Achieving Harmony of Mind

A Grounded Theory Study of People Living with HIV/AIDS in the Thai Context

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Abstract

The aims in this Straussian grounded theory inquiry were to gain better understanding of the meaning of spirituality and of the process of spiritual development in people living with HIV/AIDS in the Thai context. In Western contexts, spirituality has been described as the essence of human existence. However, in the Thai context, where Buddhist teachings underpin the understanding of life as body and mind, rather than as body, mind and spirit, the concept of spirituality is little understood by lay people. This gap in understanding called for an inductive approach to knowledge generation.

HIV/AIDS is a life-altering and deeply stigmatized disease that results in significant distress and calls into question the meaning and purpose of life for many who are diagnosed with the disease. Nevertheless, some Thai people living with the disease successfully adjust their lives to their situation and are able to live with peace and harmony. These findings raise questions firstly as to the process by which those participants achieved peace and harmony despite the nature of the disease and the limited access to ARV drugs at the time of that study; and secondly as to whether or not the peace and harmony that they described could be linked to the Western concept of spirituality.

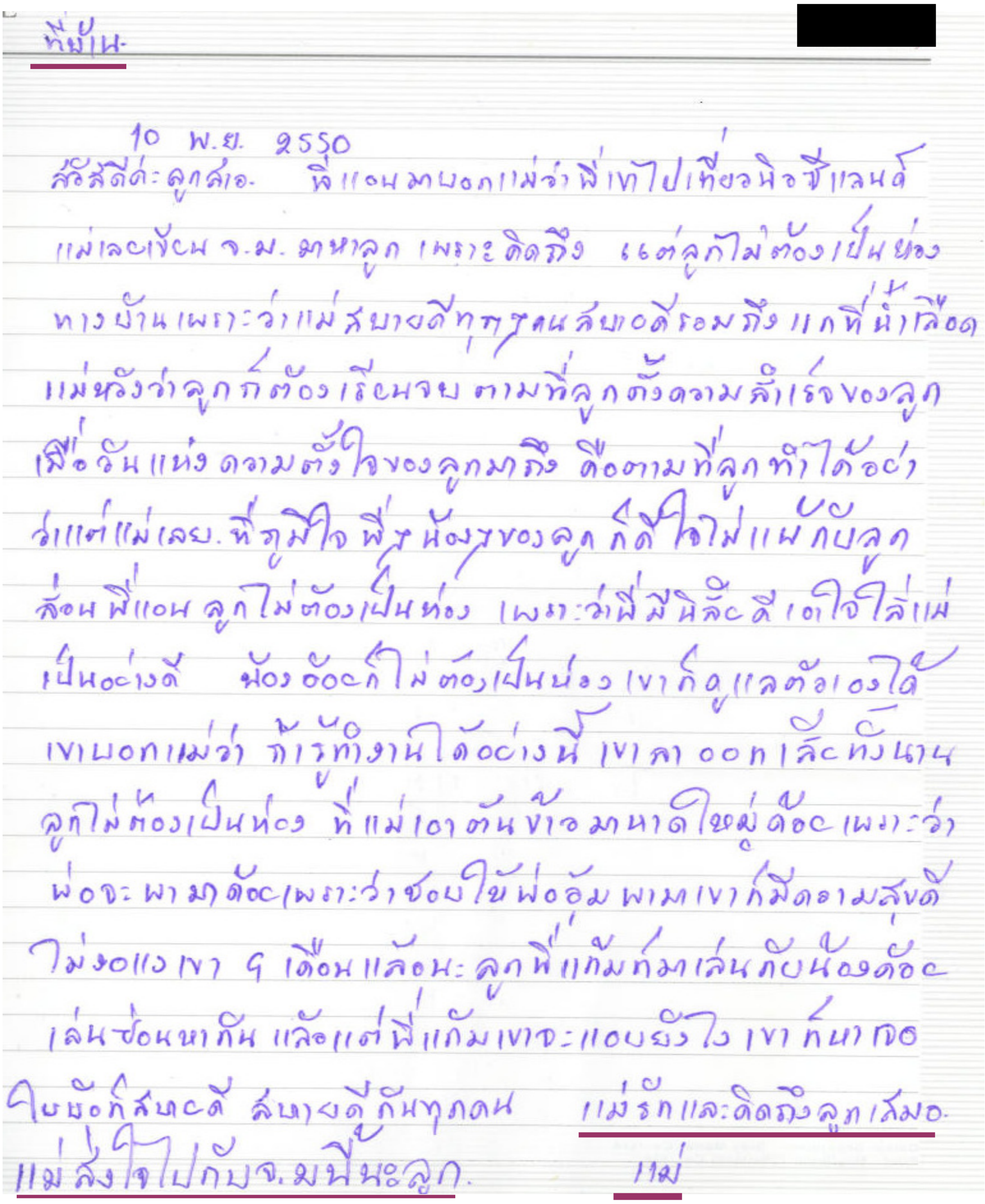
Data were gathered from 33 participants from the South of Thailand, who had lived with HIV/AIDS for 5 years or more, were aged 18 years or older, and were willing and able to participate in this study. Purposive, snowball and theoretical sampling techniques were used to select participants. Data collection using in-depth interviews and participant observation methods was undertaken over a nine-month period in 2006. The process of data analysis was guided by Strauss and Corbin's grounded theory and resulted in the development of a substantive theory.

The substantive theory of **Achieving Harmony of Mind** comprises two categories: **struggling to survive** and **living life**. Each category has two subcategories: *encountering distress* (*tukjai*) and *overcoming distress* (*longjai*), and *accomplishing harmony in oneself* and *discovering an ultimate meaning in life* respectively. The metaphor of 'an eclipse' was used to describe the process of the development of mind of people living with HIV/AIDS and represents the extent to which the individual's mind is overshadowed by the diagnosis of HIV/AIDS and its consequences. Diagnosis of this disease turns participants' lives upside down. Yet selective disclosure of one's HIV status, resulting in the receiving of support and connectedness with others, enables participants to find meaning and purpose in life that enables them to recover the will to live and to attempt to stabilise their lives by learning to live with HIV/AIDS. Most participants were able to adjust their mind to accept their new situation and find new self value enabling them to feel free from the shadow of HIV/AIDS and live life with HIV/AIDS as normal. Fewer participants found an ultimate meaning in life – consistent with Buddhist teachings about suffering and uncertainty, and the impermanence of life that links with an understanding of '*nonself*' – that enabled them to obtain peace and harmony of mind (*kwarmsa-ngobjai*). It is this latter stage that represents spirituality in Buddhist terms. This form of spirituality differs significantly from that found in other religions because it does not involve an engagement with a divine and transcendent reality.

The findings of this study enhance knowledge about spirituality in the Thai context, and provide a guide for health professionals and education curricula with the aim of achieving more holistic care for patients.

Dedication

I dedicate this Thesis to my parents.



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สวัสดีค่ะ ลูกสาว. พี่แอนมาบอกแม่ว่าพี่เขาไปเที่ยวนิวซีแลนด์ แม่เลยเขียน จ.ม. มาหาลูก เพราะคิดถึง แต่ลูกไม่ต้องเป็นห่วงทางบ้านเพราะว่าแม่สบายดีทุกๆคนสบายดีรวมถึงแกที่น้ำเลือด แม่หวังว่าลูกก็ต้องเรียนจบ ตามที่ลูกตั้งความสำเร็จของลูก เมื่อวันแห่งความตั้งใจของลูกมาถึง คือตามที่ลูกทำได้อย่าว่าแต่แม่เลย. ที่ภูมิใจ พี่ๆ น้องๆของลูก ก็ดีใจไม่แพ้กับลูก ส่วน พี่แอน ลูกไม่ต้องเป็นห่วง เพราะว่าพี่มีนิสัยดี เอาใจใส่แม่เป็นอย่างดี น้องอ๊อดก็ไม่ต้องเป็นห่วง เขาก็ดูแลตัวเองได้ เขาบอกแม่ว่า การทำงานได้อย่างนี้ เขาลาออกแล้วทั้งนาน ลูกไม่ต้องเป็นห่วง ที่แม่เอาต้นข้าวมาหาดใหญ่ด้วย เพราะว่าพ่อจะพามาด้วยเพราะว่าชอบใช้พ่ออุ้ม พามาเขาก็มีความสุขดี ไม่งอแงเขา 4 เดือนแล้วนะลูก พี่แก้มก็มาเล่นกับน้องด้วย เล่นซ่อนหากัน แล้วแต่พี่แก้มเขาจะแอบยังไง เขาก็หาเจอ ไปยังก็สนุกดี สบายดีกันทุกคน

แม่รักและคิดถึงลูกเสมอ.

แม่ส่งใจไปกับจ.ม.นี้นะลูก.

แม่

Letter from Mom

At home, 10 November, 2007

To my dear daughter,

Your sister (Pee Ann) told me that your friends will go to New Zealand. Therefore, I wrote a letter to you because I miss you a lot. My dear, you do not need to worry about anything at home because everyone is well including your grandmother.

I hope that you succeed in your studies. When you are succeed, I (Mae) will be proud of you, and so will your sisters and brother also feel proud of you.

Please do not worry about me because your sister (Pee Ann) takes care of me very well. Please, my dear do not worry about anything at home because everyone is good.

I pass my love with this letter to you.

Always love and miss you my dear daughter

Mom

Acknowledgements

Becoming a Ph.D. student was an important point in my life. This journey has been a mixture of happiness and sometimes suffering, but that is the nature of life. However, my experience of being a Ph.D. student has not caused me too much difficulty, because throughout this process, I have received an abundance of support. I cannot mention, in the limited space available in this paper, all of the people who have helped me. However, all of them will always remain in my mind.

I always appreciated my academic way of life. I thought that in this way I would have the chance to make those I love feel happy and also proud of me. Our connectedness makes me strong to face the difficulties in life. My mother, who is the best woman in my eyes, always encourages me and comforts me in many ways. For my father, who is always in my mind, I am willing to do my best. I also would like to say thank you to my sisters, brothers and brother-in-law as they took care of our parents very well and that helped me worry less and be able to focus on my study while I live overseas. They also always trust and respect me and kept encouraging me. I would like to express my deepest gratitude from my heart to my grandmother and great grandmother who always asked me to search for the purpose in my life by asking the question "What would you like to be when you grow up?" They also planted the feeling of gratitude in me. I also learnt about Buddhist teaching from both of them which makes me live my life in the right way. Although both of them have passed away, I still trust that they always look after and support me on the path that I have chosen to follow. I also thank my uncles, in particular Ajarn Chareonjit Balthip, and aunts.

The turning point in my life of becoming a Ph.D. student at Massey University was when my good friend, Dr. Piyaporn, helped me to contact Professor Julie Boddy at the School of Health and Social Services, Massey University, and Professor Julie agreed to supervise my study. Therefore, I would like to express my gratitude to my excellent supervisor, Professor Julie Boddy. Her door is always open for me. I trust in, and appreciate, her supervision and support. Without her kindness, I would not have had the chance to study at Massey University and conduct the research in which I am interested. Luckily, she agreed that I should study this topic that has rewarded me with greater understanding about the meaning of life. I would like to thank also

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Another group of people who are most important for me are those living with HIV/AIDS and their families – in particular, my participants and their families who have been very generous about sharing their experiences. I also would like to thank the lovely and helpful nurses and health volunteers. Without them, I could not have succeeded in this study. While studying, I always received abundant support and suggestions from two field supervisors: Assistant Professor Dr. Wipawee Kong-In and Assistant Professor Kittikorn Nilmanat, who gave me good advice and support at all times. Assistant Professor Dr. Kanittha, Dr. Petchawan, Assistant Professor Dr. Tippamas, Associate Professor Dr. Praneed, Dr. Kalinga, Assistant Professor Dr. Urai, Associate Professor Usanee, and Assistant Professor Dr. Plernpit also encouraged me and made helpful suggestions and took care of me as if I were their younger sister. Thank you also to Professor Dignam and Dr. Wilson for their help in writing this thesis using grounded theory – very valuable. Writing this thesis in English has not been easy for me as a Thai student. But with the kind help of Ms. Lois Wilkinson, who acted as my aunt, Mrs. Karen Stanley, Mrs.Vivian & Mr. Tony McGlynn, Mr. Wayne Lapwood, Mr. Robert O'Connor, and Ms Victoria Sibley many difficulties were solved.

I also would like to extend my gratitude to those who were my kind teachers such as Associate Professor Dr. Arphorn Churpraisilp, Assistant Professor Patchareeya Chailanga, Associate Professor Dr. Sunutra Taboonpong, Associate Professor Cholada Phantusena, and Associate Professor Dr. Aranya Chaowalit. I also feel fortunate because throughout my life I have had many good persons who are always by my side such as Associate Professor Dr. Jirapa, Assistant Professor Malee, Dr. Somsaowanuch, Dr. Kuephan, Dr. Duljira, Dr. Angkana, Dr. Martin, Dr. Regina, Dr. Alan Winton, Dr. Pisini, Dr. Russel, Dr. Duangrat, Leslie (New Zealand father), Mike, Sally, Pee Paw, Pee Fun, Pee Pun, Pee Noi, Pee Bee, Pee Jueng, Manvir, Pee Mouy, Pee Ma, Pee Aied, Alisi, Kevin, Pee Pap, Lilly, Manvir, Dianne, Nong Nui, and Nong Keng.

Thanks also go to my faculty. Finally, I would like to acknowledge the Royal Thai Government and Prince of Songkla University for providing the scholarships which assisted in the completion of this study. Thank you one and all.

List of Acronyms and Glossary

Acronyms

3TC	Lamivudine
AIDS	Acquired Immunodeficiency Syndrome
ANC	Ante Natal Care
ARC	AIDS - related complex
ARV	Antiretroviral
AZT	Zidovudine (Azidothymidine)
CD4	T-Lymphocyte Count
D4T	combination of stavudine
GPOvir®	Single tablet 3 drugs 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
NAP	National AIDS Prevention and Control Plan
NGO	Non Government Organization
NNRTI	Non-nucleoside Reverse Transcriptase Inhibitor
NRTI	Nucleoside Reverse Transcriptase Inhibitor
NVP	Nevirapine
OI	Opportunistic Infection
OPD	Out Patient Department
PCP	Pneumocystis Carinii Pneumonia
PLWHA	People Living with HIV/AIDS
RTG	Royal Thai Government
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

Glossary

Thai

A

A ho si karm:	Forgiveness or reconciliation. It occurs when people need to forgive someone who has hurt them or made them suffer. It is the way to let go of the suffering.
A nat ta:	Non-existence (one of the Three Principle Aspects of Existence in Buddhist teaching)
A nic ca:	Impermanence, transience of all things (one of the Three Principle Aspects of Existence in Buddhist teaching)

B

Barb:	The bad *karma* or demerit. Thai Buddhism has the concept of *boon* (good deed or good *karma*) and *barb* (bad *karma* or demerit).
Baht:	Currency unit ($ 1 NZ = 20 baht – In January 2009)
Boon:	Merit, virtue or good *karma*
Bun khun:	Gratitude, a deep sense of obligation and the need for affiliation and security (Mulder, 1996).

D

Dhar ma:	Buddha's teachings, Dharma justice, Buddha's doctrine
Duk kha:	Suffering, distress, torment (one of the Three Principle Aspects of Existence in Buddhist teaching)

G

Guy:	Physical form
Guy kang rang:	Being healthy or healthy body

I

*It ti bath si***:**	True equanimity

J

Jai:	A mind or a spirit
Jai dee:	Kindness, a person who is *jai dee* means a person who has the sense of loving kindness, compassion.
Jai kem kang or *Jai kang:*	The mind that has power and becomes strong and able to face any situation (inner strength or strong mind).
Jai sa-ngob:	Calm mind, peace of mind
Jit:	A mind or a spirit
Jum yom:	Accept with conditions

K

Kam lang jai:	*Kamlangjai* is made up of two words: 1) *kamlang* means power, and 2) *jai* means mind. *Kamlangjai* is used in two situations. The first is described as "a state of mental well-being that occurs when the participants have a strengthened mind and feel confident in facing any situation with a sense of purpose in living" (Namjantra, 2003, p. 144). The second can be described as one kind of support.
Kao jai:	To understand, to comprehend
Karm:	*Karma*
Kar ma:	Act, action, deed or sin
Ka ru na:	Compassion
Kem kang:	Strong, vigorous

Ki lase:	Desire, greed, craving
Kreng jai:	Used to describe social order, avoid personal conflict, and maintain harmony in relationships (Bechtel & Apakupakul, 1999).
Kwarm jing kong chee wit:	The truth about life. It is based on Buddhist beliefs and includes: life has both ups and downs; both happiness and suffering are not permanent; death and dying comprise a truth that every human being will encounter as well as the truth that nothing is permanent.
Kwarm sa-ngob jai:	A peace of mind. It is a goal that is based on Buddhist beliefs and practices (Ross, Sawatphanit, & Suwansujarid, 2007).
Kwarm suk jai:	A happiness in the mind

L

La mad:	It refers to muslim prayer. It is a daily reverence and respect paid to God.
Learm or *mai kid:*	Let go, to forget
Long jai:	The mind that feels relief from suffering or distress.

M

Mae:	Mother
Mae che:	Nun
Mai yud tid	Flexible, let go, what will be, will be
Mu thi ta:	Altruistic joy
Met ta:	Loving kindness
Mun jai:	Feeling confident (with something or someone)

N

Na ma:	Mind or mental phenomena
Na ma-ru pa:	The union of mental phenomena (*nama*) and physical phenomena (*rupa*) (Sutheravut, 2007).
Nong:	It means younger sister or younger brother. Sometimes can be used to refer to me or I.

Non clink pai clink ma:	The metaphor of “rolling back and forth in bed” to express the idea of happiness.
Non self (*a nat man* or *a nat ta*):	One of the Three Dharma Seals in Buddhist teaching. It is a key to unlock the door or reality (the same as the Seal of Impermanence). It aims to help people live life more deeply, suffer less, and enjoy life because it teaches them to understand that we are all of the same reality and we have to interrelate with everything else. “*Nonself* also means that you are made of elements which are not you” (Hanh, 2004, p. 135).

O

On jai:	Weakness of mind, the tired feeling that comes from the mind. No energy to move on.

P

Pa lang jai:	*Palangjai* is made up of two words: 1) *palang* means power, and 2) *jai* means mind. It is a state of strengthened mind in facing any situations.
Pee:	It Menas older sister or older brother. Sometimes can be used to refer to me or I.
Plong:	Accept
Ploy:	Release, lay down, let go
Ploy pai:	Let go
Ploy wang:	Accept and let go
Pom doi:	The feeling of being inferior as a consequence of having less sense of self-value.
Pre cept:	It provides the preliminary groundwork for the cultivation of mental (mind) development. There are *five precepts* in Buddhist teaching that consist of 1) admonitions against the destruction of life, 2) not to take things which are not given, signifies respect for others’ rights to posses wealth and property, 3) not to indulge in sexual misconduct,

4) not to tell lies or resort to falsehood, and 5) to refrain from intoxicants.

R

Ru pa:	Body, matter or physical phenomena (Sutheravut, 2007)

S

Sa buy jai:	The state of mind where you are happy and relaxed.
Sa-ngob jai:	A peace of mind
Sa thi:	Mindfulness
Sia jai:	Sadness
Sin wang:	A mind that feels a sense of hopeless
Su:	A mind that feels strong and able to face challenge and face with any situation or fight with any situation.
Suk jai:	A happiness of mind

T

Tam Jai:	To accept, to calm down
Tam dee dai dee, tam sure dai sure:	If people do a good deed, they will also receive a good deed in return.
Tao kae:	A rich person. Normally, it refers to Chinese people who are rich or have a business.
Tor jai or *Toe tare jai*:	A feeling of distress or giving up that relates to a feeling of hopelessness.
Tuk jai:	The mind experiences the feeling of giving up and/or wanting to give up, distress, and suffering.

U

U bek kha or *u pek kha* or *epeksha:*	Equanimity

W

Winyarn:	A mind or a spirit

Y

Pa ya yam mai kid:	Try not to think, let go
Yo ga:	A kind of activity undertaken as either physical exercise or to aid meditation – or both.
Yom rub:	To accept
Yud yun:	Flexible, what will be, will be

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Preface

My interest in the topic of spirituality was sparked in 1997 when I undertook qualitative research for my Master's thesis that opened a door to the world of people living with HIV/AIDS and highlighted the issues of early death from the disease – at that time no antiretroviral (ARV) drugs were available – and the strong discrimination that these people faced. While some participants in that study perceived that people with HIV/AIDS died without dignity, others conducted their lives full of hope, demonstrating a will to live, and apparently achieving harmony and peace in their lives despite their life-threatening circumstances. Some became volunteers to help others with HIV/AIDS, and I noted that a number of participants had lived more than five years despite the unavailability of ARV drugs.

Since that time ARV drugs have become more readily available in Thailand, enabling people living with HIV/AIDS to have hope that they may be able to manage their illness as a chronic, rather than a rapidly terminal, disease. However, the availability of ARV drugs is not sufficient to ameliorate the distress that occurs when people are diagnosed with HIV/AIDS; indeed some people consider committing suicide. Thus I became interested in finding out how people who had lived with HIV/AIDS for five years or longer were able to find peace and harmony in their lives despite living with a deeply stigmatised and life-threatening illness.

There is considerable Western literature that suggests that spirituality provides a buffer against illness and enables people to find personal fulfilment in adversity. Such literature has been influential in education programmes for health professionals in Thailand where the curricula have drawn on a Western body of knowledge and practices. For example, Thai nurses are taught to base their practice on holistic care that meets the physical, psychological and spiritual dimensions of human beings. However there is virtually no research that addresses the meaning of spirituality and the process of spiritual development in the Thai context.

At the outset of this study, as a nurse academic, I was a novice in relation to the meaning of spiritual care; I recognised only that spirituality was an interesting concept that was linked in Western literature to the meaning and purpose of life in human beings. However, I did not have a clear understanding of the concept of spirituality and how it is important to human beings. Therefore, I thought that if spirituality helps people living with HIV/AIDS to find peace in their lives, it is very important to understand and study. Nevertheless, the concept of spirituality is not clearly understood by Thai people as Buddhist teachings are that life consists of body and mind, rather than body, mind and spirit. Thus, I approached participants with questions about what was going on in their lives and what helped them to move on with daily living, in order to inductively derive an understanding of what might enable them to find peace and harmony in their lives and whether the concept of spirituality might fit and be understood in the Thai context.

Please note that the meanings of Thai words presented in this thesis can be viewed either in the squared brackets behind the words or in footnotes. The meanings are summarised in the Glossary.

CHAPTER 1

Introduction and Background to the Study

1.1 Introduction

The aims in this grounded theory inquiry were to gain a better understanding of the meaning of spirituality and of the process of spiritual development in people living with HIV/AIDS in the Thai context. In Western writing, spirituality has been described as the “essence” of human existence (Burkhardt & Nagai-Jacobson, 2002). However, in the Thai context, where Buddhist teachings underpin the understanding of life as body and mind, rather than as body, mind and spirit, the concept of spirituality is little understood by lay people. This gap in understanding called for an inductive approach to knowledge generation.

The choice to explore notions of spirituality in the context of HIV/AIDS was based on the characteristics of HIV/AIDS as a life-altering and deeply stigmatized disease that results in significant distress and calls into question the meaning and purpose of life for many who are diagnosed with the disease; and on the findings in my masters thesis that some participants exhibited peace and harmony in their lives despite living with HIV/AIDS for five years or longer. These findings raised questions firstly as to the process by which those participants achieved peace and harmony despite the nature of the disease and the limited access to antiretroviral (ARV) drugs at the time of that study; and secondly as to whether or not the peace and harmony that they described could be linked to the Western concept of spirituality.

In this chapter, background information on HIV/AIDS is provided that situates the progression and impact of the disease within international and Thai contexts. This section is followed by overviews of Buddhist teachings about life, and the manner in which the notion of spirituality has been introduced and applied in the Thai context. These three sections support the rationale for the grounded theory study undertaken. The significance of the study is identified, the research questions are described and an outline of the structure of the thesis, including a summary of each chapter, is provided.

1.2 Background Information about HIV/AIDS

HIV/AIDS is one of the main causes of illness and death of mature adults in the world (Barnett & Whiteside, 2006). Although progress has been made in the global fight against HIV/AIDS, the epidemic continues to devastate in both developing countries such as Thailand (Ministry of Public Health [MOPH], 2009) and developed countries such as the United States (National Institute of Allergy and Infectious Diseases [NIAID], 2009). The death rates are higher among HIV-seropositive individuals than among HIV-seronegative individuals. By the mid-1990s large numbers of people were becoming ill with AIDS and they required treatment, care and support (United Nations Development Programme [UNDP], 2004). Also the numbers of deaths were starting to mount substantially (Knodel & van Landingham, 2003). In Thailand, life expectancy has decreased as a consequence of the HIV/AIDS epidemic. The mortality rate, in particular of the working-aged population, has increased with HIV/AIDS which has become the first ranked cause of death in this group (Ministry of Public Health [MOPH], 2009). Although a number of policies in healthcare in Thailand – such as Thailand's 100% Condom Use Program and prevention of mother-to-child transmission – have been launched, the MOPH reported that by 31 January, 2009, almost 345,196 Thais were living with HIV/AIDS and that nearly 93,034 had died of the disease (MOPH, 2009). Additionally, the spread of HIV is more varied than a decade ago. HIV continues to spread among diverse population groups such as young people and drug users. HIV prevalence among drug users is high (UNDP, 2004; Joint United Nations Programme on HIV/AIDS [UNAIDS] & World Health Organization [WHO], 2008). Moreover, the number of men who have sex with men has stayed consistently high because Thailand's 100% Condom Use Program has not targeted men who have sex with men (UNAIDS & WHO, 2008).

1.2.1 Modes of transmission

HIV is a fragile virus, therefore although HIV has been found in saliva, tears, nervous system tissue and spinal fluid, blood, semen, vaginal fluid, and breast milk, it is hard to transmit. HIV infection is not spread by casual contact such as hugging, touching items previously touched by a person infected with the virus, or by mosquitoes. It can be transmitted only through direct human-to-human contact. There are the three main modes of transmission. The first mode is unsafe sex including oral, vaginal, and anal sex. Sexual intercourse is the most common method of transmission worldwide including in Thailand. In Thailand, this mode of transmission accounts for 84% (MOPH, 2009) of the total cases. The second mode is transmission from infected mother to child. A pregnant woman can transmit the virus to her foetus through their shared blood circulation, at the time of delivery, and through breastfeeding. The third mode of transmission is through exposure to contaminated blood or the use of contaminated syringes and needles (Barnett & Whiteside, 2006; Neville & Henrickson, 2008). In Thailand, this route of transmission is the second most common method of transmission of HIV because the prevalence of drug users remains high (UNAIDS & WHO, 2008).

In Thailand, since 1989, the MOPH has conducted an HIV National Sentinel Sero-surveillance Survey among specific populations to track the epidemic. The survey reveals that over time different population groups have demonstrated a rapid increase in the incidence of HIV/AIDS infection. The first wave of infection occurred among intravenous drug users. The second wave of infection was among female commercial sex workers (CSWs), with the first direct and then indirect CSWs. The difference between direct and indirect CSWS is that direct CSW service is exclusively sexual; these women always live in brothels and work in or from brothels. Conversely, indirect CSWs are also waitresses, attendants in massage parlours, and entertainers such as dancers (Klunklin & Greenwood, 2005a). The third wave of the Thai epidemic was amongst male clients of CSWs becoming infected with HIV. The fourth wave was amongst wives or girlfriends of men who had contracted HIV in the third wave. The latest wave was amongst the children born from HIV-positive mothers who had contracted the virus (Klunklin & Greenwood, 2005a). Thus the successive waves of infection were related with mode of transmission. Because the first and the second wave of HIV/AIDS infection occurred in intravenous drug users and commercial sex workers, the disease has always been strongly stigmatised in Thai society.

1.2.2 Stages of infection and symptoms

Basic to the immune system are the mononuclear lymphocytes (B cells, T cells) and macrophages (Lovejoy & Sisson, 1989). The process of infection occurs when HIV attacks the human immune system; T cells (CD4 cells) and macrophages are the prime targets. Once the virus fuses with the CD4 receptor of the T cell and implants genetic material (RNA) inside the cell it is safe from the immune system because the virus cannot be identified and destroyed by the defence mechanisms of body (Barnett & Whiteside, 2006; Kenny, 2004). HIV kills immune cells and causes the destruction of the immune system. With reduced immunity, people infected with HIV become susceptible to opportunistic infections, the body vulnerable to many diseases and cancer (Kalichman, 2009). In addition, HIV is also able to infect the neurons of the nervous system, resulting in loss of function such as hearing loss and sensory and motor peripheral neuropathy (Lovejoy & Sisson, 1989). People infected with HIV may have no symptoms for ten years or longer, but they can still transmit the infection to others during this symptom-free period.

CD4 cells are one marker of immune system function (Neville & Henrickson, 2008) and therefore the level of CD4 is often used by researchers to classify HIV/AIDS (McReynolds & Garske, 2001). CD4 counts can also be used to predict the risks for particular conditions such as *Pneumocystis carinii* pneumonia. This can help decide who will benefit from prophylactic (preventative) therapy (Poz Ireland, 2005). The clinical consequences of HIV infection may be classified in four stages (Neville & Henrickson, 2008; Pratt, 1995). The first stage is acute primary infection. In this stage some individuals develop an acute ‘glandular fever-like illness’ 2-6 weeks after primary infection with HIV. This is a result of an immunological response to rapid and widespread dissemination of HIV following primary infection. The early infection stage may last from several months to up to ten years or more. During this time the person may be clinically asymptomatic or have only mild symptoms such as fatigue. Some individuals develop generalized, swollen lymph glands in response to acute HIV infection, which resolve in several weeks (Pratt, 1995). People with antibodies to HIV, detected with an HIV test, are considered HIV positive (Smith, 1996).

The second stage is antibody positive phase. It may refer to asymptomatic HIV infection. Pratt (1995) divided this stage into two phases: asymptomatic HIV infection and persistent generalized lymphadenopathy. In this stage an individual may remain asymptomatic for many years prior to developing clinical illness as a result of infection. Many people may develop a persistent generalized lymphadenopathy which is defined by palpable lymph node enlargement (more than 1 cm.) at two or more extra-inguinal sites, persisting for more than 3 months. The presence of persistent generalized lymphadenopathy does not affect the patient's clinical prognosis and is now considered to be compatible with asymptomatic HIV infection. Currently, it is not known how many individuals who are asymptomatically infected with HIV become ill. In general, the majority will develop symptomatic disease within 10-15 years (Pratt, 1995).

The third stage is early symptomatic disease or AIDS-related complex (ARC) (Neville & Henrickson, 2008). The CD4 cell count is in the range 200-499 cells per cubic millimetre. This stage occurs when there has been no treatment and the immune system gradually weakens, and AIDS develops. Individuals may develop a variety of indicators of ill health due to HIV infection without developing major opportunistic infections or secondary cancer. A person may appear chronically ill and may show a variety of minor opportunistic infections such as oral candidiasis (Pratt, 1995).

The last stage of diagnosis is late symptomatic disease (AIDS). It occurs when the CD4 cell count is less than 200/cubic millimetre and is marked by the presence of opportunistic infections caused by common bacteria, yeast, parasites, and viruses that do not normally develop in individuals with healthy immune systems. However, these opportunistic infections can cause serious disease and fatal illnesses in people living with HIV/AIDS. Patients are admitted to hospital for a variety of opportunistic infections associated with this syndrome. These pathogens depressed the immune system to establish clinical illness (Pratt, 1995).

The common opportunistic infections with a CD4 count below 350 cells per cubic millimetre are herpes simplex virus and tuberculosis. The common opportunistic infections with a CD4 count below 200 cells per cubic millimetre are *Pneumocystis carinii* pneumonia (PCP pneumonia) and Candida esophagitis – a painful yeast infection of the esophagus. The common opportunistic infections with a CD4 count below 100 cells per cubic millimetre are conditions such as Cryptococcal meningitis, AIDS dementia, toxoplasmosis encephalitis – an infection of the brain by a parasite – and wasting syndrome. The common opportunistic infections with CD4 count below 50 cells per cubic millimetre are mycobacterium avium – a blood infection caused by a bacterium related to tuberculosis, and cytomegalovirus infection – a viral infection that can affect almost any organ system (*The New York Times*, 2009).

The most common opportunistic infection of people living with HIV/AIDS in Thailand is mycobacterium tuberculosis (TB), either pulmonary or extrapulmonary. In January 2009, 101,398 persons (29.37%) of those diagnosed with opportunistic infections had TB, 69,447 persons (20.12%) had Pneumocystis carinii, 48,948 persons (14.18%) had Cryptococcosis, 17,140 persons (4.97 %) had Candidiasis (trachea, bronchi) and 11,663 persons (3.38%) had recurrent Pneumonia (bacterial) (MOPH, 2009). The numbers of people with these opportunistic infections have increased compared with 2007 (MOPH, 2007), despite the fact that ARV drugs and prophylactic drugs and treatment are now widely available in Thailand.

Furthermore, the pandemic of HIV/AIDS has led to increased incidence of pulmonary tuberculosis thus undermining the past success in control of that disease. Moreover, people infected with both HIV/AIDS and tuberculosis report that they are faced with double stigma (Balthip, Churprasilp, Chinnawong, & Anumas, 2002).

1.2.3 Treatment

The HIV virus is a retrovirus; therefore, antiretroviral drugs have been developed with the aim of inhibiting the replication process at various stages. A combination of several antiretroviral agents – highly active antiretroviral therapy or HAART – has been highly effective in reducing the number of HIV particles in the blood stream, as measured by a blood test called the *viral load*. Combinations of antiretroviral drugs are used because HIV is very mutable, and quickly develops resistance to one or more of these drugs. The goals are to suppress the HIV viral load to an undetectable level, increase the CD4 count to as close to normal as possible, and delay HIV disease progression (Kenny, 2004). These outcomes can help the immune system recover from the HIV infection and improve T-cell counts (Barnett & Whiteside, 2006; Neville & Henrickson, 2008). A normal CD4 count in people without HIV infection will be approximately 800 to 1,200 CD4+ T cells per cubic millimetre (mm^3) of blood. Some people who have been diagnosed with AIDS have fewer than 50 CD4+ T cells in their body (NIAID, 2009). Although there is no cure for AIDS at this time, a variety of treatments – new therapies, new drugs, and new combinations of drugs – are available that can delay the progression of disease for many years, improve the quality of life of those who have developed symptoms, and reduce mortality rates (Barnett & Whiteside, 2006; Neville & Henrickson, 2008). Life can be significantly prolonged and improved (Barnett &

Whiteside, 2006). In particular HAART is changing HIV/AIDS from a short-term terminal illness to a long-term or chronic condition (McReynolds & Garske, 2001). Medications are also used to prevent opportunistic infections if the CD4 count is low enough. This keeps AIDS patients healthier for longer periods of time. In the rich world, on average people live for ten years before they become ill. In the United States most patients survive many years following diagnosis because of the availability of HAART resulting in increased time from diagnosis to death. However, in poor countries where there are poor nutrition and less access to health care, the illness progresses more quickly (Barnett & Whiteside, 2006). Kalichman (2009) stated that although HIV plays a role in AIDS, HIV itself is too weak to cause AIDS. Many factors can facilitate the progress of HIV/AIDS such as alcohol and conditions of poverty. Thus, those who believe that HIV is insufficient to cause AIDS, encourage people living with HIV/AIDS to make a lifestyle changes such as eating a balanced diet and reducing stress together with the use of antiretroviral drugs.

Antiretroviral drugs must be taken exactly as prescribed (Kenny, 2004), and care must be taken to follow instructions such as those concerning diet. HIV may become resistant to HAART in patients who do not take their medications on schedule. When HIV becomes resistant to HAART, salvage therapy is required to suppress the resistant strain of HIV (Neville & Henrickson, 2008). Treatment with HAART also has other complications. Some common side effects are nausea, headache, weakness, malaise, and fat accumulation on the back and abdomen. When used long term, these medications increase the risk of heart attack by affecting fat breakdown. Moreover, it has been reported that some people do not take precautions against infection as they perceive that this disease is chronic and manageable (Barnett & Whiteside, 2006).

HIV/AIDS treatment in Thailand is based on research findings and recommendations from developed countries. In 2000, the MOPH aimed to make HAART available as a triple-drug regimen. In late 2000, the first national guidelines on the clinical management of HIV infection in children and adults, using triple-drug therapy, were published and distributed. These guidelines included criteria for when and how to start combined ARV. The guidelines also included the management of HIV/AIDS in infants and children, prevention of mother-to-child transmission, and management after occupational exposure as well as clinical approaches to various symptoms of HIV infection such as skin disease, pulmonary problems, and prophylaxis of opportunistic infection. In Thailand, ARV drugs are recommended for people with symptomatic HIV infection, an AIDS-defining illness, or with a CD4 count less than 200-250 cells per cubic millimetre. The first choice for HAART, used with patients who are treatment-naïve, is two nucleoside reverse transcriptase inhibitors (NRTI) and one non-nucleoside reverse transcriptase inhibitor (NNRTI). The least expensive regimen is a combination of stavudine (d4T), lamivudine (3TC), and nevirapine (NVP), which is locally marketed as GPOvir® (Phoolcharoen, Kunanusont, Pitisuttithum, & Bhamarapravati, 2004).

In 2003, the Royal Thai Government launched a programme called "Access for All" meaning that everyone in Thailand – including the general population, asymptomatic HIV-positive people, and symptomatic people living with HIV/AIDS who require ARV treatment – has access to healthcare services. By 2004, through this national access the government aimed to provide ARV to cover 50,000 AIDS patients. Thailand has also been involved in clinical trials of HIV vaccines (Phoolcharoen et al., 2004).

1.2.4 Impact of HIV/AIDS

HIV diagnosis is a life-altering event (Moser, Sowell, & Phillips, 2001) that affects all dimensions of life – body, mind, and spirit – and also impacts on relationships, roles, and lifestyles. People living with HIV/AIDS inevitably face high levels of insecurity and intense suffering because the diagnosis causes physical losses (Dalmida, 2006; McReynolds & Garske, 2001; Richards & Folkman, 1997), psychological trauma, insecurity, uncertainty (Hoy-Ellis & Fredriksen-Goldsen, 2007; McReynolds & Garske, 2001), despair and hopelessness (Kylma, 2005; Kylma, Vehvilainen-Julkunen, & Lahdevirta, 2001) that are associated with the desire to cause self-harm, including suicide (Cooperman & Simoni, 2005).

The prospect of having HIV/AIDS is a distressing circumstance for a number of reasons. Firstly, AIDS has been perceived as a disease associated with death (Portillo, Tom, Lee, & Miramontes, 2003; Songwatthana & Manderson, 2001). HIV/AIDS disrupts people's life plans and family dynamics as well as threatening the meanings and purposes of their life because the course of the illness cannot be accurately predicted and medical knowledge itself is limited. People living with HIV/AIDS must face the possibility of impending death as well as the metaphorical death of hopes and life expectations (Balthip, 1999; Holt, Houg, & Romano, 1999). Furthermore, people living with HIV/AIDS together with their families, friends, loved ones, and caregivers, will most likely experience multiple losses. Currently, although advances in medication are changing the status of HIV/AIDS from that of a terminal illness with an early death to that of a chronic illness, deaths resulting from HIV/AIDS are still occurring (Hoy-Ellis & Fredriksen-Goldsen, 2007).

Secondly, people living with HIV/AIDS and their families have to deal with the stigma and rejection associated with HIV/AIDS (Crawford, 1996; Nilmanat, Street, & Blackford, 2006; Mak et al., 2007; Mak et al., 2006) that erodes the sense of self, changes the perspective of their lives and their relationships with others (Moser et al., 2001). The stigma attached to HIV/AIDS is reported to be greater than that of other comparable illnesses (Balthip, 1999; Crawford, 1996; Mak et al., 2006; van Rie et al., 2008). Furthermore, in some areas – including Thailand – although the ARV drugs are available, discrimination related to HIV/AIDS still continues to occur, including discrimination by healthcare providers who are the main sources of information and knowledge as well as the main supporters of people with HIV/AIDS (Sringernyuang, Thaweesit, & Nakapiew, 2005). The longer people live with the stigma and feelings of inferiority, the more long-ranging psychological effects they have (Holt et al., 1999). Goffman (1963) states that people with stigma often feel as if they are being inhumanly treated and given only a limited chance to live normal lives in society.

Thirdly, the vulnerability, sickness and death of a mature adult in the family does affect the whole family because of the increased dependence of those who are infected with HIV/AIDS on the other family members and on others in society. The family is vulnerable when the family leader or adult who is the main support of the family is infected with HIV/AIDS and becomes ill or dies (Barnett & Whiteside, 2006). Elderly people become caregivers of younger family members who are sick and there is an increase in the number of orphans needing care (Barnett & Whiteside, 2006; Safman, 2004).

Fourthly, the toxicity and side effects of drugs (Schaefer, 1995) lead some people with HIV/AIDS to continue to view the disease as terminal (Hoy-Ellis & Fredriksen-Goldsen, 2007). In some cases, the difficulty of complying or the inconvenience of the regimens (Gold & Ridge, 2001) causes this attitude also. In addition, the regimen of people who take antiretroviral drugs needs to be carefully managed and monitored; adherence to restrictive regimens for self-care, frequent medical appointments, and increased need for certain medications in order to keep themselves healthy and reduce the chance of drug-resistance are all required (Portillo et al., 2003; UNDP, 2004) (as discussed previously).

A number of Thai studies have shown that people living with HIV/AIDS are trying to take care of themselves and manage their situation including taking ARV drugs in order to maintain their health status, with the hope of living a normal life with HIV/AIDS (Namjantra, 2003; Oonkatepon, Nilmanat, & Songwathana, 2006; Siriwatanamethanon, 2008). However medical advances and strict medical and self-care regimens are not sufficient to address the significant distress and questions about the meaning and purpose of life that living with a diagnosis of HIV/AIDS generates. People living with HIV/AIDS have to reconcile themselves to leading a life with a chronic stigmatised and life-threatening illness. Thus a better understanding of the concept of spirituality in the Thai context has the potential to contribute new knowledge of relevance for the well-being of Thai people living with HIV/AIDS.

1.3 Overview of Buddhist Teaching about Life

In view of the facts that more than 90% of Thai people are Buddhist and Buddhism has been integrated into Thai society for more than 2000 years, Buddhism has a strong influence on Thais' way of living – including their perspective on life. According to Buddhist teaching (Dhammananda, 1993) life is a combination of the mind (*nama*[1]) and the matter (body, *rupa*[2]) or *nama-rupa*[3] rather than the three dimensions: physical, mental and spiritual. The whole of one's body that one clearly perceives constitutes a group of material qualities (*rupa*). Physical or matter phenomena are acts of consciousness (mind, *nama*) (Sutheravut, 2007). *The mind* consists of the *combination of sensations, perceptions, volitional activities and consciousness*. *Matter* consists of the *combination of the four elements of solidity, fluidity, motion and heat* (Dhammananda,

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[1] *Nama (Pali/Sanskrit literary language)* means mental phenomena or mind.

[2] *Rupa (Pali/Sanskrit literary language)* means physical phenomena or body.

[3] *Nama-rupa* means the union of mental phenomena (*nama*) and physical phenomena (*rupa*) (Sutheravut, 2007).

1993). The mind or mental phenomena consist of four kinds and four functions: 1) sphere of feeling, 2) sphere of initial sensation (perception or recording or memory), 3) sphere of sustained sensation (mental formations or activity sphere), and 4) sphere of recognition. The four functions are 1) detection, 2) data logging and recording, 3) data processing and matching (memory search), and 4) output that leads to understanding, right-knowledge and points the way to self-realisation. The expression of the mind acts upon the body via vocal or bodily intimation in terms of human personality, behaviour, and emotion. Both positive (moral) and negative (immoral) expression depends on the human state of mind (Sutheravut, 2007). The mind is the key of life (Bhavilai & Freyer, 2006). In the Thai language, lay people use the terms *jai* (mind) and *guy* (body). Thus Thai lay people would say that *jai* and *guy* comprise life.

Buddhists believe that when people have a good mind, the result is good *guy* as when people have a calm mind; they have the ability to gain understanding and insight into the truth, insight about suffering and uncertainty, and the impermanence of life that links with an understanding of *nonself*[4]. This leads to feeling free from need or craving and gaining peace (Hanh, 2004; Suttisakorn, 2006). Bhavilai and Freyer (2006) also highlighted the significant role of mind in Buddhist teaching in that the mind is always creating, affecting the world and all people. The mind affects both the present and the future of individuals. If people use their minds wisely, with compassion for other living beings, the tremendous power of their minds can bring more joy, success, freedom, and happiness into their own lives.

This notion shows clearly that Buddhism gives more credit to the mind than to the body. Buddhists also believe that the mind can be trained. Thus, Buddhism focuses on teaching people to train and develop their minds. This is presented in the first Dharma (Buddhist doctrines) teaching after enlightenment of the *Four Noble Truths* which are: 1) all living things experience suffering, 2) there is a cause of suffering, the cause of suffering is personal desire, 3) there can be an end of suffering or overcoming personal

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[4] *Nonself* is one of the Three Dharma Seals in Buddhist teaching. It is a key to unlock the door or reality (the same as the Seal of Impermanence). It aims to help people live life more deeply, suffer less, and enjoy life because it teaches people to understand that we are all of the same reality and we have to inter-be with everything else. "*Nonself* also means that you are made of elements which are not you" (Hanh, 2004, p. 135). Some books refer to the *nonself* term as *anatman* or *anatta* (Hanh, 2004).

desire, and 4) one can take actions to end suffering called the *Noble Eightfold Path*[5] that includes right mindfulness which is the heart of the Buddha's teaching (Hanh, 2004).

Mindfulness meditation is the method to bring people back to the present moment and assist them to come to an end of suffering (*dukkha*). The Buddha taught that the three causes of suffering are attachment, aversion, and delusion (Bonadonna, 2003). Therefore, when people have mindfulness, they are able to be present, to nourish the object of their attention; to relieve both their own suffering and the suffering of others, being calm and having concentration, understanding, and transformation. As a consequence, practising mindfulness can heal and refresh elements of life, lead to a happy and healthy life, and bring peace, joy and freedom (Bonadonna, 2003; Hanh, 2004). Thus, in the *Noble Eightfold Path* that provided the ways for human beings to be free from suffering, right mindfulness is the core. Buddha asserted that once right mindfulness is present, the *Four Noble Truths* and the seven other elements of the *Eightfold Path* are also present (Hanh, 2004). Furthermore, the Buddha also provided the way to practise meditation (mindfulness) that has been illustrated in many Buddhist books (e.g. Hanh, 2004). This traditional Buddhist view about life has been challenged by the introduction of the concept of spirituality that, for the majority of Thais – who are Buddhist – does not have a clear meaning.

1.4 Spirituality in the Thai Context

Thailand still faces some difficulty with the word *spirituality* and its translations from English into Thai, not only because of technical aspects but because, as illustrated above, this word and concept are being grounded in a different culture and religion. Western understandings of spirituality are likely to be influenced by their preferred religions, such as Christianity (Sheldrake, 2007), whereas the concept of spirituality to Thai people is influenced by Buddhism in particular (Tongprateep, 2002). At the outset of this study (2005), there was debate at a scholarly level about the concept of spirituality. Some Thai scholars have argued that spirituality is only a consequence of the mind that has been trained because one of the results of training the mind is gaining wisdom or insight (e.g. Phra Dhammapitaka, 2003). This argument is supported by Wasi (2000)

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[5] *Noble Eightfold Path* is one truth of the *Four Noble Truths*. It is the path to guide human beings to be free from suffering. It consists of the Eightfold Path: right thinking, right mindfulness, right view, right speech, right action, right diligence, right livelihood, and right concentration.

who states that spiritual well-being is the well-being that is augmented when people do a good thing or the mind is touched by a good thing such as engaging in, and following, a religious doctrine or following the Dharma (Buddhist teachings).

There was also discussion at governmental levels as Thailand attempted to integrate elements of the World Health Organization (WHO) definition of health into a Thai definition of health. Since 1980, member states of the World Health Organization in the Eastern Mediterranean Region have attempted to include "spiritual health" into the World Health Organization's (WHO) definition of *health* (Chokwiwatana, 2008). Finally, in 1997 the Executive Board of the WHO proposed the following amendment of the definition of health as, "*Health is a dynamic state of complete physical, mental, spiritual and social well-being and not merely the absence of disease or infirmity"* (Khayat, 1998, p. 5). However, the proposal was not accepted as a resolution at the World Health Assembly. Thus the definition of health remains the same as stated in the preamble of the Constitution of WHO – "the state of complete physical, mental and social well-being and not merely the absence of the disease or infirmity" (Chokwiwatana, 2008, p. 28).

Influenced by discussion at the World Health Assembly and by the writings of Khayat (1998) an attempt was made in Thailand to create a definition of spirituality for a culture where the Buddhist majority believe that health is the harmony of body and mind. This attempt brought about strong controversy rooted in some leading Buddhist organisations which rejected the "spiritual dimension" as a concept influenced by a theistic paradigm which is opposite to Buddhism. The first Thai adaptation of the WHO definition of health was "the dynamic state of complete physical, mental (*jit*), spiritual (*jitwinyarn*) and social well-being and not merely the absence of disease or infirmity" (Chokwiwatana, 2008, p. 28; The Network of Buddhist Organizations of Thailand, 2003, p. 3). This definition joined two words *jit* and *winyarn* that have the same meaning (which is *mind* in Buddhism) in order to define the term spirituality (*jitwinyarn*). This definition was disputed on the basis that, from the Buddhist point of view, grouping two words that have the same meaning (in Buddhism) together, appeared to discredit Buddhism (The Network of Buddhist Organizations of Thailand, 2003). Furthermore, the new term to refer to spirituality in Thai words was not familiar to Thais (Bhawilai, 2003). Thus, the Network of Buddhist Organizations of Thailand

and other Thai scholars tried to find a new word and definition that were more acceptable for the term *spirituality.*

In March, 2007, the Health Act 2007 was announced. Finally, consensus had been reached on acceptance of the term "intellectual well-being" as the fourth dimension of health (Chokwiwatana, 2008). This Act included a new definition of *health* as "the state of human being which is perfect in physical, mental (*jit*), spiritual (*panya*) and social aspects all of which are holistic in balance" (Chokwiwatana, 2008, p. 28). It also proposed the Buddhist way of development of the four dimensions of health (Chokwiwatana, 2008). In this, in the Health Act 2007, the term referring to spirituality in the Thai language was changed from *jitwinyarn* to *panya*.

> *Panya*, in this definition, refers to a state (of mind) that is able to feel, perceive, understand, and able to identify between the good and the bad, valued and not-valued, and that enhances a state of moral, pleasurable and generous mind that consists of loving-kindness, compassion, and altruistic joy (The National Health Committee, 2007, p. 1).

Therefore, the definition of health in Thailand includes a spiritual dimension that is consistent with the precepts of the WHO. However, from my point of view, the new definition of health which was launched after the commencement of my doctoral research still shows the gap that exists between the perspectives of lay people and academics. The new notion of spirituality was accepted by scholars, the Thai academic community and those at government level only. It was still not fully understood and widely known by many Buddhist and lay Thai people. Furthermore, although in the new definition some words were changed for greater clarity, the words "human being" are used as a central focus which is contrary to the Buddhist emphasis on "life" that is familiar to lay people.

As a consequence, although some healthcare services in Thailand are alert to the need to provide spiritual care – such as providing a prayer (*lamad*) room for Muslim patients and allowing monks to visit Buddhist patients who are admitted to the hospital – there is no clear picture of how spiritual care ought to be provided in the health care services. Therefore, more knowledge about spirituality in the Thai context is urgently required.

In particular, there have been few studies that report what role spirituality plays in overcoming the distress of people living with a life threatening illness such as HIV/AIDS. Also much prior research involves quantitative measures that provide an indication of the relative association of differing variables, but do not provide health professionals with sufficient depth of understanding to enhance their practice. Through more research, this concept could be made more practical and ways developed that could enhance the well-being of people. If all sectors recognise the importance of spirituality and endeavour to make spirituality clearer, this goal could be achieved.

1.5 Significance of the Study

Although Western literature shows a significant role for spirituality in finding meaning and purpose in life, nurturing good health, healing, and well-being (Amenta & Bohnet, 1986; Coleman, 2003; Sessanna, Finnell, & Jezewski, 2007); and providing inner strength, comfort, peace, wellness, and wholeness (Walton, 1999), there is no evidence of any in-depth studies that address the meaning of spirituality and the process of spiritual development in people living with HIV/AIDS in the Thai context. For the reasons outlined in the previous sections the meaning of spirituality and process of spiritual development in Thai people remain unclear.

Thai nursing education and curricula have been strongly influenced by the Western body of knowledge and practices including the notions of body, mind and spirit (Tongprateep, 2002). Sometimes, the knowledge and practices are not compatible with the understanding and context of ordinary people, most of whom are Buddhists. As a nursing professional and healthcare provider, I wonder how healthcare providers communicate with local people if they use different terms and they have a different paradigm of life and health.

In research undertaken about spirituality in the Thai context the Western concept of spirituality has, for the most part, been adopted without any questioning of its validity for that context. For example, a number of researchers have used existing (Western) questionnaires about spirituality as the basis for their research (e.g. Samuksaman, 2007) or have studied selected aspects of spirituality such as spiritual health (Rattanapun, 1997), spiritual need and spiritual practice (Saisuk, 2001) and self-transcendence

(Kasemkitwhattana & Rojanapakorn, 2004) – concepts which are difficult to understand when translated into the Thai language. Tongprateep (2000) conducted a phenomenological study on spirituality among rural Thai elders and identified the essential elements of spirituality as being spiritual beliefs (the law of *karma* and life after death); religious practices (merit making, observance of moral precepts[6], gratitude and caring in the family and meditation); and consequences of spirituality (coping with the vicissitudes of life, being hopeful and having a peaceful mind). More recently Ross et al. (2007) also cited the practices of women living with HIV/AIDS in Thailand that were based on their understanding of Buddhist beliefs as evidence of spirituality. The lay understanding of the concept of spirituality was not addressed in these studies. I have been argued in Western literature that spirituality is allied to religion, but is separated from it (Galanter, 2005) and is broader than the person's religious preference, religious beliefs and religious practices (Sessanna, et al., 2007). However, in the Thai context spirituality has been associated with religion – in particular, with Buddhism (Ross et al., 2007; Samuksaman, 2007; Tongprateep, 2000; Wasi, 2000). In many documents in Thailand the attributes of spirituality are often defined as related with religion – in particular with Buddhist teaching.

Research to date is also limited by the methods and methodologies used. The majority of studies are quantitative cross-sectional studies, which are limited in their ability to provide in-depth understanding of spirituality or to question assumptions as to the validity of the concept. The phenomena of the meaning of spirituality and the process of spiritual development in the Thai context are little understood; therefore an inductive approach to knowledge generation using grounded theory methodology is appropriate with this study (de Laine, 1997; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Researchers using grounded theory look for processes which are going on in the social scene and are interested in patterns of action and interaction between and among various types of social units (Stern, 1994) (as discussed in Chapter Three).

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[6] *Precepts* provide the preliminary groundwork for the cultivation of mental (mind) development. There are *five precepts* in Buddhist teaching that consist of 1) admonitions against the destruction of life, 2) not to take things which are not given, signifies respect for others' rights to posses wealth and property, 3) not to indulge in sexual misconduct, 4) not to tell lies or resort to falsehood, and 5) to refrain from intoxicants.

1.6 Research Questions

In this study I proposed to illuminate the meaning of *spirituality* and the process of *spiritual development* from the perspective of people living with HIV/AIDS for five years or more in the South of Thailand. The two principal questions at the outset of this study were:

1. What does spirituality mean to people living with HIV/AIDS in the Thai context?
2. How do people living with HIV/AIDS in Thailand develop their spirituality?

However, because the Western term *spirituality* [translated into Thai as *jitwinyarn* at the time of data collection in 2006] was not likely to be clearly understood by participants in the study, I approached participants with two main interview questions about what was going on in their lives and what helped them to move on with their daily lives, to inductively derive an understanding of what might enable them to find peace and harmony in their lives and whether the concept of spirituality might fit and enhance understanding (Strauss & Corbin, 1990) in the Thai context.

1.7 Outline of the Structure of the Thesis

This study is presented in eight chapters. In Chapter One, background information about HIV/AIDS has been provided that situates the progression and impact of the disease within international and Thai contexts. This section is followed by overviews of Buddhist teachings about life and the manner in which the notion of spirituality has been introduced and applied in the Thai context. These three sections support the rationale for the grounded theory study that was undertaken. The significance of the study is identified, the research questions are described and an outline of the structure of the thesis, including a summary of each chapter, is provided.

In Chapter Two, there is an outline of the concept of spirituality which is composed of three parts: firstly, spirituality in the Western context; secondly, spirituality in health, and finally, spirituality and the nursing profession.

In Chapter Three, the concept of *grounded theory methodology,* the epistemology and philosophy that underpin grounded theory methodology, the evolution of grounded theory methodology, and nursing and grounded theory are illustrated. The rationale for selecting Straussian grounded theory methodology to direct this study to achieve the aims of the researcher is provided. Also the ethical considerations, designs and methods and establishing research trustworthiness are described.

In Chapter Four, an overview of the phenomenon of **Achieving Harmony of Mind**, the core category that was generated from dialogue with participants who had lived with HIV/AIDS in Thailand for five years or more is outlined. The first category – **struggling to survive** – and the first subcategory (*encountering distress*) are explained and discussed using the format of the paradigm model – conditions, actions/interactions (strategies), and consequences. The process that occurred when the participants perceived that their lives were turned upside down is presented.

In Chapter Five, the second subcategory of **struggling to survive** – *overcoming distress* – is described. *Overcoming distress* describes the process by which the participants learn to survive and overcome their distress. In this process, finding meaning and purpose in life is the key action/interaction (strategy) that enables participants to move through their life-altering situation.

In Chapter Six, the overview of the second category – **living life** – and the first subcategory – *accomplishing harmony in oneself* – are demonstrated. **Living life** consists of two subcategories which are *accomplishing harmony in oneself* and *discovering an ultimate meaning in life.* This process also showed the phenomenon that the participants also have two possible choices to go through. The final result of the first choice is living as normal (discussed in Chapter Six). The final outcome of the second choice is achieving peace and harmony (discussed in Chapter Seven). In Chapter Six, the process of *accomplishing harmony in oneself* when the participants understand and accept themselves as a people living with HIV/AIDS is presented.

In Chapter Seven, the second subcategory – *discovering an ultimate meaning in life* – is described. *Discovering ultimate meaning in life* is the subprocess in **living life** that describes the process by which the participants learn to live their life in order to reach the ultimate goal of life. In this process, understanding the truth about life and living life with contentment are the keys that assist participants to gain peace and harmony or *kwarmsa-ngobjai.*

In Chapter Eight, the concept of theory development and the substantive theory **Achieving Harmony of Mind** are explained and discussed with reference to extant literature, studies or knowledge. In addition, the limitation, the implications, and recommendations of this study are examined.

1.8 Conclusion

The purpose of this study was to gain knowledge about the meaning of spirituality and the process of spiritual development in people living with HIV/AIDS in the Thai context. Understanding the process of spiritual development permits the transmission of instruction that enables nurses to move beyond the mere physical approach to a holistic approach to care.

The study findings could be applied by Thai nurse educators/scholars to develop new nursing curricula or provide a critique for current curricula that are based on Western culture. A new curriculum developed according to the study results would be more suitable for the Thai cultural context and the real situation of local and ordinary people. Therefore, I hope that this study can help health professionals to approach and provide spiritual care with fewer gaps because they would have guidelines that stemmed from the local Thai people rather than being influenced by other cultures. Last but not least, the findings could be used as fundamental knowledge guiding authorities and policy makers to formulate spiritual concepts in Thailand in a more practical way that suits the Thai context in general as well as promoting spiritual well-being in people living with HIV/AIDS in Thailand.

CHAPTER 2

Literature Review

2.1 Introduction

In the previous chapter, I presented the introduction and background to the study including overviews of Buddhist teachings about life, and uses of the term ‘spirituality’ in the Thai context. As explained in the previous chapter, Western notions of spirituality have been strongly influential on the Thais’ perspective in particular at a scholarly level. Thus, this chapter is a review primarily of Western literature about the meaning of spirituality and spirituality in relation to health and health care both prior to undertaking this study and literature located throughout the duration of the study. The literature review encompasses three parts: firstly, spirituality in the Western context; secondly, spirituality in health, and finally, spirituality and the nursing profession.

There is some debate about the position of a literature review in qualitative research which includes grounded theory. Proponents of Glaserian grounded theory disagree with the use of literature before entering the field, while Strauss and Corbin acknowledge that experience and knowledge are what sensitise researchers to significant problems and issues in the data and allow them to see alternative explanations and to recognise properties and dimensions of emergent concepts (Strauss & Corbin, 1990). In addition, in the context of doctoral study, a preliminary review of the literature can assist the researcher to identify gaps in previous studies, provide a rationale for the proposed research, and guide research questions before data collection is commenced. Later, the literature review can play an essential role by supporting the emerging theory. Thus, in this study a literature review was undertaken in two stages. At first the literature review was undertaken in order to identify the significance of the study and analyse the gaps in existing knowledge in order to ensure the potential for contribution of new knowledge prior to submitting a proposal for doctoral study. The first stage of the literature review is mostly presented in this chapter. In the second stage, a more in depth literature review was conducted after the categories had finally emerged and these categories are either included in this chapter or, where appropriate, fully explained and discussed in conjunction with the data that emerged in the findings chapters (Chapters Four to Eight).

2.2 Spirituality in the Western Context

Basically, from around the period of the 16th century, the great philosophical distinction between mind and body that was mainly supported by Rene Descartes (1596-1650) had a strong influence on the Western perspective (Wozniak, 1966). Descartes distinguished between the *res cogitans* which referred to the soul or mind, and the *res extensa* which referred to the body. In more recent years, Western neuroscientists and cognitive psychologists have argued that this ontological separation of mind and body is no longer acceptable (Bracken & Thomas, 2002). Bracken and Thomas (2002) argued that the doctrine – mind-body split – may undermine the ability to understand human beings.

Spirituality has been described as an abstract, multifaceted dimension interacting at many levels of awareness (Stoll, 1989). It is a unique and dynamic process because people experience their spirituality in special ways and through an ongoing process. A number of researchers describe spirituality as *an individual experience, subjective experience* (Meraviglia, 1999) *and a way of being* (Burkhardt, 1994). Barnum (2003) argued that spirituality is a term that is used in many societies but that the term means different things to different people. Because spirituality is a unique and individual experience, a way of being, it cannot be accurately described (Fawcett & Noble, 2004; Meraviglia, 1999; Van Loon, 2005).

The origins of the concept of spirituality lie in Christianity in particular, although the term is also applicable in other religions that are underpinned by theism as illustrated by the push from the Eastern Mediterranean region at WHO for the inclusion of spirituality in the definition of health (addressed in the previous chapter). In Christian terms spirituality refers to *"the way our fundamental values, life styles, and spiritual practices reflect particular understandings of God, human identity, and the material world as the context for human transformation"* (Sheldrake, 2007, p. 2). However, sometimes the term is unclear and difficult to define because the use of the term has deviated from its origin (Sheldrake, 2007). Thus, some authors (e.g. Sims & Cook, 2009) said that spirituality and religion have overlapping but distinctively different meanings.

The term *spirituality* is rooted in the Latin *spiritualitas* (Sheldrake, 2007) or the verb *spirare* which means 'to breathe'. The adjective "*spiritualis* means of or belonging to breathing or to air" (Wiseman, 2006, p. 1) which is a Western word that refers to the breath (Chiu, Emblen, Hofwegen, Sawatzky, & Meyerhoff, 2004; Sheldrake, 2007). Spirit is opposed to body and material reality (Wiseman, 2006). Burkhardt and Nagai-Jacobson (2002) claimed that spirituality is very similar to breathing, which, as well as spirituality, is essential to our human existence. Thus, it is noted that this word is important for life because it is only through breathing that human beings can stay alive (Speck, 1998; Wiseman, 2006). Spirituality is also described as an integrating force (Culliford & Eagger, 2009) energy, power, courage, motivation, guidance, a striving for inspiration, a unifying force (Burkhardt, 1989, 1994; Chiu et al., 2004) the core of life and a search for existential meaning (Speck, 1998) that enables and motivates human beings to search for meaning and purpose in life (Barnum, 2003; Sellers & Haag, 1998; Sheldrake, 2007). However, Sheldrake (2007) argued that spirituality has had broad uses beyond an individual quest for meaning – rather, it appears in debates about public values or the transformation of social structure.

In this study I aimed to understand the meaning of spirituality and spiritual development in people living with HIV/AIDS in a Thai context and to develop a substantive theory based on this phenomenon. Therefore, this literature review is focused on spirituality in health.

2.3 Spirituality in Health

Spirituality is fundamental to humanity and therefore it is an important factor in the health, illness, and well-being of people (Khayat, 1998; Thoresen, 1999). Khayat (1998) – the Deputy Regional Director of WHO's Office for the Eastern Mediterranean – highlighted the concerns expressed by Dr. AI-Awadi (1983, cited in Khayat, 1998) that the progress in control of material matters – materialism – is leading people to seek full control of all aspects of life that cause anxiety, restlessness, as they strive desperately to find tranquillity and peace of mind, while feeling loss, and uncertainty. Anything which we do "to provide health care for the body and the mind, man shall remain lost and restless until we provide for the spiritual aspect of life" (Khayat, 1998, p. 2). In other words, people cannot find peace if they cannot receive spiritual support. However the provision of spiritual support is dependent on an understanding of the meaning of spirituality in the context of health and health care.

2.3.1 Definitions, attributes, and empirical indicators of spirituality in health care

Although some studies (e.g. Chiu et al., 2004; Sessanna et al., 2007) have focused mainly on critiquing the concept of spirituality in nursing and health, findings differ because it is difficult to completely define the concept of spirituality (Burkhardt, 2007; Meraviglia, 1999). This is consistent with McSherry and Cash (2004) who developed a taxonomy of spirituality in nursing and argued that spirituality in nursing has many layers. While the ‘extreme left’ of spirituality in nursing defined this concept based on religion, the ‘extreme right’ of spirituality in nursing defined this concept based on secular, humanistic, and existential elements.

