics in Clinical Nutrition, 20*(3), 243-251.

Paterson, B. L., Russell, C., & Thorne, S. (2001). Critical analysis of everyday self-care decision making in chronic illness. *Journal of Advanced Nursing, 35*(3), 335-341.

Paxton, S., Gonzales, G., Uppakaew, K., Abraham, K. K., Okta, S., Green, C., et al. (2005). AIDS-related discrimination in Asia. *AIDS Care, 17*(4), 413-424.

Phengjard, J., Brown, M. A., Swansen, K. M., & Schepp, K. G. (2002). Family caregiving of persons living with HIV/AIDS in urban Thailand. *Thai Journal of Nursing Research, 6*(3), 87-100.

Plattner, I. E., & Meiring, N. (2006). Living with HIV: The psychological relevance of meaning making. *AIDS Care, 18*(3), 241-245.

Plummer, M. L., Mshana, G., Wamoyi, J., Shigongo, Z. S., Hayes, R. J., Ross, D. A., et al. (2006). ‘The man who believed he had AIDS was cured’: AIDS and sexually-transmitted infection treatment-seeking behaviour in rural Mwanza, Tanzania. *AIDS Care, 18*(5), 460-466.

Phongphit, S. (2004). *Behavioral background paper for the economics of effective AIDS treatment: Evaluating policy options for Thailand*. World Bank, Washington, DC.

Phoolcharoen, W. (2005). *Report on the review of the national AIDS prevention and alleviation 2002-2006.* Bureau of AIDS, TB and STIs, Department of Disease Control. Ministry of Public Health, Thailand.

Phoolcharoen, W., Kunanusont, C., Pitisuttithum, P., & Bhamarapravati, N. (2004). HIV/AIDS in Thailand. In Y. Lu, M. Essex, & E. Stiefvater, (Eds.). *AIDS in Asia* (pp. 3-33). New York: Kluwer Academic/Plenum Publishers.

Pratt, R. (1995). *HIV&AIDS: A strategy for Nursing Care* (4th ed.). London: Arnold.

Preedasawadi, P., Pradubmook, P., & Puranan, A. (1987). Self-care behaviours of rural persons: Case studies in Isaan villages, Thailand. In P. Preedasawadi, P. Kaweewongprasert, & A., Puranan (Eds.), *Self-care: The socio-cultural perspectives* (pp. 261-320). Monograph Series, Center for Health Policy Studies. Bangkok: Sangdad.

Pretorius, H. G., Goldstein, N., & Stuart, A. D. (2005). Meaning-making of a group of South Africans in their experience of living with HIV: A phenomenological study. *Health SA Gesondheid, 10*(1), 41-51.

Punpanich, W., Ungchusak, K., & Detels, R. (2004). Thailand’s response to the HIV epidemic: Yesterday, today, and tomorrow. *AIDS Education and Prevention, 16* (Supplement A), 119-136.

Redding, C. A., Rossi, J. S., Rossi, S. R.,Velicer, W. F., & Prochaska, J. O. (2000). Health behavior models. *The International Electronic Journal of Health Education*, *3* (Special Issue), 180-193.

Rhucharoenpornpanich, O., & Chamratrithirong, A. (2001). Demographic impact of AIDS on the Thai population. *Asia-Pacific Population Journal, 16*(3), 71-88.

Rojanapithayakorn, W., & Hanenberg, R. (1996). The 100% condom programme in Thailand. *AIDS, 10*(1), 1-7.

Ruengsuwan, J. (1977). *Khong dee Isaan*. Bangkok: Religious Printing.

Rujkorakarn, D., Sangsuwan, J., Nuntaboot, K., Siriwatanamethanon, J., Nantsupawat, W., Boonyareraphan, S., et al. (1997). *Model development on the promotion of quality of life among AIDS patients in Khon Kaen Province*. Northeast Center for AIDS Prevention and Care. Khon Kaen University, Thailand.