Nowadays, many researchers and scholars both from nursing and health-related and other areas have tried to conduct research in various contexts and among many groups of people including those with HIV/AIDS (e.g. Hall, 1998; Meraviglia, 1999; Walton, 1999) in order to build up a clearer conceptualisation of spirituality. Each document and researcher in Western culture (e.g. Barnum, 2003; Burkhardt, 1994, 2007; Fawcett & Noble, 2004; Golberg, 1998; Highfield, 1992; Meraviglia, 1999; Martsolf & Mickley; 1998; Newshan, 1998; Relf; 1997; Sessanna et al., 2007) shows both similarities and differences in their definitions, attributes, and empirical indicators of spirituality and these have been grouped and labelled. So, the definitions of spirituality are varied. In general spirituality includes one or more of the following definitions, attributes, and empirical indicators.

2.3.1.1 Spirituality is interchangeable with religious concepts

Some researchers (e.g. McSherry & Cash, 2004; Sessanna et al., 2007) have reported that spirituality overlaps with the concept of religion which is the ‘old traditional or historical form’ from the taxonomy of spirituality which is identified by McSherry and Cash. Therefore, in some documents spirituality has been defined as a religious system of beliefs and values (ultimate values) including church attendance; church affiliation; having belief in a higher power or being; and residence in a religious community (Sessanna et al., 2007). This may be because religion provides a way to express beliefs, attitudes, and pattern of behaviours towards the supernatural (Halstead & Hull, 2001).

Furthermore, belief and trusting in themselves, others, and God or another supreme being significantly influence hope, the will to live, and meaning and purpose (Meraviglia, 1999).

2.3.1.2 Spirituality is the meaning and purpose in life and/or fulfilment in life

Some authors have said that the meaning of life or search for meaning is a significant task of human beings and it is the essential component of spirituality giving purpose to their lives and way of living (Barnum, 2003; Burkhardt, 1994; Dyson, Cobb, & Forman, 1997). McSherry and Cash (2004) claimed that authors who defined spirituality related with meaning and purpose in life represents the ‘new or post modern form’. Meaning is the ontological significance of life, making sense of one’s life situation (life, illness and pain) (Newshan, 1998), and deriving purpose from existence (Martsolf & Mickley, 1998). Therefore, finding a meaning and purpose in life refers to the desire of the person to find the answers to ultimate questions about the meaning of life, illness, and death so as to live life with fulfilment and with satisfaction (Chiu et al., 2004).

2.3.1.3 Spirituality is connection

Spirituality is defined in terms of relationship and connectedness (Burkhardt, 1989; Chiu et al., 2004; Meraviglia, 1999; Newshan, 1998). In some articles (e.g. Dyson et al., 1997; Sessanna et al., 2007) the meaning and purpose in life have been integrated into connectedness because these authors claim that those attributes are derived from a sense of relatedness and the promotion of interpersonal bonds. Finding a meaning in life emerges from the relationships between self, others, God and the environment (Martsolf & Mickley, 1998; Meraviglia, 1999; Relf, 1997; Sessanna et al., 2007) which brings hope to our existence (Chiu et al., 2004). Thus, meaning can be articulated in the context of those three key elements – the relationships among self, others and God. Connectedness is composed of two aspects – the vertical and horizontal dimensions. The vertical dimension represents one’s relationship, expressed through prayer, with God or supreme beings. The horizontal dimension includes one’s relationship with the self, others, or nature (Meraviglia, 1999). Self, others and God provide the key elements within a definition of spirituality and spirituality also focuses on the relationship between self, others and God. This includes the need for reconciliation and forgiveness, and the need for friends, families and relationships, expressing guilt and expressing anger with self and others (Newshan, 1998). This provides a force to activate or influence the individual and the purpose of life (Dyson et al., 1997). In addition, some authors have claimed that spirituality is the essence of being, becoming, and doing that develops in relation to others; what they do for others, the world, and themselves (Burkhardt, 1994; Stoll, 1989). This response illustrates the human connection with something bigger than themselves and involves both a receptive openness to life and an active seeking, and discovering (Martsolf & Mickley, 1998).

In nursing, studies have shown that *connection* is the core of nursing. Golberg (1998) revealed that although the phenomenon of spirituality can be divided into two kinds of relationships: 1) the physical relationship (presence, touch and healing) and 2) emotional relationship (meaning, empathy/compassion, hope, love, and religion/transcendence), in nursing care, spirituality is collapsed into only *connection*. This links with Burkhardt (1994) who revealed that spirituality is described in terms of relationship and sense of connection. In nursing, *connection* refers to *the relationship between nurse and patients* or *the work that nurses do for the patients* (Burkhardt, 1994) that sometimes can refer to *the presence of nurses to patients*. Thus, some nursing authors (e.g. Burkhardt, 1994; Golberg, 1998; Walton, 1999) have found that *presence* is the essence of spirituality – in particular, in nursing care. *Presence* is described as *a holistic way of being interpersonally, transpersonal, and spiritually with another in a relationship*. Presence is *a way of being that involves a deep contact* or *connection* and presence can be *a way of being-with and being-there that provides the sense of comfort and of being cared for* (Covington, 2003). Walton (1999) defined a new conceptualisation of spirituality in people with an acute myocardial infarction who receive presence from God, nature, friends, family, and community which was the greatest influence and nurtured them with life-giving force which led to recovery. In this study Walton claimed that presence is an important attribute of spirituality. Consequences of connection are love, harmony, and integrative wholeness because a close relationship where there is unconditional acceptance (Chiu et al., 2004; Dyson et al., 1997) produces love. Buddhism also mentions love.

> Love is an active force. Every act of the loving one is done with the stainless mind to help, to succour, to cheer, to make the paths of others smoother and more adapted to the conquest of sorrow, the winning of the highest bliss (Dhammananda, 1993, p. 167).

Universal love or *metta* can never end in disappointment or frustration because it expects no reward. It creates more happiness and satisfaction (Dhammananda, 1993). Having connectedness is also enhancing harmony (harmony with oneself, others, and God) (Dyson et al., 1997). Burkhardt (1994) explored women's understandings of spirituality with 12 women and revealed that women perceived that a sense of relationship with others, with God, and taking time to be in touch with themselves, and the world were all sources of nourishment for them.

2.3.1.4 Spirituality is a metaphysical or transcendent phenomenon

Spirituality is also viewed as a metaphysical or transcendent phenomenon (Reed, 1992; Relf, 1997). Markham (1998) summarised spirituality into three elements: 1) "it is opposed to a reductionist account of personhood" (p. 74), 2) "it provides a meaning expressed in certain beliefs and values" (p.74), and 3) "it is linked to the transcendent" (p. 74). Highfield (1992) described spirituality in terms of *self-transcendence* – transcending the awareness of self – that is the essence of human beings. In some documents *transcendence* is described as an attribute of spirituality – but in others this concept is described as an outcome of spirituality (Meraviglia, 1999). Several researchers (Chiu et al., 2004; Martsolf & Mickley, 1998; Sessanna et al., 2007) have conceptualised *transcendence* as *a level of awareness through which a person achieves new perspectives and experiences and appreciation of a dimension beyond self, exceeding ordinary physical boundaries and moving beyond the physical or transcending the physicality of the immediate situation*. They also transcend the present context of reality and exist throughout and beyond time and space, which leads to expanded consciousness, metaphysical issues, transcending reality, and being multidimensional. Transcendence is related with increasing mental well-being and decreased perception of illness distress in people living with HIV/AIDS (Coward & Lewis, 1993).

2.3.1.5 Spirituality comprises of hope and will to live

Other attributes that are important and stand for spirituality are *hope* and the *will to live*. These are closely linked, and both are forces which are vital to life (Hall, 1994; Relf, 1997; Ross, 1995). Being alive is necessary for an awareness of one's spiritual dimension (Meraviglia, 1999). It is a basic resource for humans and contributes to the continuity of life by giving the strength to live and carrying a person through difficult times (Cutcliffe, 1995; Kylma, 2005). "The consequences of hope are (good) life, wishes and pleasure" (Kylma, 2005, p. 624). Lin and Bauer-Wu (2003) reviewed 43 primary research studies of psycho-spiritual well-being in patients with advanced cancer, showing that it was important for patients to have a sense of hope together with knowing that life has meaning and purpose. Hope and the will to live are reported to play an essential role in both overcoming an illness and overcoming a death sentence and are closely linked to various health-related outcomes such as physical health, spiritual well-being, and experiencing a sense of meaning in life (Chiu et al., 2004).

2.3.1.6 Spirituality as part of universal dimension of mind

Another definition of spirituality is as *part of the universal dimension of mind.* Helminiak (1996, cited in Newshan, 1998) claimed that spirituality can be considered to be a subspeciality of psychology and that the defined mind has two interrelated components: 1) the *psyche,* which is characterised by emotion, memory, personality, thoughts and dreams, and 2) the *spirit,* which is characterised by self-awareness, insight, creativity and self-determination. It is difficult to distinguish the spiritual from the psychological because they are interrelated.

Mind in psychology, as defined by Wundt (cited in Suttisakorn, 2006), is *the consciousness that is composed of sensation, image and feeling.* Sarter (2002) claimed that a healthy mind can think rationally, can learn new ideas and express them clearly to others, and is able to solve new problems. A healthy mind is actively learning no matter what the person's age, and is associated with a sense of optimism that is important for mental health. This notion is consistent with the recent study in Thailand (Sutheravut, 2007) and Buddhist teaching (Suttisakorn, 2006) that when people develop their mind and gain a stable state of mind so that their mind is settled, clear and pure, they can learn and understand situations such as the truth of illness, themselves, and life and death, and they are able to accept these without prejudice. However, it is noted that as a consequence of the very broad and inconsistent definitions of spirituality (e.g. Fawcett & Noble, 2004; McSherry & Cash, 2004), some authors are concerned that the complexity can lead to lack of significance of this concept and may obstruct application of the concept within practice and education (McSherry & Cash, 2004; Van Loon, 2005).

2.3.2 Significance of spirituality for health

As described, in Western culture, spirituality has been documented as one of the most important dimension of human beings (Amenta & Bohnet, 1986; Barnum, 2003; Coleman, 2003; Meraviglia, 1999; Thoresen, 1999). It plays a vital role in nurturing good health, healing, well-being (Amenta & Bohnet, 1986; Coleman, 2003; Sessanna et al., 2007) and an integrative growth process (Chiu et al., 2004). It also provides inner strength, comfort, peace, and wholeness (Walton, 1999) in many groups of people. Spirituality is also reported to enhance coping (Bosworth, 2006; Walton, 1999). Chibnall, Videen, Duckro, and Miller (2002) studied psychosocial- spiritual correlates of death distress in patients with life-threatening medical conditions including HIV/AIDS and found that spiritual well-being was negatively correlated with death distress – maybe because spirituality buffers the fear of death. Patients' spiritual beliefs can offer support at the end of life (Lyon, Townsend-Akpan, & Thompson, 2001), help them to deal with unanswerable questions about death (Hall, 1998), and remain calm in the face of difficulties in life as well as provide comfort and peace (Walton, 1999).

Many authors have found that spirituality influences recovery from illness and motivates one's life, health, behaviour and relationships (Coleman, 2003; Golberg, 1998; Oldnal, 1995; Walton, 1999) and that it is necessary to promote greater cost-effectiveness and efficiency (Oldnal, 1995). Spirituality also grants a sense of meaning, purpose and coherence to life (Bosworth, 2006) that is expressed in one's being, knowing, and doing, and is experienced within caring connections with self, others, nature, and ultimate other (Burkhardt, 1994). A qualitative study that was focused on patients with serious mental illness showed that the participants became more connected to religion or spirituality as a way of moving forward (Ochocka, Nelson, & Janzen, 2005). People who are spirituality grounded have been reported to live longer and show significant improvement of quality of life and life satisfaction (Belcher, Dettmore, & Holzemer, 1989; Cotton, Puchalski et al., 2006; Cotton, Tsevat et al., 2006; Thoresen, 1999; Tsevat, 2006; Tsevat et al., 1999; Tuck, McCain, & Elswick, 2001). For people whose partners had died from AIDS, it was illustrated that spirituality involving beliefs, experiences, rituals, social support, and roles were used to help them incorporate the facts of death and these were appraised as sources of comfort and meaning in life (Richards, Acree, & Folkman, 1999; Richards & Folkman, 1997). A systematic review in the context of cancer research shows that although, when living with cancer, people have to face uncertainty and unpredictability, individuals who are successful in their search for meaning appear to achieve positive effects such as enhanced self-esteem, greater life satisfaction, and less distress (Lee, Cohen, Edgar, Laizner, & Gagnon, 2004).

Spiritual well-being, psychological well-being, and physical well-being are also outcomes of spirituality and spirit is something that motivates the body (Golberg, 1998). In Western culture, spiritual well-being is a behavioural expression of spiritual health that is shown by a sense of inner harmony and is the opposite of despair, apathy and meaninglessness (Golberg, 1998). It has been described as a state of perception of life having meaning, a life-affirming relationship, self-integration, or harmonious interconnectedness with a supreme being, self, community, and an environment. It enables individuals to deal with life's challenges, provides a sense of belonging, direction and order to life and transcends the present (Burkhardt, 1989; Halstead & Hull, 2001).

Highfield (1992) claimed that spiritually healthy persons are those who have satisfactorily met their spiritual needs for self-acceptance by a trusting relationship with self, relationships with others and with a supreme being that presents them with nonconditional love, trust, and forgiveness also those persons who have a positive future. If people cannot find a meaning in life and cannot meet their spiritual needs (Sarter, 2002; Stoll, 1989), spiritual distress, a feeling of emptiness and despair will take its place (Dyson et al., 1997). In other words, without a reason for living, it is possible for humans to die (Ross, 1994). *Spiritual distress* may also refer to spiritual pain, and anger. Spiritual distress or spiritual pain is the most intense suffering of the human spirit. Spiritually distressed persons are those who feel profoundly hopeless, lack a meaning and purpose in life, have do not have satisfactorily met their spiritual needs for self-acceptance, have no sense of connection (a total alienation), have a sense of the worthlessness of life, impairments in faith and a religious belief system, value system, self-transcendence, lack of inner peace and harmony, and inner strength and energy (Highfield, 1992; Sarter, 2002; Stoll, 1989; Villagomeza, 2005). The signs and symptoms are presented by a broad range of emotions including crying, withdrawal, anxiety, apathy, and a feeling of hopelessness (Callister, Bond, Matsumura, & Mangum, 2004). Spirituality and health are closely connected; spiritual despair causes depression and suicide. Depression is linked with loneliness and anxiety and leads to significant impairment in immunity (Sarter, 2002) and increased vulnerability of health.

2.3.3 Spirituality in people living with HIV/AIDS

People living with HIV/AIDS, as shown in the overview in Chapter One, are obviously confronted with life-threatening situations and faced with extreme distress. They have much higher suicide rates than the general population and those with other life-threatening illnesses (Cooperman & Simoni, 2005). Hence, they need spiritual care for comfort. Spirituality has been shown to have a direct relationship with cognitive and social functioning and is inversely related to HIV symptoms (Coleman, 2003). At the same time, the literature also reveals that although the experience of living with AIDS is a critical problem in people's lives, its challenges can produce growth and stimulate spiritual reflection as well as a sense of spiritual well-being (Szaflarski et al., 2006). Therefore, spirituality and HIV/AIDS have a reciprocal relationship.

The significant role of spirituality in buffering the torment and turmoil for people living with HIV/AIDS is similar to its role in other kinds of chronic illness and life-altering situations (as discussed under the subheading "Significance of spirituality for health"). Several studies illustrate the complex nature of spirituality's positive relationship in people living with HIV/AIDS (Banks-Wallace & Parks, 2004; Coleman & Holzemer, 1999). In fact, many researchers have reported that persons living with HIV/AIDS indicated that their spirituality/religion was helping them to love or help others, facilitating direct communication with God, making them better spouses, helping them to love themselves (Woods & Ironson, 1999), and helping them to live longer (Belcher et al., 1989; Cotton, Puchalski et al., 2006; Cotton, Tsevat et al., 2006; Tsevat, 2006; Tsevat et al., 1999) or slow the disease's progression (Ironson, Stuetzle, & Fletcher, 2006). Solomon, Ironson, Balbin, and Fletcher (2002) emphasise that religious/spiritual behaviours are one factor that has an impact on health and survival with HIV infection and AIDS. On the other hand, a lower level of spiritual well-being was related to significant depressive symptoms (Yi et al., 2006). This is confirmed by the study by Fryback and Reinert (1999) who found that spirituality was viewed as a bridge between hopelessness and meaningfulness in HIV/AIDS patients.

Spirituality influences people through self-empowerment, giving courage and knowledge of how to heal, making them optimistic, and more relaxed (Woods & Ironson, 1999). This is consistent with the fact that spirituality has a significant relationship with hardiness that leads people to find meaning and purpose in their lives (Carson & Green, 2004). Having a sense of meaning and purpose is indicative of their state of psychological well-being (Coleman & Holzemer, 1999). This was supported by women who are living with HIV/AIDS in New York city who also exhibited considerable strengths as they had high levels of spirituality, a sense of mastery and good social support (Simoni & Cooperman, 2000). This result was consistent with that in another study by Kotarba, Haile, Landrum, and Trimble (2003) who found that inner strength improved the managed care for HIV positive women who had reliance in a higher power, including both spiritual and religious aspects. In addition, an African-American gay man living with AIDS used his spirit, religion, and cultural strength to struggle with his AIDS condition. By using these strengths he was able to refuse to accept his physician's prediction of death, and develop his spiritual activity (Miller, 2005).

Also, spirituality is a major theme in the lives of those who were able to face an HIV/AIDS diagnosis with equanimity (Kendall et al., 1989, cited in Holt et al., 1999). Furthermore, people who perform daily spiritual rituals develop a personal philosophy to deal with unanswerable questions (Hall, 1998). These findings from Western research literatures are consistent with the finding that some people living with HIV/AIDS in Thailand feel safe and balanced, accept the prospect of their untimely death and perceive that death is a natural part of life as guided by Buddhist teaching. They achieved a sense of equilibrium or balance in a mode of being that is central to Eastern traditions (Balthip, 1999).

In the same time, not only does spirituality help people living with HIV/AIDS overcome life crises and live with harmony, but also life-threatening situations – living with HIV/AIDS – provides positive impacts on spiritual development and human beings as well. Many people, who live with life-threatening diseases such as HIV/AIDS, can master their diseases and develop new life goals as well as have spiritual growth. Women with HIV/AIDS also described several forms of positive changes resulting from their illness. They noted that their illness was a motivating factor to make positive behavioural changes. They recognised that HIV/AIDS had contributed to their religious and spiritual growth. They also described growth in relationships with children, family, friends, and lovers, saying that these became closer and more important. Furthermore, HIV/AIDS was seen as a catalyst for resolving past differences and using their remaining time to express and affirm their love for one another. Many women felt that HIV/AIDS changed the value of their life. They had greater appreciation of life, and often reported helping others through AIDS advocacy and education (Bouthillette, 2001; Moser et al., 2001). Some women who are living with various stages of HIV have repeated that certain components important in their psychological and spiritual growth are life affirmation, creation of meaning, self-affirmation, and redefining relationships (Dunbar, Mueller, Medina, & Wolf, 1998). Additionally, some people living with HIV/AIDS in Thailand changed their life style by doing good and regularly practising meditation (Saeloo, 2000). Through starting a new lifestyle and preparing for their own death, they made a harmonious life (Balthip, Churprasilp, & Chailanga, 2001).

As a result of becoming more spiritual (and/or religious), people living with HIV/AIDS reported that their lives were in a better condition than they had been before they were diagnosed with HIV/AIDS (Szaflarski et al., 2006; Tsevat, 2006; Tsevat et al., 1999). Therefore, it is possible to draw the conclusion that there is a positive relationship between spirituality and well-being in persons living with HIV/AIDS. However, there has not yet been any research focused on how people living with HIV/AIDS in the Thai context develop their spirituality.

2.4 Spirituality and the Nursing Profession

As previously stated, Thai nursing education and curricula have been strongly influenced by the Western body of knowledge and practices including the notions of body, mind and spirit (Tongprateep, 2002). From the Western perspective, the holistic paradigm values each person as a whole – an integration of body, mind, and spirit as well as having interaction with the environment. Within the holistic perspective, spirituality cannot be separated from our lives. Most nursing theorists claimed that spirituality infuses all of who we are and pervades all other dimensions including the physical (that allows the person to be in touch with the world through the five senses – namely, touch, taste, hearing, seeing, smelling) and the psychological (that gives the person self-consciousness and personality through emotion, intellect, the will, and moral sense) of the person (Burkhardt & Nagai-Jacobson, 2002). This is consistent with Stoll (1989) who proposed that “the person is a whole being and cannot be separated into segments... People are more than and different from the sum of their parts… Our beings (body, mind, and spirit) are dynamically woven together, one part affecting and being affected by other parts” (p. 8).

Meeting the spiritual needs of patients is now cited as a desirable goal for nursing care (Barnum, 2003; Belcher et al., 1989; Vance, 2001). Nursing professionals mention that spiritual care is the essence, is at the heart, of caring for the whole person and a vital concern of nursing (Burkhardt & Nagai-Jacobson, 2002; Stoll, 1989). In other words, providing for the spiritual needs of patients is a fundamental part of holistic nursing care (Dyson et al., 1997). Thus nursing professionals now have this awareness and agree that spirituality is important for people and that they, as nursing professionals, have a role to provide the spiritual care (Stoll, 1989).

With regard to realising the holistic paradigm and the significant role of spirituality for people and their health as discussed, in the area of nursing and health, although the concept of spirituality has been brought into prominence only during the past two decades (Chiu et al., 2004; Sawatzky & Pesut, 2005) and the concept of spirituality is unclear (Fawcett & Noble, 2004; McSherry & Cash, 2004), many nursing scholars endeavour to contribute knowledge about the concept of spirituality. The role of spirituality in promoting health and improving patients' responses to illness has been receiving increasing scholarly attention (Chiu et al., 2004; Sessanna et al., 2007; Sawatzky & Pesut, 2005). Thus, the number of research articles in which this concept is dealt with is proof of the increasing interest in, and curiosity about, its part in people’s lives (Sessanna et al., 2007). Burkhardt (2007) noted that:

> Although no single definition of spirituality captures the entire essence of the concept, each definition is like a finger directing our attention to a fuller understanding of spirituality and important elements of spiritual care… Nurses need to be proactive in incorporating spiritual care into practice based on the fullest understanding of this elusive concept that we have at this time (p. 264).

Nightingale, who was the founder of modern nursing, often dealt with spirituality. She presented the sense of selfless, giving, and love to others (McSherry & Cash, 2004). She believed that spirituality is intrinsic to human nature, extending beyond the bounds of religion. Nightingale felt that to more fully know God, people must explore and understand the beliefs and practices of the world's major religions and spiritual traditions. She also believed that inner connection to God is a source of creativity, insight, and knowledge that helps people understand life events and experiences such as illness (Burkhardt & Nagai-Jacobson, 2002). Nightingale's ideas are presented in Newman's theory that "disease is not necessarily bad but may be a signal of growth, re-patterning and expanding consciousness" (Barnum, 2003, p. 30). This notion shows that Nightingale had a spiritual concern.

Martsolf and Mickley (1998) argued that although some nursing theorists from the United States such as Peplau, Orlando, King, and Orem say little or nothing about spirituality and some such as Leininger, and Rogers present spirituality as an embedded concept, some such as Neuman, Newman, Parse, and Watson present the reciprocal interaction world-view and include spirituality as a major concept. In many documents in the Western nursing professions (e.g. Burkhardt & Nagai-Jacobson, 2002; Stoll, 1989), it is mentioned that nursing professionals have a role to provide holistic care and they meet patients' spiritual needs through the understanding that individuals are composed of biological, psychosocial, and spiritual dimensions.

2.5 Conclusion

In this chapter, the literature review, the focus has been on the concept of spirituality especially in the Western cultures that have had a strong influence on the Thai context. Spirituality comprises many definitions, attributes, and empirical indicators. Each culture utilises different terms and some different unique attributes to define spirituality. However, there are shared attributes of spirituality. Notable in many studies and commented on by many authors is the fact that spirituality is a core and essence of human beings that enhances peace of mind and living life with harmony. However, in Thailand, there are no comprehensive studies on how spirituality enhances well-being in people living with HIV/AIDS and how they develop their spirituality. Therefore, this literature review has enabled the researcher not only to gain understanding about the concept of Western spirituality, but also to identify the gap that needs more study. A grounded theory approach was therefore employed in this study in order to fill this gap in knowledge and guide nursing practices so nurses can better meet the spiritual needs of patients. The research will also add to knowledge about the meaning of spirituality and spiritual development in the changing contemporary Thai context and demonstrate any difference from the understanding of spirituality in other cultures.

CHAPTER 3

Methodology and Methods

3.1 Introduction

In this study the aim was to explore the meaning of spirituality and the process of spiritual development in the context of people living with HIV/AIDS in Southern Thailand. This topic called for an inductive approach to knowledge generation. Grounded theory methodology, which provides practical techniques and procedures for studying social processes, interactions and relationships between and among various types of social units, was selected as an appropriate research methodology with which to develop a substantive theory concerning the notion of spirituality in people living with HIV/AIDS in the Thai context.

In this chapter, the epistemology and philosophy that underpin grounded theory methodology are outlined. The evolution of grounded theory methodology and the assumptions of grounded theory as well as grounded theory in nursing are discussed. The appropriateness of the methodology for this study and a rationale for the selection of Straussian grounded theory is explained. This section is followed by a description of the process of obtaining ethics approval. Then the study design and methods – including the process of data collection, and data analysis – are illustrated. Lastly, the trustworthiness of the study is discussed.

3.2 Grounded Theory Methodology

Grounded theory methodology is a qualitative research design with which the researcher aims to generate theory which is grounded in data (Chenitz & Swanson, 1986; Glaser, 1998). In other words, theory is generated on the basis of data that are systematically gathered in naturalistic settings, and concurrently analysed (Creswell, 1998; Cutcliffe, 2000; Punch, 2005; Speziale & Carpenter, 2003; Stern, 1994; Strauss & Corbin, 1990, 1998). In grounded theory methodology, "data collection, analysis, and eventual theory stand in close relationship to one another" (Strauss & Corbin, 1998, p. 12). It is recognized form of sociological inquiry (Eaves, 2001; Morse & Field, 2002; Speziale &

Carpenter, 2003). There are two types of theories that can be developed using grounded theory methodology: formal theories and substantive theories. First, a substantive theory is the most common type of theory that evolves from the study of the phenomena situated in one particular situation context and is developed for narrower empirical areas of study such as the care of the dying. Second, formal theories deal with a conceptual area of enquiry and are usually derived from studying phenomena under a variety of conditions. More formal theories are less specific to a group and place and apply to a wider range of disciplinary concerns and problems (Strauss & Corbin, 1990, 1998).

Grounded theory plays a significant role in areas in which little work has been done. Thus, one of the major uses of grounded theory has been in preliminary, exploratory, and descriptive studies (Chenitz & Swanson, 1986). Grounded theory methodology has no specific methods and techniques for data collection; rather it has similar methods to those of other forms of qualitative research, such as in-depth interviews and observation. However, it has a systematic set of data analysis techniques.

3.2.1 The epistemology and philosophy of grounded theory

Grounded theory methodology was developed by two sociologists: Barney Glaser and Anselm Strauss and first described in their 1967 book *Discovery of Grounded Theory.* Although they came from different philosophic and research backgrounds, their contributions were equally important. Barney Glaser came from Columbia University and was influenced by Paul Lazarsfeld, who was known as an innovator of quantitative methods (Strauss & Corbin, 1990). Thus, Glaserian grounded theory was "founded upon Glaser's epistemological assumptions, methodological terms, inductive logic, and systematic approach" (Charmaz, 2000, p. 512).

Anselm Strauss came from the University of Chicago which had a strong tradition in qualitative research and his thinking was inspired by such as George Herbert Mead. Therefore, his experience was influenced by interactionist and pragmatist writing (Morse & Field, 1996; Strauss & Corbin, 1990). Charmaz (2000) pointed out that "Strauss brought the pragmatist philosophical study of process, action, and meaning into empirical inquiry through grounded theory" (p. 512). This background contributed to the following assumptions underpinning the methodology:

> 1) the need to get out into the field, if one wants to understand what is going on, 2) the importance of theory, grounded in reality, to the development of a discipline, 3) the nature of experience and undergoing as continually evolving, 4) the active role of persons in shaping the worlds they live in, 5) an emphasis on change and process, and the variability and complexity of life, and 6) the interrelationships among condition, meaning, and action (Strauss & Corbin, 1990, p. 24-25).

There are two mainstream underpinnings of the development of grounded theory methodology. First, the trust in American Pragmatism that focuses on action and the problematic situation, and the requirement for considering of method in the context of problem solving. Second, the influences of the tradition in Chicago Sociology at the University of Chicago that has operated field observations and intensive interview as data-collecting techniques, and emphasised the actors' perspectives for understanding interaction, process, and social change. In both the philosophical and the sociological traditions it is assumed that change is a constant feature of social life, but that its specific directions need to be accounted for. Grounded theory also has been integrated with social interaction and social processes (Strauss, 1987). As a consequence of the mainstream underpinning, although most authors (e.g. Chenitz & Swanson, 1986; Morse & Field, 1996; Stanley, 2006) refer to only symbolic interaction as a theoretical basis for grounded theory, Wuest (2007) argued that there are two key underpinnings: pragmatism and symbolic interaction. This may be because, although the central tenet of grounded theory is symbolic interactionism, symbolic interactionism is rooted in the philosophy of pragmatists from the ideas of many scholars such as John Dewey, and George Herbert Mead (Blumer, 1969; Heath & Cowley, 2004; MacDonald & Schreiber, 2001).

Pragmatism is employed both as *a general belief system for social science* and as *a specific justification for combining qualitative and quantitative methods* (Morgan, 2007). In other words, pragmatism refers to what constitutes method and any theoretical position that ties theory to practice (Seigfried, 1998). In the feminist view, pragmatism sometimes refers to "any theoretical perspective that emphasizes the practical that subordinates theoretical to useful concerns, or that rejects theory altogether for actively changing unjust social conditions" (Seigfried, 1998, p. 49). Wuest (2007), who focuses on feminist grounded theory, claimed that pragmatism supports the purpose of making change through inductive exploration of human experience with reflexive confirmation and use of applicable existing knowledge because pragmatists believe that truth must be developed inductively with constant empirical verification. Furthermore, truth is discovered in relation to time and place.

In Morgan's view (2007), pragmatism provides alternative methodological issues in social sciences. He summarised the three main comparative distinctions which distinguish pragmatism from the two most common methodologies (qualitative and quantitative research methodology). Firstly, the connection of theory and data: those using the pragmatic approach rely on 'abduction' that moves back and forth between induction and deduction. Also, one of the uses of 'abduction' in pragmatic reasoning is "to further a process of inquiry that evaluates the results of prior inductions through their ability to predict the workability of future lines of behaviours" (Morgan, 2007, p. 71). Secondly, in relation to the research process, the emphasis in pragmatism is on an intersubjective approach. In pragmatism, *intersubjectivity* is the key to social life and the emphasis of pragmatism on creating knowledge through lines of action points to the kind of "joint action" that different people can achieve [the concept of joint action is discussed in the following section and illustrated in the symbolic interaction theory which has been written about by many authors such as Mead (1934) and Blumer (1969)]. In addition, the researcher needs to involve not only a sufficient number of people to participate in the research, but also readers, reviewers, or colleagues to review the research findings. Lastly, the researcher draws inferences from data in the process of working back and forth between inductive and deductive reasoning, therefore, proponents of the pragmatic approach claim that their research findings from a specific area will apply also to other settings.

Symbolic interaction is a theory about human behaviour (Blumer, 1969; Chenitz & Swanson, 1986; Eaves, 2001; Mead, 1934). It is "a down-to-earth approach" (Blumer, 1969, p. 47) and applied to the study of human group life and human conduct in their natural settings. This theory sees human living as ongoing activity and proposes that human beings construct and create their own reality from the situation they encounter and interpret through interaction both within themselves and others and then, they behave and interact based on how they interpret or give meaning (symbol) (Blumer, 1969; Chenitz & Swanson, 1986; Morse & Field, 2002; Speziale & Carpenter, 2003). Speziale and Carpenter stress that "the study and exploration of the social processes that present within human interactions in grounded theory are linked directly to symbolic interactionism" (p. 111).

Blumer (1969) stated that symbolic interaction is grounded from a number of basic ideas (root images) linked with the nature of the following subjects: human groups or societies, social interaction, objects, the human being as an actor, human action, and the interconnection of the lines of action. This is consistent with the views of Mead (1934) who described the five central matters of human society (symbolic interaction).

Firstly, the self – human – is an organism who has a self and self-interaction. Mead explained symbolic interaction in the process of self development. He believed that humans interact with the world by interpreting and defining the social object of the situations in which they are involved. Human beings are actors and can be the objects of their own action. The self is composed of two components which are the "I" and the "me" (Mead, 1934). The "I" is the active, dynamic interpreting component of the self. The "me" is the object of self-reflection (Klunklin & Greenwood, 2006). In the symbolic interaction, the individual acts both toward other and toward himself or herself. Self is part of the actor's environment that he or she acts toward. Therefore, sometimes, self is an object because it arises from social interaction (Charon, 2004) and presents in terms of the "me".

Secondly, the act, a human being has to identify both what s/he wants (self-interaction), check herself/himself, and interpret the action of others and figure out what to do. Thirdly, social interaction, as claimed symbolic interaction involves interpretation; human association consists of a process of such interpretation and definition (Blumer, 1969). Charon (2004) discussed the effects of social interaction on the individual, stating that "social interaction (not biology) both creates the society we live in and gives us the core qualities that make us unique in nature: our symbols, self, and mind" (p. 71). Fourthly, object – according to Blumer, human beings live in a world or environment of objects and their activities are formed around objects. *Objects* refer to *anything that can be designated*. Blumer defined three kinds of object (physical object, social object, and abstract object). Lastly, social action or joint action, in Blumer's book is the larger collective form of actions from each participant that fit together.

Blumer (1969) summarised the foregoing by saying that symbolic interactions rest on only three simple principles or premises. The first principle indicates that "human beings act toward things on the basis of the meaning that things have to them" (p. 2). Such things include everything that human beings note in their world such as physical objects, other human beings, and categories of human beings. He also said that the meanings of things for human beings who are acting are that used to account for their behaviour. The second principle is that "the meaning of such things is deriving or arising from the social interaction that one has with one's fellows" (p. 2). This principle is based on the view that meaning arises in the process of interaction between people. The last principle emphasises the interpretive process in which "these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters" (p. 2). Blumer said that "the use of meaning by the actor occurs through a process of interpretation" (p. 5). He also argued that human beings interpret each other's action and respond based on the meaning which they attach to such action.

This is consistent with the thinking of Charon (2004) who outlined the five core ideas of symbolic interaction. The first is the role of social interaction. *Symbolic interaction* focuses on *the nature of social interaction, the dynamic and social activities taking places among actors*. Interaction means that the acts of each individual are built up over time, depending on what others do in the situation in relation to them. Thus social interaction is essential to what we do. The second is the role of *thinking*. Human action occurs not only by interaction between individuals but also by interaction within the individual – thinking. People act according to how they are thinking. Therefore, thinking is of central importance to what we do. The third is the role of *definition.* Humans act according to their *definition* (meaning). "Definition is everything; what we do does not result simply from reality as it is but from how we define what it is" (p. 29). The fourth is the role of *the present* that Charon extended from the previous premise outlined by Blumer. Charon said that:

> What we end up doing depends on how we define our situation right now, our interaction right now, our thinking process right now… The present, not the past, must be understood in order to understand the cause; what is going on right now in our present situation makes the real difference in how we act (p. 29).

The last core idea of symbolic interaction is the role of the *active* human being. Symbolic interaction describes the actor as a being who interacts, thinks, defines, applies his or her past, and makes a decision in the present based on factors in the immediate situation.

Blumer summarized the methodological stance of symbolic interaction by saying that it is directing examination of the empirical social world. It recognises that such direct examination permits the researcher to meet all of the basic requirements of an empirical science:

> 1) to confront an empirical world that is available for observation and analysis, 2) to raise abstract problems with regard to that world, 3) to gather necessary data through careful and disciplined examination of that world, 4) to unearth relations between categories of such data, 5) to formulate propositions with regard to such relations, 6) to weave such propositions into a theoretical scheme; and 6) to test the problem, the data, the relations, the propositions, and the theory by renewed examination of the empirical world (p. 48).

He also said that symbolic interactionism recognises that the genuine mark of an empirical science is to respect the nature of its empirical world – to fit its problem, its guiding conceptions, and its theories to that world. Therefore, from a symbolic interactionism perspective, “the nature of the empirical social world is to be discovered, to be dug out by a direct, careful, and probing examination of that world” (Blumer, 1969, p. 48). The methodological stances described above are consistent and support the principles of grounded theory methodology as employed in this study. For instance, both processes of data collection and data analysis occur concurrently. In the process of data collection, participant observations and in-depth interviews with prolonged engagement in the field were employed in order to collect the data from the empirical world in the natural setting. In the process of data analysis a variety of analytical tools, such as theoretical comparison and theoretical memos, were utilised in order to raise the possibility of the emergence of data. In addition, in order to construct categories, the processes of open coding, axial coding and selective coding were employed efficiently. Once the core category had emerged, the process of tidying up and linking the core category and other categories along their properties and dimensions was wrapped up. Finally, the categories and the substantive theory of **Achieving Harmony of Mind** were tested (as discussed in the following section, under the subheading "Design and method" and "Establishing research trustworthiness"). Symbolic interaction enables the researcher to explain rather than merely describe the relationship of strategies used by the actors to deal with their situation or environment (Klunklin & Greenwood, 2006). Thus, symbolic interaction leads to the methodological principles of grounded theory.

3.2.2 Evolution of grounded theory methodology

The development of Grounded theory methodology can be seen as a methodological spiral that started with Glaser and Strauss's original version in 1967 and has continued evolving until today (MacDonald & Schreiber, 2001). During this period of evolution, there have been philosophical differences in the process of theory generation between the two original authors resulting in differing approaches – Glaser's version (Glaserian – traditional grounded theory) and Strauss's version (Straussian – evolved grounded theory) (Heath & Cowley, 2004; Mills, Bonner, & Francis, 2006; Wuest, 2007).

Glaser (1978, 1992, 2003) remained a classic grounded theorist, whilst Strauss and Corbin (1990, 1998) produced a reformation of the classic mode by developing analytic techniques and providing guidance to novice researchers. Glaser argued that Strauss's version is no longer grounded theory, but full conceptual description (Glaser, 1992; Heath & Cowley, 2004). Glaser emerges from a realist view of truth. For Glaser, "there is a real reality out there waiting to be discovered" (Annells, 1997, cited in MacDonald & Schreiber, 2001, p. 44). Charmaz (2000) argued that "Glaser's position often comes close to traditional positivism, with its assumptions of an objective, external reality, a natural observer who discovers data, reductionist inquiry of manageable research problems, and objectivist rendering of data" (p. 510). Therefore, theory development reflects the correspondence to reality. By contrast, note Strauss and Corbin's transition from a realist view to a more relativist perspective on the nature of reality in which theory development reflects a constructed reality (MacDonald & Schreiber, 2001).

Charmaz (2000) commented that Straussian grounded theory moves into post positivism because:

> Their stance assumes an objective external reality, aims toward unbiased data collection, proposes a set of technical procedures, and espouses verification… They also propose giving voice to their respondents, representing them as accurately as possible, discovering and acknowledging how respondents' views of reality conflict with their own, and recognizing art as well as science in the analytic and process (p. 510).

Glaser emphasised identifying symbols, interactions and the immediate context, and the socially constructed world of participants. In contrast, Strauss and Corbin's main focus is on both the micro and the macro and includes structural, contextual, symbolic and interactional influences on individuals and groups (McCann & Clark, 2003b). As Stern (1994) summarised it, the difference between the two approaches is that Glaser focused on the data and asked "What do we have here?" to allow the data to tell their own story. Strauss examined the data and asked "What if?" because he aimed to consider every possible contingency that could relate to the data, whether it appeared in the data or not. However, Glaser argued that this approach of Strauss and Corbin interrupts true emerging, may not find out what is really going on and does not emphasise the emergence of theory (Duchscher & Morgan, 2004). Strauss and Corbin acknowledge the importance of a multiplicity of perspectives and truths and the actions/interactions of humans that enable analysis of data and make a reconstruction of theory richer and more reflective of the context in which the participants are situated. I also agree that asking "what if?" provides a chance for the researchers to search for possible data that they have not found. In addition, the data that they find from this approach are still grounded in the natural setting of the participants.

Regarding the role of literature, although proponents of both approaches acknowledge the important role of literature, they use it in very different ways. Glaser suggested that the researcher should not enter the field with any preconceived notions about what constituted the problem because he was concerned about contaminating, constraining, inhibiting, stifling, and forcing of the data by preconceptions (Glaser, 1992; Mills et al., 2006). He claimed that a literature review should be carried out only after analysis in association with the emerging of the research theory from the data (Glaser, 1978; Heath & Cowley, 2004). Alternatively, Strauss and Corbin (1990, 1998) said that a literature review is valuable for giving a preliminary review of the area and later the main literature review can support the emerging theory (as described in Chapter Two).

For analysis, coding is the fundamental analytic tool that is used to uncover an emergent grounded theory. Although both Glaser and Strauss use the word *coding*, they present it in different ways that reflect the different methodological assumptions (Walker & Myrick, 2006). In this section, I have given only a brief overview of the process of data analysis of each approach because the debate and argument over the difference between Glaserian and Straussian grounded theory in the process of data analysis has already been discussed by many authors (e.g. Duchscher & Morgan, 2004; Heath & Cowley, 2004; Walker & Myrick, 2006).

Glaser (1978) described two levels of coding: substantive coding and theoretical coding (Heath & Cowley, 2004). *Substantive coding* consists of two subphases (open and selective coding) (Walker & Myrick, 2006). Proponents of Glaserian grounded theory, in the process of analysis, view induction as the key compared with deduction and verification. Glaser suggested that grounded theory should be carried out in a flexible way and kept simple. He claimed that line-by-line analysis alone was enough to gain and verify saturation of data. Thus, in this approach all data are viewed as important and all other considerations are encompassed. Glaser suggested that only by the use of patience, toleration of confusion, hard work, and going over and over the data using constant comparison will the concepts (as well as the categories and their properties) emerge (Heath & Cowley, 2004; Walker & Myrick, 2006). By contrast, Strauss and Corbin emphasised that “the role of induction should not be over-stressed” (Heath & Cowley, 2004, p. 145) because induction, deduction and verification in the analysis process play their own roles. In the process of coding, the researcher is constantly moving between inductive and deductive thinking and that is the interplay between proposing and checking (Duchscher & Morgan, 2004; Walker & Myrick, 2006). Heath and Cowley (2004) commented on Strauss and Corbin grounded theory that:

> Rather than emphasising deduction followed by verification, they talk of deduction followed by validation and elaboration from further data comparisons which ensure emergence. The researcher shapes the data by their interpretations, which moves analysis beyond description; but they are also shaped by the data and validation prevents distortion (p. 145).

Strauss and Corbin outlined three kinds of coding: open coding, axial coding and selective coding (as discussed under the subheading "Data analysis") (Strauss & Corbin, 1990, 1998; Stern, 1994). They provided a more structured approach, to guide the data collection and analysis – in particular, for the novice or student. However, Glaser criticised that by providing many techniques and more structure – in particular in the process of "axial coding" (see p. 69) – Straussian grounded theory forces the data to emerge rather than allowing theory emerge itself (Duchscher & Morgan, 2004; Liamputtong, 2009). By contrast, from Annells' perspective (1997, cited in MacDonald & Schreiber, 2001) the work of Strauss and Corbin, in its presentation of a more elaborated set of analytic procedures, reflects the modernist quest for respectability.

Consistent with their differences in methodology and methods, Glaser and Strauss provide different sets for judging the adequacy of theory. Glaser provided four criteria: 1) fit, 2) work, 3) relevance, and 4) modifiability (Glaser, 1992). Strauss and Corbin have four different criteria: 1) fit, 2) understanding, 3) generality, and 4) control (Strauss & Corbin, 1990). The criterion of generality is mostly relevant to the term t*ransferability* used by Lincoln and Guba (1999) that is one of the four criteria for establishing the trustworthiness of qualitative data (as discussed under the subheading "Establishing research trustworthiness"). Strauss and Corbin accepted that "the researcher's cognitive processes, in part, shape the results" (MacDonald & Schreiber, 2001, p. 43). However the criteria for judging grounded theory ensure that the research findings are congruent (fit) with participants' experiences and understanding.

Although grounded theory has evolved over time and each theorist has differences in methodology and methods, Eaves (2001) claimed that for all grounded theory development, there are seven major assumptions that underlay the process of grounded theory. These can be summarized as follows (Eaves, 2001, p. 655).

1. Inquiry is structured by the discovery of social and social psychological processes.
2. Data collection and analysis phases of research proceed simultaneously.
3. Both the processes and products of research are shaped from the data rather than from preconceived logically deduced theoretical frameworks.
4. Analytic processes prompt discovery and theory development rather than the verification of pre-existing theories.
5. Theoretical sampling refines, elaborates, and exhausts conceptual categories.
6. Grounded theory methodology is not only aimed at studying processes, but also assumes that making theoretical sense of social life is itself a process.
7. The systematic application of grounded theory analytical techniques leads progressively to more abstract analytic levels.

In summary, grounded theory is a highly systematic methodology for the collection and analysis of qualitative research data. Grounded theory has a range of approaches including Glasserian and Straussian grounded theory. Therefore, researchers can choose the version that is compatible with the purposes and aims of their research and their cognitive style, and develop analytic skills through doing research (Duchscher & Morgan, 2004; Heath & Cowley, 2004). However, they have to maintain the rigour of the methodology and its philosophical underpinning (Chiovitti & Piran, 2003).

3.2.3 Nursing and grounded theory

Grounded theory methodology has been utilised by nursing researchers since its development in the 1960s (Mills et al., 2006), and has proved useful for developing nursing knowledge and directing nursing practice as well as providing explanatory theories of human behaviour (Chenitz & Swanson, 1986; Morse, 2001; Wuest, 2007). Schreiber and Stern (2001) reported from a review of Cumulative Index to Nursing and Allied Health Literature (CINAHL) that in the previous 10 years grounded theory was the second most popular qualitative research method in published nursing papers. Chinnawong (2007) reported that in the period 2001-2006 a search of nursing databases (CINAHL, Nursing full text, and Ovid MEDLINE) produced 3,637 nursing research projects in which a grounded theory methodology had been applied.

In the context of Thailand, Chinnawong (2007) identified that the first grounded theory project was presented in 1991. Grounded theory projects undertaken from this period until 2006 included 20 research projects that had been conducted mostly by Masters and Doctoral students. The studies focused on many areas. For instance, they emphasised the concepts of caring, coping process, self-care, and health-seeking behaviours, as well as a variety of chronic illnesses such as HIV/AIDS, stroke and acute illness. Thus grounded theory methodology has been widely applied in the nursing field.

3.2.4 Rationale for selecting Straussian grounded theory methodology

In understanding, exploring, and explaining the phenomenon of the meaning of spirituality and spiritual development in persons living with HIV/AIDS in the Thai context, I have chosen to apply the Strauss and Corbin version rather than other versions of grounded theory methodology for the following reasons.

First, I value the relativist view of the nature of reality of Straussian grounded theory. Second, because little is known about spirituality in the Thai context (as discussed in Chapter One), I would like to understand any structural, contextual, symbolic and interaction influences on individuals and groups. Also, I pay attention to the cultural scene because Thai people have a long history of culture that influences their way of life. Therefore, with Straussian grounded theory methodology I can deal with possible contingencies that could relate to the data. Third, Strauss and Corbin valued both literature review and experience. I believe that my work experience in HIV/AIDS is important as a guideline for this study. I am a novice in both spirituality and grounded theory methodology – as I have acknowledged – so a literature review is significant to guide the research question (but it has not framed the research analysis) because as Liamputtong (2009) argued “we construct the theory from our data” (p. 212). The literature review also helped me to identify the current gaps in knowledge, and provide a rationale for the proposed research. In particular, the literature review enhanced my theoretical sensitivity to the Western concept of spirituality, of which I had little knowledge.

Furthermore, Strauss and Corbin (1998) acknowledge that it is difficult for the researcher to go to the field with a blank mind and emphasise that it is not possible for a researcher to be completely free of bias. This shows that Strauss and Corbin understand the constructed reality of human beings, the world and social interaction. Lastly, Strauss and Corbin provide a set of techniques, including a paradigm model which is helpful in the processes of both data collection and data analysis. Although some techniques may seem to limit the creativity of the researcher and some authors (e.g. Glaser, 1992; Stern, 1994) have said that some techniques may force the data to emerge (Glaser, 1992), Strauss and Corbin suggested that the researcher should not use these techniques rigidly (Strauss & Corbin, 1998). Therefore, although they mention many tools and techniques which seem very strict with many steps to follow, the researcher is able to choose the techniques or steps that are appropriate for his/her particular study.

3.3 Ethical Considerations

This study involved human lives; therefore, ethical considerations applied. Holloway and Wheeler (1996) point out four issues regarding ethical concerns for qualitative research. First, following ethical approval of the research proposal, individual informed consent must be obtained from participants. Second, it is impossible to "bracket" out the entire background of the researcher. Therefore, it is better to express this as part of the research and make these experiences explicit in the report. Third, immersion of the researcher could cause tensions to the participants. To resolve these differing perspectives, the researcher should describe how the circumstance is managed in the research process. And fourth, there should be an ongoing assessment in the data gathering with other field notes and transcriptions. For instance, in student projects, a supervisor should be involved and give advice at all stages.

I followed these suggestions because, prior to conducting this project, I had finished the research proposal including the interview guide, information sheet and informed consent under the supervision of the major supervisor. The next process was that I sent a letter to ask permission from the director of the hospital or the authorised person of each study site to conduct the research; as example letters presented in Appendix A. Then, I was granted permission to conduct the study in their settings as indicated in some of the permission letters which form Appendix B. Following all the procedures mentioned, I, then, was able to apply for ethics approval from the Massey University Human Ethics Committee (MUHEC) (Appendix C). This procedure was to ensure that the study was properly planned and the rights of the participants were going to be protected. After approval had been granted I advanced the study to the next process, collecting study information.

In the process of data collection, the participants were informed about the study as shown in the participants' information sheet (Appendix D) that was translated into the Thai language (Appendix E) in order to ensure that participants clearly understood their choices to participate in this study. I obtained permission from the participants before I met them. I explained the purpose and procedures of the study to people living with HIV/AIDS who met the criteria. All participants received a detailed explanation, both verbally and in writing, of what the research involves, including the aims and processes of the research, and the participants' involvement. They were informed that participation in this study was voluntary and was confidential. They were assured that they had the right to full disclosure. They had the opportunity to ask questions, make comments, and express concerns that they might have concerning the project. Also, the participants were informed that there was no major risk involved. I also informed them that they had the right to withdraw from being study participants at any stage or to refuse to answer any questions. In addition to the procedure of obtaining informed consent, I informed the study participants during the interview that there were no "right" or "wrong" answers.

Once an individual agreed to participate in the study, I obtained a written consent to participation (Appendix F) that was translated into the Thai language (Appendix G). They were informed that all identifying information would be kept separately from research materials in a locked place. Only the researcher is able to match the real names and identities with the tapes, reports or descriptions and the names of individual study participants were not mentioned in the written report. Sometimes, participants asked me to stop tape recording when they needed to tell me something which they considered was "top secret". I also promised them to keep confidential the topics that they expressed as secret. Privacy and confidentiality were ensured throughout the research. I informed the participants that if they wished, they could listen to, or amend, the information record (Appendix H) that was translated into the Thai language (Appendix I). The data were stored anonymously in a safe place and will be retained for five years. Not only were pseudonyms used for the participants in order to protect their confidentiality, but also in the stories that had been described in the findings I was careful not to refer to the participants using their real names. At the same time, the participants also agreed to keep the study confidential (Appendix J, K, English and Thai language respectively). The participants of this study were informed that the interviews were tape recorded and transcribed verbatim and the tapes would be erased a year after the research had been finished. The transcriber had no chance to know who they were. The transcriber has worked as my research assistant for nearly five years; thus, I trust her honesty and ability to correctly transcribe the recorded interviews. Also, she has never worked in the locations where I conducted this study; therefore, it was unlikely that she would know the study participants. She also signed the transcriber's confidentiality agreement (Appendix L, M, English and Thai language respectively).

At the beginning of interview sessions with each participant, I again introduced myself, explained the purpose of the study, and the confidential nature of data gained. Along the process of data collection, I was closely supervised by two field supervisors whom I could access while I was conducting the data collection and preliminary analysis of the information gained in Thailand. In addition, I was concerned about appropriate location and timing of interviews for participants (Speziale & Carpenter, 2003), tried not to take up too much of their time, and was prepared to give emotional support to participants when necessary (Holloway & Wheeler, 1996) both by providing emotional support by myself and by referring them to other experts such as counsellors and the mentor of the HIV/AIDS group support.

3.4 Study Designs and Methods

The general characteristics of grounded theory as discussed and defined by a range of authors, (e.g. Glaser, 1992; McCann & Clark, 2003a; Mills et al., 2006; Strauss & Corbin, 1990, 1998), are theoretical sensitivity, theoretical sampling, constant comparative analysis and asking questions (Liamputtong, 2009; Strauss & Corbin, 1990), coding and categorising the data, theoretical memoranda and diagrams, treatment of the literature and integrating of theory. Straussian grounded theory is based on the concept-indicator model (Strauss, 1987), which involves the constant comparison of indicator to indicator and many empirical indicators (behavioural action and events) are examined comparatively by the researcher (Strauss, 1987). Each incident is compared to other incidents at the property or dimensional level in order to provide the researcher with a way of knowing or understanding the categories (Strauss & Corbin, 1998). By doing this, the researcher discovers what is similar and different about each category and then defines the category. The process of constant comparison continues until a theory with sufficient detail is generated. Therefore, data collection, analysis, and theory stand in reciprocal relationships to each other (Strauss & Corbin, 1990).

In this study, I employed many techniques – in particular, theoretical comparison and asking questions – that were guided by Strauss and Corbin (1990, 1998). Data collection and data analysis were undertaken in parallel with both processes moving back and forth until data saturation was achieved. In this section, I would like to present the stages of doing field work, and the relationships among those characteristics that I have employed in this grounded theory in order to understand the meaning of spirituality and the process of spiritual development in people living with HIV/AIDS in the Thai context as shown in Figure 3.1 and explained below.

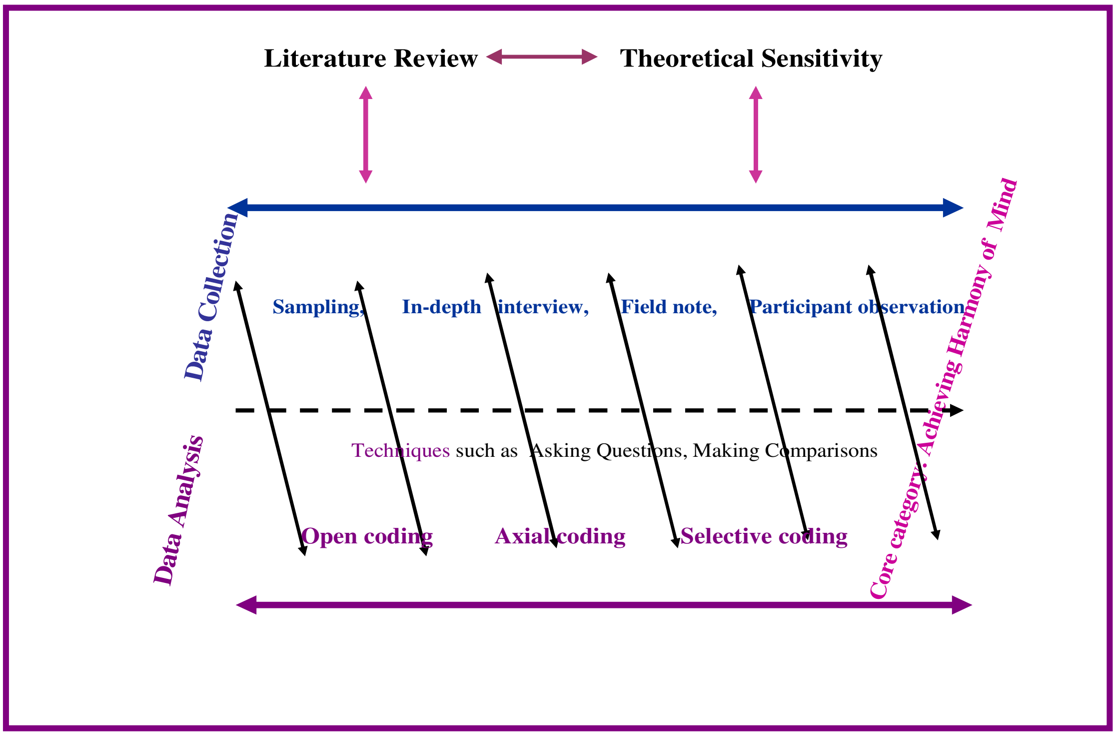

Figure 3.1: The relationships among literature review, data collection, data analysis and core category

3.4.1 Data collection

This study was undertaken in six sites in the South of Thailand that were selected because they would provide the opportunity to recruit participants from both rural and urban areas and to meet people who did and did not participate in any HIV/AIDS group support. From some sites, I expected to collect Muslim participants. However, in the period of doing data collection, the areas in which I had expected to select Muslim participants were unsafe therefore, the number of Muslim participants is limited (as discussed under the subheading "Limitations of the study" in Chapter Eight). In these six sites, people living with HIV/AIDS were willing to share their experience. The sites are not named in order to protect the anonymity of participants.

The data of this study were gathered through in-depth interviews and audio-tape recordings, observations in the field, and field notes. Data collection was undertaken over a nine-month period in 2006. Both multiple sites and prolonged engagement are necessary in order to enhance credibility of results and findings, make it possible for the researcher to obtain empathetic understanding of the insider's point of view, and to explore and uncover the meanings the participants give to their ideas, feelings, experiences and perceptions (McCann & Clark, 2003a). In this section, the sampling techniques, access to the participants, the stages of doing the interview, interview guides, participant observations, field notes, and participants' demographics are explained.

3.4.1.1 Sampling techniques

In this study, I applied three sampling techniques in the process of selecting the participants – purposive sampling, snowball sampling and theoretical sampling. In the initial stage of data collection, I had six inclusion criteria for selection – persons who 1) had been diagnosed as HIV-seropositive, 2) were aged 18 years or older, 3) accepted that they were HIV infected persons, 4) had lived with HIV/AIDS for five or more years, 5) were mentally alert (no cognitive impairments) and able to communicate in the Thai language, and 6) were willing to participate in this study – in order to guide the purposive sampling. Purposive sampling was employed in both hospital and community settings. I also applied snowball sampling to search for further participants by asking nurses, health volunteers, and the leader of the HIV/AIDS groups to suggest people whom I could approach, as suggested by Polit and Hungler (1999).

In grounded theory, most participant selection is based on theoretical sampling. Theoretical sampling is an essential sampling technique in grounded theory (Strauss, 1987) and was the main method I used. It is the process of data collection for generating theory and is based on preceding data collection and analysis. The researcher decides which data to collect next and where to find them, in order to develop the theory as it emerges. Thus, sampling becomes more specific with time and the process of data collection is controlled and influenced by the emerging theory (Glaser & Strauss, 1967; Morse & Field, 2002; Strauss, 1987; Strauss & Corbin, 1990, 1998). In this study, theoretical sampling was employed when I collected new data which I then used to compare with emerging categories and establish conceptual boundaries that were related to the evolving theory – for instance, when I found that participants who have children have a will to live for their children, I asked myself the question "Do persons living with HIV/AIDS who do not have children have a will to live?" Therefore, I recruited participants who did not have children, in order to clarify the question or hypothesis: "What encourages their will to live?" and "For whom do they live their life?"

Sampling and analysis occurred simultaneously as the study progressed (Morse & Field, 2002; Speziale & Carpenter, 2003). The sampling was continued until theoretical saturation or category saturation was reached which was when the participants were saying nothing new about the concepts being explored, no new codes emerged (Cutcliffe, 2000; Speziale & Carpenter, 2003), and no new data emerged during coding – that is, no new properties, dimensions, condition, action/interactions (strategies), or consequences are seen in the data (Strauss & Corbin, 1998) which are relevant to particular categories and subcategories.

3.4.1.2 Access to the participants

In order to protect the rights of the participants and to obtain essential and comprehensive data, I demonstrate, in the following section, how I accessed the participants to clarify my concerns about both ethics and methods. There were three main ways to access the participants in relation to the key persons. The first group of participants I met through being introduced by nursing staff who worked at the outpatient department (OPD) of the hospital where the HIV/AIDS clinic was located. The participants in this group were those who came to the hospital and received services at the OPD. Some of them lived in this community but some came from other areas so as to keep their HIV status secret. Some hospitals created a special name for the HIV/AIDS clinic in order to disguise the services provided at the clinic aiming at protecting patients' confidentiality. In this setting, most participants kept their HIV status strictly secret. Most participants in this group did not participate in any HIV/AIDS support group. Therefore, in the first interview, staff nurses provided me with a private and comfortable room to meet participants and, if they agreed, to interview them. However, I could make an appointment with participants for a follow-up interview in other places which were convenient to the participants.

The second group of participants, I accessed by meeting with nursing staff who were the mentors of the HIV/AIDS groups and by meeting with the leader of the HIV/AIDS group. Most HIV/AIDS support groups in the South of Thailand are arranged by hospitals or healthcare professionals. Both key persons explained my study project to the persons living with HIV/AIDS who joined their support groups. After the persons living with HIV/AIDS gave permission to me, I approached them. The HIV/AIDS support groups also have unique names. With this group, mostly, I interviewed them after they finished their group meeting. For the follow-up interview I met them in other places of their choice in which privacy remained the top priority since most of the participants disclosed their HIV status only to the group members, but still kept their HIV status secret from the public. Sometimes, I interviewed them at their homes. (The concerns regarding interviewing at home are discussed in the following section).

The third group was different from the first and second groups because for the first meeting, I met them at their houses or in their communities and not at the hospital. Some of them did not participate in any HIV/AIDS groups but some did. I gained access to them via health volunteers who worked with, and helped, persons living with HIV/AIDS in their designated areas. Also I accessed this group through the leader of the HIV/AIDS group. Both health volunteers and the head of the HIV/AIDS group asked persons living with HIV/AIDS, whom they looked after, whether or not they were willing to grant permission for me to meet them (as discussed under the subheading "Ethical considerations"). In this setting, some participants' diagnosis of HIV status was secret. Therefore, when I met them at their homes, I carefully planned how to protect their confidentiality. For instance, I disguised myself as their relative or friend who came to visit them. And following a suggestion by Swanson (1986), I dressed casually when I went into their communities. That author highlights that the manner of dress must be appropriate to the site and during the interview. It not only helps the researcher to gain access to participants, but also gain their respect. Furthermore, instead of driving a car to their houses, I commuted by a motorcycle to the participants' places in order to avoid arousing the suspicions of neighbours.

3.4.1.3 Participant demographics

In this study, theoretical saturation of data was achieved with 33 participants, 24 women and 9 men. One participant identified himself as 'gay'. They ranged in age from 29-58 with an average age of 37 years. The period of time since diagnosis ranged from 5 to 15 years. Twenty five of the participants had been infected with HIV/AIDS for 5 to 10 years, while eight participants had been diagnosed with HIV more than 10 years. Their educational level ranged from *completed primary school* to a *four-year bachelor degree.* Twenty-eight participants were Buddhist and only five were Muslim.

At the time of carrying out the data collection, 29 participants reported that they had enough income and five of that group had good economic status. Eight participants were employed as volunteers by HIV/AIDS support groups. Five participants worked in construction. Three worked in a factory as unskilled workers. Another five participants worked in a rubber plantation, two sold vegetables, one made ceramic dolls, one was employed as unskilled worker in a prawn farm and one was a self-employed worker in the family business. Another one was a Lotto seller, and one worked as a cashier at the hotel. Another five participants were unemployed.

Twenty-nine participants were infected with HIV by having sexual intercourse, two from drug use and two participants did not know the source of infection. Eleven participants were diagnosed on routine attendance at an antenatal care clinic and a further 11 found out when they had tests following an illness. One was diagnosed on routine annual physical examination. Another one found out when he had a blood test done for HIV as part of preparing to get married. Another one was diagnosed after she was raped. The remaining participants found out after partners became sick or died or left and were known – or suspected – to have had HIV/AIDS. At the time of data collection, 24 participants had a partner. Sixteen of the 24 reported having partners who were HIV infected (two HIV/AIDS couples were interviewed). One participant's partner had not been tested for HIV. Eight participants were widowed or separated. Only one was single.

Twenty-two participants reported having children (range 1-3); the youngest child was nearly 3 years old. Four of these living children were HIV positive. Five participants who reported no children had previously lost a child to HIV/AIDS. Thirty-two participants lived with someone – either with their children, mother partner or friend. Two participants appeared to live alone including one who became a nun. Nine participants did not participate in any HIV/AIDS support group. Only five participants had disclosed their HIV/AIDS status to the public.

Eighteen of 33 participants had experienced infection with opportunistic diseases such as pulmonary tuberculosis and meningitis as well as wasting syndrome. Their opportunistic infections were treated and cured. At the time of data collection, 28 participants reported taking antiretroviral drugs. Two participants began to take ARV drugs in 2000 at their own expense. Since 2001 some people have received ARV drugs free of charge as it is funded by the Thai government. Then, a number of people living with HIV/AIDS – including participants – received ARV drugs free of charge. Twenty-four participants reported that their CD4 significantly increased after taking ARV drugs. However, some of those who took ARV drugs experienced a variety of side effects, such as fat accumulation and drug allergy. At least nine of the 28 participants who took ARV drugs changed their ARV drugs regimen after experiencing side effects. Because of lack of knowledge, one of them who had CD4 of more than 200 took ARV drugs because she did not know the criteria for when ARV drugs should be taken. She thought the sooner she took ARV drugs the more they would benefit her condition.

Only five of the 33 participants reported not taking ARV drugs because their CD4 levels were high (from 200 to 800). One in five participants avoided taking ARV drugs while two in five had registered for the quota of receiving ARV drugs if their CD4 levels decreased to less than 200. Unexpectedly, at least one participant takes less care of his health now that ARV drugs are available than he did before they were made available.