Rujkorakarn, D., Siriwatanamethanon, J., Kiewying, M., Sukmak, V., & Tangvorapongchai, J. (2000). *Mobilizing community resources to eradicate AIDS-related stigma and to promote care for mothers with HIV infection and their children.* Faculty of Nursing, Mahasarakham University, Mahasarakham and Northeast Center for AIDS Prevention and Care. Khon Kaen University, Thailand.

Rutledge, S. E., & Abell, N. (2005). Awareness, acceptance, and action: An emerging framework for understanding AIDS stigmatizing attitudes among community leaders in Barbados. *AIDS Patient Care & STDs, 19*(3), 186-199.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8*(3), 27-37.

Sae Tang, P., & Nantachaipan, P. (2001). *A synthesis of knowledge from direct experience: Home care for HIV infected persons, AIDS patients and their families by the church of Christ in Thailand AIDS Ministry*. (1991-2000). Thailand: The CCT AIDS Ministry, The Church of Christ in Thailand.

Sangchart, B. (1997). *Culture of self-care among persons with HIV infection and AIDS: A study in the northeast, Thailand.* Unpublished doctoral dissertation, Mahidol University, Thailand. (Thai)

Sarangi, S., & Candlin, C. N. (2003). Categorization and explanation of risk: A discourse analytical perspective. *Health, Risk & Society*, *5*(2), 115-124.

Schreiber, R. S. (2001). The "how to" of grounded theory: Avoiding the pitfalls. In R. S. Schreiber & P. N. Stern (Eds.). *Using grounded theory in nursing* (pp. 55-58). New York, NY: Springer Publishing Company.

Schroeder, J. R., Latkin, C. A., Hoover, D. R., Knowlton, A. R., Zenilman, J., Strathdee, S., et al. (2001). Social factors related to antiretroviral therapy use in injection drug users. *AIDS & Behavior*, *5*(4), 363-369.

Siegel, K., & Lekas, H. M. (2002). AIDS as a chronic illness: Psychosocial implications. *AIDS*, *16*(S 4), S69-S76.

Simoni, J. M., Frick, P. A., & Huang, B. (2006). A longitudinal evaluation of a social support model of medication adherence among HIV-positive men and women on antiretroviral therapy. *Health Psychology*, *25*(1), 74-81.

Singhanetra-Renard, A., Chongsatitmun, C., & Aggleton, P. (2001). Care and support for people living with HIV/AIDS in northern Thailand: Findings from an in-depth qualitative study. *Culture, Health & Sexuality, 3*(2), 167-182.

Smith, J. M. (1996). *AIDS and society*. New Jersey: Prentice-Hall.

Songwathana, P. (1998). *Kinship, karma, compassion and care: Domiciliary and community based care of AIDS patients in southern Thailand.* Unpublished doctoral dissertation, University of Queensland, Australia.

Songwathana, P., & Manderson, L. (1998). Perceptions of HIV/AIDS and caring for people with terminal AIDS in southern Thailand. *AIDS Care*, *10*(S2), S155-S165.

Spirig, R., Moody, K., Battegay, M., & Geest, S. D. (2005). Symptom management in HIV/AIDS: Advancing the conceptualization. *Advances in Nursing Science*, *28*(4), 333-344.

Sringernyuang, L., Thaweesit, S., & Nakapiew, S. (2005). A situational analysis of HIV/AIDS-related discrimination in Bangkok, Thailand. *AIDS Care*, *17*(supplement 2), S165-S174.

Srisuphanunt, M., Sukeepaisarnchareon, W., Kucherer C., & Pauli, G. (2004). The epidemiology of HIV-1 subtypes in infected patients from northeastern Thailand. *Southeast Asian Journal Tropical Medicine Public Health, 35*(3), 641-648.

Sritanyarat, W. (1996). *A grounded theory study of self-care processes among Thai adults with diabetes.* Unpublished doctoral dissertation, The University of Texas at Austin.

Stanley, M. (2006). A grounded theory of the wellbeing of older people. In L. Finlay & C., Ballinger (Eds). *Qualitative research for allied health professionals: Challenging choices* (pp. 63-78). England: John Wiley & Sons, Ltd.

Stein, J. A., & Rotheram-Borus, M. J. (2004). Cross-sectional and longitudinal associations in coping strategies and physical health outcomes among HIV-positive youth*.* *Psychological and Health*, *19*(3), 321-336.

Stevens Barnum, B. J. (1994). *Nursing theory: Analysis, application, evaluation* (4th ed.). Philadelphia: J.B. Lippincott.

Stine, G. J. (1996). *Acquired immune deficiency syndrome: Biological, medical, social and legal issues* (2nd ed.). New Jersey: Prentice-Hall.

Stine, G. J. (2003). *AIDS update 2003: An annual overview of acquired immune deficiency syndrome*. New Jersey: Prentice-Hall.

Strauss, A. L. (1987). *Qualitative analysis for social scientists.* Cambridge, New York: Cambridge University Press.

Strauss, A. L., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques.* Newbury Park, CA: Sage Publications.

Strauss, A. L., & Corbin, J. (1994). Grounded theory methodology: An overviews. In N.K. Denzin, & Y.S. Lincoln (Eds.). *Handbook of qualitative research* (pp. 273-285). Thousand Oaks, CA: Sage.

Strauss, A. L., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage publications.

Streubert, H. J., & Carpenter, D. R. (1995). *Qualitative Research in nursing: Advancing the humanistic imperative* (pp. 145-177). Philadelphia: J.B Lippincott Company.

Stringer, E., & Genat, W. J. (2004). *Action research in health*. New Jersey, Pearson: Merrill-Prentice Hall.

Subbarao, S., Vanichseni, S., Hu, D. J., Kitayaporn, D., Choopanya, K., Raktham, S., et al. (2000). Genetic characterization of incident HIV type 1 subtype E and B Strains from a prospective cohort of injecting drug users in Bangkok, Thailand, *AIDS Research Human Retroviruses, 16*(8), 699- 707.

Sunthrajarn, T., Wongkongkatehp, S., Onnom, C., & Amornwichet, P. (2005). *Health promotion: The challenge in the prevention and control of HIV/AIDS. In 6th Global Conference on Health Promotion (6GCHP), 7-11August 2005, Bangkok, Thailand, Policy and partnership for action: Thailand context*, (pp. 24-27). Technical Papers.

Supakankunti, S., Phetnoi, W., & Tsunekawa, K. (2004). *Costing of "The national access to antiretroviral programs for people living with HIV and AIDS" in Thailand*. WHO collaborating centre for centre for health economics. Faculty of Economics, Chulalongkorn University, Bangkok, Thailand.

Suwanaleid, S. (1973). *Phii Poop-Phii Kouw: Psychological perspective*. Bangkok: Borpit Printing.

Thaineua, V. (2007). *The HIV/AIDS epidemic in the North: Epidemiology and public health.* Retrieved July 15, 2007, from http:// www.hsph.harvard.edu/ hai/education/conferences/Thailand_report/t.

Thanasetaungkul, S., Karnrussamee, P., Siriwatanamethanon, J., Kosumvacharaporn, S., Viyatusana, P., Siripul, P., et al. (1992). *Health behaviour of rural people, Muang district, Khon Kaen Province*. Faculty of Nursing, Khon Kaen University, Thailand.

Thanprasertsuk, S. (2004). *HIV/AIDS in Thailand: Current situation, successes, and remaining challenges.* Bureau of AIDS, TB and STIs, Department of Disease Control, Ministry of Public Health, Thailand.

Thanprasertsuk, S. (2007). *Condom programs for prevention of HIV Transmission in Thailand.* Bureau of AIDS, TB and STIs, Department of Disease Control, Ministry of Public Health, Thailand. Retrieved July 2, 2007, from http://aidsthai.org/aidsenglish/condom02.html

Thongcharoen, P. (1990). AIDS in Southeast Asia: Thailand. *Medical Progress, 7*, 19-22.

Thongprateep, T. (2000). The essential elements of spirituality among rural Thai elders. *Journal of Advanced Nursing, 31*(1), 197-203.