3.4.1.4 The stages of doing an interview

There are five stages to achieving a successful interview. Firstly, there is the arrival process. The significant keys to success in the interview – in particular, with persons living with HIV/AIDS – are respect and rapport. In Thai culture the feelings of some people living with HIV/AIDS of being inferior and stigmatised, and my position as a lecturer could create a gap between them and me. Therefore, when I first met the participants, I expressed my respect, trust, and rapport to them. Rapport, trust, and respect can be presented in many ways. For instance, when I met them, I greeted them with a smile and said "Sawasdee" (Hello). I walked to them (instead of waiting for them to walk to me). If they sat on the floor, I sat with them. I helped them as much as I could. We ate meals together. I listened to them. I expressed my appreciation to participants that they were willing to participate in this study (Wilson, 2004). I also told them some stories of my life when appropriate. They called me "*Nong* O" or "*Pee* O" (O is my nickname) in order to minimise the gap.

These prefixes are culturally used by Thais to present their respect to each other. It is considered impolite to address one by name without a prefix, especially for younger persons to address older ones by their names only. However, it is acceptable for those who are at the same age not to use a prefix before each other's names. As a result, asking someone's age is acceptable in Thailand because knowing the age of one's conversation partners enables each one to choose an appropriate prefix to address them. In this study, I also used *Pee* (older sister or brother) in front of the names of persons who are older than me. I also used the term *Nong* (younger sister or brother) in front of the names of persons who are younger than me.

Secondly, when the participants felt familiar and comfortable with me, I moved on to the next step – that is, introducing the research topic, research aims, what their involvement was to be, and when I would terminate this study. I explained their role and my role.

Thirdly, as for starting the interview, this took place after the participants felt familiar with me, usually during the second visit for new participants (persons whom I had not known previously) and in the first visit for the participants whom I already knew. In conducting each interview, I started with social talk or an opening question and used two ways of communication (Swanson, 1986). Every participant's concern was dealt with, and every question was answered. If they were engaged with work, I did not interrupt. Sometimes, if they were doing some work that I could do, I helped them. I realised that helping them and doing everything that I could do with them was another way to establish relationship, trust and respect. While doing fieldwork, I participated in many activities such as attending an HIV/AIDS group meeting, going to the funeral of the mother-in-law of one participant, giving financial support for them when appropriate, taking them to hospital, and driving them to places that they wanted to go (sometimes) such as beaches. I always prepared snacks when they had a meeting. I also brought some food, fruit, and a gift for participants. In return, the participants treated me kindly and well. They always welcomed me to their homes. Also, I kept in mind that not all questions could be asked at once – especially not in the first interview – although this was concerned mainly with demographic data. I asked each question when it related to the topic of each conversation. Strauss (1987) suggested that the researcher should not assume the analytic relevance of any traditional variable such as sex and education, until it emerged as being relevant.

Fourthly, during the course of in-depth interview the questions used were more focused and specific, depending on the data that emerged. In this study I used in-depth or unstructured interviews (Legard, Keegan, & Ward, 2003). I applied two types of unstructured interview. First, I applied the unstructured formal interview because as I am a novice, I prepared the interview guide before I entered the fieldwork. However, I did not rigidly follow question by question. Second, I utilised the informal interview. Informal interviews were most often used throughout the process of data collection, were conducted after I had established rapport with participants in the follow-up interview, and related to the data that emerged. Chenitz (1986) regards the informal interview as an interview which is similar to natural conversation, having no ceremony surrounding the interview, no particular meeting time, length or place, no predetermined and agreed-upon theme(s) or topic(s) for interview. Chenitz mentioned that an informal interview may last only a few minutes – as occurred in this project. At this point I could not do any tape-recording, but I captured and noted the key words and main idea in my field notes and discussed them with participants later. Most interviews were audio-taped and each interview was transcribed verbatim.

The time and place for each interview depended upon the convenience of participants. In this study, interviews were conducted at various places including participants' homes, hospitals, temples, beaches, and restaurants. The duration of in-depth interviews ranged from 30-120 minutes. However, sometimes the interview was longer than two hours. This was because, in some cases, I allowed them to spend time expressing their feelings as they wished. I mostly interviewed participants when they were alone because, from my experience, some participants have their own secrets which were not disclosed even to their partner with whom they were closest. Interviews when other persons were present occurred only when participants preferred this. However, no one else was present for some sensitive questions such as "How did you feel when you discovered that you had HIV?" I asked them when nobody else was present, especially anyone else who was infected with HIV. This was because I understood that most Thai people feel "*krengjai*[7]" and have difficulty in responding to this kind of question in front of others. Although some participants invited me to interview them at their house, I interviewed them when they were home alone. For instance, I went to a participant's house when her sons had gone to school. Then, after I had been to her house often and we had established trust, respect and relationship, she felt comfortable for me to meet her sons.

However, I registered some advantages of the presence of other persons in the interview. For instance, I sometimes interviewed Nong Keng when his grandmother, who was an elderly woman and who took care of him when he was very sick, lay down on the bench and joined our conversation. She told me what happened to Nong Keng and to her and how she took care of him. The information given by the grandmother supported Nong Keng's data. Furthermore, I understood the essence of feeling of love and caring from her (as illustrated under the subheading "Field notes"). During each interview, I constantly observed aspects such as how participants felt, and after each interview I updated my field notes. Many times when participants expressed feelings of distress such as crying and sadness, I gave them time to express their feelings and offered them support and comfort.

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[7] *Krengjai* is used to describe social order, avoid personal conflict, and maintain harmony in relationships (Bechtel & Apakupakul, 1999). In this context, *krengjai* is focusing on avoiding personal conflict, and maintaining harmony in relationships.

Lastly, as regards closing an interview, Legard et al. (2003) suggests that around five to ten minutes before an interview finishes, the researcher should signal to the participant that the interview is nearly finished. After finishing the first interview or first meeting, participants were asked whether they would be prepared to be interviewed again later. I arranged appointments in advance by telephone or after finishing each interview. Or if they wanted, they could contact me. The selection of participants for subsequent interviews was based on the data that emerged that related to theoretical sampling. After every interview, before leaving I summarised the information gained and gave the participants a chance to ask questions; again, all questions were answered. Then I expressed my gratitude for their time and willingness to participate in the study.

Multiple interviews were conducted with nearly all participants in order to enhance credibility, and clarify and expand information and my understanding of the information as suggested by Kylma et al. (2001). Overall, the number of visits ranged from one to seven visits per participant. Only four participants were interviewed once – I could not make an appointment for follow-up interview for two of them (one because I could not locate her house although she had given me her address and directions and she had no telephone connection; and the other participant, although she was willing to participate and felt comfortable about being interviewed, would do so only at the hospital. However, she was a healthy person and was not at the hospital often). I interviewed two other participants only once because I had recruited them when the data were about to become saturated.

In the stage of transcribing, after each interview, I listened to the tape recording to gain the understanding, feeling or essence of the interview as well as compare it with my field notes – in particular, with regard to the behaviours that I could not record on tape such as emotional response – crying, smiling, tone of voice (quiet or loud or silent) – in the period of the interview and prepared for the next interview. The analysis took place immediately because the incoming data from the participants guided the information sought and theoretical sampling (Strauss & Corbin, 1990). Then I hired a transcriber to transcribe the recorded interviews. After that I read and validated the transcribed interview and then, I did intensive data analysis (as discussed under the subheading “Data analysis”).

3.4.1.5 Interview guides

As previously discussed, the Western term *spirituality* was not likely to be clearly understood by lay participants in the study. Therefore, although some previous Thai researchers have used the term spirituality directly in their questions – for instance, "what does spirituality mean to you? What kind of spiritual resources are important to you" (Tongprateep, 2000, p.198) and, at outset of the research, I also prepared focus questions about spirituality (as illustrated in the following section), I found that some participants felt a lack of confidence to give an answer to what is "*jitwinyarn*" (spirituality). Although I informed them that the question had no right or wrong answer some still felt worried about their answer and would ask 'is my answer right?' Thus, I considered that direct questions using the term *jitwinyarn* were framed by Western culture that might be an obstacle to gaining profound understanding of the meaning and the process of spiritual development of Thai people living with HIV/AIDS.

Thus, at the outset of this study; I divided the questions into two sets. Firstly, I employed broad questions. I approached the participants with two main questions: 1) what is going on in your life (as you deal with this disease)? And 2) what helps you to move on in your life day by day? Then questions to probe for more in-depth information based on the information given by the participant were employed. For instance, how did you feel when you first knew you have this disease? Why? What are your experiences in managing and living with HIV/AIDS? What positive and negative outlooks do you have about your future? From your experiences, what advice would you give to a person encountering a diagnosis of HIV/AIDS (in order to overcome their suffering)? How do you gain and maintain happiness (you said you have happiness)? And how do you gain peace in your life?

Secondly, I used focus questions. Although, the term for "spirituality" in the Thai language is not widely used, during interviews, I asked some participants (11 of 33 participants who had higher education or worked in HIV/AIDS support groups) a focus question about spirituality. For instance, "Have you ever heard the word *spirituality*?" If they said "No" I would give them the example of some context in which this word is often mentioned, such as a sports player and teacher, and ask "Have you ever heard of the spirit of a teacher?" If they had no idea, I altered the direction and form of the questions. By contrast, if they said "Yes" I asked other questions, for instance, "Could you please tell me what is your perception of spirituality? How about you, what does spirituality mean to you?" And "Has your spirituality changed since you have had HIV, and (if so) how?

3.4.1.6 Participant observation

Many authors (e.g. Blumer, 1969; Morse, 2001; Ritchie, 2003) have recommended that interviewing alone is not enough to both understand the world of the participants as they see it and to validate information gained. Blumer claimed that observation assists the researcher to clearly understand from the actors how they see objects, how they have acted toward the objects in a variety of different situations, and how they refer to the objects in their conversation with members of their own group. Furthermore, Ritchie claims that observation is important when study is conducted to investigate a process involving several actors and when nonverbal communications is one of crucial features for that study. Mostly in this study, I undertook observation together with an in-depth interview. However, sometimes I only observed interaction between the participants and others. I wrote the observation notes in a private place in order to avoid making the participants feel uncomfortable. I perceived that observation is beneficial in order to gain further understanding of the phenomenon.

3.4.1.7 Field notes

Field notes are important in the process of data collection and I always wrote down key words while I was interviewing or observing. Then, I wrote detailed field notes immediately after I had finished the field work in order to remember the essence of the situation that I had found. Polit and Beck (2006) categorise field notes into two types according to their purpose. First, *descriptive notes* (or *observational notes*) are *objective descriptions of events and conversations.* Descriptive notes should contain contextual information about time, place, and actors to provide a full understanding of the situation. Second, *reflective notes* are *the notes of researchers' personal experiences, reflections, and progress while in the field*. Reflective notes have different purposes. For instance, "*theoretical notes* are interpretive attempts to attach meaning to observations. *Methodological notes* are instructions about how subsequent observations will be made. *Personal notes* are comments about the researcher's own feelings during the research process" (Polit & Beck, 2006, p. 307). The following is an example of a personal note.

Personal Note: at Nong Keng's house (31 July, 2006)

I found the positive point of interviewing at a participant's home. It occurred when I interviewed "Nong Keng" at his home around 06.00 pm. I had more understanding of his story. Nong Keng is a Gay man. He lives in a wooden house with his grandmother – an elderly lady who has a warm personality, and a soft voice. She took care of him when he was sick. His house is located in a community that has many houses built close to each other the same as houses in the (old) city. In front of his house, I saw the vegetables placed on the table because his grandmother sells vegetables in the morning market. I understood the situation when Nong Keng told me that in the past when he had very severe symptoms, including skinny, wasting, and dark skin and people knew he was infected with HIV, they did not buy the vegetables. His grandmother who lay down close to us also said that people refused to buy vegetables because they felt disgust as they pictured the flies which touched Nong Keng landing on the vegetables.

Also, I understood what was going on when Nong Keng told me that he taught teenagers to protect them in order to have safe sex because I saw a group of teenager talking together in front of his house on the opposite side of the road. They said hi to Nong Keng. Nong Keng also received many phone calls while I interviewed him – he had a good relationship with others (who do not have HIV).

Data collection was terminated when I reached theoretical saturation of the data. After I had finished my field work, I gave some special things to all participants both individuals and groups in order to express my sincere thanks for their dedication, effort and their generous mind. For instance, I donated money for HIV/AIDS support groups of some of the hospitals to support their group activities. I gave money to some participants and I gave some books to the participants who love reading. Because of the good relationship between them and me, some of them still keep in contact with me. When I visited Thailand, in July-September 2008, I went to visit them not only to validate my data but also to indicate to them that they are important to this study.

In the future, I expect to conduct further projects beneficial to this group of the Thai population.

3.4.2 Data analysis

As mentioned earlier, data collection and data analysis were conducted concurrently. Strauss (1987) noted that the major differences between grounded theory analysis modes and other qualitative analysis modes is the differences per stage in the combinations and permutations of the operations that are significant to the development of tightly integrated theory. The grounded theory analytic method is called *coding*. It is an intensive analysis and carefully integrated into both examination and interpretation of data. The purpose of coding is to conceptualise the data by analysing them and identifying patterns or events in them. In this study three steps were used for coding – open, axial and selective – as guided by Strauss and Corbin (1990, 1998). In the coding process, each step moves back and forth among three kinds of coding. In particular open coding and axial coding occur concurrently as outlined in Figure 3.2 below.

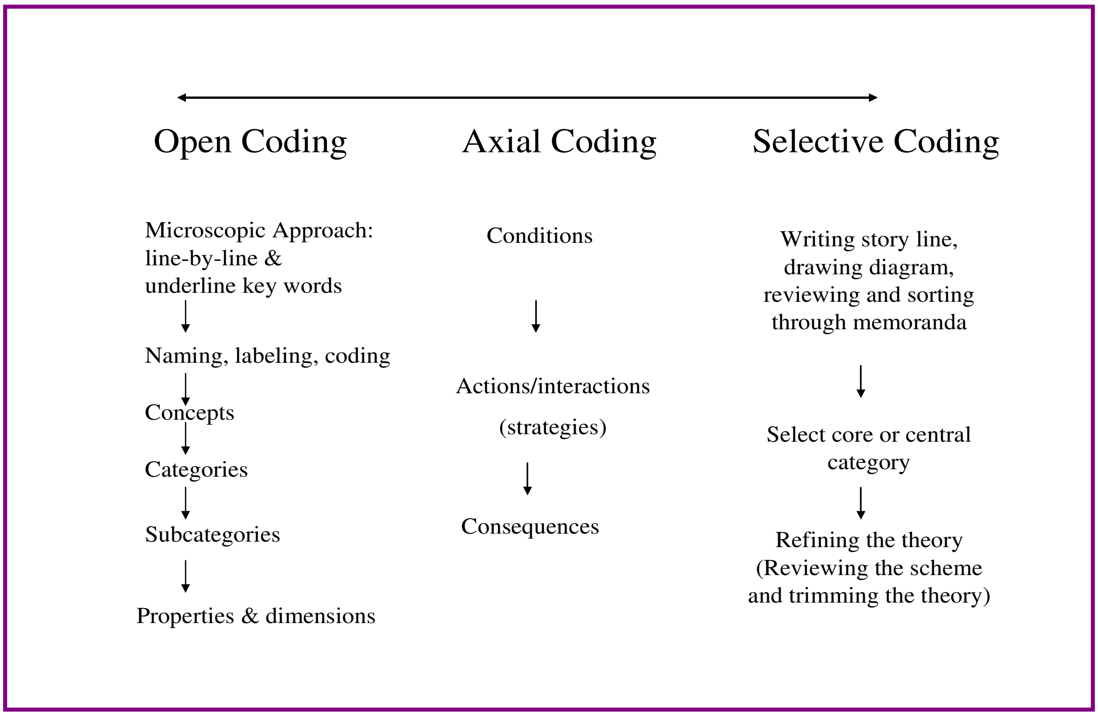

Figure 3.2: The process of data analysis: open coding, axial coding, and selective coding (Adapted from Eaves, 2001)

3.4.2.1 Open coding

The aim in open coding is to name (label, code), identify, categorise and compare phenomena according to their properties and dimensions (McCann & Clark, 2003a; Strauss & Corbin, 1990, 1998). The process of open coding in field work was carried out as follows. Firstly, I used a microscopic approach, in which process each transcript would be read very carefully and the key words underlined. In the beginning of the analysis process, I applied line-by-line and sometimes word-by-word analysis in order to avoid neglecting important categories as suggested by Strauss (1987).

Secondly, the data were coded, after they had been broken down into discrete incidents, ideas, events, and acts, and then each was given a name or code to represent it. These codes were written in the right hand margin of the transcript. The sources of these codes come from either the researcher or from the words of participants and are called "in vivo codes" (Strauss & Corbin, 1998) as shown in Table 3.1. Because theory is not discovered but rather is formulated then verified, simultaneously with line-by-line analysis, I made comparisons and asked questions (also applied in axial coding). For instance, I compared the data that emerged from the first interview with those from the next interview of the first participant. Then I also compared and contrasted her data with those of the other participants. After that I put the same code in two transcriptions as exemplified in Table 3.1 "HIV changed life" (in purple).

Thirdly, I identified the concepts and named them, grouping similar names or codes that shared common characteristics or related meaning, under more abstract codes called "concepts". An example of open coding is illustrated in Table 3.1. There were two participants who had not suspected that they had HIV. One of them discovered her diagnosis of having HIV when she went to ANC clinic. Another one found out when he had a blood test done for HIV as part of preparing to get married. From those many codes was a group under the concept of "HIV/AIDS turned life upside down". This name comes from an "in vivo code" (in pink).

Table 3.1: Open coding of "HIV turned life upside down" concept

Excerpt from data	Codes	Concept
I think that what's happening to me is really serious… very painful! HIV has changed my life… It (HIV) extremely changes my life. My hope changed. Not the same… Everything has changed either the society or even mind. Mind is the most important that in my mind always think that I'm different from others, normal people... Especially when I live with normal people, I keep thinking that I'm different from others. We are not the same (Pee Ning, 27 March, 2006).	HIV changed life. [How, why, when?] Everything in her life changed. HIV makes different from others. HIV makes her (mind) feel different from others who are normal people. [How, why, how often?]	HIV turned life upside down.
Basically, I think everyone has hope… I also have hope but… this disease changes my life… It is extremely changed!! In the past I had a lot of hope…I hoped to help my mother. I hoped to work… All changed… Life turned upside down. In the moment of knowing my diagnosis, I felt absolutely lost. My hopes disappeared. I hoped to work but it shut down (Nong Wut, 24 April, 2006).	HIV changed life. HIV shut down hope. HIV turned life upside down. HIV causes loss. Loss of hope in working.	

By constantly moving between the data and the interpretations within the same transcript and across different transcripts several times, I gained more understanding and became more sensitive to the data. Strauss and Corbin (1990) also suggested that in order to understand more about the category (phenomenon), the researcher can use basic questions such as who, when, where, what, how, and why as illustrated in blue in Table 3.1. I found that comparisons were often suggested by asking questions that guided me to gather in-depth information. When asking a question, it is important not only to ask "what is going on?" in a descriptive sense, but also how this incident compares dimensionally along relevant properties with the others already identified. For instance, in the process of encountering distress most participants expressed the desire not to live. I found the participants perceived that "HIV/AIDS is a cause of death". I asked "What if" "What would happen if they perceived it a different way?" and "What factors could make them perceive in a different way?"

Fourthly, the categories were discovered. *Categories* are *groups of concepts that are derived from data and stand for phenomena.* Phenomena are important analytic ideas that emerge from data and they answer the question "What is going on here?" Categorising is the process of grouping concepts that seem to pertain to the same phenomena together (Strauss & Corbin, 1990). After I had identified some concepts, similar concepts were grouped together in order to develop categories.

Lastly, came the process of developing categories in terms of their properties and dimensions. Once a category had been identified, I began to develop it in terms of its specific properties and dimensions. "*Properties* are *the general or specific characteristics or attributes of a category. Dimensions* represent *the location of a property along a continuum or range*" (Strauss & Corbin, 1998, p. 117). Properties and dimensions are important because they form the basis for identifying relationships between categories and subcategories. For instance, with the category of **struggling to survive** I wanted to define what was meant by **struggling to survive**. And also I was interested in how these properties vary along their dimensions.

3.4.2.2 Axial coding

In axial coding, the data are put back together in a different way through categorising them and making links between a category and its subcategories guided by the paradigm model (Figure 3.3). The researcher begins to build up a dense texture of relationships around the "axis" of the category which is being focused on (Strauss, 1987). The basic components of the paradigm model are conditions, actions/interactions and consequences (Strauss, 1987; Strauss & Corbin, 1998). *Conditions* are *sets of events or happenings that create situations and explain why, how and when persons or groups respond on certain ways.* Condition shift and change over time and combine in various ways along different dimensions. The actions/interactions (strategies) are the strategies or routines individuals or groups use to handle situation or problems or events that arise under the conditions (Strauss & Corbin, 1998). In other words, *strategies* are *purposeful acts that are taken to resolve a problem.* Actions/interactions are represented by the questions "By whom?" and "How?" The last component of the paradigm is *consequence*. This describes *the outcome of actions/interactions*. Consequences are represented by questions about what happens as a result of those actions/interactions. Figure 3.3 presents the example of axial coding of the **struggling to survive** category.

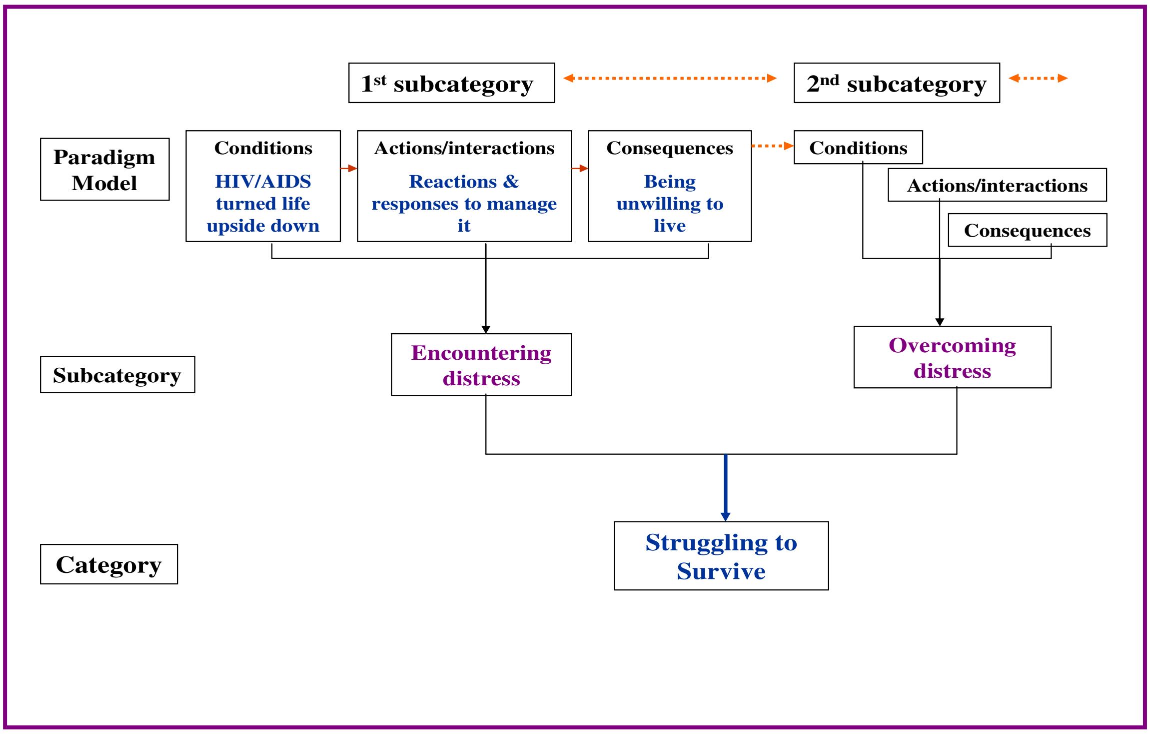

Figure 3.3: The relationship among conditions, actions/interactions (strategies), consequences, subcategory and category

Strauss and Corbin (1998) suggested that the way to build up a dense texture of relationship around the "axis" (in axial coding) of the category is to use four steps. First, the properties and the dimensions of a category are laid out as they emerge in the open coding process. Second, identifying the variety of conditions, actions/interactions, and consequences associated with a phenomenon. Third, relating a category to its subcategories. Last, looking for clues in the data that denote how major categories might relate to each other. The concepts that are shown as conditions, actions/interactions, and consequences in Figure 3.1 are concepts, properties, and dimensions of the category that emerged in the process of open coding. However, Strauss and Corbin contend that the important issue is not so much identifying and listing which conditions are causal, intervening, or contextual. Rather, the researcher should focus on the complex interweaving of events (conditions) leading up to a problem to which persons are responding through some form of actions/interactions, with some sorts of consequences.

Data analysis is non-linear. As mentioned earlier, open coding and axial coding occur simultaneously. So, while I identified the categories in terms of their properties and dimensions, I continued analysing in the axial coding process that is the process of relating subcategories to a category to form more precise and complete explanations about phenomena. In order to generate the category, I not only moved back and forth between data collection and analysis again and again and made sure that the categories were generated from the data, but also I returned to the literature review to stimulate my theoretical sensitivity (discussed in the following section) until theoretical saturation was reached (as shown in Figure 3.1). Strauss and Corbin (1998) suggested that when the researcher uses axial coding, s/he should answer the questions of why or how come, who, when, where, why, how and with what consequences and then s/he will be able to relate structures (why) and process (how) to capture the dynamic and evolving nature of events.

3.4.2.3 Selective coding

Selective coding is the last process of data analysis. Its aim is to identify a core category, establish links between the core category and other categories, integrate the categories along the dimensional level to form a theory, validate the statements of relationship among concepts, and fill in any categories in need of further refinement (Strauss & Corbin, 1998). The core category presents the main theme of the research because it has analytic power to pull other categories together to form an explanatory whole and explain most of the variation among the data (Morse, 2001; Strauss, 1987, Strauss & Corbin, 1998).

From my experience, the process of selective coding requires additional critical thinking and consciousness and mindfulness as well as being time consuming. In this study in order to facilitate identification of the core category of **Achieving Harmony of Mind** and integration of concepts, I applied many techniques: writing a story line, making use of diagrams, and reviewing and sorting of memoranda. I wrote many story lines in order to describe and explain the process of spiritual development in persons living with HIV/AIDS in the Thai context. For instance, I wrote the story of the “the rocky road journey”. I compared people living with HIV/AIDS to driving a car on a rocky road (having HIV/AIDS). The story line helped me to integrate each piece (categories, subcategories, concepts) of the jigsaw to put together in the story of **Achieving Harmony of Mind**.

I also used diagrams. In my opinion, drawing a diagram is effective in the process of selecting the core category because it presents clear relationships and directions among concepts, subcategories and categories. I applied the diagrams in order to show the development process of the mind, to show the flowing within each category and between categories. I always prepared blank paper and pencil to draw a diagram when I did data analysis. I not only drew a diagram to generate the core category, but also I drew diagrams of each participant to link the concept that I found from them. Then I merged the diagrams of each participant in order to see the big picture of the phenomenon. In the path of developing **Achieving Harmony of Mind**, I drew many diagrams. The following figure shows the diagram which I called "life is no longer dark".

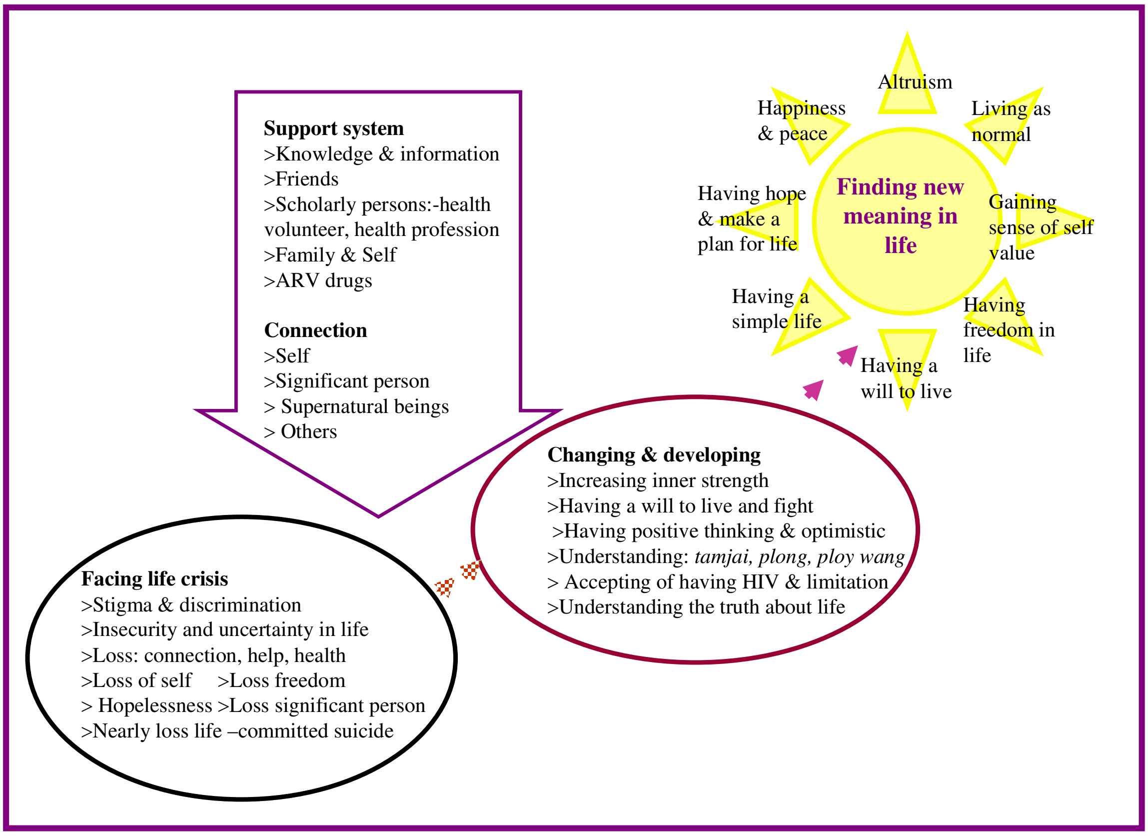

Figure 3.4: Using a diagram to develop the core category

In addition, I reviewed using memoranda. Writing a theoretical memorandum is an important task in doing data analysis because it includes ideas that I generated during the process of data analysis. As some authors (e.g. Chenitz & Swanson, 1986) have said, writing memoranda is one part of writing the theory because they serve to store ideas generated about the data. While I did data analysis, my memoranda were written in several ways. I wrote them whatever I thought of something relevant to my hypotheses. I also wrote questions that came to my mind. I also wrote them as field notes. I wrote intensive memoranda when I started to do data analysis. I would take notes of how I found categories, how they related to each other. Moreover, sometimes, my memoranda were the early drafts of my research findings.

Memoranda are very useful data for building up a core category or theory (as described). Many times, when I had a problem such as categorising data, I not only went back to raw data, discussed it with my supervisor, returned to the literature review, but also I often went back to read my memoranda. They helped me to recall what I was thinking in the past. What was the reason behind the concepts or categories? Why and how can I develop each category? Although I did not put each memorandum in a separate file, I put date, month, and year as well as the main concept or key words for each. Finally, I felt surprised when I found that I had more than 80 pages of memoranda.

After I discovered the core category; I reviewed the scheme for internal consistency and filled in the gaps in the developed categories (Strauss & Corbin, 1998). Reviewing the scheme occurred both with the core category and each category. Filling in occurred until the final writing phase had begun. I did a thorough review of memoranda and raw data, and returned to the field. The ultimate criterion for determining to finalise the data-gathering process is theoretical saturation (as illustrated). Furthermore, sometimes, I found that I had an excess of data and some ideas did not fit the theory. So, I had to drop or regroup them – called *trimming the theory*. From the long process of data collection and data analysis that moved back and forth many times and involved many techniques, finally, the diagram presenting the core category of **Achieving Harmony of Mind** in the Thai context was found as presented in Figure 4.1 (see p. 83).

3.4.3 Theoretical sensitivity

As outlined in Figure 3.1, another an important concept in grounded theory is theoretical sensitivity. *Theoretical sensitivity* or *entering the field with an awareness of the subtleties of the data* is related to *the ability to have insight*, *understand and give meaning to the data and to detach the relevant from the irrelevant*. Theoretical sensitivity can also be gained from a preliminary review of the literature and from professional experience (McCann & Clark, 2003a). In the process of data analysis, theoretical sensitivity and constant comparison must be exercised not only in relation to data that emerge, but also in the process of comparing them with the literature. In addition, the literature review guided the following data collection and theoretical sensitivity. Exercising theoretical sensitivity enabled me to decide what concepts to search for and where to search for their indicators. Moreover, when more sensitivity had developed, I was able to further explain what was going on based on the data, the nature of life, the literature, and discussions with my supervisors. Hence, this is the process of interplay between induction and deduction as well as verification in order to build the core category – **Achieving Harmony of Mind**.

3.4.4 Literature Review

As discussed in Chapter Two and outlined in Figure 3.1, the literature review plays an important role in two aspects – both in the preparation of the research proposal and in supporting the emerging theory. In the processes of data collection and data analysis that involved the process of induction, deduction, and verification, I found that the literature was beneficial because it enhanced theoretical sensitivity, provided a useful secondary source of data, gave rise to questions about the data, guided theoretical sampling, and supported the validation of the theory as suggested by Strauss and Corbin (1990).

In summary, Straussian grounded theory provides not only three kinds of coding (open coding, axial coding, and selective coding), but also a variety of techniques in order to build up the theory. Furthermore, the processes of data collection and data analysis are linked with other procedures including literature review and the exercising of theoretical sensitivity.

3.5 Establishing Research Trustworthiness

Trustworthiness is a term used in the evaluation of qualitative data (Polit & Hungler, 1999). Lincoln and Guba (1999) said that the basic issue in relation to trustworthiness is how researchers can convince their audiences that the findings of an inquiry are "worth paying attention to and worth taking account of" (p. 398). Lincoln and Guba have suggested four criteria for establishing the trustworthiness of qualitative data: credibility, dependability, confirmability and transferability. In this study I claim that my data are trustworthy based on the following criteria.

3.5.1 Credibility or authenticity

Credibility "is related to whether the researcher's findings capture what is really occurring in the context and whether the researcher learned what he or she intended to learn" (Pitney, 2004, p. 26). There are several techniques to enhance credibility: 1) activities that ensure that credible findings and interpretations will be produced such as prolonged engagement, persistent observation, and triangulation; 2) an activity that provides an external check on the inquiry process (peer review); 3) an activity aimed at refining working hypotheses as more and more information becomes available (negative case analysis); 4) an activity that makes possible checking preliminary findings and interpretations against archived raw data; and 5) member checking by providing the study participants with the data or interpretations of the results, in order that they can verify their accuracy based on their experience (Lincoln & Guba, 1999; Pitney, 2004). Similarly, Glaser and Strauss (1967) emphasised, in explaining the credibility of grounded theory, that the researcher should give an extensive abstract presentation of the overall framework and its principal associated theoretical statements and segments throughout it. Using a codified procedure for analysing data, which allows readers to understand how the data analyst obtained the theory from the data also adds to credibility.

In this study, I followed the foregoing suggestions and in the process of obtaining credibility, I employed several techniques. First, I had *prolonged engagement* (over nine months) in order to have an in-depth understanding of the cultures, language, or views of the participants by both in-depth interview and ongoing observation. Additionally, prolonged engagement is also essential for building trust and rapport with informants.

Second, *triangulation* (*the use of multiple references to draw conclusions about what constitutes the truth*) was also used to enhance the credibility of my qualitative findings (Lincoln & Guba, 1985, cited in Polit & Hungler, 1999). There are four types of triangulation: data triangulation, investigator triangulation, theory triangulation, and method triangulation. In this study, triangulation was obtained by 1) data triangulation – multiple interviews and observations with 33 participants, 2) investigator triangulation – I was closely supervised by two supervisors in the field and we analysed and discussed preliminary data together, 3) theory triangulation – the new data that emerged from the field work were compared with previous data and the literature review to find similarities and differences, and 4) method triangulation – interview, observation and field notes were used.

In this study, I conducted data collection at six sites, each of which was unique. As Chenitz (1986) emphasised, validity is established during the ongoing process of data collection and analysis by "using methods, sites, sources, and participants that enable the full range and variation of behaviour of the phenomena under study to emerge" (p. 89).

Third, as for external checks, *peer debriefing* is *a session held with one or more objective peers to review and explore various aspects of the inquiry*. Peer debriefing is a process that exposes the researcher to the searching questions of others who are experienced in the methods of inquiry, the phenomena being studied, or both. The process of peer debriefing was enhanced by the field supervisors who always participated in monthly discussions. The chief supervisor was experienced in qualitative methodology. In addition, I often had discussions with colleagues who were expert in HIV/AIDS, spirituality, and qualitative research – in particular, grounded theory. Furthermore, the findings of this study were accepted and approved by the public who were able to examine them through presentations made at three international conferences (Appendix N).

Last, a *member check* refers to *the provision of feedback to the study participants regarding the data and the researcher's emerging findings and interpretations*. The process of member checking took place when I returned to Thailand (July to September 2008). I described the analytic categories that emerged to some participants. These participants agreed that these categories and the core category were consistent with their experiences.

3.5.2 Dependability

Dependability (reliability in a conventional paradigm) (Liamputtong, 2009; Polit & Hungler, 1999; Pitney, 2004) of qualitative data is "based not on whether particular findings can be reported by another researcher but rather *whether they are reasonable based on the data collected"* (Pitney, 2004, p. 27). According to the practical application of grounded theory, "it must be sufficiently general to be applicable to a multitude of diverse daily situations within the substantive area, not to just a specific type of situation and it must allow the user partial control over the structure and process of daily situation as they change through time" (Glaser & Strauss, 1967, p. 237). Although some procedures that enhance credibility – such as a member check (Pitney, 2004) and the triangulation method (Polit & Hungler, 1999) – can also provide dependability, the researcher should include a strong solution to deal with dependability directly. This is the *inquiry audit* (Polit & Hungler, 1999).

An *inquiry audit* requires *two components: the detail of the process and the product of the research.* An external reviewer should scrutinise all of the data and relevant supporting documents (Polit & Hungler, 1999). The dependability of this research is accounted for and presented in this chapter and should enable an external reviewer to be satisfied about the research procedures. Additionally, the outcomes of the research are presented intensively in Chapters Four to Eight. In other words, the two tasks of the inquiry audit are to examine the process and product (findings, interpretations, and recommendation).

3.5.3 Confirmability

Liamputtong (2009) stated that "confirmability is comparable to objectivity or neutrality. It attempts to show that findings and the interpretations of those findings… are clearly linked to the data" (p. 22). In qualitative studies, *confirmability* focuse*s* on *the characteristics of the data*. Inquiry audits can be used to establish both the dependability and confirmability of the data. In an inquiry audit, the researcher must develop audit trails (a systematic collection of materials and documentation) that allow an auditor to come to conclusions about the data.

In this study, confirmability is presented throughout the eight chapters including the preface in which the roots of the research inquiry – background information, literature review, the research methodology and methods, the research findings, discussion, and lastly the implications – are presented. The quotations of the participants' statements are reported adequately to demonstrate that findings were grounded from the data rather from the preconceptions of the researcher. In addition, most of the time, the labels of the concepts or the categories were selected from in vivo codes. Furthermore, the data from the processes of data collection and data analysis – such as tape transcriptions and field notes – are stored anonymously and securely to allow for audit.

3.5.4 Transferability or applicability

Transferability or *applicability* (external validity in the conventional paradigm) (Pitney, 2004) or fittingness (Chiovitti & Piran, 2003) refers to the *generalisability of the study's result*, that is, *the extent to which the findings from the data can be transferred to other settings.* Researchers need to provide sufficient descriptive data in the research report so that consumers can evaluate the applicability of the data to other contexts. However, the researcher must be cautious that too much detail may break the participants' confidentiality (Liamputtong, 2009). Pitney (2004) suggested that use of multiple settings is one of the strategies necessary in order to obtain transferability.

In this study, the processes of data collection and data analysis occurred concurrently alongside the processes of induction, deduction, and verification and a variety of techniques such as theoretical sampling and theoretical comparison were utilised, together with prolonged engagement through multiple interviews with the 33 participants (as described under the subheading "Participant demographics") in the six sites. Most interviews were recorded and transcribed verbatim (as discussed previously). These created the "thick description" that explicates accurately and precisely the phenomenon and meanings of spirituality and spiritual development of people living with HIV/AIDS in the South of Thailand. This process not only facilitated assessment of transferability by the reader, but also enables wider generalisation of the theory.

3.6 Conclusion

In this chapter, grounded theory methodology has been explained and discussed. Strauss' version of grounded theory methodology was chosen as being the most appropriate to understand the meaning of spirituality and process of spiritual development in persons living with HIV/AIDS in the Thai context. The process of this research, and methods used to analyse the data have been described. The issues of trustworthiness and credibility were matters of concern. Participant protection was taken into consideration throughout the process. In the subsequent chapters, the research findings are reported, beginning with an overview of the research findings – **Achieving Harmony of Mind** – and the category – **struggling to survive**.

CHAPTER 4

Struggling to Survive: Encountering Distress

4.1 Introduction

In the previous chapter, grounded theory methodology and the logic for selecting this methodology to explore the meaning of spirituality and the process of spiritual development of people living with HIV/AIDS in the Thai context were discussed. In addition, the designs and methods of the research were explained. In this chapter, an overview of the phenomenon of **Achieving Harmony of Mind,** the core category that was generated from dialogue with participants who had lived with HIV/AIDS in Thailand for five years or more is outlined. The first category – **struggling to survive** – and the first subcategory (*encountering distress*) are explained and discussed using the format of the paradigm model – conditions, actions/interactions (strategies), and consequences.

4.2 An Overview of the Research Findings

In this study it is proposed that the process of **Achieving Harmony of Mind** – the core category identified – has a number of stages that are represented by two categories and four subcategories. The first category, **struggling to survive,** incorporates two subcategories (*encountering distress – tukjai*[8] – and *overcoming distress – longjai*[9]) that are detailed in this chapter and the next chapter respectively. Another category, **living life**, also consists of two subcategories (*accomplishing harmony in oneself* and *discovering an ultimate meaning in life*) that are described in Chapter Six and Chapter Seven respectively.

Figure 4.1 demonstrates the relationship between these two categories and the relationship among the four subcategories as well as the position of the core category that represents the process of **Achieving Harmony of Mind** of the Thai participants who have been living with HIV/AIDS for five years or longer.

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[8] *Tukjai* means the mind experiences the feeling of giving up and/or wanting to give up, distress, suffering.

[9] *Longjai* means the mind that feels relief from suffering or distress.

Achieving Harmony of Mind while living with HIV/AIDS, as shown in Figure 4.1, is the phenomenon that explains the continuously changing state of the mind of people living with HIV/AIDS that moves back and forth between the two processes of **struggling to survive** and **living life**. There are two kinds of movement in the process of **Achieving Harmony of Mind**. First, a person's state of mind moves within each circle or the subcategory (subprocess) that is presented (in Chapters Four to Seven) in terms of the conditions, actions/interactions, and consequences in each subcategory. Second, there is an overall development of the mind in the whole process of **Achieving Harmony of Mind** which has HIV/AIDS as a main condition. There are a variety of strategies such as finding meaning and purpose in life which can be employed to assist this overall development of the mind. As a consequence, the participant's state of the mind settles and gains peace and harmony. The whole process of development of the mind is explained and discussed in Chapter Eight in terms of the core category or substantive theory.

In Figure 4.1, the two categories – **struggling to survive** and **living life** – are represented as ovals, symbolising each stage in the process of **Achieving Harmony of Mind**. The four subcategories – *encountering distress, overcoming distress, accomplishing harmony in oneself,* and *discovering an ultimate meaning in life* – are represented as circles, symbolising each stage in the subprocess of **Achieving Harmony of Mind**. Each circle represents the state of the mind in each part of the process. The different colour tones of the circles indicate the different states of the mind that people living with HIV/AIDS go through. The dark colour of the first circle represents the most weakness and the mind deeply overshadowed by HIV/AIDS. The colour of the later circles becomes lighter from left to right, representing participants' increasing ability to regain their strength, manage their lives – including feeling free from the shadow of HIV/AIDS – and obtaining a peaceful mind while they continue to live with HIV/AIDS. Each oval (category) and circle (subcategory) is related to each other and often the consequences of the previous process or subprocess become conditions of the next process or subprocess.

The line running through the four circles symbolises HIV/AIDS as a shadow and a chronic health condition, which people living with HIV/AIDS have to live with for the rest of their lives. The different colour tone of the line indicates the different degree of

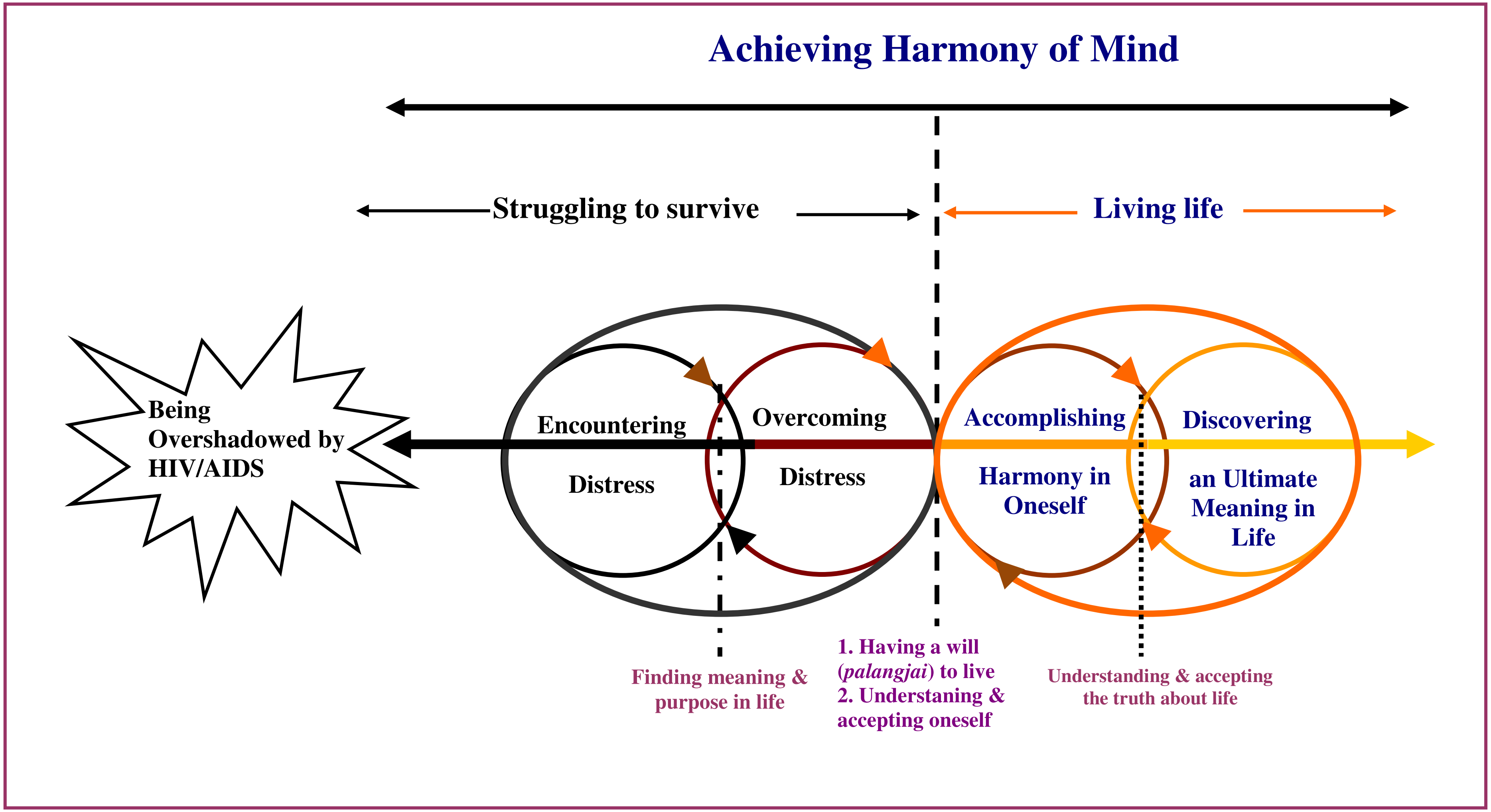

Figure 4.1: The process of Achieving Harmony of Mind

impact of HIV/AIDS on participants' lives. The dark colour at the beginning of the line represents the most severe impact of HIV/AIDS which is when the mind is feeling weakest as participants' feelings are deeply overshadowed by HIV/AIDS. The colour of the line becomes lighter as it traverses the circles from left to right, representing participants' increasing ability to regain their strength, take control of their lives and state of the mind, and prevent HIV/AIDS from overpowering their lives.

4.2.1 The first oval: struggling to survive

The first oval symbolizes the process of **struggling to survive** by the participants when their life (composed of the mind and the body) – in particular, their mind – was overshadowed by HIV/AIDS which is viewed as a life altering situation. The condition that enabled participants to make the transition from **struggling to survive** to the next process of **living life** (addressed in Chapter Six and Chapter Seven) involved experiencing finding meaning and purpose in life and having a will to live. Two subcategories: *encountering distress* (discussed in this chapter) and *overcoming distress* (addressed in the following chapter) comprise **struggling to survive**.

4.2.1.1 The first circle: encountering distress

This circle represents the beginning of the process when the participants were first diagnosed with HIV/AIDS or first knew their life was involved with HIV/AIDS. The dark colour of this circle represents the time of weakness of the mind when the participants felt as if their lives had been completely turned upside down. Within this process, the participants may react and manage their lives in a pessimistic direction described as "waiting to die and living life with lethargy". Most HIV/AIDS persons going through this process experienced the feeling of **struggling to survive**. The conditions, actions/interactions (strategies), and consequences of *encountering distress* (*tukjai*) are described further in this chapter.

4.2.1.2 The second circle: overcoming distress

Having encountered distress, participants faced a choice of continuing to live with lethargy (waiting to die) or finding meaning and purpose in life and a will to live. Selective disclosure of one's HIV status resulting in the receiving of support and connectedness with others, and devising strategies to develop a strong mind and feelings of self-worth are conditions and strategies of *overcoming distress*. The conditions, actions/interactions (strategies), and consequences of *overcoming distress* are discussed in more depth in Chapter Five.

The broken line, between these first two circles illustrated in Figure 4.1, indicates that there is no clear point or level of strength of the mind that separates the two stages from each other, as the state of the mind of a person living with HIV/AIDS is likely to change in response to differing circumstances. The gaps within the first line are greater than the gaps within the second or the third broken lines, signalling the greater possibility of the participants regressing from the second to the first stage in the process. This backwards movement (of the mind) is possible because they have not yet successfully regained their strength of mind and will to live and may allow HIV/AIDS to again dominate their minds.

4.2.2 The second oval: living life

The second oval symbolises the process of learning to live in the circumstance of having HIV/AIDS – **living life**. Once the participants have been through the previous process, and they have developed a will to live, they attempt to stabilise their lives both physically and intellectually (the body and the mind) by learning to live with HIV/AIDS. Throughout this process, the participants move across the boundary symbolised by the second broken line, from **struggling to survive** to **living life**. However, some participants who arrive at this stage can still move backwards to the previous process. Therefore, they may still be faced with the feeling of **struggling to survive**. This category or process divides into two subcategories or subprocesses; *accomplishing harmony in oneself* and *discovering an ultimate meaning in life*.

4.2.2.1 The third circle: accomplishing harmony in oneself

The participants who possess a better understanding (*kaojai*) and are able to adjust their mind to accept (*tamjai* and/or *yomrub*) their new situation – as well as having successfully learnt to live with HIV/AIDS – progress to the next stage in the process, while those who still struggle to adjust themselves to their new situation are prone to move backward. However, the possibility of one returning to the previous stage is not as great as those in transition from the first to the second stage because most participants are able to resume their strength and establish a stable state of the mind. This explains why the gaps of the second broken line are smaller than those of the first. The conditions, actions/interactions (strategies), and consequences of the subcategory *accomplishing harmony in oneself* are discussed in depth in Chapter Six.

4.2.2.2 The fourth circle: discovering an ultimate meaning in life

Some participants not only have the ability to integrate HIV/AIDS into their lives and live with this circumstance as normal (discussed in the third circle and Chapter Six), but also were able to find an ultimate meaning in life that was enhanced by having HIV/AIDS. Some participants arrive at the fourth stage *discovering an ultimate meaning in life* and living with peace and harmony or having *kwarmsa-ngobjai*[10] when their minds gain insight and wisdom to understand and accept the reality that they are encountering. In particular, participants who reach this stage understand and accept the truth about life[11]. Thus, they begin to learn how to live their lives harmoniously and happily under their new circumstances. The participants who have reached this stage have built their peace and calm mind as the strongest protection ─ represented by the least permeable line. Thus, they are unlikely to return to the earlier stages. The conditions, actions/interactions (strategies) and consequences of *discovering an ultimate meaning in life* are discussed further in Chapter Seven.

Having completed an introductory overview of the substantive theory of **Achieving Harmony of Mind**, in the remainder of this chapter the first category – **struggling to survive** – and the first subcategory (*encountering distress)* are explained and discussed using the format of the paradigm model – conditions, actions/interactions (strategies), and consequences.

4.3 Struggling to Survive

Struggling to survive is the first of the two categories of the research findings that build towards the core category **Achieving Harmony of Mind**. This phenomenon was started when HIV/AIDS became involved in participants' lives both directly and indirectly. Figure 4.2 shows that when participants face a life-threatening condition

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[10] *Kwamsa-ngobjai* or finding peace – is a goal that is based on Buddhist beliefs and practices (Ross et al., 2007). This notion is addressed more fully in Chapter Seven.

[11] The truth about life – (*kwarmjingkongcheewit*) – is based on Buddhist beliefs. For instance, life has both ups and downs; both happiness and suffering are not permanent; death and dying comprise a truth that every human being will encounter as well as the truth that nothing is permanent. These notions are addressed more fully in Chapter Seven.

such as being diagnosed with HIV and are confronted with its consequences, they arrive at a metaphorical intersection like crossroads where there are two possible paths to choose (Kylma, 2005). One pathway shows the process of *encountering distress* (*tukjai*) of the mind that leads to being unwilling to live or a destructive frame of the mind of giving in to hopelessness and the other shows *overcoming distress* of the mind or a constructive frame of the mind leading towards having a will to live (*palangjai* or *kamlangjai* [12]).

The first pathway, illustrated in Figure 4.2, is *encountering distress* (represented in a dark brown colour). Some participants may choose to despair and give up. Several participants reported feeling stuck and depressed; they despaired, lost hope, and lost their sense of self, with the result that they were unwilling to live. Despite the fact that some participants were sinking into the first process of *encountering distress*, other participants could overcome their life crisis and find meaning and purpose in life thus taking the second pathway of *overcoming distress* and having a will to live. However, those who had chosen the first pathway would be able to come back to the second pathway of *overcoming distress* depending on their ability to adjust their frame of the mind (*jai*) based on their conditions and actions/interactions (strategies) (represented in an orange – broken line) in order to gain a will to live (discussed in the next chapter).

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[12] *Palangjai* and *kamlangjai* are present as both subject and object. *Palangjai* is made up of two words: 1) *palang* means power, and 2) *jai* means mind. *Kamlangjai* also is made up of two words: 1) *kamlang* means power, and 2) *jai* means mind. *Kamlangjai* is used in two situations. The first is described as "a state of mental well-being that occurs when the participants have a strengthened mind and feel confident in facing any situation with a sense of purpose in living" (Namjantra, 2003, p. 144; "*Kamlangjai*" in Thai-English and Buddhist dictionary, 2009). The second can be described as one kind of support and works as an object. Therefore, the first meaning of *kamlangjai* has the same meaning as *palangjai* which is a state of strengthened mind in facing any situations. Thus, in order to make a clear statement, in this study, for the term state of mind that strengthens a person or a will to live the term *palangjai* is used rather than *kamlangjai*, while the term *kamlangjai* is used in the context of "one kind of support".

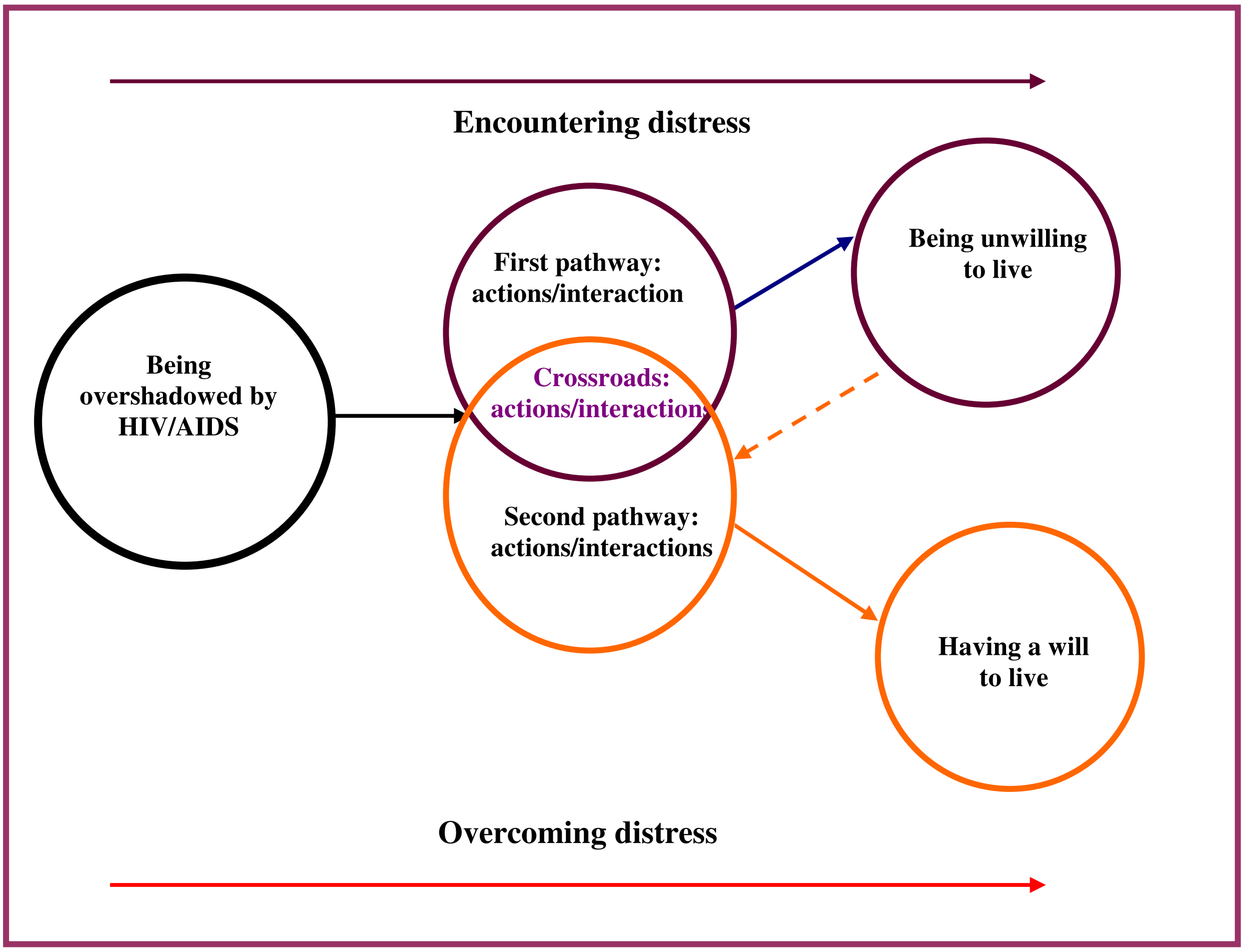

Figure 4.2: The first crossroads – where there are two possible paths to go through

4.4 Encountering Distress

Encountering distress is the first subcategory of **struggling to survive** that contributes to the core category **Achieving Harmony of Mind**; the subcategory includes three concepts. The first concept is called "HIV/AIDS turned life upside down" which is the condition of this subcategory. Then the second concept, "reactions and responses to manage it", consists of actions/interactions (strategies). Finally, the last concept "being unwilling to live", encompasses the consequences. The conditions, actions/interactions (strategies), and the consequences of *encountering distress* are depicted in Table 4.1.

Table 4.1: Encountering Distress: conditions, actions/interactions (strategies), and consequences

Conditions	Actions/interactions	Consequences
HIV/AIDS turned life upside down	**Reactions and responses to manage it**	**Being unwilling to live**
1. HIV/AIDS causes insecurity, uncertainty, and hopelessness > HIV/AIDS causes death > HIV/AIDS causes severe opportunistic disease > HIV/AIDS requires living with restrictions 2. HIV/AIDS erodes sense of self and leads to feeling inferior > HIV/AIDS is a stigmatised disease > Feeling 'useless' as a person 3. HIV/AIDS causes multiple losses	1. Reactions to distress > Shock, disbelief, and denial > Thinking about ending life > Confused and mixed up feelings > Feeling relief 2. Ways to manage the situation of having HIV/AIDS > Writing a diary > Concealing and camouflage > Forgetting and ignoring > Taking antidepressants > Escaping to Buddhist temple and monks > Seeking support from health professionals > Turning to supernatural and supreme beings > Searching for alternative treatment	1. Planning for dying 2. Living life with lethargy > Lacking motivation to live > Nonadherence to restrictive self-care requirements

4.4.1 Encountering Distress: HIV/AIDS turned life upside down

This concept illustrates the condition "HIV/AIDS turned life upside down" that leads to "*encountering distress*". The participants perceived that their life was torn apart and turned upside down by HIV/AIDS because diagnosis with HIV infection was often a life-altering event that caused suffering and distress (*tukjai* and *tortarejai*). The magnitude of having HIV intruded on their whole life and they had to face various constraints. HIV eradicated the entirety of some participants' plans for their lives, destroying these hopes and plans either gradually or suddenly.

> Basically, I think everyone has hope… I also have hope but…this disease changed my life… It is extremely changed!! In the past I had a lot of hope… I hoped to help my mother. I hoped to work… All changed… Life turned upside down. In the moment of knowing my diagnosis, I felt absolutely lost. My hopes disappeared. I hoped to work but my hope shut down (Nong Wut, 24 April, 2006).

Some participants stated that when suffering occurred, a torrent of suffering came into their life simultaneously, which was overwhelming as if the suffering had a need to destroy them. The participants reported that they encountered double or triple distress from HIV. For example, firstly, they themselves were infected by the HIV virus. Then, they may have lost someone close to them from this disease. Lastly, they suffered side effects from ARV drugs or opportunistic infection drugs and nearly lost their lives. Therefore, the perspective that HIV/AIDS turned life upside down was held not only at the initial diagnosis of HIV, but as long as HIV remained in their life as a shadow. These circumstances led them to experience distress.

Three subconcepts were identified in relation to the condition or the concept "HIV/AIDS turned life upside down": 1) HIV/AIDS causes insecurity, uncertainty, and hopelessness, 2) HIV/AIDS erodes one's sense of self and leads to feeling inferior, and 3) HIV/AIDS causes multiple losses. This concept and its subconcepts, as outlined in Table 4.1, will be addressed in the following sections.

4.4.1.1 HIV/AIDS causes insecurity, uncertainty, and hopelessness

HIV/AIDS causes insecurity, uncertainty, and hopelessness is the first subconcept as the condition of "HIV/AIDS turned life upside down". Fifteen of the 33 participants were young adults who were between 17-25 years old when they first knew their HIV diagnosis. Diagnosis with a fatal disease that was perceived as devastating, terrible, life threatening, incurable, and causing death quickly, shut down their life and hope. They did not know how to deal with it. Some participants perceived that this disease was their "enemy" that was destroying their lives. They could not imagine how their life would be with the disease. It was difficult to plan for the future and life had to be lived within limitations. Thus the diagnosis of HIV caused insecurity, uncertainty, and hopelessness, a condition that continued beyond the time of diagnosis to be described by those who had been living with HIV/AIDS for more than five years.

> When I think about my future such as how long can I live, it blurs!! I don't know what will happen in the future because I have HIV. I also feel sad especially when I look at my daughter as I don't know how she can live, and I don't know about her future. How can she survive without me? I feel I have lost my heart (Pee Ying, 18 March 2006).

In particular participants who lived alone, or who had less support or no person to depend on, expressed insecurity, uncertainty and hopelessness. For example, Pee Porn worried about her future in her work, selling Lotto tickets, because if her body image changed (so that she showed visible signs of AIDS) people may be less willing to buy tickets from her. Three circumstances were identified that underpin the subconcept of "HIV/AIDS causing insecurity, uncertainty and hopelessness".

Firstly, HIV/AIDS causes death. Living with HIV/AIDS equates to living with uncertainty, insecurity, and hopelessness because HIV/AIDS causes death. Several participants experienced nearly dying or the death of others from HIV/AIDS, which led them to feel insecure in life and to perceive that they were close to dying soon. It seems they have walked into a dying situation when they are not ready to die. This perspective occurs intermittently throughout one's life with HIV/AIDS, often triggered when a distressing situation occurs such as seeing others dying from HIV/AIDS.

> At the first time when I know I have HIV, I feel scared. I feel worried about how long I can live because at that time a lot of people who were infected with HIV died. In this area, it seems that people died every month. So, I felt scared (Nong Tin, 6 October 2006).

The knowledge that HIV/AIDS is incurable and that people still die from HIV/AIDS even though antiretroviral drugs are available, contributes to participants' feelings of insecurity and uncertainty. Thus, although this study was conducted in the era of ARV drugs and many participants think positively about ARV, uncertainty in life was engendered because of concerns about the long-term availability and clinical effectiveness of medication. One participant reported that although ARV drugs were available, he could not rely on ARV drugs alone because he did not know if his body would resist these kinds of drugs. Some participants – who had witnessed side effects of ARV drugs from their peers' experience – tried hard to maintain their health status and their CD4 level above 200 cells per cubic millimetre (as previously stated, in Thailand, ARV drugs are recommended for people with a CD4 count less than 200-250 cells per cubic millimetre) in order to extend the time in which they do not need to take ARV drugs. Other participants described facing deteriorating health status and declining CD4 levels that left them near death.

> The most suffering in my life is the period when I got sick… I had a lot of symptoms… My symptoms increased every day. At first, I lost weight, became slimmer and had muscle pain all over my body. Then, I had thrush in my mouth…got eye problems…blurred vision… I had skin lesions… I was very weak. I could not get up. I had pressure sores because of being thin and bony. I got every symptom of this disease. Much suffering! (Nong Keng, 11 April, 2006 and 23 August, 2006).