Thongsa-aad, W. (2003). The HIV/AIDS situation and its impacts in zone 10. *The Sangha Metta Newsletter, 14,* 3-4.

Thongsa-aad, W. (2004). Anti-HIV/AIDS drugs. *The Sangha Metta Newsletter, 17*, 3-6.

Thorne, S., Paterson, B., Russell, C. (2003). The structure of everyday self-care decision making in chronic illness. *Qualitative Health Research, 13*(10), 1337-1352.

United Nations Development Programme (UNDP). (2004). *Thailand's response to HIV/AIDS: Progress and challenges*. Thematic MDG Report.

Viddhanaphuti, C. (1999). *A cultural approach to HIV/AIDS prevention and care*. UNESCO/UNAIDS Research Project: UNESCO.

Vithayachockitikhun, N. (2006). Family caregiving of persons living with HIV/AIDS in Thailand: Caregiver burden, an outcome measure, *International Journal of Nursing Practice*, *12*, 123-128.

Vyavaharkar, M., Moneyham, L., Tavakoli, A., Phillips, K. D., Murdaugh, C., Jackson, K., et al. (2007). Social support, coping, and medication adherence among HIV-positive women with depression living in rural areas of the Southeastern United States. *AIDS Patient Care and STDs, 21*(9), 667-680.

Walker, D. & Myrick, F. (2006). Grounded theory: An Exploration of process and procedure. *Qualitative Health Research*, *16*(4), 547-559.

Wasi, C. (1995). “Monitoring HIV variability at the potential vaccine evaluation sites in Thailand”. In C. Studi & M. D. Sanita (Eds.). *Biotechnology and AIDS* (pp. 171-177). Roma: Instituto poligrafico E Zecca Stato.

Wattradul, D. (2002). *Improving health care for HIV/AIDS in Thailand: Learning from those who suffer*. Unpublished doctoral dissertation, Mahidol University, Thailand.

Wilson, D. L. (2004). *Nga Kairaranga Oranga, the weavers of health and wellbeing: A grounded theory study*. Unpublished doctoral dissertation, Massey University, New Zealand.

Wong, W. C. W., Gray, S. A., Ling, D. C., & Holroyd, E. A. (2006). Patterns of health care utilization and health behaviours among street sex workers in Hong Kong. *Health Policy, 77*(2), 140-148.

World Bank. (2006). *The economics of effective AIDS treatment: Evaluating policy options for Thailand.* Washington, DC: The World Bank.

World Health Organization (1983). *Health education in self-care: Possibilities and limitations*. Geneva: WHO.

World Health Organization. (1996). *Handbook on AIDS Home Care.* New Delhi.

World Health Organization. (2001). *HIV/AIDS in Asia and the Pacific region*. Regional Office for South-East Asia and Regional Office for the Western Pacific: WHO.

World Health Organization. (2003). *HIV/AIDS: Confronting a killer*. The World Health Report 2003. Geneva: WHO.

World Health Organization and Food and Agriculture Organization of the United Nations. (2002). *Living well with HIV/AIDS: A manual on nutritional care and support for people living with HIV/AIDS*. WHO and FAO: Rome.

Wuest, J. (1995). Feminist grounded theory: An exploration of the congruency and tensions between two traditions in knowledge discovery. *Qualitative Health Research, 5*(1), 125-137.

Wuest, J. (2007). Grounded theory: The method. In P. L. Munhall (Ed.). *Nursing research: A qualitative perspective* (4th ed., pp. 239-271). Boston: Jones and Bartlett Publishers.

Xiridou, M., Van, G. F., Tappero, J. W., Martin, M., Gurwith, M., Vanichseni, S., et al. (2007). The spread of HIV-1 subtypes B and CRF01_AE among injecting drug users in Bangkok, Thailand. *Journal Acquire Immune Deficiency Syndrom, 45*(4), 468- 475).