Secondly, HIV/AIDS causes severe opportunistic disease. Having a severe opportunistic disease that is very difficult to treat greatly increases the insecurity in life because it can cause death. As one could expect, nothing is simple when life is dominated by HIV. The most complicated and intricate issues involved with HIV are becoming a vulnerable and compromised host. These participants were more vulnerable to opportunistic infections than the general population because of low immunity. Not only is a cure for HIV/AIDS not yet possible, but also the detection and treatment – if not cure – of opportunistic infections can be difficult and such diseases can cause death.

> The doctor gave me antibiotics because I had lung disease [Pnuemocystis carinii pneumonia]… I had to go to the hospital every week for a month. The doctor said my illness was different from others and more severe than others… I had an appointment with him more often than others (Pee Pang, 11 August 2006).

Participants who nearly died from opportunistic diseases such as pulmonary tuberculosis and meningitis perceived that not only does HIV terminate their life, but also opportunistic diseases may be as severe as HIV and these destroy their quality of life many times once HIV/AIDS is presented. Som described his experience of meningitis when the doctor who treated him informed him and his wife that he had a lesser chance of survival. Other people who visited him agreed that he would die soon. He stated that the meningitis was both difficult to diagnose and difficult to treat and it brought him close to death.

> I was unconscious. The doctor said that I was in coma. I wasn't conscious. I didn't know anything. Somebody visited me and said that I almost died… Also, when I was given a medicine, a yellow medicine [normally – it is an

> amphotericin B medicine], I had allergic [reaction] to it. It was difficult to treat (Som, 03 August, 2006).

Thirdly, HIV/AIDS requires living with restrictions. As HIV/AIDS causes people to be fragile and vulnerable, people living with HIV/AIDS have to be very concerned about how they live their life – as Pat mentioned, "it takes a mere moment of carelessness could lead to the ending of life". They perceived that they have less freedom in life. Restrictions occur in many aspects of living. For instance, some participants revealed their restriction in terms of how they have to live in a place where it is easy to access a healthcare support system. For some participants, the limitation in their way of living was induced by having to have an appointment with a doctor and attend a clinic as well as following the information for advanced treatment and care of this illness. They could not move to somewhere they wanted to live. Most mentioned having restrictions imposed by their self-care such as taking ARV drugs and hiding them. They have to take ARV drugs with them secretly (hide them) at all times so they can take them on time.

> I take it [ARV drugs] with me every time. When I go to work, I take it with me but I have to put it in another container. I removed it from its original package (Pee Pang, 11 August, 2006).

The experience of living with restriction also occurs when they have to have a restriction in working that relates to the decline in their health status. The participants have had to change their occupations or stop working because they are perceived as having less ability (as discussed in the following section). This leads to the feeling of insecurity in life and hopelessness. As one participant reported:

> My life no longer has direction… I can't do hard work. It is like everything that I do it should have a negative effect to my health. So, I don't want to do anything because if I get worse, it's difficult to recover. I should concern very much about myself (Nong Moo, 22 April, 2006).

Another kind of the most serious constraints that the participants expressed in living with restriction is that they have limitations in having a complete family. The limitation includes an inability to start a new life, to have children without transferring the disease to their baby or partner. This was the case in particular for the participants who were young adults. Some of them have never been married and some of them have never had any children. They feel an uncertainty about life and feel reluctant to plan for the future either to get married or to have children – in particular, those whose partners are not infected with HIV, such as Nong Tin. Although he wishes to have children, he feels it difficult to make a decision to have children without infecting his wife.

> I wish to have a complete family [father-mother-children]. I wish to have children. Although my wife is not infected with HIV, she will say 'yes' if I wish to have children. But I feel worried. I don't want my wife to be infected with this disease. I feel worry that if she gets infected with this disease how can she live a social life. I feel worried that she will encounter an unhappy life (Nong Tin, 06 October 2006).

4.4.1.2 HIV/AIDS erodes sense of self and leads to feeling inferior

The second subconcept which leads to the condition of "HIV/AIDS turned life upside down" is HIV/AIDS erodes sense of self and leads to feeling inferior. Many participants experience losing their sense of self and feel inferior (*pomdoi*[13]) as a result of having HIV/AIDS for a long period. This loss of identity seems to grow even when they are undergoing treatment and their conditions are stable. Some participants reported that their minds always perceived that they are the third group of people in this society. They have no self-worth. They are different from others. Sometimes, they wonder, "who am I?"

> I think that what's happening to me is really serious… very painful! HIV has changed my life… It [HIV] extremely changed my life. My hope changed. Not the same… Everything has changed both within society and even my mind. Mind is the most important that in my mind I always think that I'm different from others – normal people... Especially when I live with normal people, I keep thinking that I'm different from others. We are not the same (Pee Ning, 27 March 2006).

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[13] *Pomdoi* means the feeling of being inferior as a consequence of having less sense of self-value.

The changing and losing of sense of self through the destruction of their former self leads to feelings of inferiority which are induced by the stigma associated with spoiled social identity as mentioned by Goffman (1963) and Saylor (1990). Two circumstances were identified in relation to the subconcept “HIV/AIDS erodes sense of self and leads to feeling inferior”: 1) HIV/AIDS is a stigmatised disease, and 2) feeling ‘useless’ as a person as outlined in Table 4.1.

Firstly, HIV/AIDS is a stigmatised disease. *Stigma* is a concept used to distinguish the devalued identity from a normal social identity. People fail to meet the expectations of a society because they have unexpected attributes. On that basis they are stigmatised, leading to their experiencing less social acceptance (Saylor, 1990). Weiss and Ramakrishna (2006) defined a health-related stigma as “a social process or related personal experience characterised by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgement about a person or group identified with a particular health problem” (p. 536). Stigma has close link with discrimination. Busza (2001) said that, “discrimination is the actions based on stigma and directed toward the stigmatised” (p. 442). Both are referred to together.

All participants reported experiencing stigma and discrimination that was both direct and indirect. The social perceptions of HIV/AIDS make a person distinct from others and diagnosis with HIV infection is the prominent point of stigmatisation since sexual intercourse and unacceptable behaviour such as drug use are the main modes of transmission of HIV. Some transmission modes differ from the social norms or social values. Therefore, a person living with HIV is devalued by the social norm. Sometimes, they ask themselves, “Did I used to have a value?” “Do I have self-value?” because although they used to be good people, their value and meaning are discredited when they get this disease.

> The thing that makes me feel saddest is why the good that I have done for them [friends], for a long time is gone just because I am infected with HIV. My friends and I used to say we are close friends and have a good friendship. Where are they? My friendship was destroyed and I was judged when they know I have this illness... When my friends know about my [HIV] diagnosis, I lose them one by one (Nong Ja, 24 April, 2006).

> Even going outside, I don’t want to. I feel afraid of the society and how the society thinks about me. I don’t know if they feel pity on me or are afraid of me. I’m confused to be aware of the society. They don’t understand. They think that I have free sex. They think that I behave badly (Nong Koy, 07 March, 2006).

In addition, with HIV/AIDS the side effects from the drugs exterminate self-esteem. Often there is a feeling of stigma related to the changes in their physical condition (as described in Chapter One). The physical changes also affect outsiders, the ability to come close to them with HIV. They become repelled by the emaciated and weakened bodies of people who are extremely thin. One participant perceives that her body image is like a ghost because of her dark skin, being very skinny, and her hair being dry and falling out. “My body looks like a ghost… dark skin and slim” (Pee Bow, 06 June, 2006).

Some participants lose their self-esteem more than others, in particular those who used to be proud of their looks. One participant recalls her identity as being the most beautiful in her family and the feeling of being a beautiful woman is the only thing that made her proud about herself. However, HIV destroyed this one thing that she had. Furthermore, the participants reported that they feel scared to start to do something which involves contact with others because they worry that they will be faced with discrimination once their HIV status becomes known.

> My confidence in contacting people has diminished. The image I present is not so good any more. People look at me in a bad light now, so I am not brave enough to do anything (Pee Tim, 07 August, 2006).

The experience of stigma that has been reported by the participants is consistent with the three types of stigma as described by Goffman (1963). Firstly, the stigma that is associated with *physical changes* among others. Secondly, *blemishes of individual character* occur. This kind of stigma mostly occurs in people living with HIV/AIDS due to its association with unacceptable behaviour in terms of social norms such as drug use and prostitution. Some people reported that persons living with HIV have got what they deserved (van Rie et al., 2008). Lastly, *tribal stigma* refers to the negative evaluation of particular people because of their association with a group. Some of these stigmas are related to race, ethnicity, sexual preference, and tribe. People living with HIV were labelled as “bad” by some people, when they were linked with those who live an unhealthy and risky lifestyle. As Goffman (1963) stated, stigma is profoundly discreditable that could lead a person to be deemed almost inhuman. Furthermore, people living with HIV/AIDS bear a strong stigma because HIV/AIDS causes death (Varas-Diaz, Serrano-Garcia, & Toro-Alfano, 2005).

Despite the increase and effectiveness of ARV drugs in treating HIV, some participants perceived that the stigma linked to drug abuse and prostitution has only lessened by a small degree. It retains its original magnitude. Furthermore, HIV still disrupts and distracts people’s life plans and family dynamics. Due to the compounded stigmatisation, one participant expressed the observation that sometimes families want to protect their own dignity by leaving their son or daughter who has HIV alone because they feel embarrassed to let people know that HIV occurs in their family. Families preferred to discard their children to maintain the dignity of their families. Therefore, it is inevitable that a person who is infected with this virus will face social stigma. The degree of the stigma ranges from high to low. Some participants experienced discrimination more than others. Some participants viewed themselves as extremely infectious and literally as outcasts and reported experiencing a very high level of stigmatisation. One participant, who intended to conceal her HIV status for as long as she could because she believed that persons living with HIV incur strong disgust and are seen by society to be as bad as murderers, said:

> People who have this disease have made the worst mistake and are the same as people who kill others. People who have this disease are the same as a serious germ that no one needs to contact or touch (Nong Nid, 24 September, 2006).

As one would expect, discrimination that erodes the participants’ sense of self is similar to the metaphor of water eroding a bank and making them feel inferior, little by little, over a long period of time. Participants experience stigma both from the people who are closest to them – such as family members – and outsiders such as friends, and employers, as well as healthcare professionals. Some of them perceived that the doctor was reluctant to care for them and treated them as ‘second class’. Even though they have no other option for assistance in dealing with their symptoms and consider that health professionals could help them, they prefer to keep their HIV status confidential. Thus, some of them decide not to access healthcare services. Two participants reported their experience of stigma and discrimination from healthcare professionals:

> I became infected with tuberculosis but did not say it was TB… The doctor checked the sputum [only] once and did not find the TB bacterium, but the doctor still gave me the drugs for TB… When my X-ray (negative) came he did not look at it. Do you understand what I mean? He did not look at it [film chest X-ray] at all… How could he order the correct drugs? I got angry and stopped taking it [medicine]. I was in turmoil about it and when I arrived home I told my children that I wouldn't go to see the doctor again (Pee Tim, 19 May, 2006).

> When people living with HIV/AIDS have to be admitted to hospital, they [the doctors and nurses] will put them in an isolation room – a glass room. In general people know that those who stay in this room [glass room] are those who are infected with HIV/AIDS. Therefore, although many people infected with HIV/AIDS were very sick, they did not want to go to the hospital and be admitted to that room. They felt hopeless. Even their relatives feel hopeless. They prefer to die at home rather than be admitted to the glass room. I also felt scared and sad. I don't want to go to the hospital and stay in that room. Although I think that every person is the same [we are all human beings], they [the doctors and nurses] treat us differently. They treat us [people living with HIV/AIDS] as second class [people] (Nong Keng, 31 July, 2006).

However, some participants reported experiencing only a low level of stigma because they behaved in acceptable ways before they became infected with HIV and others know that they have not brought this disease upon themselves by their own actions.

> I am lucky that the people around me are having less disgust for me. Maybe from the past, when I was young until now, I always focus on work. I never did drugs (Nong Tin, 06 October, 2006).

Secondly, HIV/AIDS causes patients to feel ‘useless’ as people, HIV/AIDS erodes their sense of self and leads to their feeling inferior – a finding that is related to the concept of *spoiled social identity* (Saylor, 1990). HIV/AIDS forces participants to become useless people due to social restrictions and the perceptions of being fragile, vulnerable and lacking ability as well as having a serious contagious disease. Some participants felt distressed about their change of roles and identities, when they could not continue to perform their roles the same as before and this caused a loss of the respect they formerly received from others. Therefore, people living with HIV/AIDS have to face feeling devalued and discredited that lead to their losing their sense of self and feeling inferior.

> I can’t work. In the past I earned money – around 500-600 baht. Now, I can’t do the job that I used to work. I hoped to look after my mother but I can’t (Nong Wut, 24 April, 2006).

The perception of being useless occurs when people can no longer live their life in the same way as the mainstream people do. In some cases, the idea of getting married and having a baby is put on hold because people with HIV/AIDS are aware that they are carrying a contagious disease. This limitation not only destroys the participants’ hope and restricts their way of living (as discussed under the subheading “HIV/AIDS requires living with restriction”), but it also erodes their sense of self-worth and directly leads participants to lose the will to live because they feel that they are ‘nobody’. One participant reported that she cannot get married. She cannot become a mother. She is not the same as others.

> I feel sad about my life. I have nothing the same as normal people. I can’t get married. I can’t have children… I need to have children but I can’t (Nong Nid, 13 May, 2006).

4.4.1.3 HIV/AIDS causes multiple losses

The last subconcept contributing to the condition of “HIV/AIDS turned life upside down” is *HIV/AIDS causes multiple losses.* Understandably, no participants could avoid the experience of loss when their lives were overshadowed and controlled by HIV. Loss was described as one of the major factors in people living with HIV/AIDS which causes life to be turned upside down. Several participants regarded HIV/AIDS as the cause of multiple losses that have led them to loneliness and depression as well as to a lack of support. Experiencing loss can occur directly to them – loss of ability, self-esteem, health status, employment, respect, life, financial independence, freedom and happiness in life – and to the ones they love such as their partners and children.

Many participants who had been infected with HIV by their husbands who had never been known to have indulged in unacceptable behaviour were confronted with extreme loss – such as the loss of trust in their husbands, lost support and connection, lost confidence to tell children and others about their HIV status – and their families lost face from having HIV/AIDS. In some cases these women had lost their partner to the disease, so they were coping with all these problems by themselves in very isolated circumstances.

Losing a loved one such as partner, children, family members, and friends from the HIV virus causes significant loneliness and depression. The loss of a husband or wife or children means the loss of their main connection and support. Children are also a factor in tightening the connections within the family. In particular, the feelings of loneliness and depression were most severe in the people who had lost partners or husbands who were the only ones who knew of their diagnosis. They had hoped to live for each other. They did not know how to live with this disease without the other to share their feelings and give support. Nong Nui demonstrated her suffering of having HIV and being alone when she lost her husband who was the only one who had known about her HIV status.

> The day of my husband's funeral, I was fainting and very weak... When I went to my husband's funeral; I fainted because I felt lonely. No one live with me. Who can I live with? Who will take care of me (Nong Nui, 31 August, 2006).

To summarise, the concept of "HIV/AIDS turned life upside down" illustrates that HIV/AIDS has drastically changed participants' lives by causing insecurity, uncertainty, and hopelessness; it erodes their sense of self, causes feelings of inferiority, and multiple losses. These circumstances lead them to perceive that their life is put on a finite line; they are close to death and nobody needs them. These are the main conditions that cause the distress which the participants have to manage.

4.4.2 Encountering Distress: reactions and responses to manage it

This concept shows the reactions and strategies participants used to manage their situation when their life was overwhelmed by HIV/AIDS and its consequences after it turned their life upside down. The participants present a variety of actions/interactions (strategies) of responding and managing (Table 4.1). Strategies that they applied made the difference between being unwilling to live (discussed in the following section) and developing a will to live (discussed in the next chapter). If participants endorse ineffective strategies, they cannot manage their situation and their distress still remains. They continue to be unwilling to live. Conversely, participants who welcome effective strategies and can manage their situation would develop a will to live. The reactions and responses applied to manage HIV/AIDS can be divided into two subconcepts which are "the reaction to", and "the management of", HIV. This concept and its subconcepts, as outlined in Table 4.1, will be addressed in the following sections.

4.4.2.1 Reactions to distress

This subconcept is organised around the idea of a variety of reactions that the participants responded with at the time immediately following their diagnosis when their life was invaded by HIV/AIDS. Most participants did not expect to have an HIV-positive diagnosis. They were unprepared and had never thought of contracting this virus. Thus, it was very difficult for them to accept that their lives had become overshadowed by this disease (HIV). Hopefulness became hopelessness. Certainty in life became uncertainty. Beautiful life became dark life. As Nong Wut, who had no idea that he had been infected with HIV/AIDS, said:

> On the day that I went to the hospital to receive the result of my blood test [HIV test], I felt happy… I felt very relaxed because I was pretty sure that I would never get infected... At first, they didn't tell me the result of HIV but they asked me and told me some general idea about this disease... Then, the doctor said to me 'If you have HIV, you can accept (*tamjai*) it, right?' Then, I asked them, 'What is the result of my blood test?' then doctor said, 'You're infected [HIV]'. 'Oh!!!' At that point, I felt, my face… [look pale, to wear a hopeless look]. I was shocked when I heard I have HIV. From smiling to quiet… After that I didn't hear anything when the doctor talked to me. I was deaf. Speechless, tongue-tied... Then I rode my motorcycle back home. I didn't know how I got

> back home. I just know… OH!!! I already arrived home. I rode the motorcycle back home unconsciously… I got confused! Deafening! I closed my door. When my mother and sister asked me about the result, I started crying (Nong Wut, 24 April, 2006).

Finding out their diagnosis and realising that they have HIV was the time when they had the strongest reactions such as shock and disbelief and that is when reality became blurred. Some of them became distressed asked themselves the questions "Why me?" and "Why did I get this misfortune?" Some participants underwent blood tests for HIV more than one time and changed the place to have the blood tests done such was their disbelief. Moreover, related to feeling scared of knowing the blood test result, one of them avoided finding out what the result of the blood test was. The "reactions to distress" ranged from shock, disbelief, denial – especially by those who were diagnosed with HIV infection before the ARV drugs were launched – to relief (as outlined in Table 4.1).

Firstly, many participants were shocked, disbelieving, and in denial, at the moment of knowing the diagnosis both of themselves and their partners, particularly those whose lives were heading to a bright future and who therefore felt fortunate. When they discovered their HIV status, they realised that there would be tremendous changes in their life.

> I hurt, feel great pain, and suffer [*tukjai*] when I know I have HIV… My dreams and my hopes will not come true… The words when doctor said "you are infected with AIDS" still remain in my memory... I prepare myself to do ANC [antenatal care] when the doctor said I have HIV I was completely shocked. I couldn't believe it. The tears come even today... I had never thought [about this disease]. I can't believe it. The most suffering in my life, the worst situation, still remain in my mind (Pee Ning, 03 March 2006).

Secondly, in addition to the suffering discussed in the previous concepts, some participants think about ending their lives. Questions arose for which there was no answer, for instance, "Why do I have this disease? What are the things that make me become like this? How long will I live? What will be happening in the future? Am I about to die?” They lost hope for living.

> When I knew [being diagnosed with HIV/AIDS], I didn’t have anyone that I could talk to… I felt very depressed because I thought I have no other choice but dying. I didn’t want to sit [socialise] with anyone or go walking about around the neighbourhood even though no one knew [about my infection]… But I knew about it [HIV/AIDS infection]… It was there inside of me. I didn’t want to eat, just lost appetite…kept quiet at home, waiting to die. I thought if I have this disease I would definitely die. Sometimes, I thought of committing suicide, hanging myself… I thought about it (Pee Yai, 31 March, 2006).

> The moment I thought of committing suicide… I felt very lonely. I felt I had no one beside me. When I went somewhere, I felt anxious. Lost confidence. I felt scared to do anything. For my mother, she is a seller of Thai dessert but she couldn’t sell because the neighbours were disgusted. When they don’t buy her desserts, my mother cried. So, I thought I’m the person who causes the burden. I’m the source of the problem. I felt very hopeless and distressed... I think maybe it is better if I die (Nong Koy, 07 March, 2006).

The suffering affected not only the participants but also their children and family members. Some participants were focused mainly on their children and asked, “Will my baby get this disease?’ Therefore, to stop the cycle of suffering from having HIV, although all participants feel scared to die, some of them – in particular, women – thought of committing suicide, attempting suicide as well as killing their children or thinking of having an abortion. Some of them often think of committing suicide. Although “killing” is very difficult and sad for them, they saw this as the best way to end all the problems.

> [At ANC clinic]... I thought if my son has this virus [HIV], I would decide to kill him and kill myself. I don’t want anyone to know. I don’t want to tell anyone. Only the doctor and I know and that is enough. I asked the doctor to not tell my family. And I told doctor that “I don’t want to live” (Pee Taw, 04 May, 2006).

This finding is consistent with the findings from a study by Cooperman and Simoni (2005) on suicidal ideation and attempted suicide in women living with HIV/AIDS which showed that suicide ideation was high: 78% have suicidal thoughts after their HIV diagnosis and 26% reported a suicide attempt following diagnosis. Moreover, motherhood was a significant predictor of suicidal ideation and suicide attempts. HIV-positive mothers may have to struggle financially, deal with the issue of disclosure, fear discrimination against their children, and face the possibility that they will not be able to see their offspring grow up. Also, they may have to care for HIV-positive children, cope with feelings of guilt and fear about passing the virus onto their children or potentially leaving them. They also worry about their families having to care for them if they become incapacitated.

Thirdly, some participants reported confused and mixed up feelings such as sadness, blame and anger, worry, stress, fear, grief, and guilt. Two participants reported that they felt angry both with the person who infected them and with themselves for having walked into the risky situation. “I feel angry with myself that I love him [and he infected me with HIV] (Nong Nid, 24 September, 2006). “I feel angry with myself for walking into this bad thing” (Nong Keng, 11 April, 2006). Three participants perceived that it was “unfair” because they were not bad people. They were not the cause of their disease but they have faced the stigma from having HIV.

A number of participants reported feeling grief about their destiny and life because their life was suddenly turned upside down. They suffered most when they could not share their feelings of grief with anyone else. Nong Nid and Nong Ja said that they laughed at their workplace but cried at home. It means they pretended that nothing happened to them while they were at work but when they were alone, the suffering overwhelmed them and they cried. As Nong Nid said:

> I cried to myself every day…and I asked myself, “Why did I get HIV? Why has my life become like this?” (Nong Nid, 13 May, 2006).

Some participants described the sense of guilt and shame related to engaging in risky behaviours and then infecting their partners with HIV/AIDS. Also one participant had not followed her mother’s teaching. She became a prostitute and was infected with HIV.

Lastly, feeling relief – which occurs in five situations: 1) those who expected to have HIV because of either their risky behaviours or knowing their partners had HIV. If they felt shocked, it was not for so long and they were able to cope with their situation because they had more time to reconsider or review their life, 2) those who had no idea about HIV/AIDS, 3) those who were healthy when diagnosed with the HIV virus, 4) those who were diagnosed with HIV/AIDS when ARV drugs were available, and 5) those who related HIV/AIDS with *karma*. At least five participants reported that they never felt blame or anger towards anyone, including their partners who had infected them with HIV because they believe that they have this disease from their partners because of their own *karma*. Also, they have this husband who infected them with HIV because of their own *karma* as well (discussed in more detail in Chapter Six).

These reactions to HIV/AIDS were congruent with findings from many studies that show that when participants receive an unexpected diagnosis of HIV or other serious diseases the common reactions are shock and disbelief (not me), fear, and denial (Baumgartner, 2007; Firn, 1995; Klunklin & Greenwood, 2006; Namjantra, 2003; Nichols, 1985; Siriwatanamethanon, 2008).

4.4.2.2 Managing the situation of having HIV/AIDS

This subconcept showed the strategies that the participants used to manage their life altering situation arising from HIV/AIDS and its consequences. The participants encountered an abundance of difficulties. Some of them felt reluctant to tell people, even those who were close to them, that they had the HIV virus. They were concerned that revealing their HIV status would bring harm to themselves. Therefore, the strategies for managing the situation of having HIV/AIDS come from seeking both personal resources and some other limited resources. In addition, some ways of management are effective but some are ineffective. Eight strategies were identified in relation to "managing the situation of having HIV/AIDS" in order to handle the suffering as outlined in Table 4.1.

Firstly, some participants engaged in writing a diary. A number of participants reported that although they felt distress, they could not express their feelings to anyone.

> When I know I have a lot of worry, I feel worried that my mother will know. I cannot sleep… I feel stressed. But I cannot let them know I feel stress. I pretend that I am happy. I pretend that I have no disease (Pee Orn, 10 August, 2006).

One participant had no chance to express feelings of suffering, sadness, giving up, therefore, she wrote a diary. At first, she intended to write the diary for expressing her feelings, and to say goodbye to both her mother and her son, and she asked her mother to take care of her son. However, when she re-read her diary, it helped her to refrain from committing suicide.

> I felt much stressed. I don't want to talk to anyone. I don't tell anyone because I don't want them to worry about me. I release my stress by writing a diary. At the time, I felt despair, give up and I want to die (Nong Moo, 22 April, 2006)

Secondly, for some, it becomes a matter of concealment and camouflage, due to the stigma of having HIV which is associated with feelings of inferiority and loss of confidence of self esteem (as earlier discussed), together with a mistrust of others – including people who they were close to, and had a good relationship with. These worries lead the participants to prefer to resort to camouflage of signs and symptoms and keeping their status of being HIV positive a secret. As one participant said:

> Only if the society accepts having HIV or does not discriminate against people who have this disease, we are able to live with happiness. Unfortunately, in reality the society tend to reject people diagnosed with HIV. That is why we have to keep our diagnosis confidential (Nong Nid, 13 March, 2006).

This strategy was also to protect themselves and their families from stigma. Although this means of coping can relieve their torment in the initial stage, concealing themselves from the public increasingly leads to further loss of confidence and inferior feelings as well as a lack of support. The period of concealing of HIV status ranges from a few months to the whole life. Some participants even at the time of data collection (who had been living with HIV/AIDS more than five years) had not told more than two people except health professionals about their HIV status. Almost all participants preferred to conceal their HIV diagnosis as long as they could. The degree of concealment can be ranked from not concealing to fully concealing. It depends on many factors such as social support, social status, occupation, and the nature of the social environment. Although some participants start to tell other people who are close to them and whom they trust, only a few of them fully revealed their HIV status to the public.

Ways of concealing and camouflage differ from individual to individual. The participants described many ways of concealing in order to avoid being stigmatised. The most common strategy is keeping their diagnosis of HIV/AIDS confidential, suppressing the symptoms, avoiding social contact which includes moving from one place to another such as going to live in a temple as a place of sanctuary, controlling the disease, keeping hidden visible signs and imperfections on their body. They stated that "if there are no symptoms, there is no discrimination and stigma". Some participants, although they work as volunteers, still keep their HIV status secret from the public. They also hide their medications and keep their prescriptions for ARV drugs hidden. Another way of concealment is by trying to take care of their physical health in order to prolong their life and not die while they are young of the symptoms of AIDS.

> If someone asked me what kind of medicine that I take, I told them that it is vitamins (Pee Ying, 18 March, 2006).

> When my friends asked me what medicine I take, I told them I take analgesic drugs. I lied to them… Also, I use my mobile phone to remind me when I should take the medicine. They don't know about that (Pee Pang, 18 March, 2006).

Furthermore, some participants chose to avoid social contact and end their social interaction in order to avoid the continued disparagement that erodes their self-esteem, and to protect themselves from feelings of inferiority. These choices both reduced the stigma and prevented the stigma from affecting their family.

> If I compared myself with my old friends, I felt I have a low self-value. I am a valueless person. I don't like to meet them. I don't like to talk to them. I feel that there is a gap between my friends and I… I don't like to meet them. I wouldn't want them to know [I got HIV infection] (Pee Ning, 13 March 2006).

> I stopped work for three years. I don’t go out. I stay at home. I stop any kind of social contact…because I feel worried that if others know that I have this disease, my family will face difficulty. My family will be in trouble (Pee Kid, 30 March 2006).

Thirdly, some try forgetting and ignoring the problem. This is a way of distracting themselves from their suffering and trying to forget their pain. They have to learn to divert their mind from HIV into other things or try to forget having HIV/AIDS. They would stop thinking by making a busy life and escaping or running away from the reality of the diagnosis by concentration on other things. These actions result in both positive and negative consequences.

> I tried not to think, stopped thinking about being sick and dying because I thought it would happen. I just spent my life as joyfully as I could (Nong Keng, 11 April, 2006).

> I have to spend time with friends because it helps me to stop thinking in circles about my health problem. If I stay alone, I feel lonely and worried (Pee Orn, 10 August, 2006).

A young participant turned to alcohol in order to forget her suffering. However, she found that going out and drinking alcohol to relieve her feelings of anger, sadness, and loneliness helped her to forget for a short time only, and it destroyed her health. Also, her suffering and sad feelings still remained after she recovered from the hangovers. By applying this strategy, the feeling of relief from her distress lasted for only a short period of time.

Surprisingly, some other people adopted strategies that were effective to divert their minds (forgetting) and so that no further harm would be caused to their health, such as reading a book, planting, raising a pet, praying and making a vow, doing good deeds, going to the temple, and meditation. These strategies not only distracted them from their suffering, but also supported them by calming their minds. For instance, basically at first, they do meditation or pray to divert their mind from suffering, but later, those activities help them to possess a calm mind and peace. Furthermore, the advantage of reading a book is that they have more knowledge about this disease and about the truth of life. Thus, the consequences of those strategies are more positive than they expected (discussed in the next chapter).

> I often go out doing good deeds. I do it a lot… At the start [after her husband passed away] I began regularly doing good deeds [making food for monk or giving donations to the others] making merit until now. It was as if my mind was settled into serenity as I did these good things (Pee Tim, 19 March, 2006).

> At that time, my mind was unsettled and disoriented… I stopped noticing the change of day and night… When it was daytime, I thought it was night time, when it was night time, I thought it was daytime… I had sleepless nights… Sometimes, I was able to manage to have a nap during daytime, but sometimes, I was not. I was so lost, I talked to myself, I walked like I had no soul. But there is a cure to these problems, helping to calm me down. I adopt the benefit of being close to the nature [planting the orchid] to cure myself (Pee Kid, 30 March, 2006).

Fourthly, there is taking antidepressants. Only one participant reported taking antidepressants to deal with her depression. That participant was Pee Ning who faced much suffering because it had been over six years since the distress first started when she was informed of the diagnosis of HIV. She felt she killed her son indirectly because her son was also diagnosed with HIV. Later, her son got sick and died. Furthermore, she could no longer maintain her previous identity. As a consequence of these distressing circumstances, she had to consult a psychiatrist. Finally, she agreed to take a kind of antidepressant for the rest of her life, the same as taking her ARV drugs.

Fifthly, some Buddhist participants who are unable to access and support from their families or friends may deal with their illness by escaping to the monks or a Buddhist temple. Buddhist temples and the monks provide an alternative source of support including shelter and alternative treatments such as herbs. Some temples and monks teach religious doctrine to the people who stay in the temples that help them to accept their situation. Additionally, people feel calm and peaceful when talking to and being around those monks who practise Dharma or Buddha’s teachings. Therefore, another source of support for some of the participants such as Pee Ning, Nong Nid and Maeche is a monk and living in the temple that promotes their sense of security and peace. As described by Pee Ning.

> At first when my HIV status became known, I could not accept it. So I escaped to live in the temple… The temple provided shelter for AIDS people and… herbs… Also here the monks taught us to pray and understand that death is normal and the end of suffering. After that I felt strong [mind] and was not concerned how people thought about me. Living in the temple healed my mind (Pee Ning, 13 March, 2006).

Sixthly, some deal with their disease by seeking support from health professionals. The support of health professionals – in particular, nurses and doctors – is a key to assisting people newly diagnosed with HIV/AIDS to overcome this life crisis, particularly around the time of diagnosis when many participants felt overwhelmed with distress and were faced with the potential for discrimination and stigma causing them to conceal their diagnosis. Their main support came from the health professionals whom they met at the time of diagnosis and who were the sources of knowledge, treatment, and care.

> Doctor supported me and said, the diagnosis of this disease depends on yourself. If you take care of yourself well, you can live more than ten years. The doctor said it like that… I think if I take a good care of myself, maybe I can live as long as the doctor said um! Ten years (Pee Taw, 04 May, 2006).

> I overcame my suffering because I met a good doctor… I met Dr. Petch who is very kind. Every time when I met her, she always held my hand and asked me how I was. She was never disgusted by me or other patients… It made me gain more will to live. After I met the good doctor and knew my doctor was not disgusted by me, why should I be concerned about others (Pee Saw, 16 June, 2006).

However, from the 1980s when HIV/AIDS was found in Thailand until today, health professionals also are faced with the burden and trouble associated with this disease and it has been reported that health professionals also feel scared and discriminate against people living with HIV/AIDS (Sringernyuang et al., 2005). Therefore, although health professionals are the key to support services, not all people living with HIV/AIDS feel able to access this support because they feel reluctant to reveal their HIV status, to have their blood tests checked for HIV – even those whose partners are sick or have died from HIV are worried that they will experience discrimination from health professionals. Some of them have been discriminated against by health professionals. They feel mistrust (as discussed previously). Only persons who reveal their HIV status – and mostly such disclosure is unintentional and unexpected at an ANC clinic – will receive support from health professionals. Therefore, the numbers of those who seek support from health professionals are limited. As a consequence, for many of these people their distress remains for a long period of time.

Seventhly, the seventh possible way to deal with a diagnosis of HIV/AIDS is turning to supernatural and supreme beings including Lord Buddha, God (Allah), ancestors, people who have passed away, and sacred things. Particularly at the time of their diagnosis the participants felt distrust, stigmatised, and scared of death, therefore, they wanted to keep the diagnosis a secret. In addition, some of them relate their diseases as a result of their *karma*. Thus, they were seeking support from supernatural beings. Those who had no friends or significant persons to support them could at least find support from supernatural beings. Some of them trust that supernatural beings will help them to live longer.

These results are similar to those of previous studies conducted in the United States, Rokach (2000) conducted a study on persons living with HIV/AIDS, cancer patients, and the general population and found that “individuals need to feel connected to and worship a divine entity, God or Supreme Being. Through associating (affiliating) with religious groups, practicing their faith, individuals gain strength and inner peace” (p. 291). Additionally, in the study by Moser et al. (2001), 25 women dually diagnosed with HIV infection and substance use problems in the Carolinas reported that when they have a personal relationship with God (supernatural), God provides them with a sense of emotional healing. The relationship with God was a strong force in helping them to manage their life.

Lastly, in searching for alternative methods of treatment, participants described the struggle that they experienced as they continued to seek for means for care and cure. They expressed that they felt insecure in their life. Some thought that alternative medicines could help them to continue life until the drugs that can cure are available. Nowadays, ARV drugs are available but there is still no drug to cure HIV/AIDS. Some participants, such as Pee Porn, who had less support from her family, continued receiving alternative medicines. They welcomed and used alternative medicines perhaps too trustfully, having bought alternative drugs without knowing their actions or results. Regarding her alternative therapies, Pee Porn keeps these secret from the nurse at the hospital (and asked me to do this also). However, three participants felt disappointed with their results and gave up using alternative medicine.

Often, there was little support such as that which is normally given by family and other significant persons because in the first stage of diagnosis with HIV infection, the participants kept their diagnosis confidential. They pointed out that it is not simple to discuss the situation with anyone, including their family members. However, if family members knew about the diagnosis either from direct or indirect revelations, a turning point could occur. In this case, there was considerable evidence that seeking support from family or significant others does have a strong influence on increasing the will to live of the persons diagnosed with HIV/AIDS. This strategy produces different consequences (as will be discussed in the next chapter).

In conclusion, this concept shows the variety of reactions to, and ways of managing the situation once a diagnosis of HIV/AIDS has turned life upside down. These are the main strategies that the participants applied in the initial phase of their life when it was overshadowed by HIV/AIDS which led them to the following consequences.

4.4.3 Encountering distress: being unwilling to live

This concept describes the consequences of the subprocess *encountering distress* and these strategies mentioned above. Although the participants were managing their situation using a variety of strategies, their pain and distress were not relieved. HIV still pervaded their life and led them to the perception of hopelessness, loss of sense of self and feeling inferior and depressed. As a result, most participants presented the feeling of being unwilling to live. This feeling occurs not only when persons are first diagnosed with HIV/AIDS but also when they have lived with HIV/AIDS for a period of time. Sometimes, some participants at the time of the interviews, although they had lived with HIV/AIDS for five years or more, still had the feeling of being unwilling to live especially when they were faced with other distressing circumstances such as the death of one of their children. Two subconcepts were identified in relation to the consequence “being unwilling to live”: 1) planning for dying and 2) living life with lethargy. This concept and its subconcepts, as outlined in Table 4.1, will be addressed in the following sections.

4.4.3.1 Planning for dying

The first subconcept that supports the consequence of “being unwilling to live” is planning for dying. The participants decided to run away from their fear by committing suicide or formulating a plan for dying. By preparing for dying, the participants reported doing the following three activities; finding someone to continue their unfinished business; telling someone to prepare to face their death; and telling someone that they wish to die.

> I just told my parents because my health is getting worse I feel worried because death is approaching… I told my parents I have this disease because I realised that my children would depend on my parents if I die… I would like to ask my parents to look after my children (Pee Kid, 30 March, 2006).

However, in the process of preparing for death the participants have to reveal their HIV status under pressure. They told others whom they trust about their HIV diagnosis. After telling the truth of having HIV, some of them received love and support which acted as positive reinforcement to turn their attitudes from wanting to die to wanting to continue living (as will be discussed in the next chapter).

4.4.3.2 Living life with lethargy

The second subconcept supporting the consequence of “being unwilling to live” is living life with lethargy. It occurs with those people who still face overwhelming distress from having HIV/AIDS and its consequences that cannot be minimised by those managing strategies that have been mentioned. Additionally, although they are taking ARV drugs their health status, monitored using the CD4 count, does not improve. Being infected with the HIV virus makes both themselves and their families feel ashamed, upset and stigmatised. The family members may reject them as an HIV-infected person. As a consequence, this makes them feel tired of living which presents in their lacking motivation to live and non-adherence to restrictive self-care requirements as illustrated in Table 4.1.

Firstly, lacking motivation to live is an expression which occurs in some participants who have no life goals. They feel worthless. Also, they think that their self-value is lessened. They have lost direction in life and their future plans are significantly changed. They have no meaning for living and they lack motivation for living because they do not know anyone "for whom they need to live" or they ask, "Why do I have to live?" Furthermore, with regard to HIV/AIDS as a contagious and dreadful disease, their lives are no longer what they used to be. In particular, those who are young adults reflected that sometimes they could not imagine what their future would be and they do not see any point in having assets:

> Sometimes, I keep thinking to myself, hmm! It would be great if I didn't have this disease. What happened actually should not happen to me, I mean, I should not have the disease. I should be as normal as other people are. There should be medications to cure [the HIV/AIDS]. Otherwise, wait and see! Once there is a medication which could cure the disease, I would get married, have children, buy a house and a car… But nowadays, I don't feel like having anything because I don't know how long I will live. That's why I don't go forward with my plan [buying a house, getting married etc.]. I save money, but I don't build, don't buy anything… I just have enough to get by… a motorbike, nothing else… No point of gathering assets if I don't know whom I am going to give them to (Nong Nid, 13 May 2006).

Secondly, nonadherence to restrictive self-care requirements was stressed by the participants who felt hopeless in life and faced with worrying about their health status despite their compliance with all suggested regimens. Some participants stopped the restrictive procedures of care or ignored the restrictive self-care. The feelings of inferiority and being stigmatised continue to overshadow their emotions. These all together make them feel tired of living leading them to lack the motivation to live and therefore not adhere to restrictive self-care requirements. One participant deliberately rebelled against what she perceived as restrictive self-care and she returned to her former life-style such as sleeping only late at night.

> I do not adhere to my self-care. [I have released control]. Presently, I have completely taken my hands off the issue. I am tired of it. Before, I would go to bed early but now it is about 11 p.m. or even midnight and I rise late. Before, I would be careful with food and exercise but now I am relaxed about it. I just felt that I had done enough, besides; my body is back to the same as before (Pee Tim, 19 March, 2006).

> Vegetables and fruit I buy often. I eat them but it is not the same as in the past. Chiwajit-vegetarian style like that I don't want any longer. I have to sit around – Oh, I don't know. I have to sit looking for this vegetable and that vegetable, trim them, and collect them. Keep them all together in a folder. I feel like releasing it all – giving it up... Yes, give it away; give it up (Pee Tim, 09 May, 2006).

With regard to HIV/AIDS as a socially stigmatised disease that affects human beings who themselves are essentially social constructs (Mead, 1934), being diagnosed and living with HIV/AIDS destroys the sense of self and makes them feel separated from their social group. As a result of the process of *encountering distress*, the participants were still alive, they were living life with lethargy – an indicator of being unwilling to live. Most importantly, although this study was conducted in the era when ARV drugs are available and HIV/AIDS is seen as a chronic illness rather than as a death sentence, the participants still face stigmatisation and discrimination and reported being unwilling to live.

4.5 Conclusion

Encountering distress is the first subcategory of **struggling to survive**. This subcategory describes the process of distress when life is influenced by HIV/AIDS. There are three main concepts considered as the causes of distress. These are consequences of HIV/AIDS including insecurity, uncertainty, and hopelessness; HIV/AIDS erodes the sense of self leading to a feeling of inferiority; and causes many losses. Ultimately, participants perceived that this infection has turned their lives upside down.

After that the participants react and search for means to overcome the painful stages of life by a variety of ways of managing such as camouflage, keeping their distance from others and isolating and changing their place of living. They become careful about making new friends, taking antidepressants, and seeking support. As a result, for the participants who have insufficient support to manage their situation, HIV/AIDS has a tremendous influence on their life. Their distress is an ongoing situation. HIV/AIDS causes the participants to lack vitality or experience unwillingness to live, meaning that the participants are “planning for dying” and “living life with lethargy”. Conversely, if HIV comes to participants’ lives when they are in a situation with full support and strong personal resources, as well as applying different, positive strategies, the consequences are different. This phenomenon is described in the next chapter.

CHAPTER 5

Struggling to Survive: Overcoming Distress

5.1 Introduction

In the previous chapter, an overview of the research findings was provided, and then the category of **struggling to survive** and the subcategory of *encountering distress* were described. In that subcategory, life – consisting of the mind (*jai*) and the body (*guy*) as previously discussed – is weakened because it is overshadowed by HIV/AIDS, in particular the weakness of the mind or distress (*tukjai*) that led the participants to being unwilling to live.

In this chapter, the second subcategory of **struggling to survive** – *overcoming distress* – is explained and discussed. The participants who overcome their distress are those who have health-promoting surroundings and who employ effective actions/interactions (strategies) that encourage them to have a will to live.

5.2 Overcoming Distress

Overcoming distress is the second subcategory of **struggling to survive,** and it consists of three concepts. The first concept is called "promoting conditions" which is the condition of this subcategory. Then the second concept, "finding a meaning and purpose in life", consists of actions/interactions (strategies). Finally, the last concept "*obtaining palangjai* or finding a will to live", encompasses the consequences. The conditions, actions/interactions (strategies) and the consequences of *overcoming distress* are outlined in Table 5.1.

Table 5.1: Overcoming Distress: conditions, actions/interactions (strategies), and consequences

Conditions	Actions/interactions	Consequences
Promoting conditions	**Finding meaning and purpose in life**	**Obtaining *palangjai* or a will to live**
1. Feeling relief of mind > Praying, making a vow and going to temples > Reading religious doctrines > Avoiding painful situations	1. Searching for connectedness >Having self-connectedness or self-love >Having connections with others > Having connectedness with parents or an older person > Having connectedness with children > Having connectedness with a partner	1. Having a sense of self value 2. Gaining a strong mind (*jaikemkang* or *jaikang* [14])
2. Selective disclosure of HIV status > Disclosure by accident at the time of diagnosis with HIV > Disclosure when preparing for dying > Disclosure when trust in unconditional love of significant person	2. Receiving love and support (*kamlangjai*) > Being healthy in body (*guy*) and mind (*jai*) > Presenting of love and support (*kamlangjai*) from significant person > Receiving love and support from partner > Receiving love and support from parents and children > Receiving love and support from siblings > Receiving love and support from relatives > Receiving support from health professional > Receiving *kamlangjai* from friends > Receiving support from employer > Receiving support from supernatural and supreme beings	

The following quotation shows clearly that to overcome the most serious situation in life, one needs to use a variety of resources from both others and oneself, applying one's mind so that one does not give up but rather daily perseveres strongly.

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[14] *Jaikemkang* or *jaikang* means the mind that has power and becomes strong or strength and be able to face any situation (inner strength or strong mind).

> I once had a wasting condition – I couldn't walk, I was limp and needed to be carried along, and fatigued… But I am getting better… I was saved because my mind [*jai*] is tough... I went to the doctor and took medicine and the encouragement I get makes me fight… At that time, whatever I ate I vomited out again. I could not eat anything. The doctor whom I went to see encouraged me somewhat by saying that it won't be long before there is a drug to cure the disease. Finally I agreed that there really is a medicine coming… I have never been disheartened [*torjai*[15]] you know. If I am to die, then so be it, but I must try [to live] first… I think that our own self is the most important because we must help ourselves first… We must help our own selves, and try to overcome with our own efforts. We must fight until at the last we cannot go on and then we fade and die (Pee Tim, 07 August 2006).

The duration of *overcoming distress* ranges from a few months to many years. Some participants face distress for up to seven years. Alternatively, some of them face life's difficulties and arrive at the destination of having a will to live, or *palangjai* more quickly than others. They may face distress for a short period of time. Although some participants may choose to be unwilling to live because of overwhelming distress (*tukjai*) (as discussed in the previous chapter), some are able to overcome their life crisis. They shift from distress (*tukjai*) to having a will to live (*palangjai*) by experiencing different conditions and employing different strategies during this process (as discussed in the following subheading). Each person takes his/her own time, faces different conditions, applies different strategies and walks in different ways to reach this destination of having a will to live.

5.2.1 Overcoming Distress: promoting conditions

This concept illustrates the conditions that make the difference between *encountering distress* and *overcoming distress*. When the journey arrives at the crossroads between living and dying, some participants choose to live because they have the promoting conditions to provide support (as presented in Figure 4.2). Different conditions produce different strategies and consequences.

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[15] *Torjai* means the feeling of giving up or distress related to the feeling of hopelessness.

Two subconcepts were identified in relation to the condition or the concept "promoting conditions" in the *overcoming distress* subcategory: 1) feeling relief of mind, and 2) selective disclosure of HIV status. This concept and its subconcepts, as outlined in Table 5.1, will be addressed in the following sections.

5.2.1.1 Feeling relief of mind

The first subconcept in the concept of "promoting conditions" is a feeling of relief of the mind. Having a feeling of relief of the mind is the stage wherein the minds feel calm and able to recall the past experience that is important in helping to find meaning in life – in particular, the stage of "searching for connectedness" (as discussed under the subheading "Finding meaning and purpose in life"). The settled state of mind in this period occurs by accident as a consequence of some strategies such as the "forgetting strategy" in the subcategory of *encountering distress* when the participants endeavour to deal with their life-altering situation by forgetting or denial. This finding was supported by a previous phenomenological-hermeneutic study conducted by Delmar et al. (2005) with eighteen participants who had chronic conditions. They found that although the denial process can be viewed as a way of self-deception, denying can also operate as a restorative process.

Three actions were identified in relation to the subconcepts "feeling relief of mind": 1) praying, making a vow to Buddha to help them live longer and going to temples, 2) reading religious doctrines, and 3) avoiding painful situations. This subconcept, as outlined in Table 5.1, will be addressed in the following sections.

Firstly, praying, making a vow to Buddha to help them live longer and going to temples is the first action that enhances the condition of "feeling relief of mind". Although, at first, the participants did not see strategies of praying and making a vow in front of the Buddha image, as a definite way of overcoming their life crisis, they later valued those strategies which helped them to have a calm mind and move their life forward. Several participants made a clear and definite statement on the support of conventional religious beliefs. They recognised the benefit of going to a temple. Doing meritorious tasks, especially for the monks, enabled them to reach a calm and peaceful state of mind. Nong Nid stated that she understood the words "turning to the temple" when encountering suffering. She explained that going to a temple and making a vow in front of "Lord Buddha's image" calmed her mind and raised her hope and led her to happiness. In other words, she based her hope and faith on the Lord Buddha.

> First, I did what I did which was going to temple and make a vow [in front of the Lord Buddha's image]… I went to temple to make good deeds and pray for the dead… I believed that the dead would be able to receive the merit that I made and sent to them… This in return will minimise my (bad) *karma* (*barb*[16]) that are happening to me (Nong Nid, 13 May, 2006).

This belief is supported by Dhammananda (1993) who reported that Buddhists perceived the Buddha as the wisest, most kind, compassionate and holy man. Therefore, Buddhists use his statue as a symbol and as an object of concentration to gain peace of mind because when Buddhists look upon the Buddha's image, they put aside troublesome thoughts and think only of peace, serenity, and calmness. Reeves, Merriam, and Courtenay (1999) studied the adaptation to HIV infection of participants in the under-45 age group who have access to the four AIDS service organizations (ASOs) in Atlanta, Georgia. They reported that faith was the coping strategy commonly used by participants and allowed them to deal with their illness. The moment that they perceived they have someone or something to protect them, they had more strength and hope to go on in their life because this power could make miracles. Miracles were important ways that helped participants overcome their suffering. Hall (1994) also found that (religious) miracles were extraordinary ways that helped participants to get in touch with – or get control over – their problems, their emotions, and their bodies. Religion can promote faith that a cure may be on the way and that God still cares about them enough to watch over them or care for them when they cannot care for themselves. Burkhardt (1994) explored women's understandings of spirituality with 12 women and revealed that connecting with a higher power by meditation, prayer, being in nature, ritual, and talking with others reflected a sense of being united in harmony with this force and enhanced one's feeling of safety.

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[16] *Barb* means the bad karma. Thai Buddhism has the concept of *boon* (good deed or good *karma*) and *barb* (bad *karma*).

Secondly, reading religious doctrines constitutes the second action that is important to enhance a feeling of relief of mind. These practices give the participants opportunities to gain insight and understand (*kaojai*) and accept (*yomrub*) the truth about life. They can then accept death and dying which they must face eventually as well as ongoing suffering occurring during life. Furthermore, some of them find the ultimate meaning in life from experiencing having HIV/AIDS (as discussed in Chapter Seven).

Thirdly, the avoiding of painful situations is the last action that enhances the feeling relief of mind and enables the participants to reconsider their life experience. Avoiding painful situations gives them more time to reconsider or review life. Time allows the evaluation of past experiences and enables people to feel calm.

> I try to exercise choice about the people I associate with. It is our old friends who make us uncomfortable at mind. I try to choose. Currently the key issues are both making adjustments and avoidance. The things in the environment are what make me tense; I avoid (Pee Tim, 07 August 2006).

It is noted that participants who gain a feeling relief of mind in a moment are those who used to experience suffering and an unwillingness to live. Once they feel relieved, they have the ability to re-appraise the past – making connection and finding meaning in life – which helps them make sense of their difficult lives and overcome this life crisis with a sense of willingness to live. In other words, they are able to pass through the process of *overcoming distress*.

5.2.1.2 Selective disclosure of HIV status

Disclosure is a key condition for changing from wanting to die to wanting to live or overcoming distress because it opens a channel for love and support or *kamlangjai* to pour into the participant's life that has the ability to strengthen their mind to move on. A number of participants experience distress and an unwillingness to live over a long period of time before they reluctantly disclose their HIV status. Those who keep their HIV secret find it hard to receive *kamlangjai* and they suffer distress for as long as they keep the secret. This study showed that the duration of time before disclosure of HIV status from the first knowledge of their diagnosis with HIV ranged from immediately to more than one year. Therefore, the duration of distress may last from the initial diagnosis to several years. Although initially, during the period of overwhelming apprehension about life and their future, newly diagnosed participants cannot find significant strategies to cope with their condition, after they have disclosed their HIV status – either voluntarily or involuntarily – their life changes in a positive way and they are able to overcome their suffering.

Baumgartner (2007) identified three types of disclosure: 1) disclosure only to significant others because of stigma, 2) public disclosure that occurs in a support group, and 3) situational disclosure that occurs after people have integrated HIV/AIDS more fully into their life. These three kinds of disclosure also were found in this study. In addition, in this study disclosure that occurred in relation to the situation of trusting, accepting, and loving between the participants and their significant persons was highlighted in the three following situations.

Firstly, disclosure occurred by accident at the time of being diagnosed with HIV. Some participants' significant person knew of their HIV status at the same time as they did by accident. Unexpectedly, they were not disgusted but instead supported them. Thus, the participants in this group were faced with distress for only a short time. For instance, one participant overcame his life crisis within three months as his wife did not leave him. However, the participants in this group may be faced with another difficulty in life if their only significant person passes away. They have to face the distress of loneliness. They then have to face the choice of whom to inform next of their HIV status.

Secondly, disclosure takes place when preparing for dying. The second group is those who keep their HIV status secret for a long period of time, but when faced with an imminent death or their symptoms were obvious, they perceived that they must reveal their situation to a selected significant person whom they can trust (as in the overview under the subheading "Planning for dying" in the previous chapter). Thus, several participants were forced to reveal their HIV status for a particular purpose such as finding someone to take care of their children. To their surprise, those whom they told responded with sympathy which increased their *palangjai*. They received *kamlangjai* accidentally as they prepared for death.

Lastly, disclosure arises when the patient has trust in the unconditional love of a significant person. The last group is those who keep their HIV status a secret and encounter distress over a long period of time similar to the second group. They handle their distress by themselves. One day, they desire to reveal their HIV status. However, the reason underpinning their disclosure is different in that it is related to their trust in receiving unconditional love from their significant person that makes them confident to disclose their HIV status. It represents a significant turning point for them to live. Having love and a good relationship between participants and their significant others before having HIV helps them feel secure enough to reveal their HIV status. When they trust – and later prove – that the virus will not destroy the love from them/their significant person their expectation is realised. Once their significant other knows, they are not disgusted with them. They are supported and encouraged in many ways.

> After I was raped, I went to do a blood test for HIV. My youngest sister knew the result of my blood test [for HIV] before me because she worked in the hospital. She felt very sad about my bad luck. She was giving me *kamlangjai*. After that she suggested that I go to another hospital that is far from my place in order to keep my HIV status confidential. Then my sister disclosed my HIV status little by little to my other sisters, my mother, and my father. They all encouraged me to fight my circumstances. They were concerned about me (Pee Orn, 10 August, 2006).

Disclosure of one's HIV status has the potential for mixed results (Chandra, Deepthivarma, & Manjula, 2003; Greeff et al., 2008; Sandelowski, Lambe, & Barroso, 2004). Disclosure of HIV status is very difficult for people living with HIV in Thailand because of the stigma and discrimination. Although some participants reveal their HIV status to their family, friends and community, some of them find it difficult to disclose their HIV status to people outside their family. Furthermore, some women in Thailand reported that prior to disclosure they needed to prepare to confront their anxiety, sadness, guilt, blame and anger. Some mothers felt reluctant to cause their children pain and were also afraid of rejection. Therefore, a number of them did not disclose their diagnosis to their children (Dane, 2002). However, this study found that selective disclosure of one's HIV status is a key to the receipt of support from others which is

linked with finding meaning and purpose in life and leads to having the will to live.
It is noted that a significant person is not always one of their family members but rather anyone whom they trust and love as well as anyone who accepts and loves them. In summary, once HIV invades a participant's life, two promoting conditions (as mentioned above) help the participants to remain calm and re-think about their past experience. At the same time, they start to select the person whom they trust, love and accept to share their experience because they wish to receive love, comfort, and support from this person in order to overcome their distress.

5.2.2 Overcoming Distress: finding meaning and purpose in life

This concept explained the actions/interactions (strategies) that inspire the participants to find meaning and purpose in life or comprehend that their life is still important and that help them to overcome their life crisis. The actions/interactions linked with the conditions have been illustrated above. Meraviglia (1999) suggested that "meaning in life is the principal motivation of life" and "finding and making a meaning in life are described as one's capacity to discover a sense of personal worthiness and purpose in life no matter what the circumstances" (p. 28).

As one could expect, living with HIV/AIDS is usually perceived as a highly negative life altering situation associated with loss of love and support, loss of connectedness, as well as feeling the stigma of HIV and discrimination that devalue people and make them feel that life has no meaning. Thus, they have no reason and no encouragement to live (as discussed in the previous chapter). Alternatively, finding a meaning and purpose in life is life-altering. In this study, finding a meaning and purpose in life emerged when the participants recognised that their life still has value and this is enhanced by the two reciprocal processes of giving and receiving in which participants try to find the reason for living by connecting themselves ("giving") with someone or something and receiving support (*kamlangjai*) ("receiving") from others. Two subconcepts were identified in relation to the actions/interactions or the concept "finding meaning and purpose in life": 1) searching for connectedness, and 2) receiving love and support. This concept and its subconcepts, as outlined in Table 5.1, will be addressed in the following sections.

5.2.2.1 Searching for connectedness

The first subconcept in relation to the action/interaction (strategy) of “finding meaning and purpose in life” is having connection. *Connectedness* in this study means the relationship that is directed from the participants towards their significant persons or the sense of “giving”. Some participants, who perceived themselves as being worthless and descended to the deepest level of suffering, after they have found relief of mind (as discussed in the previous concept), try to find a connection with someone or something with some questions. For instance, “Why do I have to live?” and “For whom do I have to live?” After considering the answer to the question of why they have to live, they develop a feeling of connectedness that promotes a sense of self-value and leads to an understanding of their reason for living or their direction in life. They find a meaning and purpose in life. They understand that they are still important to someone. Their self-worth does not diminish. As a result, their mind is strengthened and has commitment to live. Significantly, finding connectedness is a powerful strategy for participants in order to develop meaning and purpose in life. Then they have a will to live or *palangjai* to live and a desire to go on with their life. Furthermore, for people living with HIV/AIDS having connectedness goes beyond the boundary of disclosure. The participants can find their meaning and purpose in life by having connectedness with others without needing to disclose their HIV status. Two kinds of connectedness were identified in relation to the subconcept of “searching for connectedness”: 1) having self-connectedness, and 2) connecting with others.

Firstly, having self-connectedness or self-love is the first strategy in relation to “searching for connectedness”. Self-connectedness or self-love describes a person who has a connection with himself/herself and is prompted to do everything for himself/herself. Such people have a will to live for themselves which may lead them to do some vital activities such as fight to live, to maintain life. A number of participants expressed their feeling that, “I love my self… I can’t die… I should live… I need to live…and I don’t need to die”. Sometimes, self-love or self-connectedness relates to inner strength or a strong mind. When the participants have a sense of self-love, they gain inner strength to fight for themselves and encourage themselves to live even though they do not have any support. This is consistent with Meraviglia (1999) who illustrated that one’s internal motivation and desirable concentration on the self is important to direct one’s life. For some participants the sense of self connectedness has a strong influence in finding meaning and purpose in life and overcoming their life crisis. Four main reasons were discovered underpinning “having sense of self-love or connectedness to oneself”.

The first is “unfinished business for oneself”. They consider that they are too young to die. This is related to the unfinished business one might have in this life and the next life. Some participants show a sense of self-love in terms of a need to live longer in this world because the world is still a beautiful place to live. They also said that being born as a human being is a difficult task because only a person who has enough merit is able to be born as a human. Therefore, they need to live in this world to see what is going on in the world as long as they can. Some participants – both Buddhist and Muslim – explain the sense of self-love in terms of an endeavour to store up good deeds for the next life. They intend to live their life to do more good deeds for the next life (discussed in Chapter Seven). This is another way of presenting the sense of self-love.

The second is refraining from sinning. They are not committing suicide in order to refrain from sinning. They do not want to sin further by committing suicide. This perspective is related to religious teachings. Buddhists believe that if they kill themselves, they will receive a big bad *karma* or evil or sin. Death by suicide is considered regrettable in Buddhism and if people die from suicide, it is believed that they will be born in a situation similar to that from which they now feel they need to escape (Coghlan & Ali, 2009). Therefore, a belief in the law of *karma* gives some a reason not to commit suicide. As Pee Kid said “I don’t commit suicide, because I don’t need to make sin”.

The third reason underpinning having a sense of self-love is avoiding stigma. They try not to die from HIV/AIDS (as previously discussed). A number of participants reported that they would feel pity for themselves if they died of HIV because of the stigma involved. In addition, if they die from this disease, those they leave behind will suffer from the stigma of their death.

The last reason is minimising the severity of HIV/AIDS. For some participants their sense of self-love becomes broader and is linked with the perspective of others towards HIV/AIDS. They show their sense of self-love by maintaining their health status and living their life as long as they can in order to decrease the severity of society's attitude toward this disease. They hope that as a consequence of living longer with HIV/AIDS, the stigma and people's perspective on HIV/AIDS as being a dreadful disease will gradually decline. In addition, when participants said that "they encouraged themselves to fight" it seemed to mean not only that they could fight or manage their HIV/AIDS, but also that they endeavoured to fight other things that were consequences of this illness such as the stigma they incurred from having HIV/AIDS. They have to fight to survive HIV/AIDS as well as fighting to live in a stigmatised context. A number of participants spoke about this.

> We must fight, fight against the disease, fight against society and many other consequences happening to our lives (Pee Ning, 27 March, 2006).

> I fight to show that this disease is not severe. Fight with social perception as well as fight with many [suffering] things that occur in life. I know I can't live longer, but I fight because people will know that we can live (Nong Ja, 24 April, 2006).

Secondly, having connections with others is the second strategy in relation to "searching for connectedness". This contributes to the feeling of being somebody, thereby creating more willpower and desire to live. In other words, they find their self-worth which is reflected in their value for others. This motivates them to continue their life. This concept is based on the idea that the participants have *palangjai* to live because they realise the true value of themselves. They cannot die as they have reasons to live; someone needs them or they are connected with someone.

Three kinds of connectedness were categorised in relation to "having connectedness with others" that contributes to finding a meaning and purpose in life. The first is having connectedness with parents or an older person. The important point of connectedness of a younger person is the sense of duty to care for older people; and a feeling of gratitude towards them. If the younger generation dies, who will take care of the older generation? Gratitude to older people is an important part of Thai culture. Thai children have learned how to care for their parents with sincere love, which is expressed through caring behaviours (Tongprateep, 2000). Such close personal relationships are based on *bunkhun* (gratitude), a deep sense of obligation and the need for affiliation and security (Mulder, 1996). For many participants their connectedness with parents or the older generation reflects gratitude that gives them the *palangjai* to live.

> I have to look after my parents, my family… taking care of everyone the best I could. I try to help them to live in a better condition, and prevent them from going back to the same hardship that they had experienced. I want to ensure that my parents live comfortably and have everything they need as they are approaching their last stage of life. That would release me from worrying about them. And that's all I could do (Pee Taw, 04 May, 2006).

> I tried to think, who am I living and fighting for? Is there anything I have not done? What else do I want to do?… I realised I have to live for my mother [grandmother]. If I died with whom is my [grand] mother going to live, who is going to look after her? My [grand] mother is old, who would want to take care of her? So I think, it is better if I died after my mum. I would prefer to be around to look after my mum. Because I realised all of this, it makes me have *palangjai* to fight. My mind becomes strong. I realise the purpose of my life, why I have to live (Nong Keng, 23 October, 2006).

The connectedness with parents or older people (gratitude) is not only for physical support but also for mental support. A number of participants count it in terms of psychological support. For those whose parents are still alive – and some of them were young adults – they would like to live for their parents not only to take care of them but also to avoid their sadness at losing a child. For these reasons, some participants have a stronger willpower to live when they have this connection with their elderly parents. An example of gratitude is the case of Pee Orn who has no family or husband to connect with. Conversely, she has her father and mother who are elderly. She has a commitment to live longer for her parents, not only to help her parents, but also to spare them from feeling sorrow if she dies before them. She promises to her mother that she will fight to live for her mother as long as she can. Pee Kid is another person who wants to live in order to provide psychological support for his mother.

> I couldn't die because I don't want to make mother feel sad. If I die before her, my mother would feel sad (Pee Kid, 22 April, 2006).

The second kind of connectedness with others is having connectedness between parents and their child. This kind of relationship represents the duty and bonding that reflect the meaning in life of older generations to a younger person. They feel worried about who will take care of their children when they die. They realise that they have someone whom they love and for whom they are important. For many of those participants who have families, the children are the strong bond for them to commit to continue their life. Some of them need to pass on life's experiences because they perceive that their life is coming to an end. This is also found in older generations that were studied by Nygren et al. (2007).

Thai culture emphasises the relationship between parents and children, therefore Thai culture has many metaphors that present the importance of the relationship between children and parents. One metaphor is that children are the eyes and heart of their parents – which means that children are most important thing in their parents' lives as are eyes and the heart. Another Thai metaphor depicts the importance of the mother by saying that "lacking a father is the same as lacking a paddle – but lacking a mother is the same as the boat being broken". If children have no mother it is similar to their boat being broken. They could not survive. Mother (*mae*[17]) in the Thai language is the most important relationship for their children. *Mae* provides unconditional love, care, support and comfort. Previously, in Thai culture women have had the main role in taking care of their children. Sometimes, particularly in the past, children have had a stronger relationship with their mother than with their father.

> My parents… understood my condition. Their understanding builds up the strong bonds between them and me… So I don't feel that I am alone. I am not so close to my dad, but my mum. I talk to my mum about almost everything… And my mum will be the buffer between me and my dad, convincing him little by little to accept [*yomrub*] my condition. My dad now adjusts his mind [*jai*], and understands [*kaojai*] me more… Mum and I are best friends. Whatever

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[17] *Mae* means mother

> happens to me, mum is the first person I always turn to. I am so lucky to have understanding [*kaojai*] and kind-hearted [*jaidee*[18]] mum. She gets along with everyone in the family. The luck is with me (Pee Ning, 13 March, 2006).

After the participants (in particular the women) recognise a connection with their children, they realise that they (as women) are important. Although sometimes they do not recognise just how precious they are to them, they only hope to live to see them grow. The deep longing of motherhood is the hope to see the future of their children whom they love the most. In other words they “hope to see the boat of their children arrive at the bank safely”.