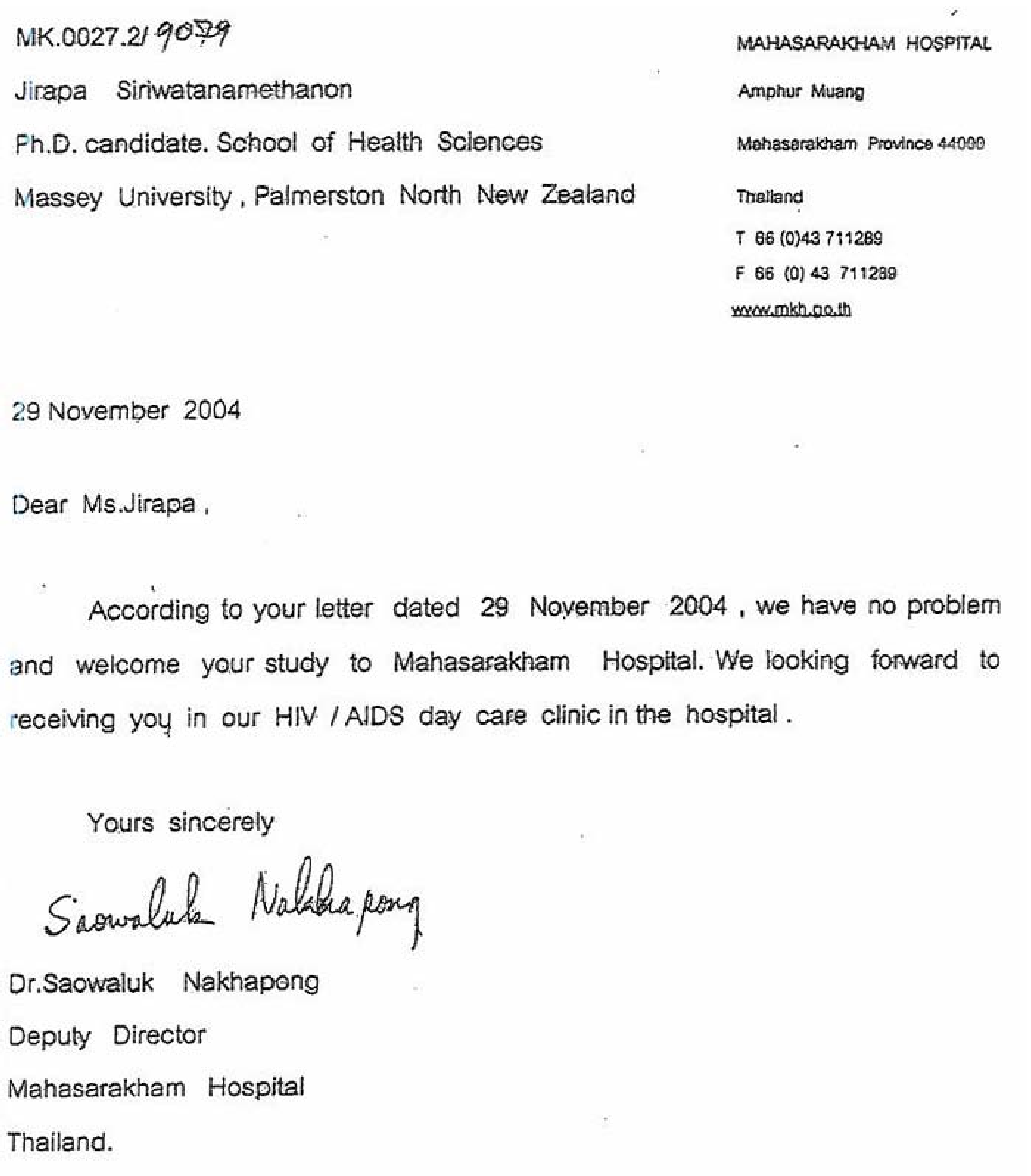
Yanwaree, N. (2002). *Receiving family caregiving as perceived by people living with HIV/AIDS*. Unpublished doctoral dissertation, Chiangmai University, Thailand.