> My daughter is my *kamlangjai*. I hope to live with her for a long time. Until, she can take care of herself… When I got sick I worried about her and was concerned about my daughter, I thought I shouldn’t give up. I can’t get worse [I should fight to get better]. I should fight. I should live for my daughter. I have to live my life for my daughter (Pee Ying, 18 March, 2006).

> Another way that could pull life back is ‘children’ who are very innocent. Only seeing their innocent eyes… Children could help me to continue life [extend life]… Children don’t need to do anything. I just connect with them. Nothing has been done, but I am waiting for them to grow up, wish to see them able to look after themselves, and have good education. If I die, who is going to look after them? There will be no future for them. I wish I could be around until the day they can stand on their own feet. Once they are grown up and able to work to support themselves, I wouldn’t mind dying (Pee Kaw, 22 April, 2006).

Therefore, the bonding of mother and child is significant in bringing the value of life back. Children are a main source of connectedness that enhances self-value and contributes to a will to live. As expected, the difference between those with healthy children and those with children infected with HIV or who have no children creates a different level of the will to live. Those whose children are infected or have died from

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[18] *Jaidee* means kindness. A person who is *jaidee* means a person who has the sense of loving kindness and compassion.

HIV have faced a significant change in their life and some of them no longer want to live. Their lives are meaningless to them and some of them consider suicide. Conversely, the group who has a connection with their children have more hope and a strong will to live even though they may be close to dying.

This finding is in accordance with one person who devoted herself to teaching meditation after she was faced with a life crisis – Na Phatthalung (2007). She explained that, when she lost her husband in a plane crash, he left behind more than one hundred million baht ($4,000,000 NZ.) of debt and a young son. She has spoken in many conferences telling how, when faced with the most difficult life crisis, the only thing that helps her to continue with her life was her son who was only eleven months old. She made a commitment to herself to live for her son, as she recognised that she is a mother who is important for her son. At the same time, her son is a significant person for her. This finding is also supported by a study by Klunklin and Greenwood (2005b) that was conducted among women living with HIV/AIDS in the rural North of Thailand which showed that the mother is the main source of support for women living with HIV/AIDS. In addition, being a mother living with HIV/AIDS enabled them to begin immediately to fight for their life.

The last kind of connectedness with others is having connectedness with a partner. The phrase "husband and wife are the same person", as Nong Ja mentioned, illustrates how close husband and wife are to each other. Partner means husband, wife, support, comfort, sharing, warmth, care and concern, and source of love. When people have a partner who shares both suffering and happiness their self-value is enhanced because they are important to their partner. As a consequence, they need to carry on living their life for each other and find meaning and purpose in life.

Finally, the participants find a meaning and purpose in life as a result of having connectedness with someone or something who – or which – answers the questions "Who am I?" and "Am I important?" that leads to their having meaning, purpose and hope in living and the desire to live. Jensen and Allen (1994) stated, from their study on "A synthesis of Qualitative Research on Wellness-Illness" that when people have connection (relationship), they attempts to maintain life – learn to live again – although they live in constrained situations.

5.2.2.2 Receiving love and support (*kamlangjai*)

The second subconcept in relation to action/interaction (strategy) of “finding meaning and purpose in life” is receiving love and support. Many participants perceived that being infected with HIV is beyond their control and they could not manage their illness by themselves. Some of them started to seek some support though there is a shortage of support in Thailand provided to people diagnosed with HIV/AIDS, especially for the first stages of the diagnosis and for those who contracted HIV/AIDS in the first era. As mentioned earlier, the barriers to seeking love and support are stigmatisation and discrimination. People have to choose whether to reveal their HIV status or not, and this is a difficult decision. They have to consider whom they trust and who loves them (as discussed in the previous concept). They feel too scared to seek support when they are first diagnosed and then some undergo feelings of surprise and appreciation when they realise that love and support are not absolutely destroyed by HIV. Some kind of love and support from others still continues. Receiving *kamlangjai* enlarges their *palangjai* and strengthens their mind (strong mind) and enhances their sense of self-worth as they know someone still needs them. They are still important for the others. It is implied that others did not strongly discriminate against them, although maybe they do not absolutely accept them either. It is pleasant for them to be made to feel less inferior and, as well, they start to think that they are the same as others. This leads the participants to feel ready to accept the challenge to fight with HIV/AIDS, and have hope or the will to live – as Nong Keng said:

> Once, I receive *kamlangjai,* that is shown by do not separate food for me and do not separate plates for me when giving food for me. It reflects that they do not discriminate against me. They treat me as normal. It makes me feel the same as them. I’m not different from them. I don’t feel inferior. It makes me feel happy and fight to live (Nong Keng, 18 March, 2006).

Pee Yai, one of the participants who received an abundance of *kamlangjai* from many sources, said “*kamlangjai* is the magic drug” which provides the power to take control of HIV/AIDS. Individuals who receive *kamlangjai* can get through a crisis situation faster than those who do not (as previously discussed). Although most participants perceived that HIV/AIDS had turned their life upside down, when they received *kamlangjai* from a variety of sources they thought that HIV/AIDS could not destroy their life. Conversely, they felt they could challenge HIV/AIDS. As Som expressed this feeling of challenging HIV/AIDS after he received *kamlangjai* from his family, “I tell myself I should survive because this disease is not dangerous for me” (Som, 03 August, 2006).

Six sources of love and support (*kamlangjai*) were identified in relation to the subconcept “receiving love and support”: 1) being healthy in the body and the mind, 2) presenting of love and support (*kamlangjai*) from a significant person, 3) receiving support from a health professional, 4) receiving *kamlangjai* from friends, 5) receiving support from an employer, and 6) receiving support from supernatural and supreme beings. This subconcept and its sources, as outlined in Table 5.1, will be addressed in the following sections.

Firstly, being healthy in the body and the mind is the first source of support in relation to the “receiving love and support” strategy. It is noted that being healthy in body (*guy*) and mind (*jai*) is an important resource in promoting the feeling of challenging HIV/AIDS because these are personal resources that people can obtain at all times without revealing their HIV status and they are available at any time, while other resources are available only sometimes. In Thai culture it is always said, “Strong mind (*jaikemkang*) (inner strength) comes together with healthy body” they cannot stand by only one. Therefore, if the participants obtain these two resources, these help them to live. Both having a strong mind and being healthy play a vital role in the process of *overcoming distress*.

A number of participants were healthy when they learnt of their HIV status. They also have lived with HIV for more than 5 years without having had any severe symptoms or being admitted to hospital. They have never encountered illness or opportunistic infection, although they were infected with HIV before ARV drugs were launched. Therefore, being healthy at all times both when first diagnosed with HIV/AIDS and when they are living with HIV/AIDS leads them to perceive that this disease cannot destroy them.

Another support from personal resources is having a strong mind. The “strong mind” that has been found in this study is very similar to the concept of *inner strength* that is an important factor in those who have a sense of survival. In some cases, having a strong mind (inner strength) is the most powerful force in pulling their life back from dying. This is supported by Low (1996) who suggested that sometimes hardiness is more important than social support in buffering the effects of stress on health. When lacking other kinds of support, enhancement of inner strength or *kamlangjai* can help people overcome the difficulty in life. Those who have an inner strength can encourage themselves to live. This is consistent with the majority of previous findings that inner strength is one factor that promotes a sense of living and self worth. This is a central human resource that promotes well-being and healing that everyone can benefit from during the course of their life (Nygren, Norberg, & Lundman, 2007). Lambert and Lambert (1999) make the conclusion that hardiness is a positive influence over well-being. A person who is able to find meaning and purpose in life is stronger. Participants then find that they can live with their illness (Schaefer, 1995). They feel confident and tell themselves that, "I can beat this disease" and "I am a resilient person". In other words, they have the capability to challenge HIV/AIDS.

> I have already passed it [the crisis]... Because I think it depends on my mind [*jai*] I don't give up. I should have a strong mind because everything depends on mind. Therefore, I should have a strong mind [*jaikemkang*]. Don't compromise or give up (Pee Pang, 08 March, 2006).

The importance of inner strength has been confirmed in other studies. For instance, Walton (1999) studied what spirituality means to patients recovering from an acute myocardial infarction and how spirituality influences recovery. By using grounded theory methodology he found that inner strength and courage gave participants the energy to face the next step in the recovery process and empowered each participant to honestly look at his or her lifestyle and identify areas that needed to improve. Similarly, McGrath (2003) found that participants with terminal illness relied on inner strengths to comfort them. Some of the participants realised their sense of inner strength or strong mind only when they were faced with suffering. Therefore, sometimes, distress and suffering in life enhance the realisation of inner strength or a strong mind. This finding can be summed up by saying that some people's strong mind presents itself when faced with a crisis. In other words, a life crisis guides people to discover their strong mind.

Secondly, presenting of love and support (*kamlangjai*) from a significant person is the second source of support in relation to the "receiving love and support" strategy. Receiving love and support from a significant person is a vital promoting strategy that can minimise the severity of feelings of discrimination, loss of self, and loneliness as well as enhance the sense of self-value. Receiving love and *kamlangjai* helps them regain and maintain their power to challenge and manage their situation as well as combat psychological hurt in particular from living with HIV. This contributes to the feeling of overcoming the challenge of HIV/AIDS and is an opportunity to win and then have *palangjai* to live. Dyson et al. (1997) revealed from their literature review of the meaning of spirituality that when someone knows that others care, it gives them hope and the will to live. Four sources of love and support (*kamlangjai*) from significant persons were identified: 1) receiving love and support from partner, 2) receiving love and support from parents and children, 3) receiving love and support from siblings, and 4) receiving love and support from relatives as outlined in Table 5.1.

The first is receiving love and support from partner. The participants who have a partner or lover share love, care and concern, some of them expressed that having each other is sufficient. In particular, those who remarried or built a new relationship also expressed their view that their partner made a significant change in their life. This finding was supported by Charmaz (1997) who showed that participants who were in a relationship found that their partners provided pivotal identity support that diminished the effects of dependency and loss.

The second is receiving love and support from parents and children. People living with HIV/AIDS fear revealing their HIV status to parents and children. They do not want them to suffer as a consequence of their HIV status and they also fear receiving disgust from their parents and children. Several participants reported that most of the suffering of being diagnosed with HIV could be decreased by receiving love from their parents (who are elderly) that produces a lot of *palangjai*. Although in the past, their parents never showed them how much they loved them, when they were diagnosed, they understood how much love their parents – especially their mothers – have for them.

> The feeling of happiness is from my mother. My happiness, my courage comes from my mother's support. I lost my appetite, not eating well for 3-4 days [when

> I was told that I was infected by the virus]. I survive because of my mother…because of the courage that she gives me. My mother said, “Living in this condition [with HIV/AIDS], getting older, you and me, I wonder who is going to go [die] first”… My mother said people were born and one day they die. That is, no one would escape dying, [it is] just the matter of who is the first to die. She also said… “Doesn’t matter what happen to you, I would not leave you, we have battled all difficulties together (Nong Wut, 24 April, 2006).

Another source of support from significant person/s is shown in the love from children to parents who are infected with HIV/AIDS. This situation occurs in participants whose children know that they have HIV but who are not disgusted by them. Conversely, they offer them an abundance of *palangjai* to live. In other words, they showed that their parents – even though infected with HIV – are important for them.

> While I was hospitalised my son went to visit me every day, but he didn’t talk much. I think he didn’t want to ask what was wrong with me... He talked to neighbours telling them that he wished his mum would get well soon. What he did gives me *palangjai* to live (Nong Moo, 22 April, 2006).

Pee Pang reported, with a smile on her face, that there are no words to explain how happy she was when her daughter said she loved her although she is infected with HIV/AIDS. This proved that her life is still important for her daughter. It filled her with happiness and created a commitment to live for her daughter as long as she can.

> My daughter knew that I have this disease but she doesn’t tell anyone. She reminds me to take ARV drugs. Sometimes, when she gives me a hug, she asked why my skin is full of lesions. So I said, “if you think my skin is full of lesions why would you want to hug me?” Her reply was “I hug you because I love you” [smile] (Pee Pang, 23 August, 2006).

The third source of support is love and support from siblings. Not only did love and *kamlangjai* from sisters and brothers contribute to participants revealing their HIV status, but this also encouraged the participants to challenge the power of HIV/AIDS (as discussed in the previous concept), but also love and *kamlangjai* from this source encouraged the participants to challenge the power of HIV/AIDS. The Thai saying, “blood has more concentrate than water” and its Western equivalent “blood is thicker than water”, convey the Thai cultural (and universal) value and priority expected and fostered within a family, characterised here by unconditional loyalty, love and support shared between family members. Sibling relationships often provided the main source of support and counsel for participants with trusting transactions assisting HIV status disclosure, acceptance, management, and the fundamental desire and will to live meaningfully and purposefully, as illustrated by Pee Tim.

> My elder sister said, “I want you to live a long time with your children” because at times I am bored with no activity to engage me. I understood that she was concerned about me. She wanted me to fight [to live]. But I am not interested at all. She said, “No matter what anyone says, we are sisters and we love one another”. My sister would say, “Others are outsiders, don’t concern and worry about. Only we love each other [that is] enough” (Pee Tim, 19 May 2006).

The last source of support from significant person/s is from relatives. As mentioned, some with HIV find it difficult to reveal their status to their parents because they do not want them to have to share their torment. If they trust and respect with a relative, they have another choice of support to relieve their suffering. As discussed in Chapter Four, social disgust is a strong negative effect that occurs with people living with HIV/AIDS. When others are not disgusted, it seems that this gives significant *kamlangjai* for participants. In particular, some participants reported that when only their family members are not disgusted this is enough for them to have the will to live (in the world) and challenge their HIV/AIDS. They do not need any other source of support.

The participants reported receiving love, care and support (*kamlangjai*) from significant person/s expressed in many ways. Basically, it is normal for some families in Thai culture not to tell their children how much they love them, Thai people do not express their sympathy by hugs, cuddles, kisses or saying, “I love you”. Instead, they express love by not showing disgust and discrimination – which implies that they accept them as people who are infected with HIV/AIDS. For instance, Nong Pat felt inferior because she had previously worked as a prostitute and had then been infected with HIV. Because her husband’s family did not feel disgusted about her past experience, she feels very appreciative and hopes to continue her life – although she thought to commit suicide in the past. She stated, “my parents-in-law love me. They encourage me and we do everything together”. Being together and accepting is important for those diagnosed with HIV because this can represent less discrimination than they used to face in the past. Also the feeling of being inferior and feeling different is replaced by a feeling of togetherness that contributes to their power to deal with their crisis situation.

In some circumstances the participants receive support by someone saying soothing words. Someone tells them the metaphor about the truth of life and reminds them to be reconciled with themselves. In Thai culture, there is a metaphor, “life is not full of roses” which has been used to comfort and support those who face suffering in life in order to understand that life has both suffering and happiness. In other words, life has some obstacles that people have to encounter while they are alive. Nong Keng received this kind of support from his uncle, who was the only one who knew his HIV status from the first test. When he was informed about the test result, he did not reject him, but gave Nong Keng support and told him that, “life is not always full of roses”. His uncle shows love and support by keeping his HIV status a secret all the time and is never disgusted by him.

> My uncle knew the result at the same time as me, giving me *kamlangjai*. He told me that, “life is not full of roses”, so I should not feel depressed and he promised that he would keep the result to himself, and asked me not to commit suicide. He protects me, and encourages me to fight the circumstances; he tells me not to give up. Up until now, my uncle has never told anyone [about the participant having HIV infection] (Nong Keng, 23 August, 2006).

A number of the participants are receiving support from significant persons who are there for them and have promised not to leave them alone, as well as showing that their life is still important. The perspective of “someone (significant) needing me and loving me” is very important for the people who are sensitive and feeling inferior – such as people living with HIV/AIDS – because it is a good protector for them from any kind of hurtful situation. It also fills them with *kamlangjai* that increases their feelings of security and warmth that enhances the feeling of fighting to live.

> My family is the source of *kamlangjai*. They are always by my side, giving me suggestions. My mother, in particular, is always there for me, talks to me, tells me that no matter how terrible I look [because of nasty rashes and lesions], I will always be her daughter… At the beginning I had suicidal ideas, but after listening to what my mum said, I couldn't bring myself to commit it [suicide]. I believe, if I didn't have my parents to give me warmth, and courage I would not have been able to live up until today (Nong Koy, 07 March, 2006).

Another way of feeling love and support is receiving forgiveness, without blame or criticism of the unacceptable behaviours. It enables the participants to feel love and support, in particular those who have engaged in risky activities and received their HIV from unacceptable behaviours. As Nong Wut reported, "they forgive me and don't blame me". This kind of support enhances *kamlangjai* to fight to live. Some kind of *kamlangjai* comes from family but occurs indirectly. It is present for some participants who reported that because they have a high position in a community and high economic status; people in the community respect their ancestors. They receive positive support in that people do not talk to them in a negative way or gossip about them because of their family's position. This thing acts like a family's guard, and in this way the family is a protector indirectly. Thus, many participants reported that parents or children stopped them from thinking of suicide. The magnitude of the will to live increases when family members provide them with love and support, show no disgust, are there for them, and respect and treat them as normal people. This finding is consistent with previous studies. There is an inverse relationship between support and distress regarding people living with HIV/AIDS (Hudson, Lee, Miramontes, & Portillo, 2001; Ncama, 2007).

Thirdly, receiving support from health professionals is the third source of support in relation to the "receiving love and support" strategy. As discussed in the previous chapter, although in some settings health professionals are an effective resource in providing support, some have not always been fully successful in providing care and support – in particular, in the first era of the epidemic of HIV/AIDS. Later, health professionals came to be one of the main and continuing sources of support. They provide access to a counselling unit, ARV drugs and treatment of opportunistic infections, and lead HIV/AIDS support groups based at the hospital. Nurses and health professionals, who listen to them without judgment, and with empathy, understanding and reassurance, contribute to positive psychological outcomes for patients (Belcher et al., 1989; Coward, 1994; Lin & Bauer-Wu, 2003). Nurses were mentioned as models of caring behaviours, particularly when family were unavailable, and helped patients feel secure (Coward, 1994).

In addition, health professionals provide patients with the courage to negotiate with other sources of support. The counselling unit assists people with HIV/AIDS and their families to accept their situation. It is often that the acceptance, empathy, understanding, reassurance and presence of nurses and doctors make an important difference to the lives of people living with HIV/AIDS. *Presence* is a way of being that involves a deep contact or connection. Also, presence can be a way of being-with, and being-there that provides the sense of comfort and being cared for (Covington, 2003) as illustrated by the comments from Som.

> Pee Mam [nurse] is a very kind person, always smiles and has a gentle conversation. She kept encouraging us to take care of ourselves and gave the opportunity for many patients, including me, to receive the ARV drugs…When my friend died, she went to his funeral [which she did not need to do]… I am very appreciative of her. She is the best nurse. If we don't have her may be [we would already be dead] (Som, 03 August, 2006).

As a number of participants acknowledge, ARV drugs are the most valuable thing for them and their life. Some participants had waited for antiretroviral drugs for more than 10 years and said they "could not live without ARV drugs". ARV drugs are not only chemicals that get rid of their symptoms, treat HIV, and prolong the lives of those living with HIV, but also ARV drugs expand their hope of cure and "becoming normal" as many participants reported:

> Now, my CD4 is more than 600. When I first started ARV drugs, my CD4 was less than zero (Pee Karn, 19 March, 2006).

> I have more hope to live when I take ARV drugs. I think ARV drugs as a part of their life. When my CD4 increased [after I take ARV drugs], I had more hope to live (Pee Ying, 18 March, 2006).

> I feel confident to live because I'm sure that ARV drugs can extend my life. Then I have *palangjai* to fight. I don't care about anything. I don't care if any person looks down on me. I am pretty sure that I will have a better life (Pee Cha, 22 March, 2006).

In addition, having ARV drugs provides evidence of advances in technology and knowledge and this amplifies their hope that one day the scientists will produce drugs to cure this disease. Moreover, they receive double luck because not only does having drugs extend life, but also they receive the drugs for free. Furthermore, health professionals arrange HIV/AIDS support groups for people living with HIV/AIDS to share experiences and knowledge. Another source of support is health volunteers who work between the health professionals and the community. They have the advantages of knowledge about care, and acceptance by people in the community and they support participants by providing information, and both material and emotional support – as illustrated by Nong Keng.

> I felt very glad and surprised when I met the health volunteer who I did not know but she gave me a lot of support. It made me gain more *palangjai* to live because a person who is not my relative and I did not know them was still good to me. If I hadn't met Aunty Jib [health volunteer] and she hadn't brought ARV drugs to me at home I would have been dead already, because at that time I could not go to the hospital. I was very sick (Nong Keng, 23 October, 2006).

In these ways, and by their accepting presence, health professionals were able to minimise the degree of distress and influence positively the opportunity to survive that leads to the will to live. Furthermore, if health professionals continue to practise care and presence, and give support in a caring manner, in the future it is more likely that health professionals will be able to access greater numbers of people living with HIV/AIDS and help them more.

Fourthly, receiving *kamlangjai* from friends is the fourth source of support in relation to the "receiving love and support" strategy. Some participants reported that new friendships were started once they joined in the HIV/AIDS support groups that at first were arranged mostly by the health professionals in the hospital. They feel brave enough to meet others and disclose their HIV status to those who share the same disease with them. HIV support groups provided a new source of friends when old friends may have rejected participants.

Friendship and friends are significant for those with HIV/AIDS who have lost their connections and networks of old friends for a long time, often since the time of diagnosis or disclosure. Interacting and sharing friendship and experiences with others who have HIV fosters the mutual realisation that they are not alone in their affliction but rather are members of a supportive HIV/AIDS network and family. Participants who were more involved with HIV support networks had more options to deal with HIV that helped them to keep going with their life. Also, friendship between fellow HIV participants forged a significant sense of "having no gap between each other" (discussed in the next chapter). Additionally, such friendships eased suffering and loneliness while increasing the will to fight for and continue their lives.

> When I meet friends, talked with friends and shared feelings with friends, I gain more *palangjai*. Friends make me feel good. It is not good to stay home alone because if stay home alone I feel stress, worry and thoughtful. Friends are the people who share the same experience and feelings. We understand the deep feelings of each other. We don't feel worry that they will be disgusted because we are the same. I feel happy when I have friends. Sometimes, when I talked with my husband [who does not have this disease], I think he can only listen but he does not understand the deep feeling (Pee Yai, 31 March, 2006).

This study showed clear evidence that when participants meet friends who share the same illness, there is an increasing abundance of *palangjai* to use to fight for life. They realise that friends are a good support for them. However, similar to what has previously been demonstrated, when first diagnosed with HIV, the majority of participants hesitated to ask for help from their friends because they felt worried that their HIV diagnosis would be disclosed.

Fifthly, receiving support from an employer is the fifth source of support in relation to the "receiving love and support" strategy. In the first phase of HIV/AIDS, many people either resigned from their jobs or felt less confident about applying for a job. For some participants, when their boss gave them a chance to continue their work, they provided another source of *kamlangjai,* which was important in maintaining self-value to enhance a will to live, as described by Nong Ja who – although faced with strong discrimination from her friends and co-workers – still received support from her employer.

> At that time [faced with discrimination from friends and co-workers], it seemed like I nearly sunk deep down into the sea. But, when my boss allowed me to continue work in the factory, even though I had to change my duties to housework, it felt like he gave me a life buoy. Although, the life buoy seemed small if compared with the big sea, it was the last chance for me to survive. He gave me the last chance to survive (Nong Ja, 24 April, 2006).

Social support plays a significant role for people with chronic illnesses, including persons living with HIV/AIDS, as has been noted in other research. Baumgartner (2007) stressed that the turning points in life are associated with interactions with others. Having support from friends helps people to keep going with their life. Similarly, Rokach (2000) who studied persons living with HIV/AIDS, cancer patients, and the general population also found that those living with HIV/AIDS described support groups as very helpful in dealing with a life-threatening disease, the loneliness they experience, and in creating the self-understanding and growth they gained through better living. Studies which were conducted in Thailand also support findings that social support helps people living with HIV/AIDS pass through their problems and keep going on living their lives (Namjantra, 2003) and influences positively the self-care needed to maintain life (Saeloo, 2000). In particular, community acceptance is reported to be the most important factor related to the quality of life of people living with HIV/AIDS in northern Thailand (Ichikawa & Natpratan, 2006).

Lastly, receiving support from supernatural and supreme beings is the last source of support in relation to the “receiving love and support” strategy. Turning to supernatural and supreme beings is one of the main sources of support that almost all participants endorsed as a way of coping with serious life crises (as discussed in the previous chapter). Almost all participants described turning to supernatural and supreme beings including making a vow in front of the Buddha image for support because it brought hope for living and helped them feel calm. Some of them feel transcendent when they dream of a supernatural being and believe that someone with a higher power is there to protect them. It demonstrates a feeling security and enhances their strength (Schaefer, 1995). Additionally, seeking support from supernatural beings enabled some participants to avoid disclosure other than to health professionals. That support from supernatural beings enhances the possibility of survival, maintains the *palangjai* to live as well as bringing peace to them. As a result, this source of support is continuing until today while the ARV drugs are available. Therefore, although some participants no longer seek support from supernatural beings after they have placed their trust in ARV drugs to act in the role of extending life for them, some of them still continue to do this because they experience and trust that supernatural beings both help them to extend life and bring a calm mind for them.

Jensen and Allen (1994) commented that social connections provide a sense of personal contribution and a positive self-identity. When they gain balance (support), the participants have a sense of peace as a result of feelings of purpose and satisfaction rather than frustration. Life is seen a challenge and they put their energy into meaningful activities that are expressions of a will to live. They feel motivation and gain a sense of power and, as a consequence, the sense of security and hopefulness prevails or overcomes distress. Most often, *kamlangjai* comes from more than one source. When people lose their first source of *kamlangjai*, if they can find another source of *kamlangjai* they can keep going with their life. Therefore, they do not give up but try to search out more connections and *kamlangjai* as even with supports they can still come across trouble in life.

As a result of both having connectedness and receiving love and support, including the accepting that enhances the sense of self-value, the participants are able to find a meaning and purpose in their lives which enhances the will to live. However, finding a meaning and purpose in life can change over time and differs individually. Some take time to arrive at this place while others take only a few months to reach this stage.

5.2.3 Overcoming Distress: obtaining *palangjai* or finding a will to live

This concept describes the consequences of the subprocess of *overcoming distress* and using the strategies mentioned above. In a moment, the participants' mind has the power or energy to move on and they feel brave enough to face any difficulties that arise as a consequence of having a will to live. In summary, the process of obtaining *palangjai* or a will to live take place when the participants build up the two ways of relationship: 1) establishing a strong bond or connection with oneself and others, and 2) receiving love and support from others. Then, both ways of relationship are counted by the participants as criteria of being wanted and/or accepted, thus losing the feeling of inferiority and relieving the oppression of being stigmatised as well as bringing a meaning and a purpose to living. After that, the sense of self-value is rising and their minds become strong. Lastly, they desire to move on with their life or having a will to live.

Thus, "the will to live" is demonstrated in two aspects: 1) having a sense of self-value, and 2) gaining strong mind (*jaikemkang* or *jaikang*). These lead them to feel brave enough to face any barriers in their life and feel ready to move on in their life or have a will to live. They change their focus from dying to living. This study also showed that people who have a will to live and are able to overcome their life crisis are those who have the following characteristics: 1) having a strong mind or inner strength, 2) having connectedness with oneself and others, 3) having a support system both within themselves and from others, and 4) realising a sense of self-value. All together these factors facilitate their "finding meaning and purpose in life".

This is consistent with the process proposed by some researchers who found that having a meaning or purpose in life is grounded in the expression of love, forgiveness and trust (Stoll, 1989) and connection (connectedness with self, others, nature, or God) (Jensen & Allen, 1994; Sessanna et al., 2007) that bring hope to people (Chiu et al., 2004). Hope is an enduring presence because "without hope there is no reason to live" (Schaefer, 1995, p. 72). Thus, maintaining connectedness, a sense of meaning and purpose in life, and perspective is the strategy associated with longevity (the will to live). In addition, the long surviving people are those who refuse to perceive that their illness is a death sentence and they also cope well with their situation that is associated with a negative correlation with viral load and a positive correlation with CD4 count (Solomon et al., 2002). Moreover, once the participants have a strong sense of purpose in life and a will to live, these enhance the sense of well-being and reduce psychological distress (Lin & Bauer-Wu, 2003) and, as well, may prevent the symptoms of depression (Lyon & Younger, 2001). A number of participants mentioned that the process of struggling with torment and turmoil came to an end (in a moment) once they gained *palangjai* from the conditions and strategies that they applied. In the aftermath of their struggling process, although some suffering still remained, the severity of suffering declined. Although they perceived and interpret that HIV/AIDS is life-altering situation, they have a driving force (strong mind) to fight, face, and deal with any situation.

5.3 Conclusion

Overcoming distress is the second subcategory in the category of **struggling to survive** that builds toward the core category **Achieving Harmony of Mind** in people living with HIV/AIDS in a Thai context. This subprocess describes way in which the participants overcome their torment and turmoil that overwhelm their lives particularly in the early diagnosis or early period of HIV/AIDS. As a result, their minds come through the distress and become strong. There are two kinds of promoting conditions (feeling relief of mind and selective disclosure of HIV status) and the significant strategy "finding a meaning and purpose in life" that enhance the feeling of readiness to challenge HIV/AIDS and generate the process of *overcoming distress*.

As many participants reported, at first they are faced with the situation of their life being turned upside down and they feel close to dying – either by HIV/AIDS or by committing suicide. All participants have to deal with overwhelming unpredictable situations, including treatment, uncertainty of a cure and planning a life with HIV/AIDS. However, once they applied the unique strategies that promote their *palangjai* or strengthen their mind these helped them to move from dying to living. This subcategory is a turning point from dying to living, because at the end of this process, the mind is strengthening and the struggle to survive comes to an end (until they are faced with future suffering). From this turning point they start to learn how to live with HIV/AIDS with balance and harmony (as discussed in the next two chapters). However, there is another concern in this process, **struggling to survive**, which is that the main source of *palangjai* to live comes from outsiders and is not manageable by the HIV patients themselves. Although some of them start to recognise their inner strength, some do not. Therefore, in the next stage of the process the participants not only have to learn to live with HIV/AIDS, but also they have to learn how to enhance their own inner strength – in particular, their mind – to augment their own *palangjai.* This is a challenging task for them.

CHAPTER 6

Living Life: Accomplishing Harmony in Oneself

6.1 Introduction

In the previous two chapters, the first category of **struggling to survive** and its two subcategories (*encountering distress* and *overcoming distress*) that build towards the core category **Achieving Harmony of Mind** for a person with HIV/AIDS in the Thai context were explained and discussed. In the process of **struggling to survive**, the participants learnt how to overcome their initial suffering enhanced their *palangjai* and came through their difficulties in life by drawing upon the support or connectivity with others, in particular, from outsiders. To some extent they become dependent upon others for their motivation to live.

In this chapter, the second category, **living life** with HIV/AIDS is described, followed by a detailed discussion of the first of two subcategories – *accomplishing harmony in oneself*. The second subcategory of **living life** – *discovering an ultimate meaning in life* – is described in Chapter Seven.

6.2 Living Life

Living life with HIV/AIDS is the second of two categories of research findings that build towards the core category **Achieving Harmony of Mind**. This stage in the process starts after the participants overcome their suffering and have *palangjai* to live as illustrated in Figure 4.1. Two concepts were identified in relation to the category of "**living life**" that enhances people's ability to live with HIV/AIDS as a part of normal life and/or to live life with peace and harmony. These concepts are: 1) the mind, and 2) acceptance.

6.2.1 Living Life: the mind

The first concept in relation to the **living life** category that enhances people's ability to live with HIV/AIDS as a part of their lives is "the mind". In the first stage of the process of **Achieving Harmony of Mind**, most of the participants found a will to live by having connectedness and receiving love and support including acceptance from others that began the process of strengthening their minds.

In this process of **living life** with HIV/AIDS, the participants acknowledge that self, which is composed of body (*guy*) and mind (*jai*) is important for them; that *guy* and *jai* have a strong connection to each other and that one influences the other (as discussed in Chapter One). Therefore, in order to live with HIV/AIDS despite the view that it is a dreadful disease that nobody needs to live with, the participants have to have both health of body (*guy*) and a strong and/or calm mind (*jai* or *jit*).

It is the mind which makes the difference in reaching the level of happiness, and as Thai people always say: "happiness or suffering depends on the mind" and also that everything depends on the mind (as illustrated in Chapter One). In other words, the mind is most important and controls everything. Thai people compare *jai* and *guy*, and say that *jai* is the "boss" and *guy* is the "servant". Nearly all participants give value to the mind for encouraging them to live with HIV/AIDS with balance and harmony. Thus, the participants strongly agree that happiness or suffering depends on the mind. Only if they have a clear, calm, insightful or peaceful mind can they face every situation, including living with HIV/AIDS, and death and dying. As one participant said, once she has a strong and calm mind, she feels that she has "immunity of mind".

Immunity of the body or *guy* is a widely used and familiar term. It means that the body has immunity physiologically, such as from its white blood cells. This immunity is observable and measurable. A person living with HIV/AIDS observes her/his immunity from the level of CD4, the level of viral load, symptoms, general appearance, visible signs and perception of being healthy. However, the notion of immunity of the mind is different; it has no direct physical measures. From this study it was found that immunity of the mind can be determined only by the perception and report of having a calm mind (*sa-ngobjai*), having peacefulness of the mind, feeling relaxed or clear, and having happiness of the mind (*sukjai*). Immunity of the mind in this study is linked with understanding of the truth about life. A mind that has immunity means a mind that is calm, peaceful and settled. The participants who succeeded in training their minds, in other words, have calm, peaceful and settled minds – (*jaisa-ngob*), perceived that they had an immunity of mind much the same as they have an immunity of body. Both have the ability to control, fight against, manage and deal with the situation of living with HIV/AIDS. Therefore, *guy* and *jai* have a reciprocal relationship with each other.

The following example presents the difference between positive and negative thinking (an attribute of mind) in relation to having HIV/AIDS. A person who has a positive mind can see the positives of having HIV/AIDS, such as the gaining of a sense of altruism. When they perceive the meaning of HIV/AIDS like this, they feel relief. Conversely, the person who has a negative mind feels and interprets that this disease has turned their life upside down. Once they think and perceive like this, they feel suffering. Therefore, relief or distress depends upon the mind and how the mind perceives and interprets the situation. If the participants can adjust and adapt their mind to think, interpret or feel in the positive way, they will have peace, calm and harmony in their life.

The mind, then, plays a significant role in living with HIV/AIDS with harmony. The participants whose minds gain insight (wisdom) or understand the truth, know how to deal and live with HIV and, as well, they are able to live with harmony and peace. Pee Tim comments on how her *jai* is important in the following quotation.

> The mind [*jai*] of my being… the centre of me. Being myself is more likely to be a person who is able to adjust to accommodate the current conditions of life. Knowing how to adapt, and having adapted, to be willing to accept the event. The conclusion comes naturally in the mind process. In life you meet with things which are very bad... Already I can easily see the total sweeping away of the things we had in our lives… Our lives rise and fall. We have to adjust [*jai*] to these fluctuations. Don't grasp and attach yourself to life… Life has ups and downs and changes. Only we can adapt and adjust to those changes… Everything depends on us ourselves to determine what happens. You have to accept yourself, accept that this is your identity. You cannot return to what you were formerly. It rests with us… You cannot just sit and be stressed out. You must accept reality and adjust to it. Everything depends on you [yourself] and your mind [*jai*] (Pee Tim, 23 November, 2006).

Most participants saw themselves as the most important factor in overcoming difficulties in life or living life with happiness because happiness depends on themselves – in particular, their mind (as discussed). This is supported by Dhammananda (1993) who stated that the Buddha taught man that “the greatest of conquests was not the subjugation of others but of the self… Even though a man conquers ten thousand men in battle, he who conquers but himself is the greatest of conquerors” (p. 30). The perception of mind that has insight or wisdom is important in leading their life to achieve peace and harmony. Thus Dhammananda (1993) said that “the Buddha knew of the power that could be developed by training the human mind. He also knew that his disciples could acquire such powers through mental development” (p. 32).

Figure 6.1 shows the important role of the mind in learning to live with HIV/AIDS. In this process, at a metaphorical intersection, their mind plays a significant role because the mind that has a clear understanding or wisdom can make the difference or make a choice for their life. One pathway shows the process of *accomplishing harmony in oneself* that rewards them with not only a feeling of triumph but also a feeling of freedom from the shadow of HIV/AIDS and living a normal life with HIV/AIDS. The other pathway illustrates *discovering an ultimate meaning in life* that rewards them with peace and harmony (*kwarmsa-ngobjai*). Although, most participants settled for the first pathway that satisfied their desire to live a normal life with family, the minds of a number of participants found the second pathway, and this finally enabled them to gain inner peace and harmony in life – the ultimate goal of life (discussed in the next chapter).

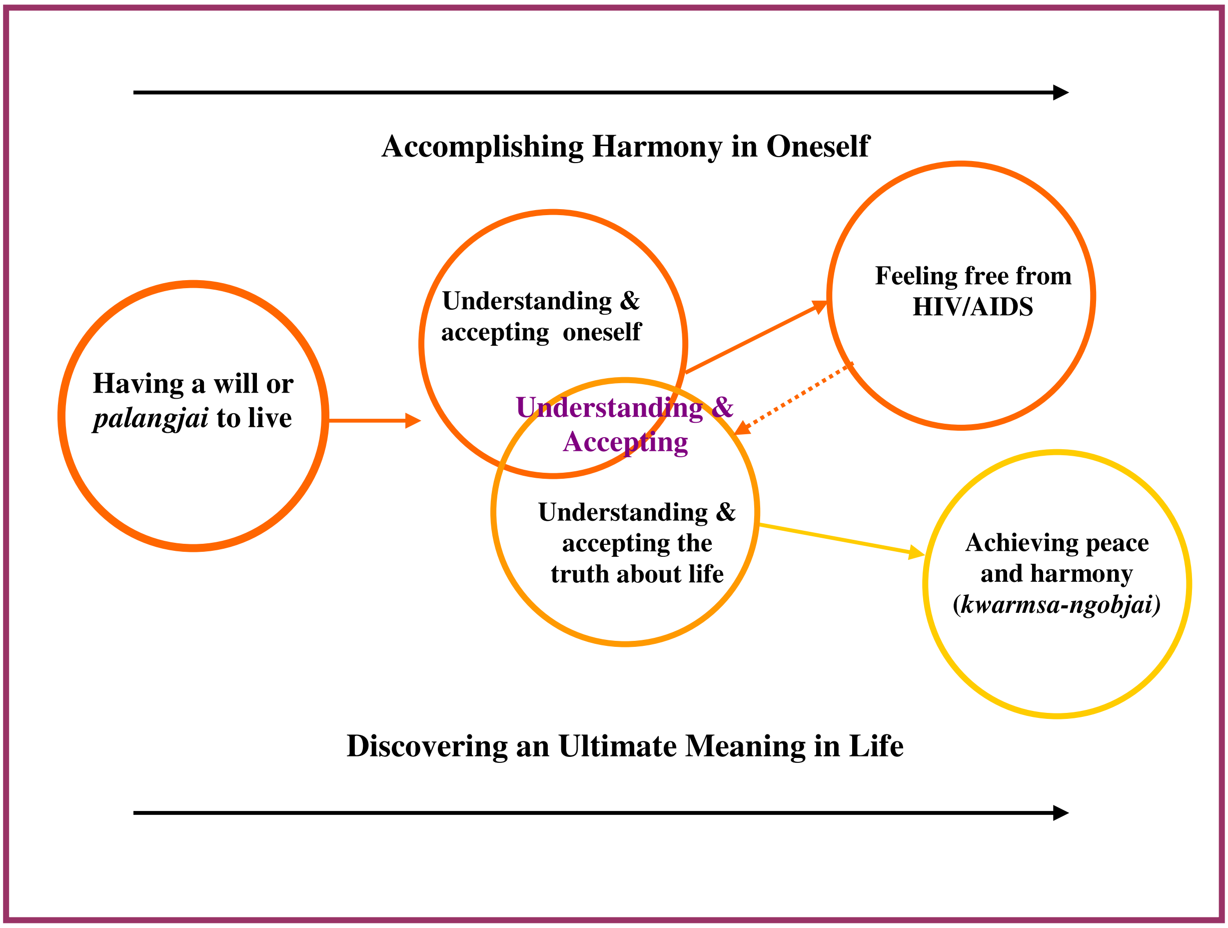

Figure 6.1: The second crossroads – where there are two possible paths to travel

6.2.2 Living Life: acceptance

The second concept in relation to the **living life** category that enhances people's ability to live with HIV/AIDS as a part of their lives is "acceptance". Sometimes, this term includes the terms "understanding" and "accepting". Acceptance has a relationship with the mind because it occurs in the level of the mind or the processing of the mind. A mind that is able to understand (*kaojai*) and accept (*tamjai* and/or *yomrub*) is the key to the category **living life,** both in the first subcategory – *accomplishing harmony in oneself* – and in the second subcategory – *discovering an ultimate meaning in life*.

Acceptance represents the coping process, in particular during the most difficult situations in life such as being diagnosed with HIV/AIDS and facing death and dying. It is the key process that facilitates the participants' transcendence from encountering distress to living with HIV/AIDS and accepting death as a truth of life (Gloersen et al., 1993). Acceptance is a cultural mechanism used by Thai people when they face a situation that they have to deal with, or when it is difficult to change the situation.

Acceptance can be defined in terms of *remaining calm when meeting obstacles in life*. Sometimes, acceptance is similar to "what will be, will be". For instance, when the participants learned that this illness was in their life and they could not change it, they had to accept it as unavoidable, because that is what will be. Three dimensions were identified in relation to "acceptance".

6.2.2.1 The expressing of acceptance

The first dimension of acceptance is *expression*. Acceptance was evident through both their verbal expressions and their behaviour. In this study, the participants expressed and applied many words that are aligned with acceptance, such as *tamjai, plong, ploy, ploywang, ploypai, jumyom, yudyun, yomrub,* and *maiyudtid* (flexibility). These words can work as either nouns or verbs. However, here they are always used as verbs.

Each word such as the three most common words (*tamjai*, *plong*, and *ploywang*) has a slightly different definition. Firstly, *tamjai* is the process for making one's mind up. *Tamjai* also means *to be satisfied* and *to accept what they have*. Secondly, *plong* is another word of expressing acceptance. *Plong* was applied when the participants *wanted to get rid of negative feelings or thinking* (Balthip, 1999; Siriwatanamethanon, 2008). Lastly, *ploywang* or, *to let it go*. This enhances their letting go of their worry, concern, and problems (Siriwatanamethanon, 2008). It also occurs when the participants are faced with a situation that could not be changed. The participants realised that *ploywang* or, to let go, is the most effective choice for them to release their suffering and stress as well as gain peace. *Ploywang* was also used in a situation where there was no more need or no high expectation or being nonattached that is consistent with "letting go of misery" as described by Gow (1999) as illustrated in the following examples:

> If I can't solve a problem, I *ploywang*… It means stop thinking and don't worry. *Maiyudtid*, flexible and adapt… Let it be (Nong Keng, 11 April, 2006).

> *Maiyudtid* [flexible] and adapt to that situation (Nong Pat, 02 May, 2006).

The finding of the important role of acceptance – in particular, the term *tamjai* – is consistent with the findings from much research that has been conducted in Thailand, and which reveals that *tamjai* is key in dealing with a difficulty in life and in finding harmony in a life crisis situation (Balthip, 1999; Klankaradi, 2008; Rungreangkulkij, & Chesla, 2001; Sangchart, 1997; Siriwatanamethanon, 2008).

6.2.2.2 Factors influencing acceptance

The second dimension of acceptance consists of the factors that influence acceptance. The main factor that influences acceptance is (a clear) understanding of the situation or life. Therefore, if the participants can open their mind to view and perceive useful knowledge and information (about their illness and themselves) and truth about life, these lead them to accept their situation of HIV/AIDS and dying and death. They have the ability to live with HIV/AIDS and welcome dying and death with happiness. They will achieve long-lasting happiness in their life. Although accepting the truth about life (life, illness such as HIV/AIDS and death as one part of life) plays an important role in the process of learning to live with HIV/AIDS, having a sense of acceptance is difficult. The conditions or factors that lead the participants to acceptance of having HIV/AIDS (illness) have been discussed in this chapter, while the conditions or factors of accepting the truth about life (life, illness, and death) will be discussed in more depth in the next chapter.

6.2.2.3 The consequences of acceptance

The last dimension of acceptance is the consequences of acceptance. Although generally, the consequences of acceptance are peace and calm, one participant said that if he cannot *tamjai* (accept), he cannot achieve a calm mind and so he also cannot live with HIV/AIDS. “If our mind is unsettled, we can’t survive” (Som, 03 August 2006). Many participants reported that once they were able to accept, they obtained a calm mind and felt that they were winning the situation of having HIV/AIDS as the following quotations show:

> I felt good after I *tamjai* because I have a calm mind (Nong Oil, 26 October, 2006).

> Being free from thinking [*ploy*] helps me to win [against] this disease (HIV) (Pee Bow, 27 April, 2006).

> Just think that having it [HIV] is the same as having another disease… We have to *tamjai* [accept] with what we are. We have to strengthen our mind [*jai*]. My *jai* has never failed me (Pee Pang, 11 August, 2006).

> I don't worry for a long time because I know it is not good. When I recognise my stress, I *ploywang* [let go]… Although sometimes I have some stress, I don't need to worry too much. Whatever will be, will be. Let it happen, if it needs to happen [what will be, will be]. I don't control it. I don't need to worry about that. I don't think [*ploy*] about that (Pee Suk, 02 May, 2006).

In this study, the participants reported many Thai words to represent acceptance (as discussed) and each word means a slightly different degree of acceptance. Thus, this creates different consequences of acceptance: temporary and longer lasting. Firstly, temporary peace and harmony occur when the participants accept under pressure or under the condition of limitations. This kind of acceptance was always represented by the terms *plong* and *tamjai*, with a situation or condition that they normally perceived could not be changed by them or that they could not manage by themselves. The consequence of this kind of acceptance is a calmness and peace but these are only temporary. If they have the chance or possibility to do so, they need to make a better or another choice. For instance, a number of participants said that if they could, they would prefer not to have HIV/AIDS. The person who accepts that s/he has HIV/AIDS is under pressure, because s/he has no chance to change or manage the situation and has to accept it although s/he does not want to. S/he feels relief and is calmer, but some part of feeling constrained still remains.

Secondly, long-lasting peace and harmony occur when the participants accept under the condition of clear understanding of their situation and the reasons that explain their situation. For instance, the participants who accept both having HIV/AIDS and the truth about life with true eyes and a clear understanding, understand and accept that illness and death form one part of the human life cycle. They have a more relaxed life style and feel calm for longer. This kind of acceptance was always represented by the terms *yomrub* and *ploywang*. This finding was supported by the writings of Porritt (1990) that referred to the work of Kubler-Ross, stating that:

> Being able to accept one's end is not giving up… When a person has reached acceptance it is kindest not to hang on but to let go… It is useful to recognize the difference between resignation and acceptance. When resignation occurs… that's the way it is, there is nothing else to do. These people are resigned to the reality of their illness but that is different from acceptance. Under duress… resigned people may still experience anger or depression or make more bargains (p. 130).

This finding is also consistent with the research of Balthip (1999) who found that resignation (*plong* and/or *tamjai*) and acceptance (*yomrub*) are different stages of the coping process, and also bring about different consequences in people living with HIV/AIDS who have a near-death experience. In some instances, some words, such as *tamjai*, denote the coping process. But *yomrub* is the consequence. For instance, some participants reported that they tried to *tamjai* (verb) with their situation of having HIV/AIDS. If they can *tamjai*, the consequence is *yomrub* or acceptance. In the process of *tamjai* they may, or may not, gain peace – whereas once they are able to *yomrub* or accept (with clear understanding), they cultivate peace in their mind.

> When I was sitting in the public transport [on the way to get the blood test], my heart was racing. When I arrived at the hospital, I ran to the counter to get my result [HIV test result] as I was desperate to know. In the back of my mind I believed my result would be "positive" because my husband has been diagnosed with the disease 4 years ago… I secretly wished that my result would be negative though I could see that it was unlikely to be what I wished for. I prayed for help. Well! When I knew I had the disease all I could do was to accept. When I was told [about the result], I thought it was good, at least I knew. I *tamjai* to accept that I have the disease (Pee Nun, 23 March, 2006).

In summary, in the **living life** category, the mind plays an essential role in both of the two subcategories. In the first subcategory – *accomplishing harmony in oneself* – the mind gains understanding (insight) (*kaojai*) and accepts (*tamjai* and/or *yomrub*) the truth about the illness and the person herself/himself. Also, the mind accepts herself/himself as a person living with HIV/AIDS. These enhance the participants' feelings of being free to live with HIV/AIDS, and to live a normal life. In other words, this illness does not have any negative effect on them; feelings of inferiority, limitations in life and stigma all decline. The subcategory *accomplishing harmony in oneself* is described further in this chapter. In the second subcategory – *discovering an ultimate meaning in life* – the mind still plays a significant role in perceiving (insight and wisdom) and understanding the truth about life (life, illness and death) that is mostly grounded in religious doctrine. If people truly understand the truth of life, they will experience a change in their way of living and in their purpose in life. In other words, their mind gains the wisdom or insight into the truth about life that leads to achieving peace in life. This peace has an effect on the whole life that enhances the immunity of a person. They feel that they have a protector over their life. This process is explained and discussed in Chapter Seven. Jensen and Allen (1994) who synthesised qualitative research on wellness-illness found that the realisation of the certainty of death makes life alive, gives an awareness of the blessing of health (awareness of living life and appreciation in living), "accept others and oneself with limitation and finding pleasure in relationships, take the unburdened journey of moving beyond and an ultimate transcendence can occur – a connectedness to what has been and what will come" (p. 357).

6.3 Accomplishing Harmony in Oneself

Accomplishing harmony in oneself is the first subcategory of **living life** with HIV/AIDS. This subprocess started when the participants were searching for a way to live with their new circumstances by adjusting their minds to understanding and accepting their illness and themselves. It is a process of coming to terms with "being a person". This subcategory is similar to the term of "becoming" that Martsolf and Mickley (1998) coined to represent "an unfolding of life that demands reflection and experience; includes a sense of who one is and how one knows among other things" (p. 294). Thus the participants come to know themselves; who they (really) are and accept who they are now, in order to continue on with life and to be able to live in their new circumstances. The conditions, actions/interactions (strategies) and consequences of *accomplishing harmony in oneself* are outlined in Table 6.1.

Table 6.1: Accomplishing Harmony in Oneself: conditions, actions/interactions (strategies) and consequences

Conditions	Actions/interactions	Consequences
Understanding and accepting of illness and oneself	**Being kind to oneself and one's mind**	**Feeling free form HIV/AIDS**
1. Understanding (*kaojai*) and accepting (*tamjai* and/or *yomrub*) the illness >Having HIV/AIDS is normal > HIV/AIDS is not severe > Having HIV/AIDS enhances a positive change in life 2. Understanding and accepting oneself >Having self-reliance > Having a better life despite living with HIV/AIDS > Being proud I am not a bad person >Maintaining former roles and identities	1. Being joyful 2. Avoiding negative situations 3. Building a new "personal" world 4. Practising a careful life style 5. Having discipline in life and being proactive in care	1. Gaining power of mind in control of HIV/AIDS 2. Having hope in living >Having hope to live a normal life > Having hope to live in a normal society

6.3.1 Accomplishing Harmony in Oneself: understanding and accepting of illness and oneself

This concept illustrates "understanding and accepting of illness and oneself" that is the condition in the subcategory *accomplishing harmony in oneself.* This is based on realising that if one needs to live with an illness, one has to reverse one's way of thinking from negative to positive and open one's mind to gain understanding in positive ways, of both the truth of the illness and the truth about oneself.

> I try to think positively… trying to compare my situation to worse situations of others and think how my situation is better than theirs. This thought releases me from being suffocated (Nong Keng, 11 April, 2006).

> Our views and thoughts have changed. In the past, it is like I live in a shallow world, but now, seeing everybody having problems, and troubles makes me realise that there are people that are more suffocated than I am (Nong Moo, 22 April, 2006).

Two subconcepts were identified in relation to the condition “understanding (*kaojai*) and accepting (*tamjai* and/or *yomrub*) of illness and oneself”: 1) understanding and accepting the illness and 2) understanding and accepting oneself. This concept and their subconcepts, as outlined in Table 6.1, will be addressed in the following sections.

6.3.1.1 Understanding and accepting the illness

The first subconcept in relation to the condition “understanding (*kaojai*) and accepting (*tamjai* and/or *yomrub*)” is understanding and accepting the illness, which occurs when the participants adjust their mind in order to know their disease with clear understanding. It includes understanding that having HIV/AIDS is something that cannot be changed. Acceptance was also described in the “Kubler-Ross crisis model”. This model described people who are in the dying process passing through the five stages from denial, anger, bargaining, depression, and finally acceptance. People who reach the acceptance stage often gain peace. Being able to accept does not mean giving up. Rather “it is kindest not to hang on but to let go” (Porritt, 1990, p. 130). Three positive perspectives were identified in relation to the subconcept “understanding and accepting the illness”: 1) having HIV/AIDS is normal, 2) having HIV/AIDS is not severe, and 3) having HIV/AIDS enhances positive changes in life, as outlined in Table 6.1.

Firstly, comes the perception that having HIV/AIDS is normal and as a number of participants have said “we (persons living with HIV/AIDS) have this disease and the others have other diseases. Each person has their own disease… Everyone has his/her own disease”. This perception was described as coming from both their experience and their religion. As adults, who have lived with HIV/AIDS for more than five years the participants have many experiences of illness; they understand that for humans the normal cycle is birth, aging, illness and death and these notions are found in their religions. Essentially, nobody is free from disease.

> When I went to a hospital, many people went there because they also have a disease. Me also, I have this disease. It’s normal [to have disease] (Pee Pang, 18 March, 2006).

Secondly, having HIV/AIDS is not severe. The four main factors in this perception are: 1) having ARV drugs available leads the participants to perceive that this disease is manageable (as discussed), 2) being able to live with HIV/AIDS for many years, in particular before ARV drugs were launched, 3) living with HIV/AIDS without symptoms and appearing to be healthy, and 4) the survival rate of persons living with HIV is increasing. People can live with this disease longer now than in the past. All of this evidence not only gives them more confidence that they will live longer, but also leads them to perceive that this disease is not severe.

Nong Keng found only the negative aspects of having HIV and at first could not find any positive aspects coming from this disease. Later, Nong Keng said he could see a positive side to this disease. When he compared this disease with other chronic diseases, such as cancer, and renal failure, he felt relief and perceived that his disease is better than other diseases which implied that this disease is less severe than some other chronic illnesses.

> Having this infection [HIV] is better than having cancer or kidney disease. People with cancer or kidney disease have to travel to hospital every day, for radiotherapy in cancer cases, and for dialysis in kidney cases. So it [living with HIV/AIDS] is better (Nong Keng, 18 March, 2006).

This finding is supported by previous studies. Hoy-Ellis and Fredriksen-Goldsen (2007), who studied whether AIDS is a chronic or terminal illness, reported that some people living with HIV/AIDS have proof, from their experience of living with HIV/AIDS for several years, that HIV/AIDS is a chronic illness. One of them said that “if it (AIDS) were terminal, I’d be dead” (p. 839). They also said that a person who dies from HIV/AIDS is a person who did not take care of themselves.

Thirdly, having HIV/AIDS enhances a positive change in life. Although at first, nearly all participants expressed only the negative side of having HIV/AIDS; later on some of them saw positive and significant changes in their life and valued HIV as a way of bringing about a positive change. This perception assists them in living with HIV/AIDS with less constraint, feeling challenged by – and receiving benefit from – having HIV. This leads to the possibility that people can integrate and accept HIV/AIDS as part of their life. Moreover, HIV/AIDS is not their enemy or foe but is their friend. Thus, despite living with a life-threatening situation, it is possible to achieve harmony. In other words, a positive change in life can be discovered through a life crisis. Seven aspects represent positive changes made while living with HIV/AIDS from the participants' perspectives.

The first is that they showed increasing altruism, loving kindness (*metta*) and compassion (*karuna*) and they were more grateful. Several participants perceived that experiencing torment and turmoil in their life changed the direction of their life. Some of them had an increased sense of altruism and compassion. They learnt to give more than they received. They became both direct and indirect volunteers by engaging in hospital and community activities. They needed to help others because they did not want others to face the same painful experience of having HIV that they had. This kind of change could bring positive feedback to them in the long run, because it has the power to minimise the magnitude of discrimination. Nong Sin said that he is willing to dedicate himself to being an example to teach others about HIV/AIDS, although to do so he has to reveal his HIV status, for which he might receive negative feedback.

Nong Wut viewed himself as a more grateful person after he received his diagnosis of HIV. He reported the difficulties in his life that also reflected how much love he had from his mother over a long period of time when he was young. This is a strong reason to bring him back to a positive view of life and for him to become a person with gratitude. His mother is the most significant person that he is trying to support. He continues to live well and concentrates on working, changing his behaviour, and increasing his sense of gratitude. He has become more polite, is less argumentative and is eager to do good things for his mother in return.

> Currently I begin to have hope, the hope that my mum will live a comfortable life. I want to work the best I could… I want to see my mum is happy at this last phase of her life… Whatever happens, I want to look after my mum [crying]…

> I don't know what to say… I have told my mum that I am fighting for survival because of her… If I could choose, I would not want to have this disease. I want to be able to have a longer time to look after my mum (Nong Wut, 24 April, 2006).

The second positive change is that they stopped unacceptable behaviour such as using harmful drugs. They changed their behaviour in order to reduce the stigma for both themselves and their families, and to be acceptable to their family and social circle. Participants do not want their families to lose face a second time or have double stigma. Their family acquired stigma when they were infected with this disease, and if they continue to behave unacceptably, their family will be stigmatised again.

> When we have this disease and behave badly [need to modify the behaviour]… If we behave in a bad way or are naughty, people will not want to get close to us… Our family will feel embarrassed or we will be an embarrassment to the family (Som, 03 August 2006).

A consequence of these first two positive changes is an enhancement of self-value. It is a positive energy that drives them to move forward with their life. This is supported by the findings of a grounded theory study, which was conducted by Siriwatanamethanon (2008) on 30 people living with HIV/AIDS in Northeastern Thailand. This study illustrates that the feeling of usefulness is derived from doing things for other people and an increase of self-value. These two positive changes also become part of their way of living that brings peace and harmony into their life (as discussed in the next chapter).

The third positive change is that they may receive real love and friendship that was never present, or was not overtly present, in the past. This includes the promoting of relationships within a family. Thus a number of participants reported that having HIV brought the family closer together. They received unconditional love from their parents, in particular from their mother (as discussed in the previous chapter).

The fourth is that they receive real friendship that may have vanished in the past. Schaefer (1995) mentioned the definition of a real friend as a person who is able to find time to share their experience and help to maintain a sense of meaning in life. HIV is seen as a dreadful illness, and most people stay away, so only unconditional love and real friendship remain. Therefore, it could be considered that HIV is a way of selecting or screening real love and real friendship, since only these relationships still continue, when others respond with discrimination.

> From my own view, I think it [having HIV] helps me to know people better… see! From having many friends around, friends, one by one, began to keep distance from me, feeling uncomfortable having me as their friend when they knew that I had the infection. In the end, there aren't many [friends] left. It [the situation] is a way to judge who the genuine friends are. A friend in need is a friend indeed (Nong Koy, 31 March, 2006).

The fifth positive change engendered by HIV/AIDS is that they have a chance to prepare for the rest of their life and therefore live carefully. It makes them aware of the value of the time they have left, and the time they need to fulfil their important goals. A number of participants reported that they have an opportunity to re-assess their life priorities, aim for what is really important, and prepare for the rest of their life with care. Some participants, who perceived that they have not succeeded in many things in life, now have a commitment to do something with intention and success before they pass away.

> Importantly, knowing that I have the disease gives me time to prepare myself. I changed from a person who has never done anything to meet any goals to a person who wants to bring my acts to successful outcomes… Living with this disease has changed me… When I am making a decision, or think about something, I am aware of consequences more than I used to be… If I want to do something, I should make an effort to do it. In the past, like I said, the same as other normal people, I did things on a superficial level… I didn't think it was a big issue, you know… It doesn't really matter much if I did or did not do [a task, activities]. Or just a bit of this and that… If I felt lazy, I just stopped doing it. But now I put more effort into doing something (Nong Wut, 24 April, 2006).

The sixth positive change is that they started understanding and accepting the truth about life. This was an important gain when beginning to live with HIV/AIDS because it became a condition that made a significant change in their way of living and in the philosophies of the participants' lives. The understanding and acceptance of death and dying enhanced a calmness and peacefulness of mind, so that they were able to live their life with harmony (discussed in the next chapter). It can be said then that HIV/AIDS actually assisted this group in discovering the ultimate meaning of their lives.

> After living with this disease I understood life more than I used to. I understand that human beings are born, get old, sick, and die is a normal cycle of human beings… In the past, I hardly thought about it [dying]. But now I witness the reality – being born, old, sick, and dying… After my child and husband passed away, I could see the reality of life, being born, old, sick, and dying…happy, unhappy… Life is a mixture of those components. This notion makes my mind settled and makes me happy. It encourages me to continue living, living with what I am. If I am feeling distress I remind myself of the understanding that it is normal for a normal person to come across the feeling and to be affected by surrounding situations. *Tamjai* to accept whatever happens in my life (Pee Ning, 27 March, 2006).

The last positive change engendered by a diagnosis of HIV/AIDS is that they feel they can tackle other problems. After facing the suffering of having HIV/AIDS, and having found the capability to overcome their life crisis, nearly all participants described their experience of suffering as contributing to their feeling of being able to face other problems that they will encounter throughout the remainder of their lives. They feel calm, secure, and have less panic in their life. This quotation from Pee Tim presents the positive feeling of approaching problems with confidence.

> Problems occur for solving and do not occur for suffering and everything has a way to solve such as this disease… can be cured. When I meet a problem, I think the problem has a solution to be found, not that the problem holds suffering for me (Pee Tim, 07 August 2006).

In some cases, participants claim that their illness enhances their self growth, a finding similar to that of other studies which claimed that although the experience of living with a life altering situation such as HIV/AIDS is a critical problem in a HIV/AIDS patient's life, it can seen as a motivating factor, and enhance the sense of self growth (Belcher et al., 1989; Bouthillette, 2001; Goffman, 1963; Hall, 1998; Moser et al., 2001; Schaefer, 1995; Siegel & Schrimshaw, 2000). The qualitative study by Siegel and Schrimshaw (2000) of 54 women diagnosed with AIDS revealed that most women reported that HIV/AIDS had changed their lives in some positive ways. HIV/AIDS was seen as a motivating factor for making positive behavioural changes, such as overcoming substance abuse. Many of these women reported that HIV/AIDS had contributed to their religious or spiritual growth. They described growth in relationships with their children, family, friends, and lovers. As a result of HIV/AIDS, they also felt stronger, more responsible, more caring, and thought their value of life had increased. They were also more helpful to others. They had a greater appreciation of life and the time they had left. Similarly, Moser et al. (2001) studied 25 women dually diagnosed with HIV infection and substance use problems in the Carolinas, and found that some women reported that as a result of HIV they had developed new life goals and had become involved in their community.

Additionally, this study's results are in line with those of Burkhardt (1994) and Kylma et al. (2001). Burkhardt proposed that the process of changing involves learning through experiences of both harmony and disharmony, and changing sometimes means struggling to reconcile new experiences with values that had guided their lives. Kylma et al. (2001) found that HIV/AIDS helps participants to become stronger as people by going through this difficulty and seeing life from a new perspective which included valuing one's life in a positive way, and developing a growing awareness of the fragility of life and acceptance of the uncertainty of life. Furthermore, having an optimistic attitude, peace of mind, happiness, and sense of satisfaction and wellness, are related to having quality of life (Lin & Bauer-Wu, 2003).

Four promoting factors were identified in relation to "understanding and accepting the illness": 1) having knowledge and information about the disease, 2) comparing their situation with others, 3) awakening to their risky behaviour, and 4) understanding that having HIV/AIDS is because of their *karma*, and their actions (such as drug abuse).

Knowledge and information about the nature of the disease, treatment and care play a significant role in changing the way of thinking of participants from a negative perception into a positive perception. It helps them to adjust and manage their situation and become comfortable in living with their illness (Schaefer, 1995). Furthermore, a person who understands his/her illness will be less depressed and will have improved psychological and spiritual well-being (Lin & Bauer-Wu, 2003). Many studies (e.g. Baumgartner, 2007; Thomas & Retsas, 1999) found that the process of incorporating their illness as part of their life, requires both knowledge and time that allows the HIV/AIDS participants to move through the acceptance of having an HIV/AIDS. Knowledge plays a significant role, not only in helping participants know how to take care of themselves, but also by enhancing the sense of self value and hope in living. A study in TB patients found the same result; that knowledge can contribute to a more positive outlook on the illness (Sengupta et al., 2006). Hoy-Ellis and Fredriksen-Goldsen (2007) who studied whether AIDS is a chronic or terminal illness, revealed that those who have more education perceived AIDS as a chronic illness. Therefore, the perception of HIV/AIDS is based on information.

Some participants compare themselves with other persons living with HIV/AIDS and persons living with other diseases. Mostly they make downwards social comparisons with persons who are less fortunate than themselves (for example, the quote from Nong Keng, p. 161). However the sense of optimism of some participants emerged from comparing themselves with others who were better off than themselves. This comparison helped them to increase their self-confidence, self-value (Ncama, 2007) and *kamlangjai* to deal with their situation and to understand more about their disease so that they have a chance to get better. Another factor that enhances self-acceptance of having HIV/AIDS is, knowing that they had a chance of contracting HIV from their previous behaviour of abusing drugs or from their ex-husband or ex-wife who was diagnosed with HIV or had died from this virus (as discussed previously).

> Must not lose hope, and must not feel scared [of the infection]. What happens is the consequence of my own act. I used needles… I knew I had the disease… I thought because all my mates passed away, the mates who had lived in this village and shared needles with me. There were about 20 of them. So I accept that my turn is not far away, soon I will be with all my mates. Then heroin was

> everywhere… injected into the veins, 10 people shared a needle (Som, 03 August, 2006).

These findings also related to Platter and Meiring's (2006) study on 10 people living with HIV that reported that one condition of acceptance was based on the perception of their own fault for catching the virus.

The last factor that encourages participants to accept is the understanding that having HIV/AIDS is because of their actions – *karma*. Once they accept that the cause of this disease comes from them, it is easier for them to accept having HIV/AIDS, and then they do not blame anyone else. In particular, those who believe that having HIV/AIDS was assigned by a power such as a supernatural being, and this is also sometimes related to their *karma*. It is difficult to change previous *karma* and *karma* is unavoidable.

> I think it's already occurred [I have this disease], we can't change [I don't know what to do]. It occurs because of our misfortune... I think it's depending on our destiny [fortune]… Sometimes, something happen because of our fortune (Pee Suk, 02 May, 2006).

> I just tell myself that I am what I am because of my life destiny [to have the disease]. I don't know whom I should be angry at… I don't feel angry at anyone. I just think that it [having the disease] is because what I did in the past life was not good enough. That's why I am having this severe disease (Nong Keng, 11 April, 2006).

Moreover, some of those who had been infected with this disease by their partners at first blamed their partners – but later they perceive having HIV in the light of their own *karma* and that they have these partners who infected them with this disease, because of this same *karma* or because something/someone who has higher power assigned them their partners. As Nong Rin said, "He is my husband, someone gave him to me". Once they perceive that everything occurs because of their own *karma* or destiny, they accept it. When they related their illness with the retribution of *karma* and supernatural beings, the participants who at first asked themselves "Why me?", "Why am I infected with this virus" can answer their question with "I received HIV because of my own *karma*".

Rungreangkulkij and Chesla (2001) stated that belief in *karma* is a source of coping with suffering. When life brings suffering, the law of *karma* can explain why people face it with either happiness or suffering. Other studies in the Thai context have also shown that participants believe that having HIV/AIDS (Ross et al., 2007; Siriwatanamethanon, 2008; Songwathana, 1998) or, having children with schizophrenia (Rungreangkulkij & Chesla) is because of their previous (bad) *karma.* Sethabouppha and Kane (2005) also found that *karma*, *boon* (merit) and *babb* (demerit), past life and rebirth and dharma appeared to influence caregivers directly. They believed that good deeds would bring them positive results. Religious doctrine that is related to the concept of *karma* helps people to accept suffering; and enables them to feel relief.

Some participants felt sorry that their destiny caused them to become infected with this disease, but when they looked around them, they understood that it is not only them who have the bad *karma* because other people also have this disease. So, they feel relief and they accept their unfortunate life.

> When I knew that I was not the only one [who has HIV], and there are many others living with this disease I knew that those people had the same level of merit as I did in their past lives. I try to stick with this positive thinking and discard negative ones. If in the whole nation, there was only me who had this disease I would think that I was the person with the biggest sin. When I realised that there are many other people facing the same situation, not having enough merit just like me, I feel better and not angry at any one, or society (Nong Keng, 11 April, 2006).

The perspective that their life is directed by their *karma* not only enabled participants to accept having HIV/AIDS, but also provided the way to decrease their bad *karma* by doing good deeds. When the participants perceived that their illness is related to their own past bad actions (bad *karma*), this focuses and activates them to do good deeds in order to both increase the good deeds and make up for some of the previous bad *karma*. Some participants become caring. In particular, some of them may add to their value by doing some good things before they die. This is supported by previous studies (Ross et al., 2007; Siriwatanamethanon, 2008). It helps them to feel relief and the need to continue their life in order to do more good deeds and release their *karma* which helps them to accept their situation more easily. This study found that although participants perceived that they were infected with HIV because of their (bad) *karma* from doing unaccepted behaviours prohibited in Buddhist doctrines such as the *Five Precepts*, they did not feel scared to turn to Buddha to help them. This may be because Buddha enacts his philosophy by love and compassion for humanity. Buddha teaches people to be free from suffering but he does not punish those who do not follow him. Rather, he teaches them to release their *karma* and triumph in the cycle of birth and death (Dhammananda, 1993).

6.3.1.2 Understanding and accepting oneself

The second subconcept in relation to the condition (concept) "understanding (*kaojai*) and accepting (*tamjai* and/or *yomrub*) of illness and oneself" is understanding and accepting oneself. As discussed, when participants live with HIV/AIDS, they feel (an aspect of mind) very distressed and suffer because their sense of self-worth changes due to stigmatisation. In this subconcept, the participants try to find positive aspects within themselves in order to minimise their feeling of inferiority or eradicate the feeling that they are tainted. Therefore, this subconcept describes the situation of self-exploring or asking "Who am I?" that leads to defining and accepting oneself. As Pee Ning reported, she tries to find her prominent points to balance the inferior points, to make her feel good about herself and her life.

> I try to find my characteristic features [the positive points] to release my inferiority complex [feeling inferior]. For example, I graduated with a bachelor's degree. I have more knowledge than them [the persons who look down on me]… My social status is better than people in my community. I'm a useful person. I dedicate myself to society. I give service to society. Also, many people still respect my relatives… I try to find my positive points to erase my inferior feelings (Pee Ning, 27 March, 2006).

Moreover, the participants who defined the meaning of a *good person* as *a person who is kind, concerned, has a good relationship, has a calm mind, is generous and less selfish,* realised that this meaning of a good person within themselves never decreased or could not be eradicated, not even through the context of their life being changed by having HIV. All these aspects of a good person still remain, or grow more than they did in the past. That leads them to perceive that they still have self-value or that they are still the same people that they were in the past. On the other hand, they do some good things more than normal people. Additionally, a number of participants add to their self-value by revealing that, although they have this disease, they have never been a burden for anyone. The phase of “although I have this disease” always comes after “I am never a burden for anyone”. They have a positive outlook on themselves and gain inner strength and self-confidence about managing and facing their situation. They know that they have the power to battle HIV, to maintain their life, to face their suffering, and to live with happiness under the conditions of having HIV. Therefore, in order to live with HIV/AIDS, perceiving self-value is important because it diminishes feelings of inferiority, as well as resulting in people being kind to themselves. People who regain a sense of self-value and have a diminished sense of being spoilt can accept their illness, accept themselves and live with their situation (Saylor, 1990).

Four positive aspects in oneself were identified in relation with the subconcept “understanding and accepting oneself”: 1) having self-reliance, 2) having a better life despite living with HIV/AIDS, 3) being proud I am not a bad person, and 4) maintaining former roles and identities. This subconcept, as outlined in Table 6.1, will be addressed in the following sections.

Firstly, *self-reliance* has meaning for the participants’ lives. Being self-reliant reminds them that they have ability and dignity and that they are not tainted people, although they are living with HIV/AIDS – a condition that is perceived as making people vulnerable and fragile. It makes them feel confident and proud of themselves. They present many aspects of self-reliance, such as financial independence, and the ability to comfort themselves and solve their own problems without any help. Current self-reliance confirms for them that they will have the ability to maintain their self-reliance, and be less dependent on others in the future. As a result, feelings of insecurity, uncertainty, hopelessness, and inferiority are minimised.

Secondly, having a better life despite living with HIV/AIDS is the next positive aspect that the participants found within themselves. A number of participants perceived that their life was changing in a positive way and was better than in the past; they felt fortunate with their life. One example is Pee Ying. She became a widow when her husband died of HIV. She lives with her 8-year-old daughter. She used to work in a fish factory and did not have a steady income. Also the work prevented her from adhering to her timetable for taking her medications, and exposed her to sunlight and rain which was not beneficial to her health. As this job was not suitable for her life-style, Pee Ying decided to look for a new job as suggested by Pee Jib (the health volunteer) and make ceramic dolls. She trained until her products were good, and now she sells them at a tourist beach. The business is gradually improving. She is able to smile as she is now happy. Pee Ying and her daughter agree that their financial status is better. Pee Ying commented that her daughter said "Our stomachs are better fed now, aren't they, Mum?" This remark illustrates Pee Ying's perception of positive thinking, which is that although she has this disease, she is able to improve her living conditions and these are now even better than before she had the disease.

The other two outstanding cases of having a better life and changing in a positive way are Pee Suk and Pee Karn. They are becoming *taokae* [19], or rich people, even since they have been living with HIV. That makes them feel proud of themselves. Every time, I met with Pee Karn she welcomed me with happiness and smiles. She told me about many positive things that have occurred in her life although she lives with this illness. For instance, she has a good husband. Her doctor admires her as a person who takes good care of herself. She is a healthy person with no side effects from ARV drugs. Furthermore, she reported that because she has her own house, new cars and a small business, people called her "*taokae*". She also presented compassion and loving-kindness, by supporting elderly people in the community. However, she still keeps her HIV status secret.

Thirdly, another positive aspect important to self-acceptance is being proud I am not a bad person. As HIV/AIDS creates a stigma and is a disease which causes strong discrimination, people who are infected with HIV are stigmatised as people who have bad behaviour. The participants reported trying many ways to show that this is not necessarily true. This included living longer than their partners who infected them, dressing carefully, and cultivating relationships with others because they need to announce to others that not all people who live with HIV have unacceptable behaviour.

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[19] *Taokae* is a person who is rich. Normally, it refers to Chinese people who are rich or have a business.

They are not bad people, and in particular, the women are not bad people and they are not prostitutes. However, it is unavoidable that they share this disease with some people who do behave in unacceptable ways.

> I'm not the source of this disease. I got this disease from my husband. I didn't get this disease because of me. My husband infected [HIV] me (Pee Nun, 23 March, 2006).

> I have to make a good impression through dressing well. Not so much to dress formally as to avoid putting too much makeup on, and wearing plunging neckline. You can't dress like that. It is better to be more presentable because… I am afraid that people might regard me in that way as much as not, that maybe I have played around… I want to tell society that I am an AIDS sufferer but that I don't dress like that or that I play around with men or that I sell my body (Pee Tim, 19 May 2006).

Lastly, self-acceptance is enhanced by maintaining former roles and identities as in the past, such as maintaining their roles as parents, maintaining a position of consultation, maintaining the ability to work, and maintaining relationships with friends and others. The ability to maintain these roles leads them to perceive that they are the same persons as they were before their infection with HIV and that they have the same ability as others, and this belief promotes their sense of self-worth.

> Don't think that we can't do this like other people can because we have the disease… We actually can do anything we want [as same as the others] (Pee Pang, 11 August, 2006).

Although HIV/AIDS is a symbol of vulnerability and tainted social identity, a number of participants continue their work as before. For three participants (Pee Suk, Nong Wut and Pee Pang) their sense of self-worth was retrieved by their ability to keep working, in particular when their boss trusted them and appreciated their work, and some of them received a higher pay than the other workers. This encouraged them to be proud of and to accept themselves.

> I work here [factory] for more than 10 years… So, I have experience and my boss trusts me. I can talk and discuss problems with him. Also, I do my best in my work for boss (Pee Suk, 22 May, 2006).

The ability to work establishes both their sense of self-worth, and promotes their sense of security and certainty in life, a finding similar to that of Maguire, McNally, Britton, Werth and Borges (2008) who stated that "employment was extremely important to some participants, providing them with a strong sense of purpose and meaning in their lives" (p. 64). As a result, the finding of positives in oneself – and a number of participants perceived that their life is much better now with HIV/AIDS than it had been in the past – increases the sense of self-value, decreases feelings of inferiority and promotes the feeling of being normal. Being able to do anything the same as normal people such as work, allow the participants to preserve their assumptions about normal people**.** Once the participants perceive that they are normal people, they can go on with their life although they have to live with HIV/AIDS. The feelings of stigma and of tainted identity cannot overshadow them once they have a sense of self-value and self acceptance. This perspective is consistent with the strategies for preserving self which is suggested by Charmaz (1997).

Self-acceptance enhances the ability of a strong mind to control the disease and to feel free in living with HIV/AIDS. Acceptance is a need of most people, and other human beings contribute to this need. However, the most important point is that one accepts oneself and does not reject oneself. Once a person accepts him or herself, s/he has an inner strength to confront everything in life and view the situation as one who is in control rather than one who feels threatened. Intasara (2005) said that reasonable people have a stable state of mind, and accept both negative and positive life events. Acceptance is an important key to solving problems. Without learning to accept (situations) some problems are unable to be solved.

Nong Koy suggests that with any kind of living with the HIV virus, the person should have self-acceptance. When she accepted that she has HIV/AIDS, she began to attend to herself so that she became the leader of her HIV/AIDS and therefore, she no longer allowed HIV/AIDS to dominate her, as it did in the past.

> At this moment, I think I am fine… I am living my life comfortably. If I take a good care of the HIV, it cannot destroy me. If I died the HIV would die as well. I do whatever to think that HIV is part of my life. It is there living in my body. Just think about it that way… I should be the leader of HIV. I do whatever to control the disease, preventing it from dominating my life (Nong Koy, 20 August, 2006).

Although acceptance of having HIV is very difficult for many participants, one participant said if he does not accept it, then he has to keep running away for the rest of his life. Therefore, they prefer to face it and not run away from it, as they did in the past. With regard to both an understanding and acceptance of the illness and themselves, they are able to clearly and calmly discern their situation, see past it and estimate their ability to face it. They understand their situation fully and they know how to approach it, deal with it and live with it. Especially when they know they can manage and control their situation, they feel confident to face it and feel it as a challenge that they are able to control. These conditions enhance their ability to live (as normal) with HIV/AIDS.

6.3.2 Accomplishing Harmony in Oneself: being kind to oneself and one's mind

This concept explained the actions/interactions (strategies) of "being kind to oneself and one's mind" that the participants employed in relation to the subcategory of "*accomplishing harmony in oneself*". Being kind to oneself and one's mind is a strategy that shows their understanding of the situations (conditions) and adaptation to their new circumstances. Pee Suk summarised from his experiences that the ability to live with HIV/AIDS depends upon many things such as the self, *kamlangjai*, and mind.

> To be able to live with this disease, it is up to our self, our *kamlangjai*, and our own thoughts [mind]. If we are worried too much about it [HIV], our conditions might be worse… The disease becomes more severe. So, I think it would be better, if we adjust ourselves to live a happy life (Pee Suk, 22 May, 2006).

Being kind to oneself and one's mind is developed from the feeling of self-love (as discussed in the previous chapter) and an understanding and accepting of the new identity as a person living with HIV/AIDS (as mentioned above). Participants know themselves and accept that something in their body has changed or is missing as well as being more fragile, but it does not mean that they give up. Knowing their situation does not mean that they understand that they lack ability to act. Conversely, they are careful and protect their weak points. They are honest with themselves, which leads them to do the best and to do the right thing for themselves. In other words, they are acting appropriately. They do everything that makes them happy and do not destroy life either directly or indirectly. They know what they should do for themselves while living with HIV/AIDS. They compromise and reconcile their actions in terms of being kind to their self and mind. They know when they have to ask for help, and they know when they can depend on themselves. Some of them said that they compromised and asked for help sometimes and because of this they have become less arrogant. This is important in living with HIV/AIDS.

Pee Yai said that HIV/AIDS could not destroy her if she took care of herself well. "If I eat well, they (HIV) live well". This sentence shows that the participants know how to deal, and live, with HIV/AIDS. One participant received a lesson on learning how and when to take care of himself, from nature by looking after orchids:

> Looking at orchid, one branch is about to die, but when it was given some water, a new branch starts to show up and grow. Then the dead one will be removed from the plant. This could be implied to the truth of human beings' life. When we neglect our bodies, we will be just like the orchid that is not being given enough water, and is being left to die. But if we look after our bodies well, we gradually regain our health status; again it will be just like the orchid that is regularly given water, having a new branch growing and continuing to live. However, we ought to know there is a time when we should not water the orchid. After midday, the orchid does not need water because it is better to leave its roots to dry to prevent the growth of bugs at night (Pee Kid, 30 March 2006).

Five subconcepts were identified in relation to the action/interaction "being kind to oneself and one's mind": 1) being joyful, 2) avoiding negative situations, 3) building a new "personal" world, 4) practising a careful life style, and 5) having discipline in life and being active in care. This concept and their subconcepts, as outlined in Table 6.1, will be addressed in the following sections.

6.3.2.1 Being joyful

The first subconcept in relation with "being kind to oneself and one's mind" is being joyful. Personal resources such as being a joyful person, having a good mood and never being stressed – or, at least, being less stressed – is one of the main ways of living with HIV/AIDS. Many participants who report having a happy personality and not worrying too much, can let go (*ploywang*) of their distress more easily than those who are not like this. It helps them to reclaim a normal feeling. Having a joyful personality is one of the strategies that presents being kind to one's self and one's mind and helps some participants to gain happiness.

> I make my life have happiness by not thinking too much and I listen to a song. I do dancing. I'm a joyful person… Actually, I'm not stressful person. I don't need to worry because when I worry I will get a headache (Pee Pang, 18 March, 2006).

This finding is supported by Schaefer (1995), who conducted research in women who live with chronic illnesses, and revealed that humour is an essential ingredient for living with a chronic illness.

6.3.2.2 Avoiding negative situations

The second subconcept in relation to "being kind to oneself and one's mind" is avoiding negative situations. Some participants keep a calm mind by avoiding negative situations. The participants have learnt from previous experiences that avoiding or ignoring hurtful situations is helpful for them, as it minimises their suffering, in particular the feeling of being inferior (as in the overview under the subheading "Feeling relief of mind" in the previous chapter). One participant gave a metaphor of escaping from a hurtful situation as staying away from the needle that pierces (stabs) them. This strategy helps them become more relaxed because they do not need to face the negative problems (circumstances) that hurt them at any time. Some of them continue this strategy throughout the process of living with HIV/AIDS.

> We can't stop people from thinking; they can think what they like. Their words are like a sharp needle which if we take [what people said] on board will hurt us. So it is up to us to pick and choose the people [with] whom we want to get

> involved… I try to exercise choice about the people I associate with. I have to know to screen my companions. I don't pick those people who are going to hurt my feelings. I don't want my mind to get hurt again (Pee Tim, 07 August 2006).

Although this strategy may not be the best way to deal with a hurtful situation, if it is compared with another strategy, such as training their mind to be calm (discussed in the next chapter), however avoiding negative situations gives quick, short-term relief.

6.3.2.3 Building a new "personal" world

The third subconcept in relation to "being kind to oneself and one's mind" is building a new "personal" world. As Nong Nid said, "human beings need social interaction and no one can live only by themselves" a statement that is consistent with Barroso and Powell-Cope's (2000) view that "although the tangible or instrumental aspect of support was viewed as important, the basis of human connectedness was the emotional support was given and received and the sense of belonging that come from social interactions" (p. 345). People living with HIV/AIDS still need social interaction. Some participants establish their own new group – a process that they called "building up an own new world". This strategy means that they are selecting friends they can associate with, or spend time with.

> Joining the group makes me happier… have more friends who share the same problems… It is great to be able to talk to each other openly. It is as if we have created our own little world. In the past I wished I could die, but I don't think about dying any more (Nong Moo, 22 April, 2006).

> It is similar to the story between black and white people. When a black person lives among whites, he would feel out of place because his appearance is different from the rest. But if he lives among blacks, it doesn't matter (Nong Nid, 13 May, 2006).

Participants who felt inferior and faced stigma when others ended relationships with them because of the presentation of HIV/AIDS symptoms were very careful and concerned about starting to have another relationship. They state that they will have a relationship only with people who make a first move to make friends with them in order to strengthen their minds, and minimise the gap between other people and themselves and their feeling of being inferior.

> This disease affects my life. I was a cheerful person and easy going, enjoying friends' company. But now I have withdrawn myself… We have to carefully observe people's reaction to see if they are going to reject us or not… I have to behave and know my place… taking time to see if the persons are willing to be friends with me or not. If they want to, I would respond the same way… If they talk to me, I talk to them… These days, I feel wary talking to people because there was a time when I talked to them, but they didn't want to talk to me. Sometimes, when I said Hello to them, they turned their faces away from me… It was upsetting… They treated me as if I was not a human (Pee Cha, 22 March, 2006).

Building a new world usually means building up new relationships with friends who share the same disease. However, later, sometimes, their new world includes people who are not infected with HIV/AIDS but who show real friendship towards them. Therefore, living with the same disease is not the only indicator of having real friendship; rather it is the way of sharing feelings and showing real friendship that are the most important. Thus, the indicators for choosing who will be a part of this new world are understanding the deep feelings of each other, sharing experiences and knowledge, having no distance between each other, comforting each other, and being encouraged to have *palangjai*.

A real friendship makes people with HIV/AIDS feel confident about life and secure. If no one needs them, at least they have real friends beside them who are ready to share, support and comfort them. Also the phrases "not only me", and "I have friends", and "we are the same" are important in decreasing feelings of inferiority and stigma, and in stabilising their state of mind and feelings of security. Once they have friends and group support, they have more power to control this disease and control their situation. This finding is supported by that of Baumgartner (2007) who also found that the sense of group unity helped others to accept their situation. The groups help the participants gain control over the disease.

6.3.2.4 Practising a careful lifestyle

The fourth subconcept associated with “being kind to oneself and one’s mind” is practising a careful lifestyle. Because the participants both understand and accept that they are more fragile and compromised now than in the past, they are concerned about their way of living – having a careful lifestyle. A careful lifestyle includes both practising healthy lifestyle behaviours such as doing meditation and avoiding harmful lifestyle behaviours. Some participants are very careful about what they eat, what they do and how they behave, in order to live longer as a healthy person and not to be a burden on anyone.

> I have to be careful of my health. If I am severely sick, it is not good for my health condition. I have to think about my social life… If friends pass a drink to me I might have a sip just to taste how it is. Then I could say that I don’t drink much lately because of my health. When I go to visit my hometown, and meet up with my old mates they would encourage me to have a drink with them. I just have a sip, and excuse myself by telling them that I don’t feel well. But I don’t tell them my real health problem. I have to look after myself more than other people do. They can drink as much as they like, get drunk if they want, and they still fine the next day… But for me, if I do the same, I might end up lying in bed for long time (Nong Wut, 24 April, 2006).

Pee Porn is another example of someone taking good care of herself. She is avoiding fatty food and taboo foods and eats healthily using her home grown herbs and vegetables, such as mint, lemon and corn. She uses these with her knowledge gained from many herb books. Pee Porn tries anything natural that maintains and helps keep her healthy, such as, using herbs, exercise, yoga, food, meditation, making merit and taking alternative medicine. She works as a lotto seller and accesses her customers on foot or bicycle. She works two shifts, one in the morning and one in the evening. Although Pee Porn has a busy life, she manages her time wisely for both her work and taking care of herself. As she said:

> I started to learn to take care of myself this way [*yoga*[20], exercise, herbs. [However] I don't know if it is good or not… Sometimes, I eat red onion 2-3 bulbs to relieve the cold. When I go to work I have to take water with me because I take some kind of drugs that affect my kidneys. However, in the night I can't drink a lot of water because it disturbs my sleep and makes me have less sleep. When I come back from work [day shift] or finish my cooking [in the morning] I do *yoga*. When I finish *yoga*, I take a shower, rest, and then go to work again [night shift]. At 11 p.m. I finish my work [night shift], come back home, pray and go to bed (Pee Porn, 03 September, 2006).

6.3.2.5 Having discipline in life and being proactive in care

The last subconcept linked with "being kind to oneself and one's mind" is having discipline in life and being proactive in care. The participants recognise that they have significantly changed and their lives have also been changed whilst having HIV/AIDS. They have to re-arrange their life schedule to fit with the new condition of having HIV. Although living with HIV/AIDS and managing their new life circumstances require significant lifestyle modification and adaptation of daily activities, such as being concerned about food and resting, doing exercise, seeing a doctor and keeping appointments, seeking medical care, and taking ARV drugs on time throughout their life, most participants said "It is acceptable. Nothing is difficult". All of them are willing to change their lifestyle and daily living if they can continue their life. In particular, when people love themselves, they want to be healthy and live longer. This activity includes observing and reacting quickly if they have new symptoms or show signs of allergy to ARV drugs; they go to see a doctor promptly. They show concern and take care of themselves as well as observing their changes:

> From being bedridden, I could walk, run within no time. I can't stay still… When I know that I am sick, I bring myself to see doctor and am determined to get better… Wherever there are treatments, I would go (Nong Keng, 23 August, 2006).

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[20] *Yoga is* one kind of activity undertaken as either physical exercise or to aid meditation – or both.

Some participants left their previous jobs because they could not take their ARV drugs on time. Several participants set their mobile phone alarm to remind them of the time to take ARV drugs. Some of them reported that taking ARV drugs is one of their duties and it is essential for their life. Although it is not easy for them to take ARV drugs on time, they attempt to do their best. Furthermore, although some of them do not need to take ARV drugs at this time, they register a quota for receiving ARV drugs as a support plan when they get worse. This is another expression of proactive care. Some of them include in their schedules, times to meet friends in an HIV/AIDS support group, in order to share knowledge and experiences, as well as providing comfort and support for each other.

Being proactive in care includes seeking knowledge and information which will enhance their hope of living and management of their situation. This helps them to understand this disease, treat this disease in the right way, increase *palangjai* to deal with this disease, and to have more hope of a cure. When Som said that the prices of new drugs to treat HIV are now only a dollar per tablet, it means he follows the information about HIV and the advancements in treatment all the time. This active search for information brings hope to them either because one day s/he will have a chance to take new drugs or, one day a scientist could develop drugs to cure this disease. The improvement in drugs and treatment could contribute to their hope to live longer. This leads them to a possible positive outcome. It is no longer a false hope – based on incorrect or incomplete information – as defined by Verhaeghe, van Zuuren, Defloor, Duijnstee, and Grypdonck (2007). They also perceived that for themselves, it is important to take responsibility for their health and have an active role in their own treatment and care (Barroso & Powell-Cope, 2000).

These strategies were congruent with findings from prior research. Uphold, Holmes, Reid, Findley, and Parada (2007) studied the healthy lifestyle and health-related quality of life among men living with the HIV infection, and found that straightforward changes in lifestyle, such as eating well, remaining active, and avoiding stressful life events, may improve quality of life. Loeb (2006) studied coping with chronic health conditions with 28 African American older adults, and reported that in problem-focused coping, which occurs in the category of "engaging in life", the participants applied the strategies of exercising, changing dietary patterns, and medicating, seeking information, and self-monitoring or body listening. In particular, self-monitoring provides them with insight into treatment and alerts them to the progression of their disease.

This finding can be described by the concept of self. Blumer (1969) argued that Mead (1934) saw the human being as an organism that has a sense of self. Human beings may perceive themselves, have conceptions of themselves, communicate with – and act toward – themselves. Therefore, they have self-interaction that takes the form of making indications to themselves and meeting these indications by making further indications. Thus, human beings can designate things to themselves such as their wants and their goals. By having self-interaction, human beings may judge, analyse, and evaluate the things they have designated to themselves (Blumer, 1969) that show in being kind to self and mind as found from this study.

Once the participants have immunity of life (having immunity of the mind and the body) by making use of the conditions and strategies that are explained above, they do not need to run away from their situation, because nothing can destroy or penetrate them; they have the ability to control their situation. This study showed that self-acceptance is significant for HIV/AIDS patients to have a strong and calm mind, because they do not feel the need to run away when people talk about this illness to them or when people talk about them. These actions help them to gain more benefits and gain control of their HIV. It leads them to have happiness and a calm mind, and they do not feel frightened. These people do not hide themselves or lie to themselves by believing that they do not have HIV (although they do not reveal this directly but it seems that they do reveal it indirectly). They feel calm because they do not need to worry about how people look at them and what people think of them. They feel relaxed if others know they have this disease and some of them can reveal that they have HIV themselves. Also, when they need to seek support, knowledge or information, they can do this openly. In addition, once they know themselves and they know their ability, they know what they can do and what things they cannot do, what things they have to avoid and they know their ability to estimate the situation. Nevertheless, the suffering process is not a straightforward one that automatically leads them to a sense of calmness but one that requires time and effort.

6.3.3 Accomplishing Harmony in Oneself: feeling free from HIV/AIDS

This concept explained the consequences of actions/interactions (strategies) that the participants employed in relation to the subcategory "*accomplishing harmony in oneself*". The consequence of those strategies is transcending HIV/AIDS, or feeling free from HIV/AIDS; that is, the person transcends his/her suffering. Feeling free from this disease means that, from this point on, this disease cannot control their life. They feel confident to face the reality and live in society, rather than running away or trying to escape from it. They feel confident to face the truth. They are able to maintain equilibrium and calmness of mind. Their distress, which was beyond their ability to control, will be released.

They also gain strength in control and deal with their situation and are able to live with HIV/AIDS. Afterwards, the participants have more immunity that is enhanced by having both self-acceptance and kindness to one's self and mind. Furthermore, they enhance within themselves the conditions and strategies that foster the feeling of being free from HIV/AIDS in this subprocess, – their self and their mind. This finding was supported by Barroso (1997) who studied the ways of becoming a long-term survivor of AIDS with 20 participants based in the Tampa/St. Peterburg, Florida who had had AIDS for at least 3 years. This study found that by the process of normalizing, focusing on living, taking care of oneself, having relationships with others, and having the feeling of triumph are the ways of becoming a long-term survivor that allowing participants to reconstruct their lives within the context of AIDS. Thus, their life crisis experiences, in particular their life's being overshadowed by HIV/AIDS, from which sickness and death are regarded as inevitable, do not affect them after they are able to accept the illness and begin to be kind to their selves and mind – in particular, by letting go or *ploywang* about their illness – they gain inner strength and HIV/AIDS is no longer seen as being harmful for them. It becomes just part of their memory.

> I let it go [*ploywang*]… I forget it [having HIV/AIDS] already. I don't think too much about my past experience… Yes, I don't worry about it because I already forget it. Although, I still think that this thing [getting HIV infection] is not good for my life, I don't worry about it. It is actually still there in my subconscious, knowing that the disease is good or bad to myself… but I stop thinking about it at this moment. It is now only a memory. However, as I told you, it took a long

> time [more than 5 years]… I gradually adjusted and changed [mind, feeling, perception] it is not solely me… It is gradually… Now, when I start to think too much, I know myself. Then I stop it (Pee Ning, 27 March, 2006).

Two subconcepts were identified in relation to the consequence "feeling free from HIV/AIDS": 1) gaining power of the mind in control of HIV/AIDS, and 2) having hope in living. These subconcepts, as outlined in Table 6.1, will be addressed in the following sections.

6.3.3.1 Gaining power of the mind in control of HIV/AIDS

The first subconcept in relation to the consequence "feeling free from HIV/AIDS" is that the mind gains the power to control HIV/AIDS. This means that in their minds the HIV/AIDS patients perceive that they can control their situation. After the participants have achieved a power of mind through self-acceptance and being kind to themselves and their minds, they are able to continue their life more smoothly. One participant, who knows about the relationship of *guy* and *jai*, said that she needs to make her mind happy in order to be a healthy person because, if she feels happy, her immunity will increase and she will become healthy. Jensen and Allen (1994) commented that when people are healthy; they have a sense of harmony and balance. When they gain balance, they have a sense of peace and satisfaction rather than of frustration. When people have a high level of immunity, they become healthy and promote their sense of control or management over the HIV virus, and this in turn increases their confidence for living with this disease.

6.3.3.2 Having hope in living

The second subconcept in relation to the consequence "feeling free from HIV/AIDS" is having hope in living. Having hope in life means that a life is no longer dark. Hope of living is supported by knowing how to live with HIV. The participants perceived that their life still has a way to go. One of two metaphors that two participants reported is that light has shone into their life, or "their life still has light". Another metaphor from Pee Cha is "the boat that has a paddle". Pee Cha gave a metaphor for becoming settled while living with HIV/AIDS as "finding the paddle for his boat". At first living with HIV/AIDS and not knowing how to deal with it, he compared himself to a boat that was floating in the sea and he had no paddle (strategy) to take his boat back to the bank.

Once he learnt to live with HIV/AIDS, after around three years, he said that he found the paddle (strategy) to take his boat to the bank. In other words, he knows the strategies to deal with HIV/AIDS and to live with this circumstance, which can enhance his hope in living.

People, who feel free from HIV/AIDS, perceive themselves as being normal people. They view the future optimistically. They can see a direction for their future. Therefore, they feel brave enough to set their life plan and have hope. A number of participants keep reminding themselves that although they are living with the HIV virus, it is not too late for them to start a new life and to have hope. They still have a chance to continue their hopes and dreams. As Nong Wut reported:

> It is not too late though I am having this health condition [HIV infection] as long as I know how to take care of my health. One of my dreams is to have my own family, children, build a house, have a piece of land to do rubber farming, and that is my entire dream (Nong Wut, 24 April, 2006).

Hope has a positive effect on participants' lives. Having hope helps them to maintain their life, future, be energised and active, not to be inert and not to give up on life. Hope activates participants to live. Kylma (2005) revealed that hope is a basic resource for human life. Hope implies recognising constructive possibilities in life situations, and believing that life is worth living both now and in the future. These participants feel confident to project their future and be optimistic about their future life. They could forecast possible and positive outcomes for their life, as in the metaphor of the light shining into their life, or their life still having light. The following quotation touches on the feeling of living with hopefulness.

> Life is a journey. I know that the destination that I wish to reach [cure from HIV/AIDS] is still far away, however, I intend to reach it even though there will be obstacles along the way, and it will be a tiring journey. I could take a rest to regain strength, and then continue my journey. I need to keep up with the journey until an effective [way] to treat this disease is found. It is a long trip, which takes a long time and I never know when the destination will be reached.

> However, I think I will continue the journey [living the life] until a new treatment is invented to successfully cure the disease and that is my goal. I keep telling myself that if there is such treatment I will not die. Though I know that the possibility of reaching the goal is limited it is still better to have hope. Having hope is better than having none at all (Nong Moo, 22 April, 2006).

Surprisingly, from initially being unwilling to live, most people living with HIV/AIDS now have a satisfying independence and purpose as well as a will to live. They concentrate their focus on living not dying. A number of participants came to understand that their aim is to hope to live. Although they had faced the biggest crisis in their life, they still preferred to live instead of dying, after they had looked at themselves through a positive lens and perceived that the “world and life are still beautiful”. Two kinds of hope were identified in relation to “having hope in living”: 1) having hope to live a normal life, and 2) having hope to live in normal society, as outlined in Table 6.1.

Firstly, in regard to having hope to live a normal life, most participants feel brave enough to have some hope that, one day; they will receive drugs to treat this disease and they can have a normal life, just as has occurred for people with other severe diseases for which cures have been found in the past decade. In particular, these are people who do not want to spread this disease to their partner or children, but one day they would like to have children.

> I just have hoped that we will have drugs to cure this disease [HIV]… because in the past we have only medicine to treat opportunistic infection. But now, we have ARV drugs. So I hope in the near future, there should be a drug to cure this disease (Nong Moo, 22 April, 2006).

Together with several participants who are single or widowed s/he hopes to start a new family and/or has planned to have children in order to become a complete family. Children and partners are meaningful sources of hope to live and sources of willpower or *palangjai* to go on with life. New life and new relationships produce new hope and *palangjai* to live. This is consistent with the finding by Siriwatanamethanon (2008) who defined the term “living a normal life” that included living with extended family and participating in the family’s activities, getting re-married and having a baby.

However, some with HIV/AIDS hoped only to be free from any opportunistic diseases that might exacerbated their illness, As Thai people always say: “Freedom from sickness or illness is the best luck in life”, and Thai people always make wishes to live a long and healthy life. The participants in this research have this hope also.

> My only hope now is [to] have no illness… I just continue to live like other people do as if I don’t have the disease (Pee Suk, 22 May, 2006).

Secondly, having hoped to live in normal society, all participants hoped that one day they can live in a community with other (ordinary) people with no disgust and discrimination. It is important to people who are living with an illness which causes others to discriminate against them, that they are able to maintain their relationships with others who are not infected with HIV. These positive relationships with others lead them to perceive that they are normal people. Some of them are successful and realise this hope by conforming to acceptable behaviours and continuing to live a normal life in their former society. Living with others and not receiving disgust from them was clearly evident in statements from a number of participants, such as, Pee Yai, Pee Pang, Nong Keng, and Nong Sin. For example, many times, when I went to visit Nong Keng at his house, I found that he had many friends who would greet him and these were not people infected by HIV. Some of them found work for Nong Keng, some of them bought meals for him, and some hired him to take their children to school on his motorcycle. (In the past, people did not allow their children to come into close contact with a person living with HIV/AIDS). Therefore, he was not living with discrimination.

However, although hope enhances the participants’ desire to go on with their life, hope should be based on reality. People should not have too high an expectation because it makes them feel suffering when their hope does not come true. So, some participants choose to stay alone or choose to stay with their partner without having children because they need to stop the spread of this disease. Also, they do not want to put their life into the uncertainty of a cycle repeating the past. For example, if they get pregnant, they will worry that their children will get this disease, although they have drugs which can resist the onset. Another worry is that if they have children, what will happen to their children if their parents die while they are still young. Also, if they have children it may make their health status more fragile. Thus those who hope to have a family and complete a family will have to deal with such unexpected situations that are more likely to occur. Nong Koy, who needed to have children, finally had a son. She worried because her son got sick often; she worried that her son would be infected with HIV although she took ARV drugs to prevent this and she had planned her pregnancy well.

6.4 Conclusion

In this chapter I have presented the category of **living life** and the subprocess of *accomplishing harmony in oneself*, which begins with the process of self-discovery. The participants gain insight, and understand that if they wish to live longer and continue their life and maintain their life's equilibrium, they have to adjust their mind in order to accept themselves, in particular as a person who has HIV/AIDS. These strategies lead them to find a way to achieve harmony within themselves in the new circumstance of living with HIV/AIDS; a coming alive in the relativity/reality of HIV/AIDS. As a result of "self-searching and exploring", they are honest with themselves and accept themselves within the reality – being kind to oneself and one's mind. They are able to gain a sense of control over their HIV/AIDS and they feel confident to face life with new hope such as in the setting up of their family and the acknowledgment that their HIV/AIDS is an opportunity for self-growth.

As a result, the participants transcended or surpassed their HIV condition, feeling free from HIV. Some participants illustrated the feeling of overcoming and feeling relief from HIV as a stage of balance in life. They have triumphed and live with this disease as a leader. They distinguish their life with a positive view; life has light that shines. Some participants feel satisfied with this stage of the journey in their life when they have the ability to live with HIV/AIDS even though they face suffering sometimes. However, a number of participants found ultimate meaning in life and have less suffering, or have a longer time of happiness or peace by following some way of living that is based on understanding the truth of life as discussed in the following chapter.

CHAPTER 7

Living Life: Discovering an Ultimate Meaning in Life

7.1 Introduction

In the previous chapter the category of **living life** and the first subcategory – *accomplishing harmony in oneself* – which describe the process of self-discovery, coming to know oneself and successful coming alive in the situation of having HIV/AIDS were explained and discussed. In the previous subcategory, the participants feel free from the shadow of HIV/AIDS and are able to live as normal. They no longer interpret HIV/AIDS as a definitely life altering event – rather, HIV/AIDS is seen as one way of stimulating positive changes in their life and HIV/AIDS is controlled.

In this chapter, the second subcategory of the **living life** category – *discovering an ultimate meaning in life* – is explained and discussed. This is another pathway of living with HIV/AIDS.

7.2 Discovering an Ultimate Meaning in Life

Discovering an ultimate meaning in life is the second subcategory of the **living life** category. Martsolf and Mickley (1998) stated that meaning in life is "the ontological significance of life; making sense of life situations; deriving purpose in existence" (p. 294). Meaning in life can be discovered many times in one's lifetime. In this study I found that there are two significant times that the participants ask questions about the meaning in life. Every time when they ask for meaning in their life, it makes a difference in their life. The first time – as discussed in Chapter Five – as part of the subprocess of *overcoming distress*, occurs when the participants face the greatest intensity in their life. As a consequence of the first finding of meaning and purpose in life, they rediscover a will to live. The second time occurs when the participants have lived their life 'as normal' for some period of time and they have faced an abundance of experiences that have led them to raise new questions – for instance, why they were born and whether or not they have done all that they are supposed to do in life. As a consequence of this new round of questioning *discovering an ultimate meaning in life* emerges when the participants gain insight and understand the truth about life that which leads to their being able to live life with contentment. This subcategory does not emerge last. In fact, this subprocess occurs concurrently with previous processes because both positive experiences and negative experiences, success and failure, happiness and suffering, up and down, and bright and dark guide the participants to understand the truth about life (illness and death) or *kwarmjingkongcheewit* that is the main condition of *discovering an ultimate meaning in life*.

Discovering an ultimate meaning in life comprises three concepts. The first concept is called *understanding and accepting the truth about life* – conditions. The second concept is called *living with contentment* – actions/interactions (strategies). Finally, the last concept is called *achieving peace and harmony* or *kwarmsa-ngobjai* – consequences. The conditions, actions/interactions (strategies) and the consequences of *discovering an ultimate meaning in life* are outlined in Table 7.1.

Table 7.1: Discovering an Ultimate Meaning in Life: conditions, actions/interactions (strategies), and consequences

Conditions	Actions/interactions	Consequences
Understanding and accepting the truth about life 1. Nothing is permanent 2. Being born as a human being causes suffering, and death is the end of suffering 3. Life is/has no ending	**Living with contentment** 1. Living with equanimity (*ubekkha*) > Living in a moment and/or having mindfulness > Practising detachment (*ploywang*) or letting go > Living a simple lifestyle and/or living with self-sufficiency 2. Living with awareness > Finishing business for themselves in this life > Preparing merit for the next life > Finishing business related to care of parents or children 3. Living with loving kindness (*metta*), compassion (*karuna*), altruistic joy (*muthita*) > Meditation and/or praying (*lamad* in Muslim) > Practising altruism and helping others > Practising forgiveness (*ahosi karm*)	**Achieving peace and harmony or *kwarmsa-ngobjai***

7.2.1 Discovering an Ultimate Meaning in Life: understanding and accepting the truth about life

This concept describes the conditions that create the process of *discovering an ultimate meaning in life*. As mentioned in the previous chapter, for the participants in this study the mind (*jai*) is the most important aspect of the process of living life with HIV/AIDS in order to be able to open up to understanding or insight (*kaojai*) and acceptance (*tamjai* and/or *yomrub*) of illness and themselves. Once they succeed in adjusting their minds, they feel free from suffering from HIV/AIDS and they can live with HIV/AIDS (as normal).

In this subprocess, *discovering an ultimate meaning in life*, the mind retains its role in opening up to understanding or insight (*kaojai*) and accepting (*tamjai* and/or *yomrub*) the truth about life (illness and death). This understanding guided participants in their way of living and helped them to live their life, remaining calm in the face of difficulties in life. Although understanding or insight and accepting the truth about life are their most difficult tasks, the result is the most valuable for them. It rewards them with peace in life. They live their life with wellness because they are happy to live and do not fear death and dying. In other words, they feel free to live their life, free to find happiness and free from feeling fear of death. Three subconcepts were identified in relation to the condition "understanding and accepting the truth about life": 1) nothing is permanent, 2) being born as a human being causes suffering and death is the end of suffering, and 3) life is/has no ending. This concept and its subconcepts, as outlined in Table 7.1, will be addressed in the following sections.

7.2.1.1 Nothing is permanent

The first subconcept in relation to the condition "understanding and accepting the truth about life" is that nothing is permanent. The notion of nothing is permanent is a significant condition in helping the participants find peace and harmony in their life. Generally, Thai people always say "nothing is permanent" especially when they are faced with the experience of loss. This is a common saying or belief within the Thai context not just a belief held by those who practise a religious doctrine deeply. Its Western equivalent is probably "nothing lasts forever". This notion can explain difficult questions – for instance, "Why do humans become ill?" Or, "Why do I have this disease?" Not only is the answer that I have this disease because of my (bad) *karma* – as shown as being an answer in the previous chapter, but also this notion can be explained by saying that it is because illness is a part of life and nothing is permanent. Thus, it is normal that human beings become ill or sick. This answer can comfort and make the participants accept their illness more easily because it is not a punishment but it is a truth of life and normal. Being born, being old, being sick and dying is the normal life-cycle – along with constant changing.

Another main question is, "Why do human beings die?" The answer is because human beings are under the same rules of impermanence and change as everything else in the world. Therefore, it is normal that their life will change. Dying and death and are the truths that every human being will encounter. Death is one part of the human life cycle that shows people they cannot avoid the rule of impermanence. Life is uncertainty, but death is certainty. They understand and accept the *Three principle aspects of existence*: *anicca* – impermanence, transience of all things, *dukkha* – suffering, disease, and *anatta* – insubstantiality or non-essentiality of reality or no permanence – nothing belongs to them, ending of a self that helps people to find an ultimate meaning in life that enhances a sense of living well and dying well (peace and harmony). This understanding that all people will die plays a vital role for a person who at first believes that only s/he is under a shadow of death by having HIV/AIDS and s/he feels fear of death. But people also understand that nothing can stay with them or belong to them forever, even their own body in this life; it is not their own body at all when they die. This understanding helps them to feel calm and peaceful and less worried about dying and death because it is normal that one day they will die.

> I feel that my life is balanced. I am able to adapt and to view the world in more different ways, and to take a broader view. I look at the reality of life more deeply than I used to – that birth, aging, infirmity and death are common and natural experiences. I view [*interpret*] life through religious principles… I have heard a saying "It happens, it takes root and it disappears". I say that everything is like that. Nothing is permanent… We should release and lay down issues [*ploywang*], ignoring them, then we can obtain inner tranquility (Pee Tim, 07 August 2006).

> To cheer myself up, I tell myself that it is just life, nothing more than that. There are many other people who have died before me, my mother for example, died long ago. So I have someone waiting for me at the other end. It is normal for human beings to be afraid of dying but we should tell ourselves not to be afraid of it (Nong Nid, 24 September 2006).

In addition, once they understand that nothing is permanent, it also can comfort them and help them to accept their situation. If they face suffering, later the suffering will disappear. In the same way, when they have happiness, happiness will change later because everything is under the same rule of nothing is permanent. If people understand and accept this truth, they will understand and feel calm when something happens and changes. They also have more comfort and do not feel sad when their happiness disappears one day. They are not distressed when they are facing sorrow. They can let go (*ploywang*). They are not overjoyed when they are having a happy time. That means their mind has developed immunity to prevent grief, sorrow or misery from invading their lives. Only the foolish person feels worry or suffering about the things that will change. A person who has wisdom does not feel stress or worry about change because it is a normal part of life. It is not worth worrying or grasping or holding the thing that is impermanent because no one can stop the changing of life. In other words, such a person is not being fooled by the uncertainty of life.

> I try to not make myself attached to anything, and keep telling myself that there is always a way out and if there is no way out, I just let it be [*ploywang*]... Some were about to go crazy because they cannot accept the truth. We must accept the truth… we have to strengthen our mind… We must be mentally strong [adjust self according to, and accept, the truth]. We have to be brave to accept situation, the certain thing is the uncertainty… no one lives forever… things change all the time… rich becomes poor, poor becomes rich (Nong Keng, 11 April, 2006).

The notion of, the truth about life, is underpinned by Buddhist doctrines. The words of Buddha mean that all must depart – all beings that have life must shed their compounded forms; component things are impermanent (Dhammananda, 1993; Hanh, 2004). Dhammananda (1993) explained in more depth that the Buddha teaches that life has mind and matter and nothing more. Apart from these realities that form the *nama-*

rupa compound, there is no self, or soul. The mind part of the compound is what experiences an object or event. Both the mind and the matter arise because of the conditions of people's lives and this is happening every moment of their lives. As a consequence, an understanding of such impermanence can free human beings from getting caught in the suffering of craving, attachment, and despair (Hanh, 2004) (as discussed under the subheading "Living with contentment").

7.2.1.2 Being born as a human being causes suffering, and death is the end of suffering

The second subconcept in relation to the condition "understanding and accepting the truth about life" is that being born as a human being causes suffering, and death is the end of suffering. The second truth about life from the participants' perspective of being born as a human being is seen as being born to suffer. By contrast, death is the end of suffering and the end of repaying *karma* and the end of *karma*. In addition, they perceived that those who die have more merit because those who are still alive are people who still have to face suffering and are not yet finished the payment of their *karma*. Furthermore, when they are faced with suffering, they understand that they are in the process of repaying and when they come to the process of dying and death, they perceive that their *karma* has also nearly come to the end. This perspective helps them either to welcome dying and death or to continue to live with peace and harmony.

> When the time comes everyone dies… think of it that way. No need to think too much, no one lives forever… This notion has come to my mind since I have been sick. I don't think anyone could live forever, even God died, people who make a lot of merit died. So who am I, I could die any day as well. I think because I have not finished paying back my sin, that's why I am still alive. When the time comes, if I am to die, I will die (Pee Kaw, 22 April, 2006).

This perception was supported by the *Four Noble Truths* – in particular, the first truth that is "all living things experience suffering" in the Buddhist teaching (as discussed in Chapter One).

7.2.1.3 Life is/has no ending

The third subconcept in relation to the condition "understanding and accepting the truth about life" is that life is continuing or has no end. Death is not the end of life. Both Buddhist and Muslim participants believe and trust in life after death that life has no end. When they die in this life, their mind will continue to the next life. In addition, some of them said that death is the pathway to another world that is life after death. In that world, they will meet someone who passed away before, such as their mother, and who is waiting for them there. Therefore, death is not the end of their life. This belief changes the perspective of dying and death for the participants.

Muslim participants believe that death is the pathway to go to the real or true life in the next life. They reported that the ultimate meaning in life is God (Allah). Allah is the only reality into which our self needs to disappear and the transcendent element is everything (Markham, 1998). Muslims also trust that after they die in this present life, their soul will move through to the next life. They believe that this present life is only one of the indefinite numbers of states of being and the next life is the real life to which their mind will go after this life passes away. This perception not only helps the participants to not fear dying, but also motivates them to do good deeds in order to have a good life in the next life.

> When I die, our life is not finished; it will continue to the next life. If I do bad things I will go to hell but if I do *lamad*[21] I will go to heaven (Nong Boon, 11 March, 2006).

Through Buddhism, the participants also trust that when death takes place and the body dies away, the mind exists and will spring up again with the support of a new physical body. Therefore, in Buddhism death is the portal to a new rebirth which will be followed by more growth, decay, and then another death. They believe that all beings will be reborn somewhere for a limited period of time as long as their good and bad *karma* remains in the subconscious (Dhammananda, 1993). Maeche, who has a strong belief in the law of *karma* and life after death, decided to become a nun because she has more chance to do good deeds. She believes that she was infected with HIV because of

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[21] *Lamad* is pray in Muslim. It is a daily reverence and respect paid to God among Muslims.

her (bad) *karma*. Hence, she needs to do more merit deleting her previous *karma* and accumulating merit for her next life. Nowadays, she perceives that she has enough merit to have a good life after she dies.

Thus, as a consequence of this condition, the participants feel calm although they live with illness that can cause death. The belief is that this life is not the final – rather, they have the next life after they die as was also found in a Western study. Woods and Ironson (1999), who conducted a study on the religion and spirituality of people facing cancer, cardiac problems, and HIV, found that to the question of "What will happen to you after you die?", most subjects expressed the view that their spirit or soul will live on in some form. Some of them reported that they will return to God, rejoin family and friends, and go to heaven – all of which makes them feel relief.

When people are able to understand and accept the truth about life, it implies that they can let go their worry or feeling of fear about dying and death. It also gives a positive meaning to death and dying because it is the truth. This finding is also consistent with those of previous studies conducted in the Thai context that participants achieved a peaceful mind and harmony and were able to accept death after they realised and accepted that death is the truth, a natural closure of life and it is a reality which happens to everyone after they have done meditation and performed enough meritorious acts (Balthip, 2001; Saeloo, 2000; Tongprateep, 2000).

As a consequence of realising the truth that nothing is permanent, people are enabled to reassess their priorities and rethink about the (real) content of their life. What are the important things that they have to do while they are alive? This finding was supported by Balthip (1999) who discovered that after the participants in her study found their purpose in their life, one of them decided to become a monk in order to help others. As a result, he gained real happiness and fulfilment in life.

> Searching for true happiness, focusing on doing good deeds, and being the shoulders for those human beings who need help, I understood the truth of life which is when we die [we]cannot take anything with us. So I ask myself, what are human beings chasing after, and why don't they go looking for real happiness?... Only if we could bring ourselves to understand what would go with

> us [when we die], blood, body and spirit are not ours. We need to rethink again what we were born for? Walking on another path which is no connection with human world, but it is the path [which I am as a monk] could help people, who have no one to turn to, to encounter the suffering (Balthip, 1999, p. 134-135).

Dhammananda (1993) claimed from the view of Buddhist teaching that understanding the truth about life encourages human beings to gain insight into "1) what we truly are, 2) what we find around us, 3) how and why we react to what is within and around us; and 4) what we should aspire to reach as a spiritual goal" (p. 74) that leads them to spend life with less of an illusion and add more contentment into their life (as discussed under the subheading "Living with contentment").

Although some participants did not mention that their happiness or sense of well-being is associated with a strong background in religion, this seemed to be the case in many instances as they sought to make good through religious rituals. This may be because they did not consciously think about religion even though through their behaviours they were demonstrating some form of religious belief. They were striving to live as good a life as possible and to integrate their new values into their everyday lives.

7.2.2 Discovering an Ultimate Meaning in Life: living with contentment

This concept is organised around the idea of the actions/interactions (strategies) that the participants endorsed to reach their life goal of having peace that was guided by understanding and accepting the truths about life. This is the ultimate goal of their life as one participant said: "Only one thing that I need is living life with happiness and peace" (Pee Tim, 23 November, 2006). Three subconcepts were identified in relation to the actions/interactions (strategies) "living with contentment" in order to achieve peace and harmony: 1) living with equanimity (*ubekkha*), 2) living with awareness, and 3) living with loving kindness (*metta*), compassion (*karuna*), and altruistic joy (*muthita*). This concept and its subconcepts, as outlined in Table 7.1, will be addressed in the following sections.

7.2.2.1 Living with equanimity

The first subconcept in relation to the strategy "living with contentment" is living with equanimity. In the Buddhist book, *equanimity* refers to the following words *ubekkha or* *epeksha, or upekkha.* Equanimity in Buddhist teaching has two meanings 1) even-mindedness; neutrality; poise, and 2) indifference; neutral feeling; neither pleasurable nor painful feeling ("Equanimity" in Thai-English and Buddhist dictionary, 2009). However, Hanh (2004) explained this term in the aspect of true love that means nonattachment, non-discrimination, even-mindedness or letting go. The person sees everyone as equal, there is no discrimination between oneself and others.

In this study, three way of living were identified in relation to the subconcept "living with equanimity": 1) living in the moment and/or having mindfulness, 2) practising detachment (*ploywang*) or letting go, and 3) living a simple lifestyle and/or living with self-sufficiency as highlighted by the Thai King, as outlined in Table 7.1.

Firstly, living in the moment and/or having mindfulness is the first way in relation to "living with *ubekkha*". It means enjoying, relishing, taking pleasure or delight in, and focusing on now including being mindful and stopping the mind from wondering about the past, and the future. Participants have the philosophy of doing the best for today and now. They do not think of the past and stop worrying about the future. Pee Suk said, "Forget the past that cannot be changed, and focus on the now and do the best for now". Then, sometimes, they refer to both "What will be, will be" and "Letting go". Concentrating on the present, thinking of what would produce positive effects and not getting tangled in what would yield negative effects are the means they used to calm their mind. Strengthening the mind (*jai*) and stabilising the state of mind (*jai*) helps them to live in the moment and be able to *ploywang* the sufferings and sadness of the past (as discussed in the next section). Pee Suk is one of the participants who represent having the life style of "living in the moment". Although he mentioned that one's life destination is pre-arranged by other forces such as supernatural beings or *karma*, he also stresses that he has to do the best for his life. He also presents the metaphor of "rolling back and forth in bed (*non-clinkpai-clinkma*)" to express his idea of his happiness. It means happiness without any worry. This outlook is a way of dealing with the present – not to have expectations beyond his ability to meet – as a result, it provides him with peace.

> The way that I spend my life is nothing special, nothing much to think about. Just think about what is in front of me, one thing at a time. Don't think or do

> many things at once because the brain might not be able to take it. Just focus on one thing and don't think too much (Pee Suk, 22 May, 2006).

Pee Porn also presents a way of living in the moment. This way of living helps her feel relaxed and less stressed with her life. As she reported:

> Asking me what I want to do, my answer is to keep on selling lotto tickets until I am unable to continue. And I don't want to think what I would do when that day arrives. I don't want to think about the future… I only think about today and tomorrow (Pee Porn, 03 September, 2006).

Through the accumulation of their many experiences in life, the participants have realised that stress is not good for them. It destroys their life. Focusing on the now or concentrating on the thinking that they do makes them feel calmness and peace. They could stop their mind when it moved to something that made them feel sad or unhappy. Practising to stop their mind from dwelling on unhelpful or negative thoughts or creating calm of mind by practising mindfulness is the way of practising living in the moment. They could follow their thinking and were conscious or mindful of their negative thinking, so they could stop. Once their mind was calm (they stopped thinking negatively), no suffering or unhappy situation could destroy them because it could not invade their minds. Moreover, when they had achieved a certain state of mind, they could control their mind to a positive way of thinking.

> The past experience of sorrow makes me understand that sorrow is self-destruction. Hence when my mind is thinking about the sorrow of the past, the conscious and intellectual part of the mind would stop me thinking about it. I try to concentrate on the present and refuse to think about the sufferings in the past. Why do I need to think? So, I don't need to be too serious because if I feel serious, it doesn't help (Pee Suk, 22 May, 2006).

This finding was supported by the writings of Suttisakorn (2006) that referred to the Phra Yarn Po Nigthera that the people who have the ability to train their mind and gain peace, happiness and a neutral mind, will gain the wisdom that leads to understanding the truth (right view) about life. If people do not have wisdom, they cannot gain this peace and a tranquil mind and they also cannot understand the truth. Finally they cannot be free from suffering and accomplishing a peaceful mind. The consciousness or *sathi* is the key achievement of having freedom of mind or having peace. It is also found in elderly people in Thailand (Tongprateep, 2000).

Secondly, practising detachment or letting go (*ploywang*) is the second way in relation to "living with *ubekkha*". As explained in Chapter Five, children are the main connection that enhances the will to live. However, in regard to the aim of finding peace in life, the participants have to reduce their connections (detachment), let go or *ploywang* other kinds of worries or suffering; otherwise they will not achieve real happiness in life (harmony). The participants learn to detach and *ploywang* not only when they cannot change things or make something possible (as discussed in the previous chapter), but also they practise this in order to bring peace to their life. Letting go (*ploywang*) is an important thing that the participants should do and they practise detachment by letting go (*ploywang*, laying down) duties, worries, needs, and connections such as children. That lets them feel relaxed and able to live their life with no worry about the future – in particular, if one day they pass away. However, prior to detachment and letting go, the participants have to try to finish their business for parents and children because they do not wish to make a burden for anyone else (discussed under the subconcept of "Living with awareness").

> Don't go and grasp things lest they become part of you, and don't hope too much [regarding the children's future]. As the children reach each stage of their life, they will change accordingly and eventually they can think for themselves. My responsibilities are to cook for my children and give them time with me… I release them and lay them down [*ploy*]… I urge them to decide for themselves [what they would like to be]... Each one has their own way of living and they can think for themselves… They must take responsibility for themselves. I have constantly prepared their mind [*jai*] for everything they may encounter, but I do not place my hopes too high for them (Pee Tim, 23 November, 2006).

Dhammananda (1993) said the Buddha went beyond the cycle of birth and death and came to an end of suffering. He was completely free from bondage after he realised that he had done everything that had to be done. When Pee Suk repeatedly says: "I think nothing. I don't worry about anything… Both in the past and in the future", it not only reflects that he focuses on now and the present moment but also it presents that he practises *ploywang* and lets go, which leads him to feel satisfied and happy with his life. The finding of practising letting go or *ploywang* (duties, worries and suffering) in order to gain a peaceful and calm mind is consistent with both the Buddhist way of living (Dhammananda, 1993) and findings from previous studies (Kruse, Heinemann, Moddy, Beckstead, & Conley, 2005; Schaefer, 1995). Kruse et al. (2005) claimed that the achievement of serenity involves being able to detach or separate oneself from suffering.

Lastly, living a simple lifestyle or self-sufficiency is the last way in relation with "living with *ubekkha*". Living a simple lifestyle or self-sufficiency is learning and adapting to living with sufficient support for basic needs and not wanting more than those basic needs – being happy with what they have. Some participants found that their happiness in life is obtained by living a simple lifestyle and living with self-sufficiency based largely on understanding the truth about life. They feel happy to have work, to be able to go to the market, and do cooking. They feel happy when they go to the beach, read religious books, read a cartoon book, watch television, or simply eat the fruit they like. They find happiness in nearly all activities that they do although those activities are very simple.

> Living simply and in a relaxed way, just the way I prefer (Pee Suk, 22 May, 2006).

> Whatever lifestyle I lead, let me have happiness – no problems, eat until I'm full, sleep well, with not too much mulling things over in my head so that I get problems coming in to strike me down. I like living quietly at home. When I have finished shopping for the meals, I come back home and prepare the food. In the mornings I read and do the housework carelessly and if I have no inclination for it, I stop. It's enough. I do not have to set my hopes high. If I am happy, then that is enough. There is no point in struggling (Pee Tim, 23 November, 2006).

> My way of living is I live my life very simply. I have a simple way, not thinking too much. If I am feeling lonely, I go to look at all the plants. They make me feel happiness [*sabuyjai*[22]] (Pee Porn, 03 September, 2006).

Pee Pang appeared to be very happy after her youngest daughter's good marriage and her subsequent departure from their family to live her adult life with security. She said that her only obligation now is to herself, especially to bring happiness to herself. When she has free time she goes to buy comic books to read and some fruit to eat and for a walk in the evening. During the day time she goes to work on a construction site. The work is very physical, but since she has worked in the construction business for a long time, she considers herself a skilled builder – mixing cement, lifting and transferring buckets full of cement – around the site and building roofs. Most importantly, her employer knows that she is a person living with HIV, but he treats it as a confidential matter. If Pee Pang needs a day off work, the employer understands and does not make it an issue. Although she now lives in a small house and shares this with a friend, rather than the big beautifully furnished house of the past, she feels contented and peaceful because she has enough. Her way of living is simple and peaceful as she said "everything seems settled and I want for nothing else" (Pee Pang, 28 August, 2006).

Living a simple life also includes learning to recognise what is sufficient for your needs. The Thai King's aim highlighted the importance of this recognition to remind people to live their life with simplicity while living well with their condition. A number of participants follow these suggestions and said "I have an appropriate amount of possessions and resources to live this kind of life". Once people apply these principles, they prove that happiness in life is not difficult to obtain.

> We know enough to do it. As His Majesty said, "If you know enough, you are OK". I mean, you can adapt and keep going, no matter what situations you are facing. Right now, we have this much money, we have to spend this much and this is how much is left over to save. This is adaptation – knowing how to adjust in order to embrace the challenges you face, and match yourself to the new reality (Pee Tim, 19 May 2006).

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[22] *Sabuyjai* is the state of mind where you are happy and relaxed

In addition, after the participants' minds have gained insight into the truth about life, they live their life with a simple lifestyle. This kind of happiness does not depend on material things, it depends on a mind that feels satisfied with what they have and who they are. Some of them perceived that their life is easier now than in the past. Another aspect of living a simple life style is not having high expectations. High expectations which sometimes mean false hopes cause a burden and difficulty in life (as discussed in the previous chapter). This is consistent with the Buddhist teaching of having duty, obligation or connection causing chaos. Therefore, some participants stop establishing burdens in their lives by stopping having children or not starting new relationships. Accordingly, the understanding that life is not permanent and, that everyone will die and when they die, they can not take anything with them assists participants in making the choice to live a simple life with happiness, doing the thing that they really want to do. However, this kind of understanding does not mean hopelessness and a life lived with difficulty. Rather they understand the truth, accept it and are satisfied with what they have, which is enough to live in reasonable comfort.

> I am not a person who tries to reach the unreachable. There is nothing that could make me afraid; it is almost unbelievable that I feel this way. I don't look for anything that is out of my reach. I hope for things that could be real [being realistic], taking one step at a time (Nong Keng, 11 April, 2006).

7.2.2.2 Living with awareness

The second subconcept in relation to the strategy "living with contentment" is living with awareness. Living with awareness means living life being careful – not careless. The participants described the positive outcomes of their illness that allowed them to reprioritise their life goals so that they were making the most of each day and living life with awareness. Living with awareness was influenced by understanding two situations. The first is that they live with the consciousness and accept that their life is more fragile and compromised. As well, the participants understand the changes that were happening to themselves and they know that their life is uncertain. One day they will deteriorate. "My health condition changes on daily basis" (Pee Porn, 03 September, 2006). Hence, those who do not want to depend on anyone, who do not have anyone to rely on them and who do not want to be a burden for anyone, have made cautious plans when they were approaching this last state of life (as discussed in the following section).

The second is that they understand the truth about life, in particular that death is the truth and everyone will face this. As well as thinking that their time of facing dying will come, it makes them live their life carefully and make a plan for life. Three ways of living were identified in relation to the subconcept "living with awareness": 1) finishing business for themselves in this life, 2) preparing merit for the next life, and 3) finishing business related to care of parents and children (as outlined in Table 7.1).

Finishing business for themselves in this life is the first way in relation to the subconcept "living with awareness". Finishing business for themselves in this life means focusing on taking care of themselves and having a careful lifestyle in order to live longer and more healthily – with less suffering. As one participant in the research finding of Balthip (1999) said:

> In preparing to live the life with care to avoid further sickness, we are afraid of repeated pain, we know that death is inescapable. But we know that we can escape from suffering, and minimise the level of pain. For example, if we live our lives carelessly we would possibly hurt ourselves five times while if we are a bit more careful we might only hurt ourselves three times. I don't want to feel the pain again, so I think I will do whatever stops the pain for me. Living the life without carelessness, trying to save the life, trying to extend the time to live with the ones I love and want to share my life with (p. 134).

Another aim of finishing business for themselves is doing their best to ensure that they will have less dependence on others. They do not want to make any burden for themselves or anyone else. This includes saving money and planning where they can live when they cannot take care of themselves.

Preparing merit for the next life is the second way in relation with the subconcept "living with awareness". Living with awareness, in particular preparing merit for the next life, was strong in participants who believed in the law of *karma* or the concept of *boon* (good *karma*) and *barb* (bad *karma*) and/or the result of (good) deeds and life after death. They had a strong belief that when the body dies, the mind will still remain alive. If people do merit, the mind (*winyarn*) will have happiness. Nearly all participants, both Buddhist and Muslim, trusted that the results of merit and sin will influence life because it will count in the next life. This is reflecting a common Buddhist belief that a person's past life (or past lives) can influence their current life (or future lives); either positively if lived well with merit or negatively if lived poorly. Some said "after we die, we can't take anything except merit". This belief led the participants to intend to do more merit to have a good effect on their future life. They hoped that the accumulated merit would have good results for them in both this life and the next life. Furthermore, when they realised that they had a limited time for doing good deeds in this life, some of them dedicated most of their time in order to do merit. This study's finding was supported by Barroso and Powell-Cope's (2000) study – a meta-synthesis of qualitative research on living with HIV infection.