Yin, R. K. (1989). *Case study research: design and methods.* Newbury Park: Sage

APPENDICES

APPENDIX A

A PERMISSION LETTER



MAHASARAKHAM HOSPITAL
Amphur Muang
Mahasarakham Province 44000
Thailand
T 66 (0)43 711289
F 66 (0) 43 711289
www.mkh.go.th

MK.0027.2/ 9079

Jirapa Siriwatanamethanon
Ph.D. candidate. School of Health Sciences
Massey University , Palmerston North New Zealand

29 November 2004

Dear Ms.Jirapa ,

According to your letter dated 29 November 2004 , we have no problem and welcome your study to Mahasarakham Hospital. We looking forward to receiving you in our HIV / AIDS day care clinic in the hospital .

Yours sincerely

Saowaluk Nakhapong

Dr.Saowaluk Nakhapong
Deputy Director
Mahasarakham Hospital
Thailand.

APPENDIX B

PARTICIPANT INFORMATION SHEET

Massey University
COLLEGE OF HUMANITIES AND SOCIAL SCIENCES

SCHOOL OF HEALTH SCIENCES
Private Bag 11 222
Palmerston North
New Zealand
T 64 6 356 9099
F 64 6 350 5668
www.massey.ac.nz

Self-Care Process with Thai People Suffering from AIDS: A Grounded Theory Approach

Information Sheet

Researcher Introduction

My name is Jirapa Siriwatanamethanon, Ph.D. student in Nursing, School of Health Sciences, Massey University, New Zealand. My supervisor is Professor Julie Boddy. I am currently undertaking research on the self-care of Thai people with HIV/AIDS. I am interested in learning more about persons with HIV/AIDS, and how they take care of themselves in their daily lives. So I would like to invite you to participate in the study. By participating in the study, you may learn more about your disease and how you take care for yourself. The result of this study is useful in that it will provide nurses and other Thai health professionals with a clearer conceptualization of self-care among Thai population. And they can provide better care for persons with HIV/AIDS at their homes and their communities, to improve their quality of life.

Participant Recruitment and Participant Involvement

Initially, People living with HIV/AIDS will be recruited from the HIV/AIDS day care clinic at Mahasarakham hospital, Mahasarakham province, Thailand. If you have experience living with HIV/AIDS, you will get the information sheets about this study and my address from the clinic. You will have more time to decide and consult your family members about participation in this study. At the first contact, I will talk with you about this study and provide the information sheet to you. I will answer your all questions about this study. An appointment will be scheduled to follow up your decision making about participation in this study at a date, time and place convenient for you. I will respect your decision. Rejection to participate in the study will not affect care and treatment at the clinic. If you are willing to participate in the study, I will go through the information sheet with you and arrange for you to sign the consent form at your home. If you have any friends who live with HIV/AIDS, please tell me.

There are no physical risks involved in this study. Some participants feel uncomfortable when an interview is tape recorded. You may ask for the audio tape to be turned off at anytime during the interview. Participants may experience some emotional discomfort in talking about their experiences of self-care practice or talking about their diseases. If you want assistance in dealing with these feelings, I will gladly help you in getting a referral to an appropriate resource. If you are willing to participate in the study, I will go through the information sheet with you and arrange for you to sign the consent form at your home. If you have any friends who live with HIV/AIDS, please tell me. That is useful for this study in that I will gain more numbers or diversity of participant and to understand the experiences and self-care practices from their perspective.

Project Procedures

Participation in this study involves being interviewed by Jirapa Siriwatanamethanon. You will be interviewed two to three times, approximately 1-1 ½ hours each time. The interviews will take place in your home that is private and convenient to you. The first, the second and the third interviews will be two to four weeks apart. You will be asked to complete personal information form that will ask about age, marital status, education, occupation and so forth. During the interview section, I will ask you about your experiences with AIDS, how do you think about your disease? how do you manage your disease in your daily life? The interview will be audiotape recorded and I will take some note for important issue about your answers. ***In addition to interviewing you, I will observe activity in your daily life which relates to health and self-care practice in order to learn about your experience and real feeling at your home such as eating food, exercise, relaxation, and other events. I will write down what I see and what you wish to tell me about your experience. The observation will be conducted in the morning, afternoon, and evening with participants' and family member permission.*** The information from your health records that I would like your permission to collect includes: treatments and CD4 cell count. Any information obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. I will send you a written summary in Thai language of the findings at the end of the study. I will take responsibility to keep the research information in a locked file cabinet at Faculty of Nursing, Mahasarakham University, Mahasarakham Province, Thailand for five years from completion of study. Then, all research information will be destroyed immediately.