Furthermore, some of the participants in this study found a strong connectedness within themselves that enhanced a strong commitment to live in order to gain merit. Living longer allows them to gain merit. They need to live as long as they can. Furthermore, gaining merit helps them have an inner peace, a calm mind and self-confidence.

> I try to look after my health the best I can with the hope that I will live long. I wish I will be in a good state of health forever… for myself… I do everything for my own benefit… I live for myself. When we are alive we can do merit. When we pass away [die], our souls remain. Trying to make merits as much as I can, however, I could only do it twice a month because I am engaged with something else [working]. I should search for happiness [real happiness], not by going out partying, but praying. Prayer gives me *kamlangjai*. It makes me feel stable [calm] [*jaisa-ngob*[23]], and increases my self-confidence (Pee Porn, 3 September, 2006).

Nong Boon, who is Muslim and has a strong belief in the life after death, reflected that he believed that "this life is not the real life but the next life is the real life". He has to do some good things, especially praying or *lamad,* because when he dies God will ask him what he did when he was a human-being. If he does enough *lamad*, God will send him to the good place. He has a strong belief that his good deed of doing *lamad* will

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[23] *Jaisa-ngob* means calm mind.

help him have a good life. Also, he has to rush to do *lamad* because he has a limitation on his life because of having HIV/AIDS. He said basically, God gave him a healthy body in order to do *lamad* but he has not practised in the past. Now, he has to do this before he dies, as he will receive a judgment after he dies. Some participants put more trust in merit because they observed the rewards of good deeds from their past experience. They trusted that good things had occurred in their life because of previous good deeds. The result of merit helped them to receive ARV drugs to live longer and so one day they may be cured from this disease. Having merit makes them healthy and not get sick and helps them live longer and not feel scared to die.

> I think, I am alive because of my good deed. My husband passed away two years after he [became] infected with this disease because he didn't do good deeds. I do merit. I maintain my *precepts*. I pray and meditate. I have discipline of *five precepts*. We should do a lot of good deeds. At least we should follow the *five precepts* (Maeche, 10 May, 2006).

The belief in life after death that leads to practising merit in order to accumulate the good deeds for the next life is based on the belief in the law of *karma.* Buddhism explained the law of *karma* as follows:

> *Karma* is an impersonal, natural law that operates in accordance with our actions. In the language of science, *karma* is called the law of cause and effect: every cause has an effect… In the *Dhammapada, karma* is explained in this manner: the mind is the chief [*forerunner*] of all good and bad states. If you speak or act with a good or bad mind, then happiness or unhappiness follows you just as the wheel follows the hoof of the ox or like your shadow which never leaves you… In its ultimate sense, *karma* means both good and bad, mental action or volition. *Karma* is volition… Some interpret this force as action-influence. It is our own doings reacting on ourselves. The pain and happiness man experiences are the results of his own deeds, words and thoughts reacting on themselves. Our deeds, words, and thoughts produce our prosperity and failure, our happiness and misery… Buddhists believe that man will reap what he has sown; we are the result of what we were, and we will be the result of what we are (Dhammananda, 1993, p. 87- 89).

Moreover, some participants hoped they would be reborn in another form such as not being born as human beings, rather born with another form that is free from suffering, which is a reward for paying *karma* and living a life with merit. It links with the Dharma teaching in the concept of *nirvana* (Dhammananda, 1993; Hanh, 2004). Dhammananda (1993) stated that the Buddha teaches people to understand the whole universe as a system of *karma* and *rebirth*. He teaches people to understand the nature of suffering, the cessation of suffering and the *Path* that leads to the cessation of suffering called the *Four Noble Truths*. The Buddha claimed that whoever constantly practises this way of teaching will go beyond the cycle of birth and death and will make an end of suffering and gain peace or attain *nirvana*. Attaining *Nirvana*, freedom from suffering, is the major goal of Buddhists. The Buddhists believe that achieving freedom from suffering or *Nirvana* is a very difficult task (Tongprateep, 2000). The participants were attempting to perform religious rites such as making merit, making donations, and doing meditation to store up (accumulate) the positive *karma* in the hope of being free from suffering and having happiness in the next life.

In addition, when the participants feel confident that they have enough merit they are not too afraid to die although death is coming soon. They live their life with happiness in this life, and feeling relaxed to face their dying and death. This is not only because they would not be separated permanently from their loved ones, but also they hope that their life will continue (in a different form) and their life after death will be better than this life because of their good *karma*. As a result, they felt brave about facing death and dying. This was supported by findings from previous studies which have been conducted in the Thai context. Tongprateep (2000) studied the essential elements of spirituality among rural Thai elders and illustrated that the participants believed in the *law of karma* and life after death. They hoped that if they accumulated meritorious acts in their lives, they would get good results both in this life and the next life. After they practice meritorious acts, they felt relief from fear, anxiety, and disappointment in life. Rather they felt satisfaction (in life) and had peace of mind.

Lastly, finishing business related to care of parents and children is the last way in relation to the subconcept “living with awareness”. Another concern of the participants is finishing off business and preparing some essential things for parents and children who will survive. The participants have two important roles: the children’s role of taking care of their parents and the parents' role of taking care of their children. Caring for parents or showing gratitude is an important task that is embedded in Thai people (as discussed in Chapter Five). Therefore, many participants have planned to finish their business for their parents. For instance, they make arrangements for someone to care for their parents if they (the participants) are not able to do this.

Another duty is finishing their obligations to their children. A number of participants were planning for the future of their children and raised their concerns about saving money for their children. One of them suggested that her children would need to save money for their own future. This is because they want to feel reassured that when they are not around, their loved ones will be able to continue to live and grow up. Then, they have happiness and are free from any duty and worry. This is also associated with practising detachment (as discussed). They can welcome death and die with "eyes closed"[24]. They also try to avoid making a second mistake, because now is the second chance for them to prepare and do something to reach their life goal after they have overcome the problems caused from having their life turned upside down by HIV/AIDS. Nong Rin is one example of a person living with awareness. She has prepared the essentials for both the person who will take care of her daughter and property for her daughter who is seven years old. After she finished this business, she felt confident that if one day soon she dies, her daughter can survive and that makes her feel relief when thinking about death.

> My only hope is that my daughter has a beautiful and convenient life. I have done everything for her. I bought property and land for her. I think the property that I have is enough for her. It is enough to make her life have happiness. If one day, I die, I am pretty sure that she can survive because she also has her grandparents. They looked after her when she was young because when she was young I had to work in another place and her grandparents took care of her… It makes me confident and sure that if I'm not here [die], my daughter will survive (Nong Rin, 23 March, 2006).

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[24] "Eyes closed" is a metaphor that is often used in the Thai context for people who die free from worry. Thai people often say that they will die with their eyes closed. By contrast, one who has worry will die with open eyes.

Living with awareness is also shown when the participants stopped doing everything that they could not finish by themselves while they are alive. For instance, some participants decided not to have children because they understand that everyone will die, and maybe they will die before their children grow up. Therefore, they show living with awareness by not having children that can be a cause of suffering or the cycle of *tukjai* for both the parents who die while their children are young and the children because they lose their parents. One of the main concerns for preparing to finish business is the worry that the participants in this study do not wish to be a burden for anyone. Some are very concerned about this. They perceive that others have enough of their own duties and that they had already helped by caring for them in the past when they were sick. This concern is also associated with the sense of *metta* and *karuna* (discussed in the following section).

7.2.2.3 Living with loving kindness (*metta*), compassion (*karuna*), and altruistic joy (*muthita*)

The last subconcept in relation to the strategy "living with contentment" is living with loving kindness (*metta*), compassion (*karuna*), and altruistic joy (*muthita)* which are found in the participants who live their life concerned not only about themselves, but also they showed care and concern to others. They intend to help others. They feel appreciative when they see others have happiness. This way of living transpires and is upheld with an underpinning of the feeling of fulfilment in life that enhances long lasting happiness, peace and serenity. Some participants value the HIV/AIDS as a way of opening a chance for them to help people that bring the feeling of fulfilment in life. As Pee Ning said, she lost many things after having HIV, but she received something in return that is a feeling of fulfilment in life as she said she feels fulfilment as if her heart is enlarged when she does a good thing for others. A number of participants have a commitment to live and they intend to help others. This group of people is sustaining their peace and do not often go back to the cycle of *encountering distress* (as discussed in Chapter Four).

There are several ways of presenting loving kindness (*metta*), compassion (*karuna*), and altruistic joy (*muthita*) that lead to achieving peace. For instance, they are practising meditation, prayer or *lamad*, temple attendance, doing merit, helping others, avoiding destruction of others by both physical and psychological means such as jealousy and thinking badly. They do not blame anyone. They do not kill animals, do not hurt, and do not feel angry towards anyone. They are also concerned not to spread this disease to others. Additionally, someone practises forgiveness, provides food for monks and others, donations and some become monks. For Thai culture and Buddhism, entering the monkhood is a way to do a good deed for Buddhist men. So a man becoming a monk is counted as doing a good deed for his parents (Tongprateep, 2000) and for themselves because in doing good for their parents, they will receive back with huge merit in return.

Some other ways are teaching children to do merit and sharing merit for others, and advising others to show gratitude to their parents, as one of the participants – Maeche – suggests (see following quotation) because they trust that making merit brings peace to life and they need the one that they love to obtain happiness in life. They feel fulfilment when they see others having happiness – *muthita*.

> Today, I donated lots of sand for the temple. I feel a calm mind when I do merit. The day before, I provide food for monks, I feel happy to do that. I use both my money and my son's money. If I use the money that my son gave me, he will receive this merit too (Maeche, 10 May, 2006).

Although there are many ways of presenting "living with kindness (*metta*), compassion (*karuna*), and altruistic joy (*muthita*)" (as illustrated above), three most common and essential ways were identified: 1) meditation and/or praying, 2) practising altruism and helping others, and 3) practising forgiveness as outlined in Table 7.1.

Firstly, meditation and/or praying are the first way in relation to "living with kindness (*metta*), compassion (*karuna*), and altruistic joy (*muthita*)". Meditation not only helps to achieve a certain state of mind (as discussed) but also helps gain a sense of *metta* and *karuna* and prevents people from committing sin. When people are doing meditation or prayer, they do not think bad things or think bad of anyone; rather, they can stop their thinking when they think badly and enhance the way of thinking well.

> While I can live in this world, I ask myself what I should do to improve my life. I forgot this disease [HIV]. I only know that I should do good things [pray or

> *lamad*] while I am alive. Muslims should *lamad* five times a day. If I do *lamad*, it can stop me doing bad things. *Lamad* helps me to stop sinning (Nong Boon, 11 March, 2006).

> When start to say a prayer, a strange but positive feeling occurs, the feeling of joy and happiness. The prayer restores strength and it is comforting my mind. It make me *ploy* of hearing what people say [gossip]… I don't take it seriously. I feel relax. Never mind… (Pee Porn, 03 September, 2006).

Pee Kid realised the link between body and mind that if he has a calm mind and healthy body, he will get the maximum benefit. He gains a calm mind and healthy body from meditation. As he said "Our bodies have comprehensive mechanisms which each of them connect to each other… The connection is to maintain the continuity of our life. The calm mind and balanced body maximize the ability of its mechanisms". Meditation assists a person in finding happiness and satisfaction in life (Sarter, 2002). Practising meditation and praying are other ways important for healing because they facilitate the journey of self-exploration and self-healing (Chang, van Servellen, & Lombardi, 2003; Sarter, 2002). Similarly, Meraviglia (2002) reported that prayer is an activity of the human spirit to communicate with God that was related to a person's health status. Weaver, Vane, and Flannelly (2008) conducted a review of the literature on Buddhism and health and found an increase in their relationship. In particular, positive relationships with health have been found for two kinds of Buddhist meditation: mindfulness meditation – a detached observance of one's mental functioning and environment, and *vipassana* meditation – practise for cultivating compassion and awareness.

Secondly, practising altruism and helping others as well as not hurting others is the second way in relation to "living with kindness (*metta*), compassion (*karuna*), and altruistic joy (*muthita*)". It includes practising every kind of unselfish behaviour such as giving donations and sharing. When the participants dedicate themselves and act *metta*, and *karuna* to others, they feel fulfilment in life that brings happiness to them. Having happiness and peace in life is a reward derived from helping others. It is like a kind of fuel that makes the participants continue their life with happiness.

> After participating in the activity [working as a volunteer], from not having any idea about medications, now I have got some knowledge of how to use ARV drugs. If someone has a symptom, I would know what it is, how to prevent its recurrence... It has been nine months since I joined this volunteer work. After returning to live in my hometown, and starting to work, the benefit in terms of money is not great, but it [volunteer work] makes me happy to have the chance to take care of others… I have come across a lot of occasions which made me feel happy (Nong Moo, 22 April, 2006).

One main reason that makes the participants repeatedly voice their desire to help others – in particular, people living with HIV/AIDS, all of whom they perceive as their friends – is that they hope to prevent HIV/AIDS in others and decrease the severity of HIV/AIDS including stigma. Some of them said that they would not wish such a fate on anyone. One participant gave the metaphor of showing of *metta, karuna* and *muthita* by helping others, as a person who holds the candle to shine into another's life to walk through their barrier. One of them said she felt like an angel, although she lived with HIV/AIDS, after she helped others including her present husband. Pee Ning, who has a lot of experience and volunteers and works at the hospital, finds her value either from her family members or her HIV/AIDS friends. She expresses her feeling of becoming a refuge for others which increases her will to live and enhances the feeling of fulfilment in her life.

> Being able to support and give shelter to other people makes me feel good. As I told you I can't die, not now anyway. I still have several people who need my help. This strengthens my will to battle the sickness. I have to fight… If we are sick we have to build up our willpower and fight against hardships... can't weep. The courage is built up from inside…can't give up… feeling tired, have a rest and when feeling better, go back to work (Pee Ning, 13 March, 2006).

Both positive and negative experiences – in particular, a difficulty in life – may possibly help the individual move beyond just a concern for himself or herself towards a wider perspective and concern for others. Additionally, if people follow *metta, karuna* and *muthita* the positive benefit helps not only them to feel peace, but also their social group can receive this outcome. Reeves et al. (1999) did a study on the adaptation by a group of participants younger than 45 years which depicted that in the period of living with HIV, altruism was the most prevalent coping strategy used by participants. Furthermore, helping others not only brought calm, peace and fulfilment into their life, but also the by-product of helping others can minimise the stigma of having HIV/AIDS.

Practising forgiveness (*ahosikarm*[25]) is the last way in relation to "living with kindness (*metta*), compassion (*karuna*), and altruistic joy (*muthita*)". Fenwick (2009) claimed that "forgiveness can be defined as ceasing to feel angry or resentful towards those who hurt you" (p. 174). Forgiveness involves a person strengthening his/her identity, which leads to a change in mental content, then the person thinks more positive thoughts which lead to a reduction in stress and allow healing. Practising *ahosikarm* both presents a sense of having *metta,* and *karuna*, and rewards individuals with a calm mind because they can let go (*ploywang*) of their suffering or angry feelings toward someone or something. Those people whom they forgive will be free from their *karma* in respect of bad things which they have done to them in the past. At the same time, they do not have to bear a grudge against anyone. Furthermore, some of them trust that if they show forgiveness to someone who used to hurt them, that person will not be able to hurt them again either in this life or the next life. They are free from any harmful connection to each other.

Maeche, Pee Porn and Nong Nid are practising forgiveness toward their partners who infected them with HIV, toward the persons who think negatively of them or blame them and toward everyone in the world – even those who have already passed away –in order to feel calm and peaceful. Pee Porn has often practised forgiveness during the past three years since she has been attending the Buddhist temple and doing merit. Pee Porn's consistent calmness and happy well-being show. Now she totally accepts her HIV situation and lives accordingly: independently, contributing positively in a generous and gracious manner in all her community interactions (despite frequent gossip, prejudice, and discrimination).

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[25] *Ahosikarm* means forgiveness or reconciliation. It occurs when people need to forgive someone who has hurt them or made them feel suffering. It is the way to let go the suffering.

> If we come across bad persons we should bless them to forgive them. I pray and send mercy for them, I feel good. I also do merit and share my merit with people who behave badly towards me… I just keep praying for them. I don't feel angry with them (forgiveness) (Pee Porn, 03 September, 2006).

> On my days off from work, I go to temple nearby my house. I go there to offer food and goods to monks, just do it on my free time. What I do makes me happy, I pray for the dead who do not have relatives, and for those people who continue talking negatively about me. I pray to forgive them. It really makes me feel better (Pee Porn, 03 September, 2006).

The living with loving kindness *(metta),* compassion *(karuna),* altruistic joy *(muthita)* and the purpose of doing good deeds for others without any expectation of reward as the participants present is consistent with the four Buddhist virtues. The first is *saddha*. A person should have faith and confidence in moral and intellectual values. The second is *sila*. A person should stop destroying and harming life, from stealing and cheating, from adultery, from falsehood, and from intoxicating drinks. The third is *caga*. A person should practise charity, generosity, without attachment and craving for wealth; that is congruent with the teaching in Islamic religion. The last is *panna*. A person should develop wisdom which leads to the complete destruction of suffering, to the realisation of *nibbana* (Dhammananda, 1993). Having a belief in a religious doctrine provided some participants with a means to reclaim their sense of who they were. This helps them achieve harmony in life; they have a stable state of mind, and they cannot be upset by gain or loss.

Although Buddhists and Muslims use different words and different ways to guide people to do good deeds rather than being selfish, both religions teach people to do good deeds and they both trust in rewards for doing good. Also, religious practices such as meditation can reduce stress and suffering as well as prevent the onset of disease and enhance peace. After the participants recognised the truth about life, they understand what is really necessary for their life and what they really want as human beings in order to enable them to live their life with calmness, peace and harmony, then they live their life with contentment (living with equanimity, living with awareness, and living with loving kindness, compassion, and altruistic joy).

7.2.3 Discovering an Ultimate Meaning in Life: achieving peace and harmony or *kwarmsa-ngobjai*

This concept presents the consequences of the conditions and the actions/interactions (strategies) that constitute achieving peace and harmony or *kwarmsa-ngobjai* that leads to living well and dying well[26]. The participants understand and realise which things bring them pleasure, peace and harmony and what cultivates their mind to gain peace and develop. As many participants said, everyone needs happiness and peace in their life. By living life with contentment such as being selfless (*nonself*) and/or less selfish, by dedicating time in life to do good deeds (as discussed), peace comes as a result of having consideration towards others. It illuminates the way for participants to cross from a world of darkness, hatred, and suffering to a new world of light, love and happiness (Dhammananda, 1993) or serenity or *kwarmsa-ngobjai*.

> Nowadays, I don't care much about how other people [how they think about me]. That's because of the calm of my mind (Pee Porn, 03 September, 2006).

Some participants obtain *kwarmsa-ngobjai* – that is the ultimate goal of life – after being diagnosed with HIV. Some of them reported that they feel satisfied and feel calm more now than in the past before they became infected with HIV/AIDS. They also found it easy to make friends with others (who need to make friends with them). They are not concerned about how rich they are, rather they value their friendship and they realise that friendships are more valuable than material things. They realise how important people are both for themselves and for others.

> I am an easy-going person who gets along well with everyone. I personally think we are all the same... no competition... Living a moderate life... No gossiping, no blaming, no arrogance (Pee Suk, 22 May, 2006).

This perspective is consistent with the concept of *nonself* in Buddhist teaching (Dhammananda, 1993; Hanh, 2004). Buddha said that component things are

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[26] Living well and dying well. Living well means living life with happiness and not feeling scared to die. Dying well means they feel relaxed when death is coming because they have no, or less, agony in this life and also they prepare their property that is merit (good deeds) for the next life. These help the participants to live with HIV infection in peace, which is an ultimate purpose in life.

impermanent and human beings are impermanent, unstable, not to last, compassed about with a self (Dhammananda, 1993). This is the nature of the concept of self that leads to the ending of a self or *nonself*. Once people feel free from self, they understand that nothing belongs to them – rather, they understand that everything *is* them. They also understand that everyone has their own value and is important. They have to have interrelations with others. As a consequence, they have fewer egos or *nonself*. The participants learnt to detach or *ploywang* some worries or duties (after they have done their best). Finally, they will gain the feeling of fulfilment in life associated with immunity. The increasing level of immunity promotes physical health and that prolongs their life and provides them with more opportunity to do more merit that continues to enhance their happiness and feeling of fulfilment in life and satisfaction in life.

This is consistent with Meraviglia (1999) who said that general well-being reflects a personal satisfaction with life. Then finally, they live with happiness and serenity or *kwarmsa-ngobjai*. Kruse et al. (2005) claimed that the serene person is the person who has the ability to cope with life by attempting to change negative situations; by contrast they can accept situations that they know they cannot change. For example, they understand that they could not change the negative thinking of others toward them, thus, they only *ploywang* or accept it. As a result, all participants understood and accepted that they are living with HIV/AIDS and understood that the disease has changed their lives. Some changes result in positive circumstances. Most importantly, it has helped them to create their peaceful mind (*jai*). Some participants know how to incorporate peace, harmony and happiness into their life. For instance, being concerned with people and good things beyond themselves enhances serenity or a peaceful mind, meaning that the mind is settled, not swinging – that augments the immunity of their mind. Although HIV/AIDS still lives in their bodies, it is the same as a shadow; it cannot eradicate them once they achieve a peaceful state of mind. The mind can not be harmed by any intruding feelings, or circumstances (i.e. obstacles, problems, sadness, sorrow, grief). They gain both living well and dying well. They acknowledge their suffering and that they had a positive change which occurred after the diagnosis in both outlook and values – and, as well, material values declined in importance for them.

These results are consistent with those in previous studies in which it has been acknowledged that illness enables people to have the feeling of personal growth and is a way of spiritual growth (Harrison, 1997; Moser et al., 2001; Siegel & Schrimshaw, 2001). Therefore, Sarter (2002) concluded that, "life-threatening illness forces a person to anticipate the severing of attachments, the bowing down of the ego, and the abandonment of desires" (p. 37).

Finding peace is a lifelong-process. Although some people cannot achieve it, some can reach this ultimate goal of life. As Dhammananda (1993) stated Buddha revealed that not everyone is expected to attain the same goal in one lifetime, since the mental impurities are deeply rooted. Some people are spiritually more advanced than others and they can proceed to greater heights according to their state of development.

7.3 Conclusion

In this chapter I have revealed another pathway of the life journey. As a consequence of understanding the truth of life, the participants changed their way of living by living with contentment, they gained a stable state of mind and the sense of living well and dying well. Most participants value the calm mind that makes them feel that they are in harmony with their situation. They also gain insight and have wisdom that a peaceful mind is the thing that they really want in their lifetime. From their experience of living with HIV/AIDS, they realise that the people who have a calm mind live longer than those who do not. Therefore, they suggest that people who have this disease should stay calm. All people have the ability to reach the feeling of being calm and peaceful or *kwarmsa-ngobjai*, even if they are poor in terms of material possessions. However, in this study I have found that not all participants had yet reached the level of peace and harmony or *kwarmsa-ngobjai*.

CHAPTER 8

Achieving Harmony of Mind

8.1 Introduction and Overview of the Study

This study aimed to understand the meaning of spirituality and the process of spiritual development in people who have lived with HIV/AIDS for five years or more. The intention to explore notions of spirituality in the context of HIV/AIDS was based on the characteristics of HIV/AIDS causing a severe life-altering event (Moser et al., 2001) that is likely to evoke spiritual distress. HIV/AIDS has been perceived as a cause of death, and is a deeply stigmatised disease that results in significant distress. However, many studies and my experience from my master's thesis showed that some people living with HIV/AIDS are able to live and gain peace and harmony in their lives despite living with HIV/AIDS.

In the Thai context, where Buddhist teachings underpin the understanding of life as body and mind, the Western term *spirituality* was not likely to be clearly understood by participants. Thus broad questions about living with HIV/AIDS enabled me to inductively derive an understanding of what might enable lay people living with HIV/AIDS in the Thai context to find peace and harmony in their lives; and subsequently to explore how those findings might relate to the meaning of spirituality and spiritual development in the Thai context, on which topic little work has been done.

This study found that the essence of life and the key factor in living life is "self". Self is composed of the "body" (*guy*) and the "mind" (*jit* or *jai*). Most participants who are Buddhist understand that life is the balance between the mind and the body. This is supported by Weaver et al. (2008) who argued that Buddhism emphasised a balanced interaction between the mind and the body. The finest condition of health is accomplished when mind and body are functioning well and interacting together as one. Illness emerges when this balance is disturbed. Thus, Buddhist practices aim to restore and strengthen the integration of mind and body. In particular, the mind plays a significant role in enhancing peace and harmony because everything depends on the mind (as discussed in Chapter Six). Buddha admired the power of mind. He knew that understanding of *the noble truths* can be developed by training the human mind (Dhammananda, 1993).

In the previous four chapters, the two categories and four subcategories that build toward the phenomenon of **Achieving Harmony of Mind** for people living with HIV/AIDS in the Thai context were explained and discussed. In this chapter the substantive theory, **Achieving Harmony of Mind**, which has been generated from dialogues with participants who have lived with HIV/AIDS in the Thai context for five years or more, is further explained by outlining the theory components and assumptions. Then the research findings about development of the mind are explicated using the metaphors of an eclipse to represent the stages of development and a padlock to represent a locked mind. The extent to which the study findings about the development of mind are supported by published literature about spirituality and living with chronic or stigmatising illness is also explored in this section. The similarities and differences between Western and Thai understandings of spirituality and spiritual development are articulated. Lastly, the limitations and implications of the study are discussed.

8.2 The Substantive Theory: Achieving Harmony of Mind

Achieving Harmony of Mind has been developed through Straussian grounded theory (as discussed in Chapter Three). Some authors (e.g. Meleis, 1997; Strauss & Corbin, 1998) stated that theory is a process of well-developed categories that are systematically interrelated through statements of relationship to form a theoretical framework that explains some phenomena. Theory is discovered for describing, explaining, or predicting events, situations, conditions, or relationships. Theory consists of concepts and positions about the relationship between concepts that are related to the phenomenon (Chenitz & Swanson, 1986).

Chinn and Kramer (1995) identified four processes which are involved in the development of a theory. These are congruent with the process of theory development that was suggested by Strauss and Corbin and illustrated in Chapter Three. The first is the process of creating conceptual meaning that identifies, examines, and clarifies the concepts within theory (open coding – Straussian grounded theory). The second is the process of structuring and contextualising theory that organises the relationships between and among concepts in a unique, creative, rigorous, and systematic way (axial coding – Straussian grounded theory). The third is the process of generating and testing theoretical relationships (selective coding – Straussian grounded theory and under "Establishing research trustworthiness") that involves three components: "1) empirically grounding emerging relationships, 2) explicating empiric indicators, and 3) validating the relationship through empiric methods" (p. 27). The last process of theory development as suggested by Chinn and Kramer (1995) is deliberately applying the theory using research to evaluate the effect of a theory in achieving the goals of nursing practice. Although the substantive theory **Achieving Harmony of Mind** has not been tested, such application could be done in the future.

The substantive theory **Achieving Harmony of Mind** is composed of two main categories: **struggling to survive** and **living life**. There are also four subcategories: *encountering distress, overcoming distress, accomplishing harmony in oneself,* and *discovering an ultimate meaning in life*. Each subcategory consists of the relevant concepts that are assigned to "conditions", "actions/interactions (strategies)", and "consequences", which are outlined in Table 8.1 and have been described in Chapters Four, Five, Six and Seven respectively. All together, the concepts have the ability to describe the phenomenon of the development of the mind – **Achieving Harmony of Mind** – which includes the meaning of spirituality and spiritual development of people living with HIV/AIDS in the Thai context. The substantive theory **Achieving Harmony of Mind** is composed of four theoretical components: the person, the others, the acts, and the environment.

The person or self is a social object that is constantly changing according to social interaction. In this study, person refers to the participants who have lived with HIV/AIDS for five years or more. Person or self is composed of two main aspects: the body and the mind. The mind plays a significant role in promoting peace and harmony while living with HIV/AIDS because the interpretive process is undertaken in the mind through social interaction with both themselves and others. Over time, the individuals' mind view of the situation of having HIV/AIDS changes; therefore, their interpretation is also different: "HIV/AIDS is life threatening or life altering", "HIV/AIDS is challenging", "HIV/AIDS is controllable" and "HIV/AIDS is neutral".

Table 8.1: The conditions, actions/interactions (strategies), consequences, subcategories, categories, and core category

Conditions	Actions/interactions	Consequences	Subcategories	Categories	Core Category
HIV/AIDS turned life upside down 1. HIV/AIDS causes insecurity, uncertainty, and hopelessness 2. HIV/AIDS erodes sense of self and leads to feeling inferior 3. HIV/AIDS causes multiple losses	**Reactions & responses to manage it** 1. Reactions to distress 2. Ways to manage the situation of having HIV/AIDS	**Being unwilling to live** 1. Planning for dying 2. Living life with lethargy	Encountering distress	**Struggling to survive**	**Achieving Harmony of Mind**
Promoting conditions 1. Feeling relief of mind 2. Selective disclosure of HIV status	**Finding meaning and purpose in life** 1. Searching for connectedness 2. Receiving love and support (*kamlangjai*)	**Obtaining *palangjai* or a will to live** 1. Having a sense of self value 2. Gaining a strong mind	Overcoming distress		
Understanding & accepting of illness and oneself 1.Understanding and accepting the illness 2.Understanding and accepting oneself	**Being kind to oneself & one's mind** 1. Being joyful 2. Avoiding negative situations 3. Building a new "personal" world 4. Practising a careful life style 5. Having discipline in life & being proactive in care	**Feeling free from HIV/AIDS** 1. Gaining power of mind in control of HIV/AIDS 2. Having hope in living	Accomplishing harmony in oneself	**Living life**	
Understanding and accepting the truth about life 1. Nothing is permanent 2. Being born as a human being causes suffering, and death is the end of suffering 3. Life is/has no ending	**Living with contentment** 1. Living with equanimity (*ubekkha*) 2. Living with awareness 3. Living with loving kindness (*metta*), compassion (*karuna*), altruistic joy (*muthita*)	**Achieving peace and harmony or *kwarmsa-ngobjai***	Discovering an ultimate meaning in life		

The others in this theory refer to all people or things with whom the participants have a relationship and influence the participant's life. They include: 1) people such as partners, children, family members, neighbours, friends, health professionals, health volunteer, and monks, 2) nature such as plants, and 3) supernatural beings such as God, Lord Buddha, and ancestors. Many times, others have a strong influence on the mind of participants. They both act as promoting and inhibiting factors. For instance, the support from mothers helped the participants overcome their life crises. At the same time, the expression of less respect or discrimination from family members causes sadness and suffering for the participants.

The acts are the actions/interactions (strategies) that the participants use in facing life crises, overcoming life crises and finding peace and harmony while living with HIV/AIDS. The acts sometimes develop within oneself, such as self-love or self-connectedness, and sometimes build up from the interaction with others, such as receiving love and support. There are a variety of actions/interactions that are identified and have been discussed in Chapters Four to Seven. Each action/interaction (strategy) plays its role and is used at a different time or situation. Each participant employs different strategies and reaches different stages in the development of the mind.

The environment is viewed as being in constant change, as is the interaction process between the individual and the environment (Jensen & Allen, 1994). There are varieties of environments that both promote and inhibit the process of development of the mind of people living with HIV/AIDS in the Thai context. HIV/AIDS is the permanent environment and makes a significant change in the life of all participants because HIV/AIDS causes stigma and discrimination that remains in the Thai context. However, nowadays, one aspect of having HIV has changed; what was once a death sentence is now a chronic illness through the advantages of medical treatment. ARV drugs are available, but HIV/AIDS is incurable. Thus, the changing of the environment affects the person. Environment includes religious background, beliefs and culture. Culture can influence one's beliefs, values, and attitudes (Jensen & Allen, 1994). In this study, the environment, such as Thai culture and religion, has a strong influence on the people and their minds. For instance, religious doctrines – Buddhism and Islam – play a significant role for people living with HIV/AIDS in gaining peace and harmony of mind. Some reactions from society, such as social disgust, may demolish the self-confidence and feelings of acceptance and security because HIV/AIDS is a social disease and can cause social stigmas.

In this study, four assumptions are described in relation to the substantive theory of **Achieving Harmony of Mind**. Firstly, participants have their own way of perceiving, interpreting, and acting/interacting with the situation or environment. Secondly, the severity of the situation or condition depends on the evaluation or interpretation of the mind. Thirdly, all participants have the capability to achieve harmony of mind, although each participant reaches different levels of harmony. Lastly, the process of **Achieving Harmony of Mind** is dynamic and is never completed. This is because human beings are "open systems".

In the following section the research findings about development of the mind are further explicated using the metaphors of an eclipse to represent the stages of development and a padlock to represent a locked mind. The extent to which the study findings are supported by published literature about spirituality and living with chronic or stigmatising illness is also explored in this section.

8.3 Development of the Mind

Achieving Harmony of Mind while living with HIV/AIDS, as shown in Figure 8.1, is the phenomenon that explains an evolving state of mind of people living with HIV/AIDS that moves back and forth between stages. The eclipse model illustrated in Figure 8.1 is employed to further explain the development of the mind and the discussion that follows draws upon Buddhist understandings of the mind as outlined in Chapter One. When individuals are disturbed by the stimulating factors of their HIV/AIDS diagnosis and its consequences, the mind would begin to interpret the information received before responding to and confronting the situation. The data processing of an HIV/AIDS diagnosis and its consequences occurs in the mind. If the mind interprets HIV/AIDS as a fastened padlock, obstructing one's normal living, it would try to regain its freedom by searching for the ways to unlock the situation. This process produces a range of results starting from the severe suffering of mind (*tukjai*) to a peaceful mind (*kwarmsa-ngobjai*) depending on additional factors (conditions and actions/ interactions – strategies) for one encountering this journey (see Figure 4.1).

These factors have been described in Chapters Four to Seven. However, even when a fastened padlock is released, meaning one's mind regains its strength and freedom, another challenging situation may 'relock' the mind. Thus, the process of unlocking will re-start. In other words, the data processing that occurs within one's mind is continuous. At times, many processes of interpretation occur simultaneously in the unsettled mind. The stages of development may occur in linear or random order and/or simultaneously. The mind may return to a stage that they have already experienced and then climb forward again. It depends on the interpretation of the mind and the conditions, actions/interactions that facilitate the process.

This study has unveiled that different promoting conditions and strategies enhance the different interpretations of the mind and lead to differing states of the mind – "distress or *tukjai*", "challenge", "control", and "neutral". Figure 8.1 demonstrates the four stages of development of the mind in relation to **Achieving Harmony of Mind** in participants who are living with HIV/AIDS: 1) distress of mind or *tukjai*, 2) recovery of mind, 3) stability of mind, and 4) having peace and harmony of mind (*kwarmsa-ngobjai*).

8.3.1 Distress of mind or *tukjai*

The first stage of the development of the mind is called "distress of mind or *tukjai*". The first circle in Figure 8.1, painted in jet black represents an individual's mind which is overshadowed by a diagnosis of HIV/AIDS and its consequences. During this process, the mind views HIV/AIDS as an enemy. The individual perceives that their life is now turned upside down and has been torn apart. They are pessimistic about finding a possible way to unleash themselves from the shadow of the disease. This occurs when the mind interprets the diagnosis of HIV/AIDS and its consequences as a deadly life threatening factor, because HIV/AIDS causes insecurity, uncertainty, and hopelessness; erodes the sense of self and leads to feelings inferiority (social disgust and social stigma); and causes multiple losses. The consequence is that the well-being of the mind is eroded. In some cases, this consequence leads the person to feelings of being unwilling to live (as discussed in Chapter Four).

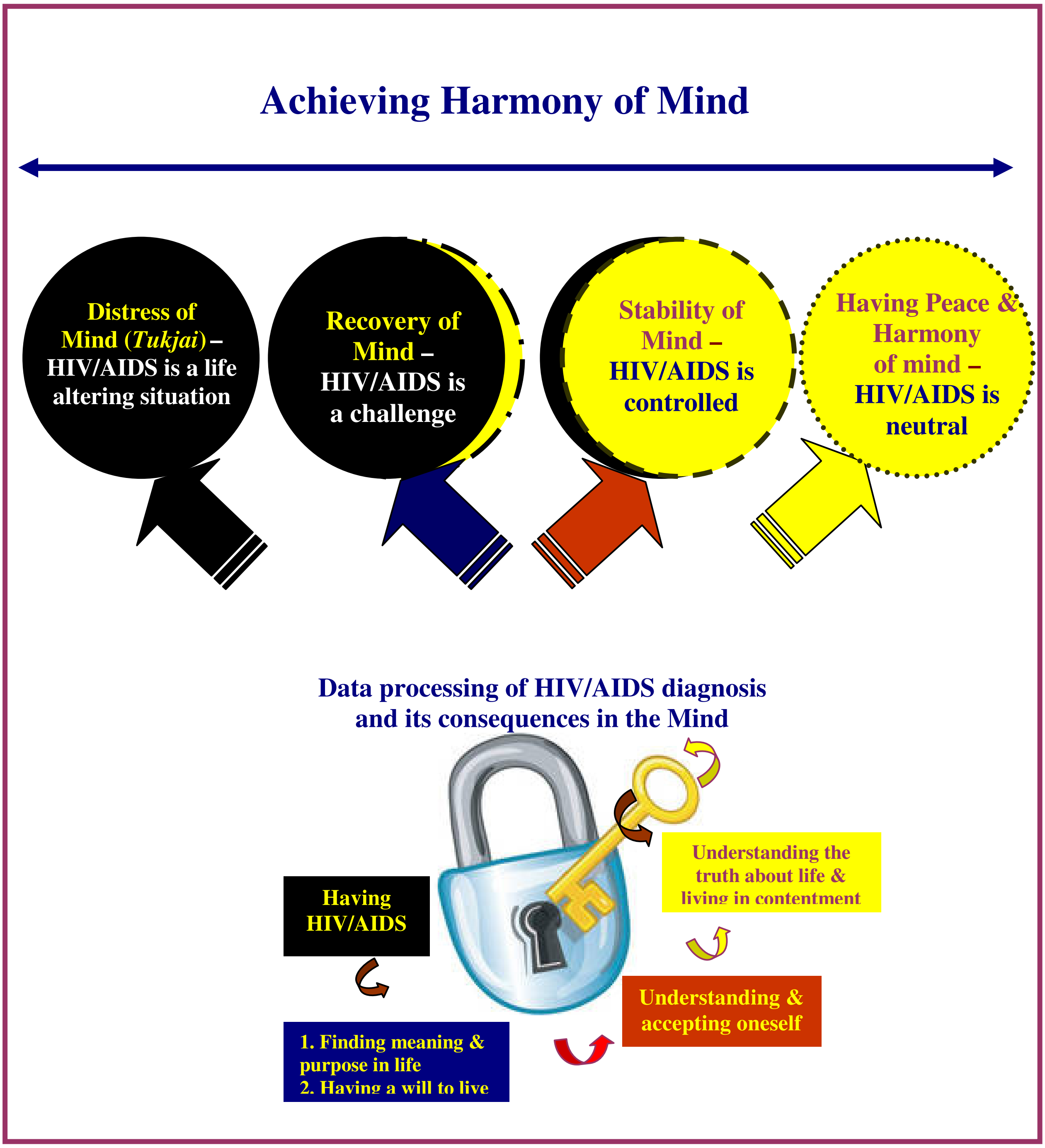

Figure 8.1: The process of Achieving Harmony of Mind: 'Eclipse model'

These findings are supported by evidence from other studies that AIDS is viewed as causing death (Portillo et al., 2003; Songwatthana & Manderson, 2001), and that the toxicity and side effects of drugs (Schaefer, 1995) lead some people with HIV/AIDS to view the disease as terminal (Hoy-Ellis & Fredriksen-Goldsen, 2007). People also have to deal with the shame and stigma of the diagnosis (Crawford, 1996; Nilmanat et al., 2006; Mak et al., 2006; Mak et al., 2007); and with the risk of encountering "social disgust" (Nilmanat et al., 2006; Siriwatanamethanon, 2008). One of the most important factors is the feeling of insecurity that emerges from such stigma and discrimination. They feel unsure of how normal people will perceive them and this is associated with inferiority (Goffman, 1963). Feeling inferior is an obstacle in continuing relationships with others and leads to an increased feelings of alienation. This results in more changes in relationships between one's self, others and their environment (Jensen & Allen, 1994). Another main cause of distress is the experience of loss. People living with HIV/AIDS may be faced with multiple losses such as loss of joy, self-respect, and potential parenthood. This is compounded with gradually losing one's health status, having to start medication and the manifestation of opportunistic infections. The unpredictabity of the disease produces uncertainty, insecurity and fear, leading to some patients voluntarily restricting their lives more than they need to. The consequences of these restrictions have many negative effects on patients' lives and these effects are related to the loss of sense of self (Charmaz, 1983).

The distress of the mind or *tukjai* which is found in the first stage of the development of the mind is similar to the phase of 'extraordinariness' that was found by Kralik (2002) in a study of women with chronic illnesses. In this phase, Kralik found that after the diagnosis of a chronic illness, women felt alienated from familiar life and felt a loss of control over their life circumstances as well as feeling different from others. In addition, the distress that participants in the current study reported, such as being unwilling to live – planning for dying, living life with lethargy and lacking motivation to live – is similar to the concept of spiritual distress that was described by Villagomeza (2005). She argued that a spiritually distressed person is a person who has impairments in their connectedness, faith and religious belief system, values system, meaning and purpose in life, self-transcendence, inner peace and harmony, and inner strength and energy.

8.3.2 Recovery of mind

The second stage of development of the mind is the "recovery of mind". This stage, shown by the complete black circle on the eclipsed yellow in Figure 8.1, symbolizes the possibility of the mind regaining its strength. This happens when an individual starts to see the opportunity to free their mind from a troublesome situation. They begin to reconnect their self to others, such as their children and parents and receive love and support. They find meaning and purpose in life. Their minds strengthen, and their hopes start to shine again (the yellow circle represents the mind overcoming distress). In other words, after facing distress, the participants start to strengthen their mind by finding meaning and purpose in life that emerges from having both connectedness and receiving love and support, or *kamlangjai*.

At the end of the process, though the participants' minds continue to interpret the HIV/AIDS as a severe life altering situation, having connectedness and receiving love and support or *kamlangjai* as well as acceptance, contributes positively to participants' feelings of self worth (Thomas & Retsas, 1999) and enables participants to find meaning and purpose in their life. In other words, finding meaning and purpose in life after being overshadowed by HIV/AIDS helps them to move forward from a situation of dying to a situation of living. As a consequence, the mind is strengthened, sees an opportunity to survive and views HIV/AIDS as a challenge. Then, they have a will or *palangjai* to live (as discussed in Chapter Five).

However, during this stage of the development of the mind, the participants will still experience occasions when the strength of mind will weaken. This happens because the power of the mind mostly comes from the connection between a person's mind and others which has the possibility of changing. For instance, when the others have changed, the status of the mind will be changed. It is represented by the wall that one builds to defend and protect their self from an enemy (HIV/AIDS) and which has not been sealed up properly. There are still gaps in the wall of the mind, illustrated in Figure 8.1 by a broken line with large gaps of the eclipsed yellow, allowing the enemy to enter its territory and weaken its hope, which could set the mind back to the first circle. The participants are not successful in developing full protection for their mind.

Finding meaning and purpose in life, having connectedness, and having a will to live which are found in second stage of the development of the mind are consistent with some attributes of spirituality in Western literature. Many authors have said that the meaning of life which emerges from the relationships (connectedness) between self, others, God and the environment is a significant feature for human beings, and is the essential component of spirituality giving purpose to their lives and way of living (e.g. Barnum, 2003; Burkhardt, 1994; Dyson et al., 1997; Newshan, 1998). Individuals who are successful in their search for meaning, by having connectedness with self, others and God, have been reported to achieve positive benefits, such as enhanced self-esteem, greater life satisfaction, and less distress (Lee et al., 2004). This brings hope, love, and harmony (Chiu et al., 2004; Hall, 1994). Thus, being connected nurtures positive feelings, provides acceptance and encourages and generates feelings of hope and love as well as enlarging a sense of self worth and enhancing a will to live. Having a common bond with others is a major part of the Western spiritual dimension that is related with giving and receiving love, and trust, and the principal sources of hope and strength (Dyson et al., 1997). Dyson et al. (1997) stated that if people find meaning in life, they can find peace no matter how severe their disease. If people cannot find a meaning in life, spiritual distress will take its place. Coward (1994) also reported that women expressed hope for living when people loved them and when they would love in return.

For some, having a sense of gratitude creates a connection with others. From a Western perspective, Highfield (2001) views gratitude – or sometimes she refers to thankfulness – as an indicator of spiritual health because she claims that gratitude can help people to connect positively with others and their deity. In addition, from the Western perspective, the will to live is significant because it enhances a sense of well-being and reduces psychological distress (Lin & Bauer-Wu, 2003). The will to live plays an essential role in both overcoming an illness and overcoming a death sentence (Chiu et al., 2004).

8.3.3 Stability of mind

The third stage of the development of the mind is “stability of mind”. This stage shown by the complete yellow circle with eclipsed black in Figure 8.1, represents participants’ ability to utilize their inner resources/strength (promoting conditions/strategies) to counter HIV/AIDS and its consequences, or in other words, to unlock the mind from the perceived restrained situation. This happens after the individual finds a will to live and starts to understand and accept oneself as a person living with HIV/AIDS. Understanding and accepting both the illness and oneself occurs after people understand their illness and find positive aspects within oneself – increasing self worth – which is one indicator of spiritual health from the Western perspective (Highfield, 1992). They know that although they live with HIV/AIDS, the definition of being a good and capable person is never destroyed by this illness. Hall (1990, 1997) summarized from her studies and her experience that learning to accept and value oneself is an important part of spirituality. These people gain a sense of empowerment and confidence (Thomas & Retsas, 1999).

When the participants reach this stage, their mind is in a stabilized state. Thus, they regain control over their lives. The participants take care of themselves and are kind to themselves. They have a self-confidence to live and continue life with HIV/AIDS. They know "who I am" and they know that they have ability to deal with HIV/AIDS. They develop confidence for selective self disclosure of having HIV and dare to face the negative consequences of being honest to themselves and others. They feel free and have a sense of victory over HIV/AIDS. They view HIV/AIDS as under their control. They no longer perceive the diagnosis as a severe life-altering situation. While the mind continues to fight the invader (HIV/AIDS), it does not to have to use as much force. Once they recognise this level of the mind's ability, they do not rely entirely on the support from others as they did in the earlier stages.

These findings are supported by Western literature. Halstead and Hull (2001) found that when women learn to accept their limits of control they can move on with their life. It is similar to the work of Hall (1998) who reported that opportunities for meaning arise from a disease without a cure, thus her participants incorporated illness and symptoms into their understanding of their spiritual being. They discovered a way to label themselves as persons living with HIV, not persons dying with AIDS. They felt challenged by their illness. They gained confidence and hope. They were active in the search for care and social support. Hall also reported another theme "after suffering, spirituality frames the life". In this process, she found that the participants became more aware of, and assertive about, the rightness for them of engaging in activities that fitted with the new definition of self, and letting go of those that did not. As a result, they felt balance, empowerment, and control as well as having a future. They had constructed their new identity of having their illness.

As a consequence of "having self acceptance", the participants feel free from HIV/AIDS that presents in both feeling control over HIV/AIDS and having hope in living (as discussed in Chapter Six). In other words, they gain self-transcendence towards their situation. Transcendence is related with increasing mental well-being and decreased perception of illness distress in people living with HIV/AIDS (Coward & Lewis, 1993). Transcendence is an attribute in Western spirituality which is identified by Markham (1998) (as illustrated in Chapter Two under the subheading "The definitions, attributes, and empirical indicators of spirituality in health care").

However, incorporating, integrating or accepting HIV/AIDS as part of life only helps participants to feel free from HIV/AIDS, to live with hope and to live life as normal (Baumgartner, 2007; Hall, 1998; Siriwatanamethanon, 2008). Although, self acceptance, self transcendence, and hope are described as attributes of Western spirituality, the current study found that all three concepts are not the way of living to bring long lasting peace and harmony into the participants' minds. The stage – 'stability of mind'– is only the third stage of the development of the mind. The mind has not yet succeeded in obtaining long lasting peace and harmony. HIV/AIDS silently remains in the back of their minds because the wall the mind has built as a safeguard remains unsealed (as illustrated in Figure 8.1 with the dotted line of the full yellow circle, although the gaps are smaller than those of the previous circle). One's state of mind could still relapse to the previous states.

8.3.4 Having peace and harmony of mind (*kwarmsa-ngobjai*)

The last stage of development of the mind "having peace and harmony of mind (*kwarmsa-ngobjai*)", is shown in Figure 8.1 as a full yellow circle without eclipse. Although HIV/AIDS still remains in their body, it only acts as a shadow that can not cause any harm to them. Their wisdom of mind has developed. At this stage, the individual's mind is unfastened from the HIV/AIDS shadow. In addition, they generally no longer dwell on the situation that could have destroyed them. They are able to live with illness in harmony (*kwarmsa-ngobjai*). Their minds stop fighting with the disease and compromise with it. They view HIV/AIDS in a more positive way, no longer as an enemy. The chance of the mind reaching this stage and then being re-locked by the shadow of HIV/AIDS and its consequence is rare. Nonetheless, there could be times when people living with HIV/AIDS who have reached this state of mind are disturbed by unexpected conditions/situations which result in the mind drifting to the dark side again. But with the inner mind settled (symbolized by the least permeable line of the circle), these persons are able to retrieve a calm and peaceful mind with little effort and in a short period of time.

This stage is reached when the participants have regained a tranquil way of living. They have adjusted their mind in order to understand (*kaojai*) and accept (*yomrub*) the truth about life (*kwarmjingkongcheewit*) and they live their life with contentment (as discussed in Chapter Seven). In consequence, some participants achieve peace and harmony in life and their minds are calm and at peace. Indeed some participants reported that they feel peace and harmony more than in the past, before being infected with HIV/AIDS. In other words, positive outcomes emerge as a result of living with this life crisis. Some participants, who used to perceive that HIV turned their life upside down, later do not think that having HIV/AIDS is a problem. In this study, only seven of 33 participants reached this final stage of the development of mind.

One of the most important truths about life is accepting that nothing is permanent and that everyone who is living is also dying – the parts of the human life cycle comprise birth, old age, illness and death. This realisation has a strong influence on the participants' perspectives and leads them to feel calm and accept (*yomrub*) as well as let go or *ploywang* their situation. This is consistent with the previous findings from Western studies and Buddhist teaching. Dhammananda (1993) argued that according to the Buddha, the miracle of realisation is a real miracle. Hall (1998) found that the feeling of anxiety with regards to living with HIV/AIDS and the imminent death was ameliorated by realizing that everyone will die. Sarter's book on '*Evolutionary Healing*' (2002) is very similar to the philosophy of Buddhist teaching that human beings have to understand that all things must change form. There is no permanence in form. If people accept change which is inevitable and understand the truth about life, they can live in harmony. Human beings should not suffer from fear of death and dying because they are is parts of the natural order of things. Furthermore, Sarter claimed that in many instances, life crisis is necessary for spiritual growth.

8.4 The Relationship of Achieving Harmony of Mind to Spirituality

In the previous section commonalities have been identified between the findings of this study and some attributes and empirical indicators of spirituality that are described in Western literature – for example, meaning and purpose in life, connection, hope and will to live, and transcendence. However, although most Western studies and literature (e.g. Burkhardt, 1989; Halstead & Hull, 2001) claim that having relationships with self

(self-in-relation) (Hall, 1997), others and God is an attribute of Western spirituality which helps people gain peace and find meaning in their lives, the findings of this study are that having relationships (a form of attachment) is not a conclusive way of achieving peace and harmony in the Thai context. For example, although some participants report gaining inner strength after they make a vow or pray in front of the Buddha image, this action is a way to help them feel relief from their distress, bringing temporary happiness. In addition making a vow is not the aim of the Buddha. Thus, although having relationships (having connectedness and receiving love and support) is essential to promote the will to live (turning from dying to living), it is not guaranteed to help the participant find an ultimate meaning and purpose in life – *kwarmsa-ngobjai*. It only brings the temporary peace to the mind.

Rather the final stage of the development of the mind is ensured when the participants understand and accept the truth about life. In addition, sometimes, having hope (too much hope) does not match with Buddhist teaching that "everything is impermanent" and which attempts to teach people to be free from suffering, greed and craving with the *Four Noble Truths* and the *Eightfold Path* (as discussed in Chapter Seven). People who still want are not successful in having a settled state of mind, and they have not found an ultimate meaning in life. Hope is one of the indicators that divide people into those who have discovered an ultimate meaning in life and those who have not. A person who has less want and lives their life with contentment is not without hope. Conversely, they feel satisfied with what they have. The most important of their wants is having a peacefulness of mind, rather than happiness from material possessions. Therefore, hope helps people live with happiness because without hope people feel despair, but this does not necessarily result in a peaceful life. However, having high expectations or too much hope, can cause suffering. As Delmar et al. (2005) found from their study on the phenomenological-hermeneutic approach, "where there is hope, there is also always the possibility for doubt" (p. 209). The highest level of living life is living life with peace and harmony (*kwarmsa-ngobjai*). If one day, people find an ultimate meaning in life, hope is more sustainable.

Religion – in this study Buddhism and Islam – plays a vital role in helping participants to understand (*kaojai*) and accept (*yomrub*) the truth about life (*kwarmjingkongcheewit*). Tongprateep (2000) studied the essential elements of spirituality among rural Thai elders and depicted that spiritual beliefs and religious practices inspired elderly people to cope with the difficulties in life. While there is debate in the Western literature about the association of spirituality and religion (e.g. Baker, 2003; Sessanna et al., 2007), these findings from the Thai context show that the process of gaining peace and harmony (*kwarmsa-ngobjai*) has a strong relationship with the understanding and practising of religious doctrine. This is consistent with previous studies conducted in Thailand which have also found that religion, Buddhism in particular, plays a vital role in helping people to accept and live with their illness or life crisis situations (Balthip, 1999; Klankaradi, 2008; Rungreangkulkij & Chesla, 2001; Sethabouppha & Kane, 2005).

In the Thai context that is influenced by Buddhism, the practice of acceptance in the face of suffering is promoted (Ross et al., 2007; Rungreangkulkij & Chesla, 2001; Siriwatanamethanon, 2008). Sethabouppha and Kane (2005) stated that acceptance is the process of understanding and having a sense of obligation and resignation to an unchangeable situation that is explained by the Buddhist teaching of *ubekkha* (equanimity) which is a principle of having a calm mind. Klankaradi's (2008) study of the experience of caring for a child with cerebral palsy also found that some participants employed the Buddhist philosophy to accept the situation by doing *plong* and letting the feelings of frustration, grief, burden go. They were then able to live with their situation with a sense of peacefulness. Dhammananda (1993) stated that religion is important because it encourages contentment and urges a person to look beyond the demands of his/her ego. If s/he does not believe in life after death, following religious teaching helps them to lead a good life, enjoying peace and happiness here and now, as well as performing actions which are for the benefit and happiness of others. Leading such a positive and wholesome life on earth creates happiness for oneself and others.

In this study, as discussed in Chapter Seven, the highest stage of the development of mind was developed when the participants began to understand the truth about life and live with equanimity (*ubekkha*). They learn to live in the moment and/or have mindfulness and clear comprehension (Sutheravut, 2007; Tawaisab, 2000). They live with a simple lifestyle and learn to detach themselves from the sense of self (*nonself*). They are practising letting go or detachment (*ploywang*) rather than having attachment in order to bring relief and calmness, happiness and freedom to the participants' minds (as previously discussed). They then have the experience of feeling freedom, relief, and fulfilment. Freedom is the only condition for happiness (Hanh, 2004). The original teaching of Buddha focuses on self-discipline, self-restraint, and cultivation of morality. Buddha encouraged people to develop their strength by understanding *the Noble Truths* in order to become free from their desires and self, as well as free from bondage (Dhammananda, 1993).

Harmony of mind also arises when the participants live with awareness. This includes finishing business for themselves in this life; preparing merit for the next life, which is mostly based on belief in the law of *karma*; and finishing business related to care of parents (presenting sense of gratitude) – or children (presenting sense of obligation or parents' roles). They can have a sense of complete contentment that emerges from having both life satisfaction, and meaning in their lives (Kunsongkeit, 2004; Tawaisab, 2000). Peace of mind is also achieved when the participants live with loving kindness (*metta*), compassion (*karuna*) and altruistic joy (*muthita*) (Sethabouppha & Kane, 2005; Tawaisab, 2000; Wasi, 2000). Weaver et al. (2008) mentioned that "central to the Buddhist approach to health and healing is its emphasis on spiritual strength and sense of purpose in life based on compassionate action for others" (p. 129). This is consistent with "altruism", the concept used in Western writing about spirituality. In addition, meditation and praying and the sense of forgiveness toward others have a commonality with other studies both Thai and Western. It should be emphasised that most aspects of peace and harmony of mind are augmented when participants do a good thing or the mind is touched by a good thing that is related to religious teachings such as following the Dharma (Buddhist teachings) (Wasi, 2000).

Although, the term spirituality is not mentioned in any books on Thai Buddhism (Bhawilai, 2003; Phra Dhammapitaka, 2003) and spirituality is not a term recognized by every religious tradition (Markham, 1998), some authors, both Western and Thai, (e.g. Markham, 1998; Ross et al., 2007; Sutheravut, 2007; Tongprateep, 2000) claim that achieving peace and harmony – the last stage of development of the mind in this study which emerges when people understand and accept the truth about life, and live life with contentment that is based on Buddhist teaching – is spirituality in Buddhism. Markham (1998), who wrote about spirituality and the world faiths, argued that the *Four Noble Truths* which is the heart of the Buddha's doctrine does not mention God or a divine being. Rather he focuses on the truth of suffering, the truth of the cause of suffering, the truth of the cessation of suffering, and the *Eightfold Path*. Thus, the heart of Buddhist spirituality is “the cultivation of certain dispositions that integrate this awareness of the transient nature of all things into one’s life” (Markham, 1998, p. 82), and a life lived compatibly with the *Four Noble Truths*, including the right resolution – *Eightfold Path*. This teaching contrasts with the form of spirituality found in other religions because it does not begin with an engagement with a divine and transcendent reality. Rather Buddha taught humans to understand the truth (*Noble Truths*) in order to end suffering (Markham, 1998).

Sutheravut (2007), who aimed to formulate spirituality from the Thai perspective rather than employ a framework based on Western spirituality, selected participants who were studying, researching, and working in spiritual health. He described four domains in spirituality and surmised that all are linked with the state of mind.

> A state of moral mind that consists of non-selfish, loving-kindness, compassionate, sympathetic mind, and equanimity. A state of human mind which is peaceful inside, an aesthetic mind, a higher stage of mind, higher quality of mind, a healthy mind, higher than the truth and the good. A power of mind that is able to feel, perceive, and know. A state of mind which is experiencing the evolution of a deep-seated sense of meaning and purpose in life and a sense of belonging. It is about acceptance, integration and wholeness (Sutheravut, 2007, p. 103).

The findings of Sutheravut (2007) are congruent with the last stage of the development of the mind in this study – “having peace and harmony of mind”. Thus, the last stage of the development of the mind identified in the current study is linked to understanding and accepting the truth about life rooted in religious beliefs (Buddhism in particular), and has commonality with Buddhist literatures (Markham, 1998) and previous studies conducted in Thailand (Klankaradi, 2008; Ross et al., 2007; Sutheravut, 2007; Tongprateep, 2000).

The study by Sutheravut (2007), used participants who were scholars with expertise in the area of spirituality, thus, the research findings represent spirituality from the Thai scholars' perspectives rather than the perspectives of lay people. Thus, the current study extends the knowledge gained from Sutheravut. Sutheravut summarised that the mind and spirituality are synonymous terms and tend to be used interchangeably, however the current study found that only some stages of the development of the mind are comparable with spirituality in both the Thai and Western contexts. It is possible that the Scholars in Sutheravut's study could have been influenced by their knowledge of Western perspectives. In contrast, lay Thai people are not familiar with the concept of spirituality. Thus, in the Thai cultural context and in particular in the Thai Buddhist context where spirituality is only understand by a group of Thai academics whose perspectives may have been based on Western spirituality, Thailand cannot declare that spirituality and the mind are the same.

In Buddhist understanding optimal health is the balanced interaction between mind and body. WHO defined health as "a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity" (Weaver et al., 2008, p. 128), and Thailand defined health as "*the state of human being which is perfect in physical, mental* (*jit*), *spiritual (panya) and social aspects all of which are holistic in balance*" (Chokwiwatana, 2008, p. 28). All have the similar aim of health; as the balanced interaction of all dimensions. In addition, when Buddhism defined life as composed of the body and the mind (mental), the mental dimension divided into two dimensions: mental and spiritual (Chokwiwatana, 2008). This is consistent with the understanding of scholar monks (e.g. Phra Dhammapitaka, 2003) who noted that within the mind many subconcepts, such as wisdom, intelligence, and enlightenment, were integrated. The mind has the ability to perceive initial sensation (perception or recording or memory), sustained sensation (mental formations or activity sphere), recognition and feeling. The mind also has four functions: detection, data logging and recording, data processing and matching (memory search), and output which leads to understanding, right-knowledge and points the way to self-realisation (as illustrated in Chapter One). The expression of the mind acts upon the body via vocal or bodily intimation, in terms of human personality, behaviour, and emotion. Both positive (moral) and negative (immoral) expressions of these depend on the human state of mind (Sutheravut, 2007).

I agree with Chokwiwatana (2008) that the difference between the dimensions within each definition of health is not the main concern. The most important aspect is that as health professionals, we expect to provide holistic care and to help our patients to gain peace and harmony whether that be defined as harmony of the body and the mind (Buddhist perspective), harmony of physical, mental, and social wellbeing (WHO's perspective), or harmony of the physical, mental, spiritual and social aspects (Thai definition). In summary, the research findings explain both the process of **Achieving Harmony of Mind** and the relationship between the mind and spirituality (in particular Western spirituality). Thus, the research findings are valuable for health professionals as they assist in enhancing peace and harmony for their patients. In addition, this research demonstrates that Thai academics or people in authority in Thailand should be careful when using knowledge from other cultures as examples of spirituality, because this knowledge may not be appropriate for Thai people who have their own culture and background. This also applies to Thai nursing scholars. I agree that some knowledge used in the nursing curriculum should be consistent with Western knowledge, such as "physical care", but there should be a greater body of knowledge in the Thai nursing curriculum that pertains to the unique knowledge that fits with Thai culture.

8.5 Limitations of the Study

This study aimed to explain the meaning of spirituality and the process of spiritual development in people who had been living with HIV/AIDS for five years or more in the Thai context. Although this study was conducted with participants who were diagnosed both before and after the ARV drugs were launched, and conducted in the era when ARV was available, if another condition changes, (e.g. a cure is developed) the consequences may also change. The substantive theory that was developed will also change to reflect the new condition.

This study has limitation in terms of participants. For instance, only five Muslim participants were interviewed because in the period of data collection (February – December, 2006) it was not safe for me to go into the field in the areas where I had expected to interview Muslim participants. Therefore, this substantive theory addresses Buddhist perspectives and is largely silent in relation to Muslim beliefs. There is a need for a further study of the process of achieving harmony in this group of people.

This study also included only one gay man and only a few persons living with HIV/AIDS acquired from drug abuse. The results thus may not fully represent the process of finding peace and harmony while living with HIV/AIDS for those groups.

Another limitation is the language. The data gathering and data analysis were conducted in Thai, but preparation of the study report needs high skills in English language which is the second language of the researcher. Thus, the barrier of language skills is a matter of concern. The last limitation is generalisability. The findings are unique to people living with HIV/AIDS, in the Thai context, that is people whose background, religion and culture are Thai in general and Buddhist in particular. Therefore, the usability of this substantive theory is limited outside Thailand. However, some concepts such as the role of religion may apply also in other countries that have a similar religious background. The concepts of love, connection, self acceptance are general concepts that people in all parts of the world can appreciate. Also, the theory can be advanced if tested in other contexts within different cultures and the similarities or differences that emerge can be compared. Although the value of this work may be directly for people living with HIV/AIDS in order to enhance their peace and harmony, some concepts that enhanced the participants' ability to pass through their life crisis such as *kamlangjai*, understanding the truth about life, living life with contentment such as living with equanimity should be able to be utilised in the general population in particular by those with chronic illnesses.

8.6 Implications of the Study

This substantive theory **Achieving Harmony of Mind** grants insight into the meaning of spirituality and the development of spirituality that occurs following diagnosis with HIV/AIDS for people who have lived with HIV/AIDS for five years or more and which helps them to live with HIV/AIDS with peace and harmony.

The concept of spirituality is unclear in the Thai context. In addition, nurses do not have a clear understanding of what constitutes spiritual care and how to provide it to patients. Therefore, this concept is often overlooked during the course of health care. The findings of **Achieving Harmony of Mind** that stemmed from the lay people in a Thai context are applicable to healthcare professionals – in particular, nurses – and could lead to further studies on spiritual care and appropriate intervention that could help individuals to move through life-altering situations and live with harmony. This substantive theory also has implications for nursing education. Additionally, the findings are a guide for further research. Furthermore, these findings provide a basis for building up the concept of spirituality and health policies in Thailand.

8.6.1 Implications for nursing practice

As a nursing professional, what I need to know is how to provide holistic care and help patients to gain peace and harmony in their life. While acknowledging the work of other scholars (e.g. Kasemkitwhattana & Rojanapakorn, 2004; Ross et al, 2007; Sutheravut, 2007; Tongprateep, 2000; Wasi, 2000) who have endeavoured to clarify the concept of spirituality in the Thai context in order to guide health professionals to provide holistic care for the patients, the substantive theory **Achieving Harmony of Mind** provided useful guidance for health professionals to help patients gain peace and harmony.

This substantive theory illuminates the conditions, actions/interactions (strategies) and consequences of each subprocess in the development of mind. It provides a guideline for all levels of the healthcare service (as outlined in Table 8.2). Thus, the value of this theory can go directly to the people living with HIV/AIDS in order to enhance their happiness, peace and harmony. In addition, it could be applied in enhancing peace and harmony for people with other chronic and terminal illnesses.