Participant's Rights

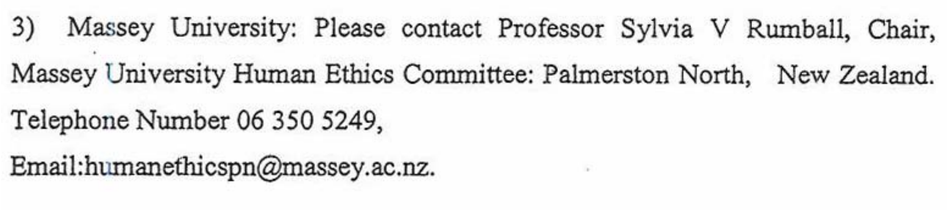
Your participation in the study is voluntary and you have the right to:

1) Refuse to answer any questions you do not want to discuss.
2) Withdraw from the study at anytime without effect on the care and treatment of you at Mahasarakham hospital.
3) You are also free to be present with your family member during the interviews.
4) Your name or other identifying information will not be on the tape or on the written transcription unless you give permission to the researcher.
5) Choose the dates, times and places for interviewing and observing that are private and convenient for you.
6) ***Ask for the audio tape to be turned off at anytime during the interview.***
7) Be given access to a summary in Thai language of the research project findings when it is completed.

Project Contacts

This research proposal has been approved by the Massey University Human Ethics Committee, PN Application ***04/186*** and permission's letter from the Director of Hospital, Mahasarakham Hospital, Mahasarakham Province, Thailand, Mahasarakham Hospital Application…MK.0027.2/ 9079...If you have any questions and have concern about the conduct of this research, please contact persons who take responsibility as follows:

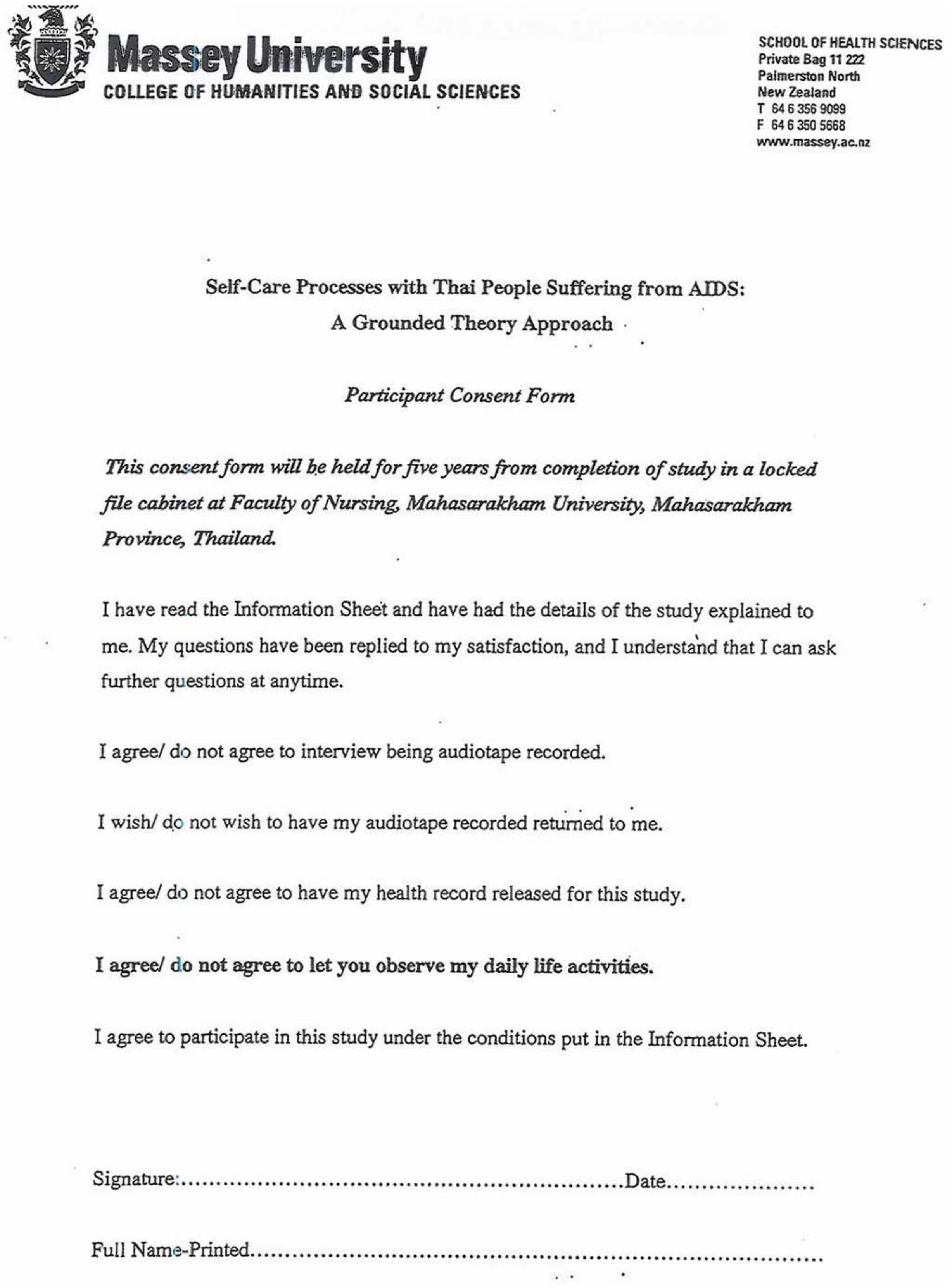
1) The researcher: Please feel free to ask or discuss with me at anytime.
   Jirapa Siriwatanamethanon, Department of community Health Nursing,
   Mahasarakham University, Mahasarakham Province, 44150, Thailand.
   Telephone Number 66 43 754357, email:jirapa_s44@yahoo.com.
2) Mahasarakham Hospital: Please contact, Kasemukda Chansiri Who takes
   responsibility of HIV/AIDS patients at HIV/AIDS day care clinic,
   Mahasarakham Hospital, Mahasarakham Province, 44000, Thailand.
   Telephone Number 66 1 261 7736 or 66 43 711289.



3) Massey University: Please contact Professor Sylvia V Rumball, Chair, Massey University Human Ethics Committee: Palmerston North, New Zealand. Telephone Number 06 350 5249,
Email:humanethicspn@massey.ac.nz.

APPENDIX C

PARTICIPANT CONSENT FORM



Massey University
COLLEGE OF HUMANITIES AND SOCIAL SCIENCES

SCHOOL OF HEALTH SCIENCES
Private Bag 11 222
Palmerston North
New Zealand
T 64 6 356 9099
F 64 6 350 5668
www.massey.ac.nz

Self-Care Processes with Thai People Suffering from AIDS:
A Grounded Theory Approach

Participant Consent Form

This consent form will be held for five years from completion of study in a locked file cabinet at Faculty of Nursing, Mahasarakham University, Mahasarakham Province, Thailand.

I have read the Information Sheet and have had the details of the study explained to me. My questions have been replied to my satisfaction, and I understand that I can ask further questions at anytime.

I agree/ do not agree to interview being audiotape recorded.

I wish/ do not wish to have my audiotape recorded returned to me.

I agree/ do not agree to have my health record released for this study.

I agree/ do not agree to let you observe my daily life activities.

I agree to participate in this study under the conditions put in the Information Sheet.

Signature:..Date....................

Full Name-Printed..