Achieving Harmony of Mind can provide direction for health professionals. Health professionals, such as nurses, who are mentors at HIV/AIDS clinics, could assess people's state of mind with a simple question – for instance, "How do you (in your mood as dictated by your state of mind) feel right now?" The presence and support of health professionals is a key to assisting people newly diagnosed with HIV/AIDS to overcome the life crisis and learn to live with HIV/AIDS. If they lack support, they risk living their life with lethargy and without motivation for living, possibly leading to suicide. Nurses can also help patients by providing them with useful and accurate information and helping them find an ultimate meaning in their lives in order that they might live with peace and harmony. Even when the outcome is death; nurses can provide for the dying well by helping them deal with unfinished business, providing support and care and allowing the patients to meet and reconnect with people with whom they want to connect. Moreover, nurses can help the patients to feel calm by discussing with them the truths about life – such as that nothing is permanent – if they wish and encourage them to accept this truth in order to help them feel peace.

For instance, in the process of *overcoming distress*, health professionals could explore and listen to the conditions and actions/interactions (strategies) of where and how people living with HIV/AIDS find meaning and purpose in life, or where they are feeling a lack of meaning. By assessing the conditions and the actions/interactions (strategies) that are being used by people living with HIV/AIDS, and then evaluating the outcomes or consequences of those strategies, health professionals can assist these people and their families to accept their situation, and can encourage them to engage in new strategies in order to overcome their life crisis, and live with the circumstance of HIV/AIDS with peace and harmony.

The guidelines as outlined in Table 8.2 can assist health professionals to become more understanding of the world of people living with HIV/AIDS as well as understanding their feelings through being with and listening closely to them. This approach can mitigate focusing only on physical care and power relationships between professionals and patients. In particular these findings show that the process of development of the mind (*jai*) incorporates aspects of Western spirituality and the process of achieving peace and harmony. *Mind* is the term that the Thai lay people are familiar with and widely use. Thus, assessment of the status of a patient's mind should include the term that is widely used by the Thai lay people. Then the health professionals will be able to assess the holistic care that covers any kind of definition of health either the concept of "body and mind" or "body, mind and spirit" because when assessing state of mind they will include both mind and spirit because spirituality is one part of the development of the mind (as discussed).

Each stage of the development of the mind may need a different approach and different question and it should be noted that the following guidelines are not a step-by-step process but rather an indication of how to apply different questions for the different stages of development of mind. Additionally, sometimes, health professionals may find that only one or two questions are necessary to encourage their patients to express their feelings and re-appraise their experience. However, not all patients may be open to discussing spiritual matters at all times, and health professionals must always be sensitive to each individual patient's needs. Indeed, Culliford and Eagger (2009) recommended that health professionals should avoid direct questions on spirituality and religious beliefs.

Furthermore, the finding of **Achieving Harmony of Mind,** in particular the last stage of development of the mind that is mainly guided by Buddhist teaching, not only guides health professionals in the Thai context, but also applies to other health professionals in other contexts and Buddhist people who live in other countries. This is supported by Weaver et al. (2008) who reported that a number of Western people are increasingly practising Buddhist doctrines and Buddhist meditation.

8.6.2 Implications for nursing education

The substantive theory **Achieving harmony of Mind** has value for nursing education in Thailand because this study was conducted in a Thai context and the theory emerges from the perspective of lay Thai people. Previously, Thai nursing education employed knowledge about spirituality based on Western cultures and this is influenced by Christianity (Kociszewski, 2004) so it is thus less relevant to Thai people, most of whom are Buddhists or Muslims (as discussed). Additionally, spiritual care in nursing education is lacking even though many definitions of spirituality have been identified in nursing literature. This mismatch between Thai culture and the spiritual concepts within the nursing programmes has resulted in ambiguity or confusion for Thai nursing students who often omit spiritual care from their care of patients. These findings can guide students to apply a concept of spirituality that fits with the Thai context of their work. Therefore, the findings can guide the writing of the nursing curriculum about the concept of spirituality in the Thai context.

Table 8.2: Guidelines to assessing the state of mind

Criteria for assessment	Sample questions
Encountering distress The conditions: first the diagnosis becomes known, and patients are facing new distress (consequences of the illness). The aim in this stage is to help the health professional to understand the world of the patient. 1. Assess the state of mind [distress-*tukjai*] 1.1 Assess the patients' perception of this disease and its severity 1.2 Assess the reactions/interactions (strategies) to disease (including observe the nonverbal reactions such as quietness, sadness, crying and/or anger) 2. Assess the resources or support system	Could you please tell me, how you feel right now [*tukjai, torjai, siajai* (sadness)]? How do you perceive this disease? How has the knowledge that you have contracted this disease affected you? What would you like to do to make you (your mind) feel better (relief)? What would you like to do about your situation? In the past, when you faced suffering, how did you deal with your situation? Are those strategies you can apply to this situation? Whom do you need to tell about this disease? Who and what can support and help you with your disease?
Overcoming distress The conditions: the participant reports having no meaning or purpose in life. The aim in this stage is encouraging the patient to find meaning in life. 1. The assessment focuses on the meaning and purpose in life 1.1 Assess his/her perception of himself/herself (self-value, self-esteem, self-worth, and life satisfaction). 1.2 Assess the sources of strength (relationship, connection or support) 2. Help him/her to realise his/her meaning and purpose in life and self-value as well as encouraging him/her to go on with life	The following questions are often useful when the participants report much distress, expressing that they have no meaning in life, have no connection or support as well as being unwilling to live Could you please tell me how you feel about yourself? Could you please tell me who are the important persons (such as parents, children, and partners) in your life? Why are they important? Whom do you feel connected to or disconnected from? Are you important for them? Would you like to live for them?

Criteria for assessment	Sample questions
Accomplishing harmony in oneself	
The conditions: preparing the patient to live his/her life with their disease. The aim in this stage is encouraging the patient to understand the disease and accept himself/herself.	The following questions are often used after providing some information and there is a need to assess the ability of the patients to face, deal and live with their situation.
1. Re-assess his/her perspective of the disease 2. Assess his/her knowledge and information, providing care and support and answering the questions that are raised 3. Provide knowledge, information about HIV/AIDS (knowledge is important to relieve distress) and offer a resource system	How do you feel right now? How do you now perceive this disease? What do you need to know about this disease? Would you like me explain more about this disease? Would you like me to tell you about the treatment, care and support available to you? Do you know someone who has this disease?
4. Assess the patient's perception of the disease, and himself/herself after providing the information 5. Assess his/her ability to live with HIV/AIDS	How do you feel (about the disease) right now? How do you feel (about yourself, self value) right now? Can you accept (*tamjai*) having this disease? If not, what can I do for you? Could you please tell me what you need to do for yourself? (planning) Do you think you can deal with this disease and how? Can you live with HIV/AIDS? Are there any needs or concerns I can help you with? If you have any question or need any help, please feel free to call me or come to see me.
Discovering an ultimate meaning in life	
The conditions: any time (first diagnosis, facing new suffering, and living with the disease) The aim of this stage is encouraging the patient to understand the truth about life and living life with contentment in order to gain peace and harmony.	In the following questions a variety of situations, both in the worst of their life crisis and when they are able to live with their disease, are reflected.
1. Assess the sources of comfort and belief	Could you please tell me your real feelings about why you have this disease? How do you feel about yourself right now? Do you believe in the law of *karma*? How do you perceive your life? Do you believe in the positive results of good deeds (*boon*)? Normally, when you are faced with a life crisis, what helps and makes you feel better (*sabuyjai*)?

Criteria for assessment	Sample questions
2. Activating him/her to understand the truth about life and live life with contentment	Have you ever practised letting go (*tamjai, plong, ploywang*) with some situation in the past? How do you feel when other acts such as *katanyu*, *metta, karuna* and *muthita* are done to you? And have you ever done these things for others? How do you feel when you act with *katanyu, metta, karuna* and *muthita*? Do you believe in the positive power of forgiving? Have you forgiven people for their actions? Can you forgive yourself? (if s/he feels angry towards himself/herself and others) In your opinion, what do people really want for their life? Why are we born? What do you think when people say "birth, being old, having an illness, and death are normal life"? What do you think about birth, being old, illness, and death? What do you want to do in the rest of your life? What is the thing that you really want (to do) in your life? What would help you gain happiness and peace (*kwarmsa-ngobjai*)? In your opinion, if people need to live with harmony with HIV/AIDS, what should they do? Are there any needs or concerns I can help you with?

Achieving Harmony of Mind – which is explained as a process of development of the mind that includes the meaning of spirituality and the process of spiritual development – should be formally integrated within the Thai nursing curriculum in order to guide nursing practice and generate an insight into spirituality in order to minimise the gap between theory and practice. For instance, the definition of the mind and the way to assess the state of development of the mind (such as *tukjai, sukjai*, or *kwramsa-ngobjai*) should be integrated in Thai nursing curriculum because the concepts fit and are understood in the Thai context. The Thai nursing curriculum should also mention holistic care (the paradigm of health) which is understood as the harmony of body and mind (*guy* and *jai*). Then, this new curriculum will have great value for nursing students as it will fit with the Thai culture and people in Thailand.

8.6.3 Guiding nursing research

During the period of this study it was found that there was a noticeable gap between the theory and practice of providing spiritual care for Thai nursing professionals, and Thai scholars still lack understanding about spirituality. Thus, further research should be focused on qualitative research to build up a clear concept of spirituality that fits the understanding of Thai people. In addition, this substantive theory needs to be tested in the Thai context with other groups of people such as those with other chronic illnesses. The findings of this study also provide guidelines for further research that is important in both testing this theory (as suggested by Chinn & Kramer, 1995) and incorporating new knowledge into the area of spirituality.

1. Based on the findings and the limitations of this study, further study on spiritual development should be explored for Muslim people, women, youth, elderly people, patients with Tuberculosis, and drug addicts as well as those with other chronic conditions. This would demonstrate a more general theory of achieving harmony of the mind in the Thai context. Moreover, in further study the process of achieving peace and harmony of Buddhist people in other countries should be explored. This would also reveal a general theory of achieving harmony of mind for people with a Buddhist context.

2. These findings clearly show the relationship of the conditions, actions/interactions, and the consequences with the process of development of the mind. Thus, further research using a quantitative methodology could be applied to assess the relationship among conditions, actions/interactions, and consequences within each subcategory and category.

3. The last finding – *discovering ultimate meaning in life* (Chapter Seven) – can guide further research for developing a model of living with harmony for people living with HIV/AIDS in Thailand utilising participation action research. Such participatory action research could involve the coordination and participation of key stakeholders such as teachers, monks, local health professionals, health volunteers, and local authorities whose work is to promote "living well" and *kwarmsa-ngobjai* for people living with HIV/AIDS.

These findings could also guide quasi-experimental research. For instance, by developing an intervention based on the participants' perspective on conditions and strategies such as by providing the schedule of teaching a religious doctrine such as the *Four Noble Truth*s, practising religious doctrines, and meditation and prayer. Measures such as the degree of depression, life satisfaction, self-esteem, will to live, peace and harmony of the mind (*kwarmsa-ngobjai*) could be measured before and after such intervention.

4. Further research could also be focused on developing a scale to measure peace and harmony (*kwarmsa-ngobjai*) in people living with HIV/AIDS in the Thai context. There are no scales for measuring their levels of peace and harmony (*kwarmsa-ngobjai*).

8.6.4 Recommendations for health policy

This substantive theory describes the unique phenomenon of development of the mind that includes aspects of Western understandings of spirituality that will help policy makers define the concept of spirituality in the Thai context. The concept of spirituality that has emerged from this study suggests that this concept was integrated into the concept of the mind that fits with Thai people and culture. It could therefore help the health policy makers to integrate a substantive theory **Achieving Harmony of Mind** which includes spirituality into the health policy in Thailand and distribute this all over the country in order to help people understand this concept. Additionally, the Thai health policy makers must recognise that some concepts, such as spirituality, cannot be duplicated or borrowed from other cultures because they do not fit and are not understood in the Thai cultural context (as overviewed). Some concepts should stem from the Thai people of many levels such as lay people, academics, or monks.

In this study I found that religion plays a significant role in both developing the feelings of peace in the participants themselves, and in their society, especially if people in the community follow religious doctrines. This theory also affirms the significant role of religious beliefs for enhancing peace and harmony in life in general. In particular, at present, some people are not concerned about the importance of religious teaching in their daily life, but this can cause a lack of support when they are faced with suffering in their life. Therefore, the government should maintain and, promote positive traditional customs and religious teaching to enhance peace and harmony.

In the area of reporting the situation about HIV/AIDS is often presented based solely on its physical and economical impacts and there is a lack of information about its spiritual impacts (holistic impact) on people living with HIV/AIDS. This evidence shows that the government also pays less attention to – or lacks information about – the spiritual impacts of this disease. Therefore, the government should support further study on this aspect that is so important for people.

The government should reinforce the concept of **Achieving Harmony of Mind** in order to enhance the well being of people in Thailand. Thailand has many positive customs that used to be practised in the past by people in order to live with harmony. These include the concept of sharing and an altruistic life style, loving-kindness, compassion (*metta, karuna*) and living life with self-sufficiency that is highlighted by the Thai King. This study also shows that the concept of *connection* – gratitude and bonding (*bunkhun, katanyu,* and *phukphan*) – that is a positive custom for Thai people is significant in the process of overcoming distress in order to find meaning and purpose in life. Therefore, the government should provide funding and support to conduct research about the unique customs of Thai people and re-introduce this concept for the new generations. Thai culture should maintain this way of living. Schooling could include education in these customs and ways of good living as was the case 30 years ago. The findings show that these concepts are essential for people to have a life enriched at all levels. Furthermore, the Thai government should promote these ways of living for the people in the country by motivating them to understand that being rich or poor or having an illness is not the issue. All people can find peace in life if they know how to live with contentment – including living with self-sufficiency. Also, if people live their life based on morality, loving kindness, compassion, and altruism, society will receive the positive outcome of peace.

8.7 Conclusion

The substantive theory **Achieving Harmony of Mind** (*kwarmsa-ngobjai*) was developed from the experience of lay Thai people living with HIV/AIDS. **Achieving Harmony of Mind** is the highest level of the development of mind and it is the ultimate goal of life. **Achieving Harmony of Mind** is developed mainly by understanding and accepting the truths about life and living life with contentment which is mostly influenced by religious teaching and by Buddhism in particular. Individuals who achieve a settled state of mind know that the distress engendered by the discovery that they have contracted HIV/AIDS can no longer penetrate them and they can let it go quickly once they have a calm mind (inner peace).

Implications for practice and further research were derived from the findings of this study. The findings enhance knowledge about the meaning of spirituality and the process of spiritual development which is integrated into the process of the development of the mind in the Thai context. The study is significant as there has been no other research conducted that has been focused on the meaning of spirituality and spiritual development in people living with HIV/AIDS. Furthermore, this study is the first conducted in which the meaning which the ordinary people give to the concept of *spirituality* has been examined and is the second study in Thailand which has been focused on the meaning of *spirituality* in which qualitative research methodology has been used. In Thailand the knowledge contributed by this study can be disseminated by educating Thai people to understand this concept of mind and thus enhance their well-being with the direction which fits into the Thai context.

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Appendices

Appendix A: An example of a letter requesting permission to conduct the research from the director or authorised person of each study site

Appendix B: Example of letters granting permission from Study Sites

Appendix C: Ethics approval of the Massey University Human Ethics Committee

Appendix D: Participants' Information Sheet (English translation)

Appendix E: Participants Information Sheet (Thai)

Appendix F: Informed Consent (English translation)

Appendix G: Informed Consent (Thai)

Appendix H: Authority for the Release of Tape Transcripts (English translation)

Appendix I: Authority for the Release of Tape Transcripts (Thai)

Appendix J: Confidentiality Agreement (English translation)

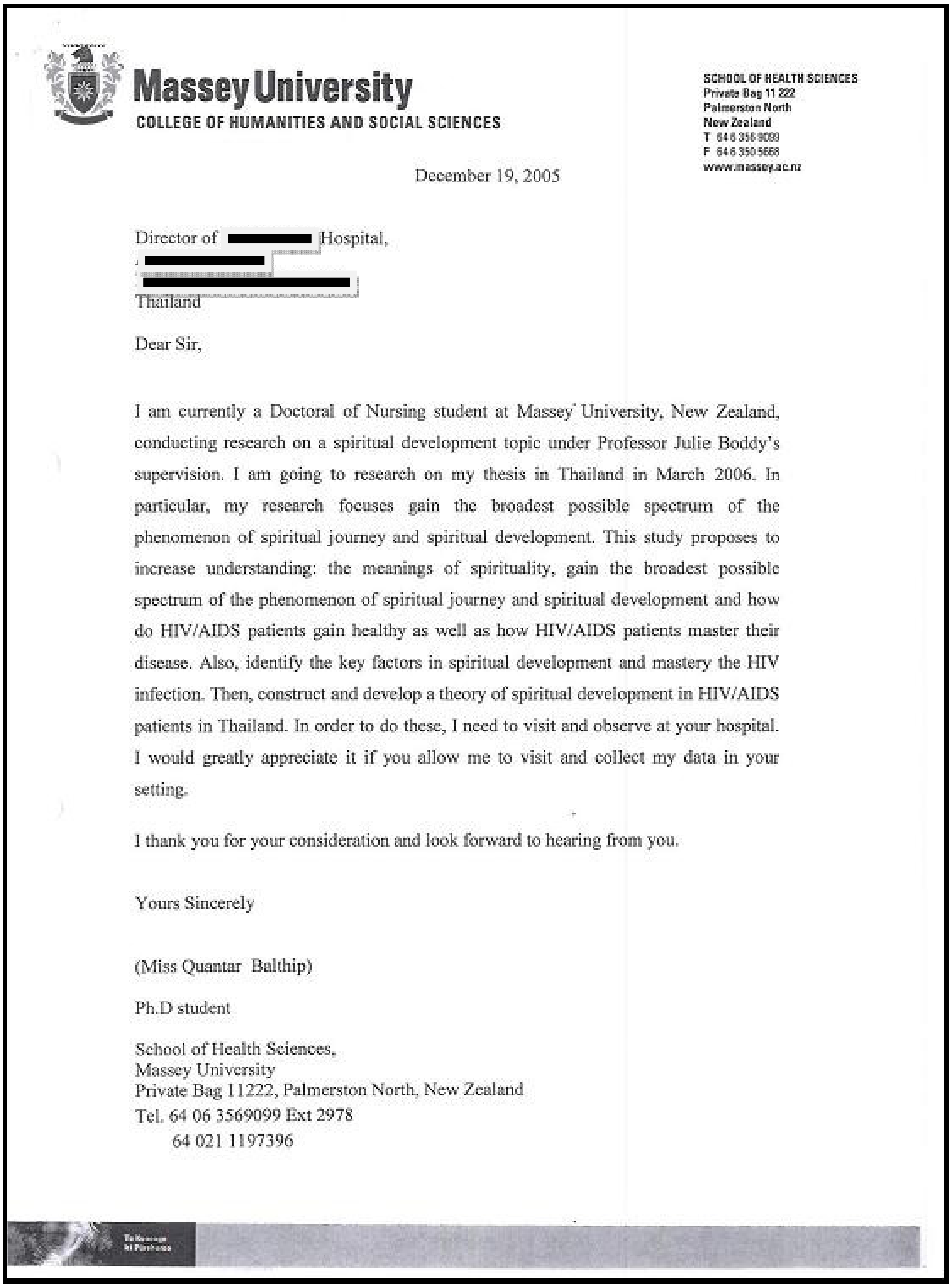
Appendix K: Confidentiality Agreement (Thai)

Appendix L: Transcriber's Confidentiality Agreement (English translation)

Appendix M: Transcriber's Confidentiality Agreement (Thai)

Appendix N: Papers presented at International Conferences

Appendix A



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December 19, 2005

Director of [redacted] Hospital,
[redacted]
Thailand

Dear Sir,

I am currently a Doctoral of Nursing student at Massey University, New Zealand, conducting research on a spiritual development topic under Professor Julie Boddy's supervision. I am going to research on my thesis in Thailand in March 2006. In particular, my research focuses gain the broadest possible spectrum of the phenomenon of spiritual journey and spiritual development. This study proposes to increase understanding: the meanings of spirituality, gain the broadest possible spectrum of the phenomenon of spiritual journey and spiritual development and how do HIV/AIDS patients gain healthy as well as how HIV/AIDS patients master their disease. Also, identify the key factors in spiritual development and mastery the HIV infection. Then, construct and develop a theory of spiritual development in HIV/AIDS patients in Thailand. In order to do these, I need to visit and observe at your hospital. I would greatly appreciate it if you allow me to visit and collect my data in your setting.

I thank you for your consideration and look forward to hearing from you.

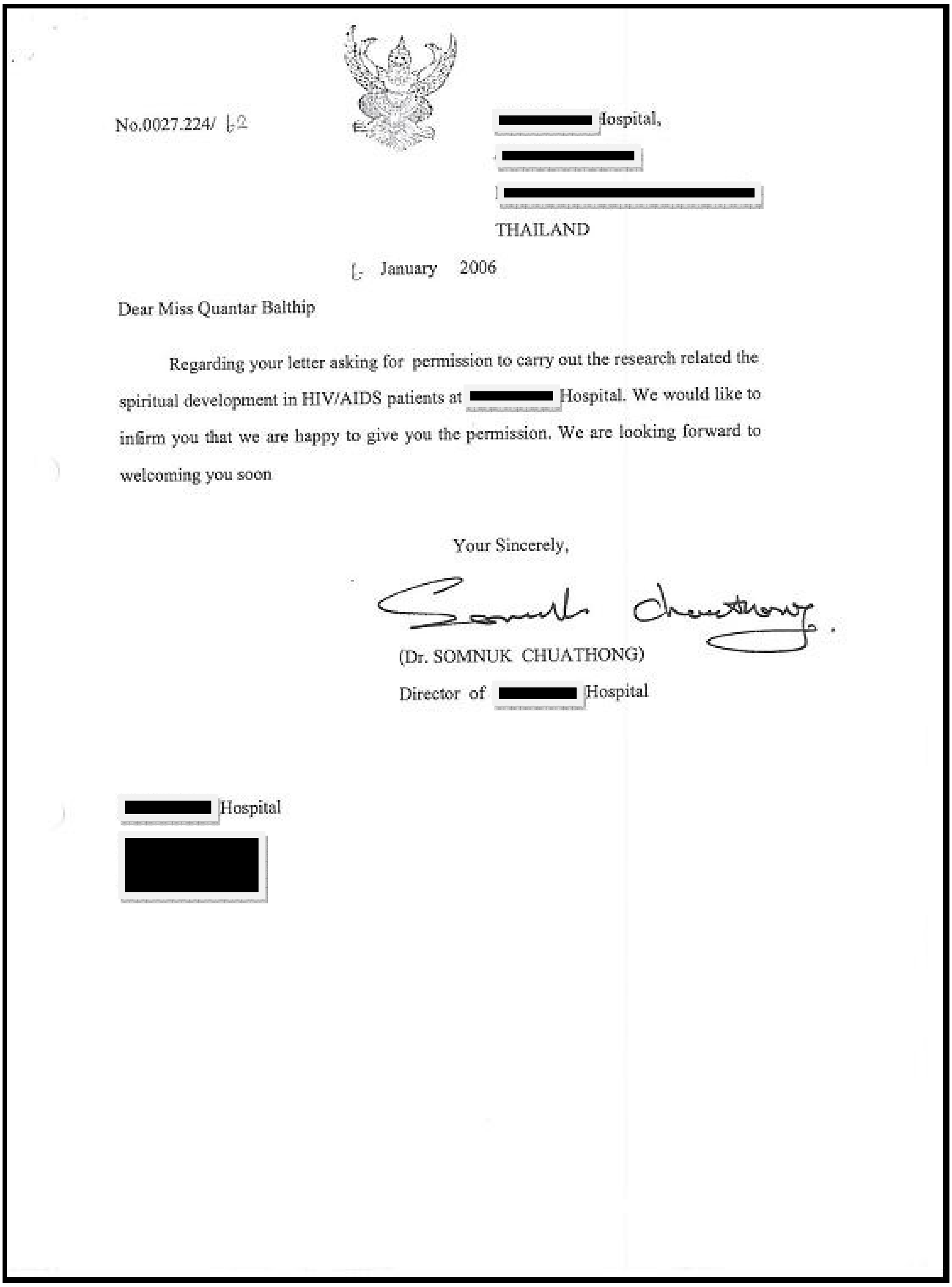
Yours Sincerely

(Miss Quantar Balthip)

Ph.D student

School of Health Sciences,
Massey University
Private Bag 11222, Palmerston North, New Zealand
Tel. 64 06 3569099 Ext 2978
64 021 1197396

Appendix B



No.0027.224/ ๖2

[redacted]ospital,
[redacted]
[redacted]
THAILAND

๖ January 2006

Dear Miss Quantar Balthip

Regarding your letter asking for permission to carry out the research related the spiritual development in HIV/AIDS patients at [redacted] Hospital. We would like to infirm you that we are happy to give you the permission. We are looking forward to welcoming you soon

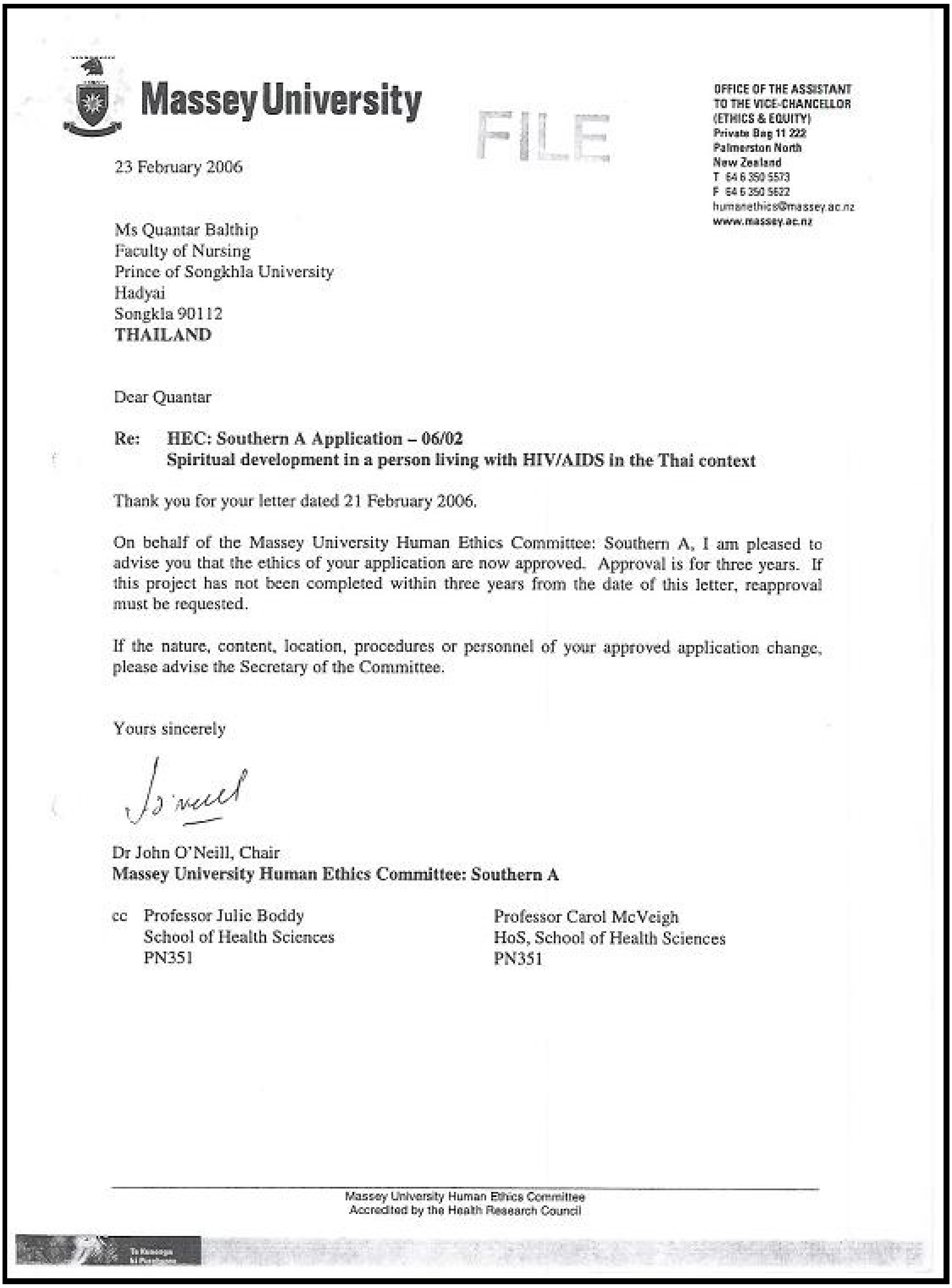
Your Sincerely,

Somnuk Chuathong.

(Dr. SOMNUK CHUATHONG)
Director of [redacted] Hospital

[redacted] Hospital
[redacted]

Appendix C



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FILE

23 February 2006

Ms Quantar Balthip
Faculty of Nursing
Prince of Songkhla University
Hadyai
Songkla 90112
THAILAND

Dear Quantar

Re: HEC: Southern A Application – 06/02
Spiritual development in a person living with HIV/AIDS in the Thai context

Thank you for your letter dated 21 February 2006.

On behalf of the Massey University Human Ethics Committee: Southern A, I am pleased to advise you that the ethics of your application are now approved. Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

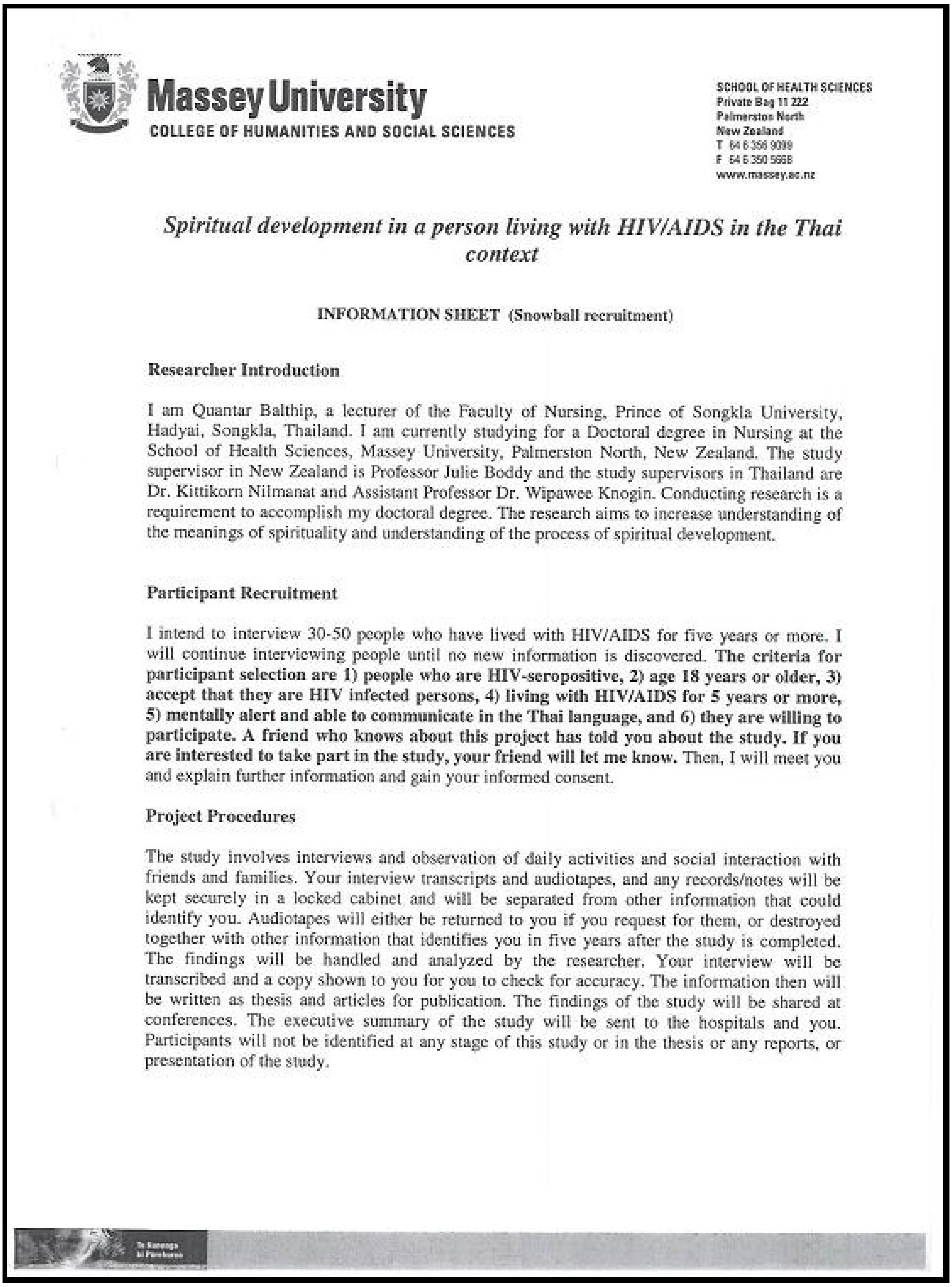
Dr John O'Neill, Chair
Massey University Human Ethics Committee: Southern A

cc Professor Julie Boddy
School of Health Sciences
PN351

Professor Carol McVeigh
HoS, School of Health Sciences
PN351

Massey University Human Ethics Committee
Accredited by the Health Research Council

Appendix D



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Spiritual development in a person living with HIV/AIDS in the Thai context

INFORMATION SHEET (Snowball recruitment)

Researcher Introduction

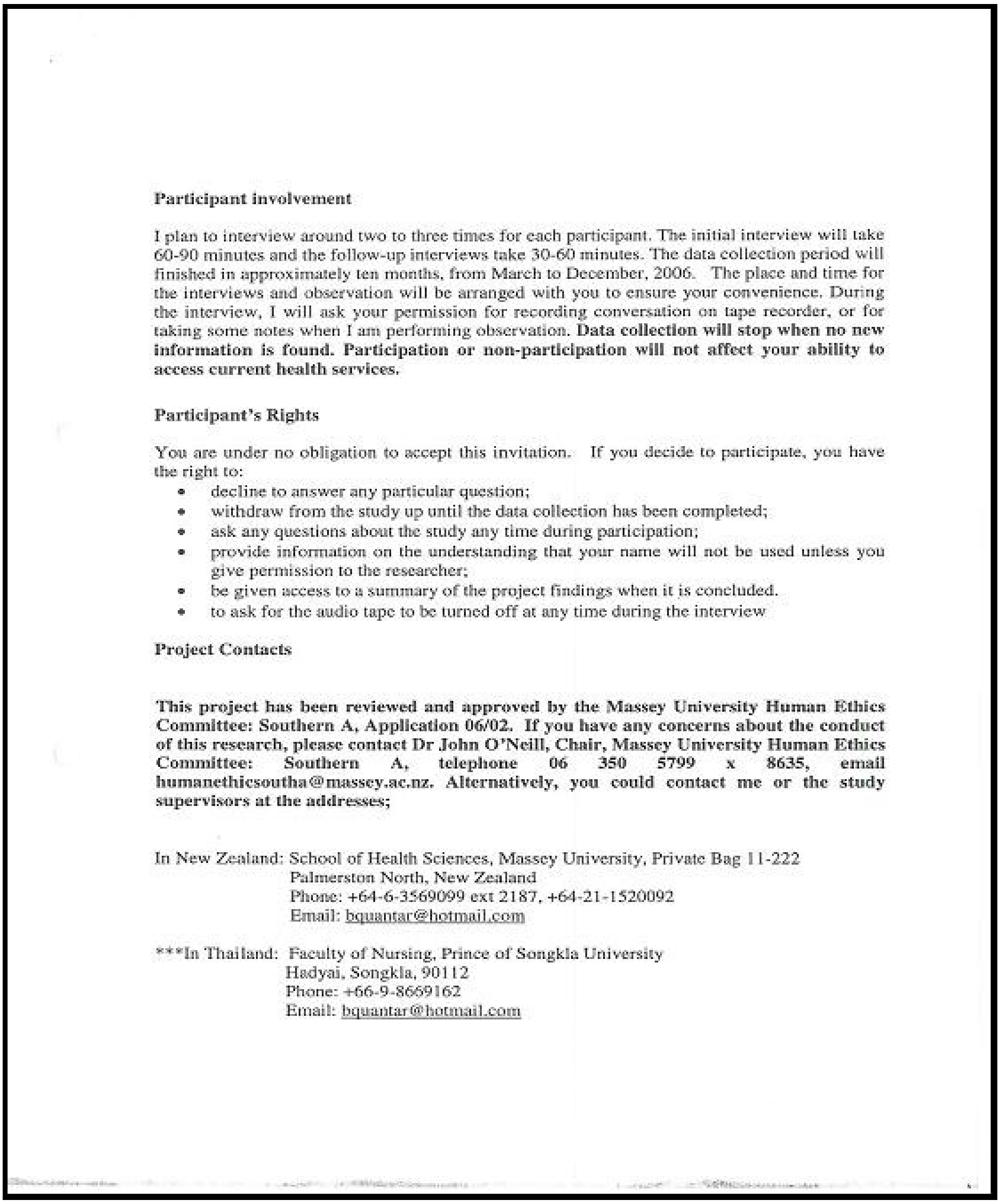
I am Quantar Balthip, a lecturer of the Faculty of Nursing, Prince of Songkla University, Hadyai, Songkla, Thailand. I am currently studying for a Doctoral degree in Nursing at the School of Health Sciences, Massey University, Palmerston North, New Zealand. The study supervisor in New Zealand is Professor Julie Boddy and the study supervisors in Thailand are Dr. Kittikorn Nilmanat and Assistant Professor Dr. Wipawee Knogin. Conducting research is a requirement to accomplish my doctoral degree. The research aims to increase understanding of the meanings of spirituality and understanding of the process of spiritual development.

Participant Recruitment

I intend to interview 30-50 people who have lived with HIV/AIDS for five years or more. I will continue interviewing people until no new information is discovered. **The criteria for participant selection are 1) people who are HIV-seropositive, 2) age 18 years or older, 3) accept that they are HIV infected persons, 4) living with HIV/AIDS for 5 years or more, 5) mentally alert and able to communicate in the Thai language, and 6) they are willing to participate. A friend who knows about this project has told you about the study. If you are interested to take part in the study, your friend will let me know.** Then, I will meet you and explain further information and gain your informed consent.

Project Procedures

The study involves interviews and observation of daily activities and social interaction with friends and families. Your interview transcripts and audiotapes, and any records/notes will be kept securely in a locked cabinet and will be separated from other information that could identify you. Audiotapes will either be returned to you if you request for them, or destroyed together with other information that identifies you in five years after the study is completed. The findings will be handled and analyzed by the researcher. Your interview will be transcribed and a copy shown to you for you to check for accuracy. The information then will be written as thesis and articles for publication. The findings of the study will be shared at conferences. The executive summary of the study will be sent to the hospitals and you. Participants will not be identified at any stage of this study or in the thesis or any reports, or presentation of the study.



Participant involvement

I plan to interview around two to three times for each participant. The initial interview will take 60-90 minutes and the follow-up interviews take 30-60 minutes. The data collection period will finished in approximately ten months, from March to December, 2006. The place and time for the interviews and observation will be arranged with you to ensure your convenience. During the interview, I will ask your permission for recording conversation on tape recorder, or for taking some notes when I am performing observation. **Data collection will stop when no new information is found. Participation or non-participation will not affect your ability to access current health services.**

Participant's Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

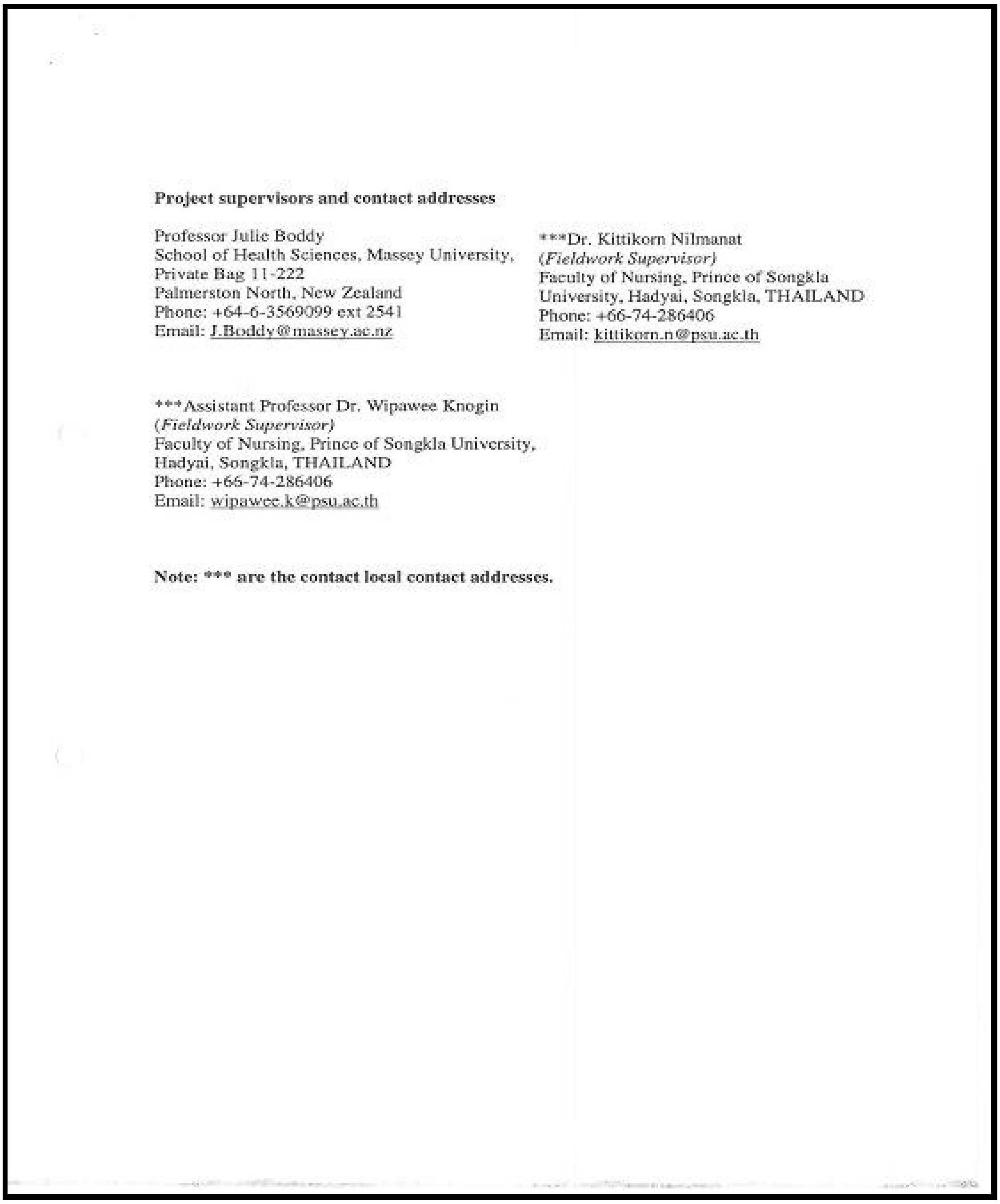
- decline to answer any particular question;
- withdraw from the study up until the data collection has been completed;
- ask any questions about the study any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the project findings when it is concluded.
- to ask for the audio tape to be turned off at any time during the interview

Project Contacts

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 06/02. If you have any concerns about the conduct of this research, please contact Dr John O'Neill, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 350 5799 x 8635, email humanethicsoutha@massey.ac.nz. Alternatively, you could contact me or the study supervisors at the addresses;

In New Zealand: School of Health Sciences, Massey University, Private Bag 11-222
Palmerston North, New Zealand
Phone: +64-6-3569099 ext 2187, +64-21-1520092
Email: bquantar@hotmail.com

***In Thailand: Faculty of Nursing, Prince of Songkla University
Hadyai, Songkla, 90112
Phone: +66-9-8669162
Email: bquantar@hotmail.com



Project supervisors and contact addresses

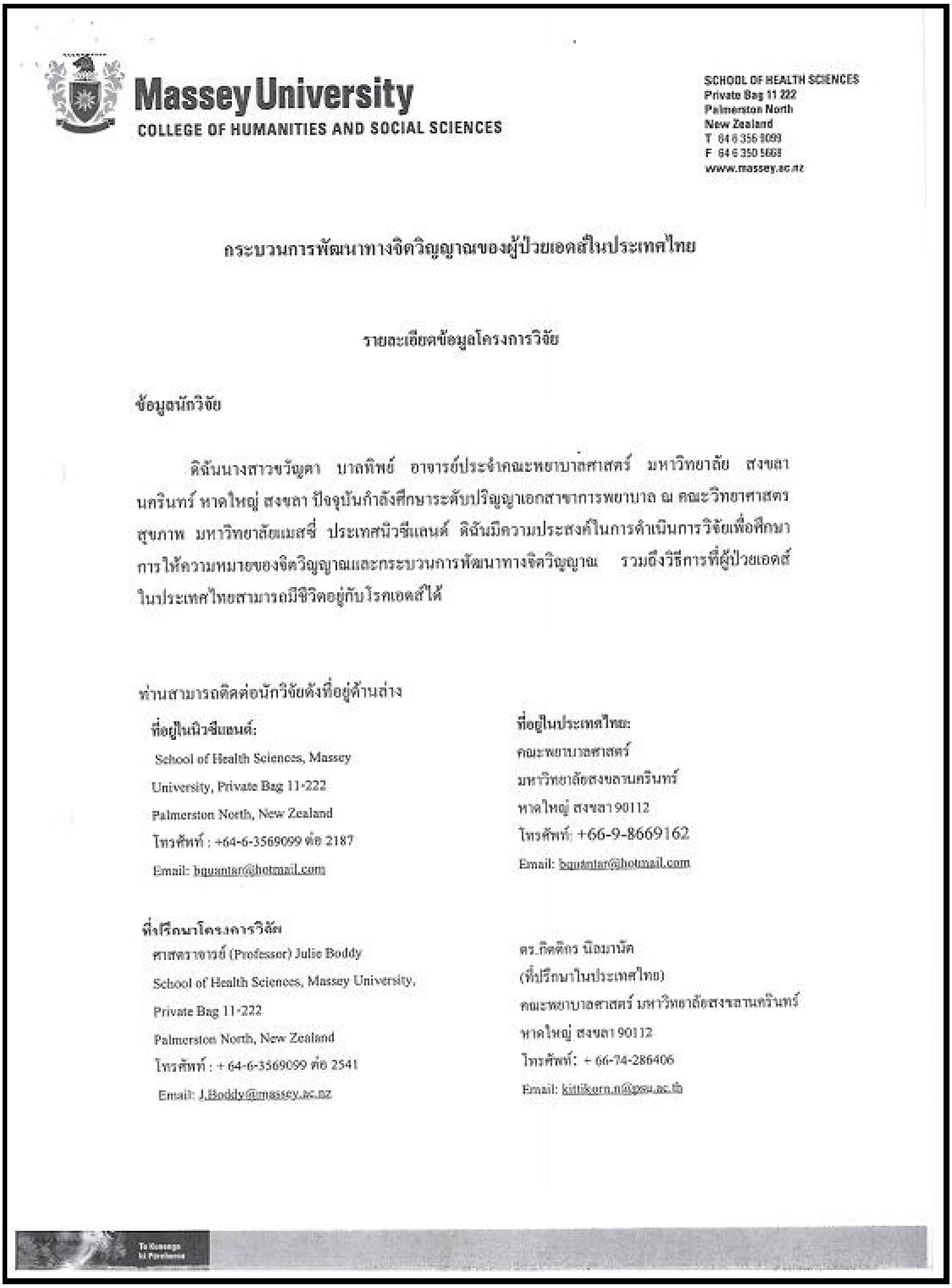
Professor Julie Boddy
School of Health Sciences, Massey University,
Private Bag 11-222
Palmerston North, New Zealand
Phone: +64-6-3569099 ext 2541
Email: J.Boddy@massey.ac.nz

***Dr. Kittikorn Nilmanat
(Fieldwork Supervisor)
Faculty of Nursing, Prince of Songkla
University, Hadyai, Songkla, THAILAND
Phone: +66-74-286406
Email: kittikorn.n@psu.ac.th

***Assistant Professor Dr. Wipawee Knogin
(Fieldwork Supervisor)
Faculty of Nursing, Prince of Songkla University,
Hadyai, Songkla, THAILAND
Phone: +66-74-286406
Email: wipawee.k@psu.ac.th

Note: * are the contact local contact addresses.**

Appendix E



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กระบวนการพัฒนาทางจิตวิญญาณของผู้ป่วยเอดส์ในประเทศไทย

รายละเอียดข้อมูลโครงการวิจัย

ข้อมูลนักวิจัย

ดิฉันนางสาวขวัญตา บาลทิพย์ อาจารย์ประจำคณะพยาบาลศาสตร์ มหาวิทยาลัย สงขลานครินทร์ หาดใหญ่ สงขลา ปัจจุบันกำลังศึกษาระดับปริญญาเอกสาขาการพยาบาล ณ คณะวิทยาศาสตรสุขภาพ มหาวิทยาลัยแมสซี่ ประเทศนิวซีแลนด์ ดิฉันมีความประสงค์ในการดำเนินการวิจัยเพื่อศึกษาการให้ความหมายของจิตวิญญาณและกระบวนการพัฒนาทางจิตวิญญาณ รวมถึงวิธีการที่ผู้ป่วยเอดส์ในประเทศไทยสามารถมีชีวิตอยู่กับโรคเอดส์ได้

ท่านสามารถติดต่อนักวิจัยดังที่อยู่ด้านล่าง

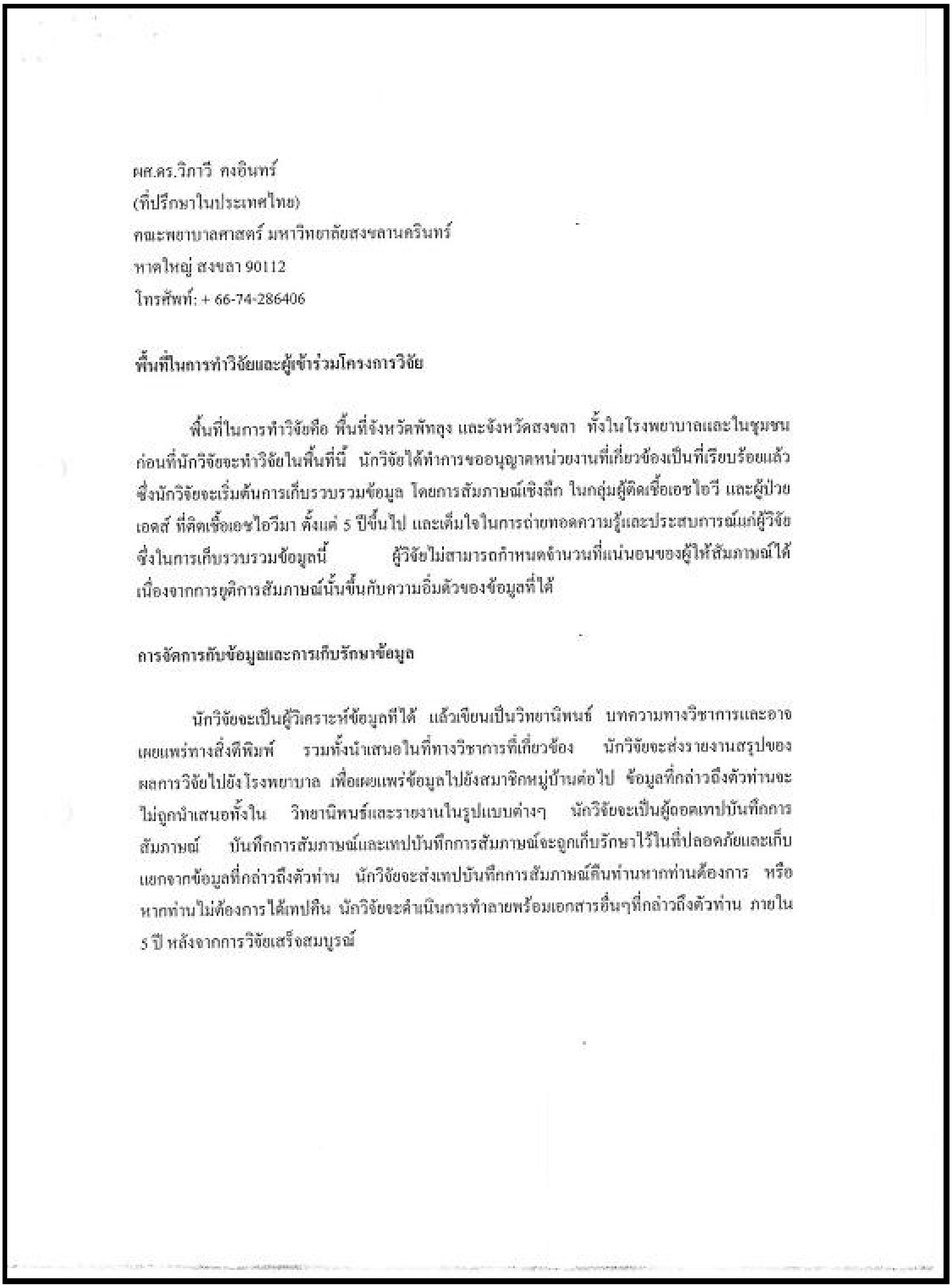
ที่อยู่ในนิวซีแลนด์:
School of Health Sciences, Massey
University, Private Bag 11-222
Palmerston North, New Zealand
โทรศัพท์ : +64-6-3569099 ต่อ 2187
Email: bquantar@hotmail.com

ที่อยู่ในประเทศไทย:
คณะพยาบาลศาสตร์
มหาวิทยาลัยสงขลานครินทร์
หาดใหญ่ สงขลา 90112
โทรศัพท์: +66-9-8669162
Email: bquantar@hotmail.com

ที่ปรึกษาโครงการวิจัย
ศาสตราจารย์ (Professor) Julie Boddy
School of Health Sciences, Massey University,
Private Bag 11-222
Palmerston North, New Zealand
โทรศัพท์ : + 64-6-3569099 ต่อ 2541
Email: J.Boddy@massey.ac.nz

ดร.กิตติกร นิลมานัต
(ที่ปรึกษาในประเทศไทย)
คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์
หาดใหญ่ สงขลา 90112
โทรศัพท์: + 66-74-286406
Email: kittikorn.n@psu.ac.th

Te Kunenga ki Pūrehuroa



ผศ.ดร.วิภาวี คงอินทร์
(ที่ปรึกษาในประเทศไทย)
คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์
หาดใหญ่ สงขลา 90112
โทรศัพท์: + 66-74-286406

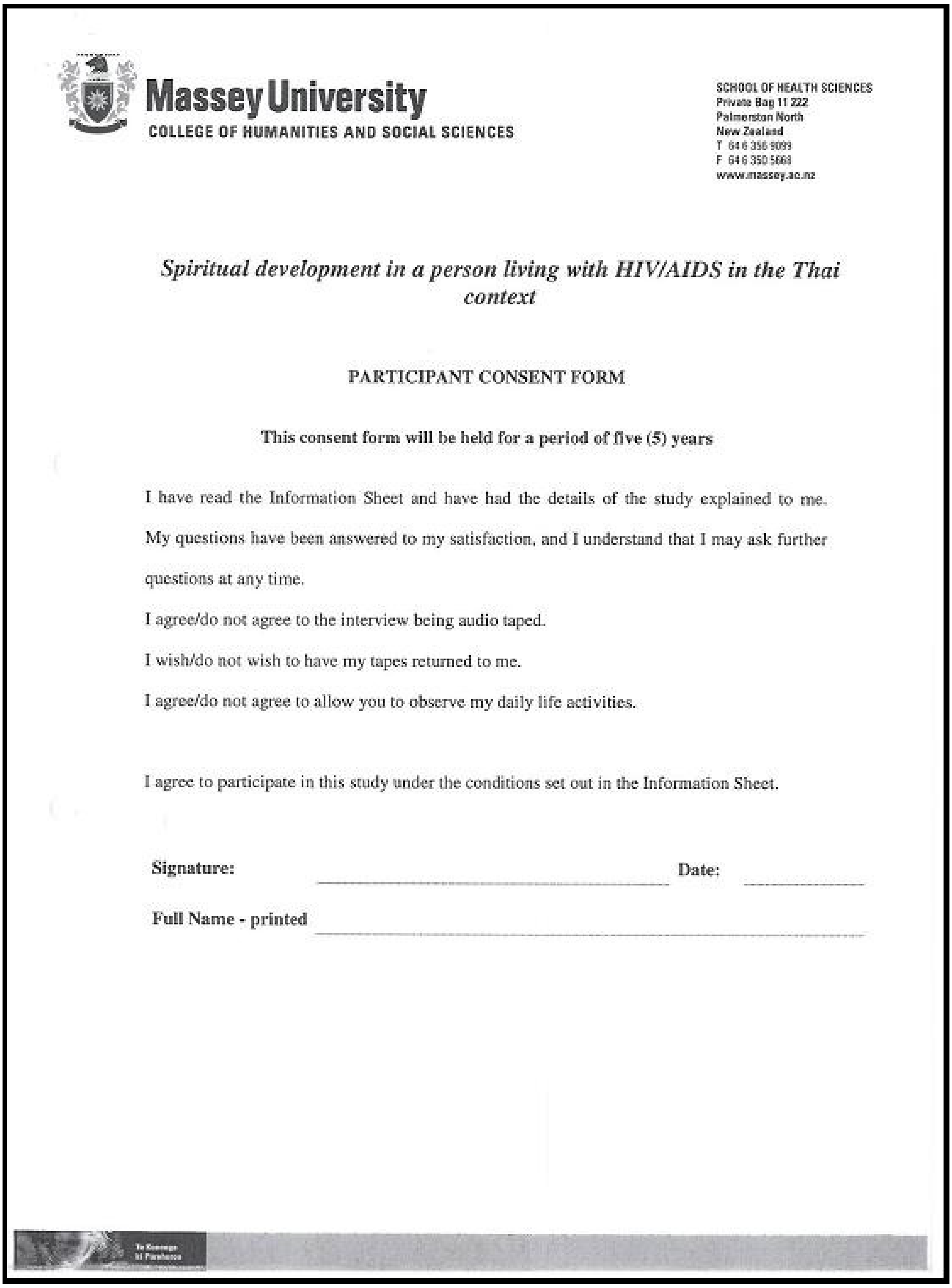
พื้นที่ในการทำวิจัยและผู้เข้าร่วมโครงการวิจัย

พื้นที่ในการทำวิจัยคือ พื้นที่จังหวัดพัทลุง และจังหวัดสงขลา ทั้งในโรงพยาบาลและในชุมชน ก่อนที่นักวิจัยจะทำวิจัยในพื้นที่นี้ นักวิจัยได้ทำการขออนุญาตหน่วยงานที่เกี่ยวข้องเป็นที่เรียบร้อยแล้ว ซึ่งนักวิจัยจะเริ่มต้นการเก็บรวบรวมข้อมูล โดยการสัมภาษณ์เชิงลึก ในกลุ่มผู้ติดเชื้อเอชไอวี และผู้ป่วยเอดส์ ที่ติดเชื้อเอชไอวีมา ตั้งแต่ 5 ปีขึ้นไป และเต็มใจในการถ่ายทอดความรู้และประสบการณ์แก่ผู้วิจัย ซึ่งในการเก็บรวบรวมข้อมูลนี้ ผู้วิจัยไม่สามารถกำหนดจำนวนที่แน่นอนของผู้ให้สัมภาษณ์ได้ เนื่องจากการยุติการสัมภาษณ์นั้นขึ้นกับความอิ่มตัวของข้อมูลที่ได้

การจัดการกับข้อมูลและการเก็บรักษาข้อมูล

นักวิจัยจะเป็นผู้วิเคราะห์ข้อมูลที่ได้ แล้วเขียนเป็นวิทยานิพนธ์ บทความทางวิชาการและอาจเผยแพร่ทางสิ่งตีพิมพ์ รวมทั้งนำเสนอในที่ทางวิชาการที่เกี่ยวข้อง นักวิจัยจะส่งรายงานสรุปของผลการวิจัยไปยังโรงพยาบาล เพื่อเผยแพร่ข้อมูลไปยังสมาชิกหมู่บ้านต่อไป ข้อมูลที่กล่าวถึงตัวท่านจะไม่ถูกนำเสนอทั้งใน วิทยานิพนธ์และรายงานในรูปแบบต่างๆ นักวิจัยจะเป็นผู้ถอดเทปบันทึกการสัมภาษณ์ บันทึกการสัมภาษณ์และเทปบันทึกการสัมภาษณ์จะถูกเก็บรักษาไว้ในที่ปลอดภัยและเก็บแยกจากข้อมูลที่กล่าวถึงตัวท่าน นักวิจัยจะส่งเทปบันทึกการสัมภาษณ์คืนท่านหากท่านต้องการ หรือหากท่านไม่ต้องการได้เทปคืน นักวิจัยจะดำเนินการทำลายพร้อมเอกสารอื่นๆที่กล่าวถึงตัวท่าน ภายใน 5 ปี หลังจากการวิจัยเสร็จสมบูรณ์

Appendix F



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Spiritual development in a person living with HIV/AIDS in the Thai context

PARTICIPANT CONSENT FORM

This consent form will be held for a period of five (5) years

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being audio taped.

I wish/do not wish to have my tapes returned to me.

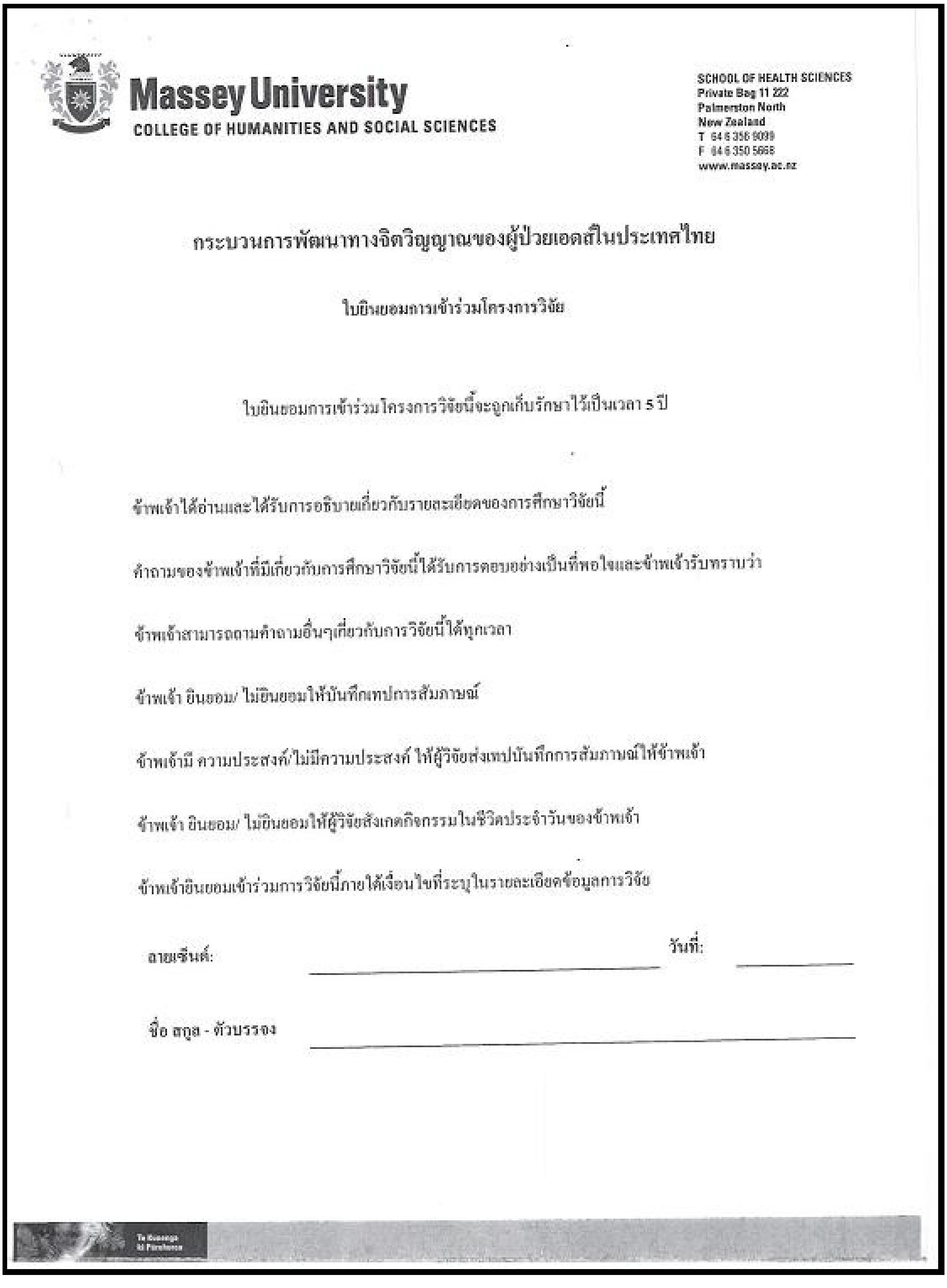
I agree/do not agree to allow you to observe my daily life activities.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: ______________________________ **Date:** ______________

Full Name - printed ____

Appendix G



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กระบวนการพัฒนาทางจิตวิญญาณของผู้ป่วยเอดส์ในประเทศไทย

ใบยินยอมการเข้าร่วมโครงการวิจัย

ใบยินยอมการเข้าร่วมโครงการวิจัยนี้จะถูกเก็บรักษาไว้เป็นเวลา 5 ปี

ข้าพเจ้าได้อ่านและได้รับการอธิบายเกี่ยวกับรายละเอียดของการศึกษาวิจัยนี้

คำถามของข้าพเจ้าที่มีเกี่ยวกับการศึกษาวิจัยนี้ได้รับการตอบอย่างเป็นที่พอใจและข้าพเจ้ารับทราบว่า

ข้าพเจ้าสามารถถามคำถามอื่นๆเกี่ยวกับการวิจัยนี้ได้ทุกเวลา

ข้าพเจ้า ยินยอม/ ไม่ยินยอมให้บันทึกเทปการสัมภาษณ์

ข้าพเจ้ามี ความประสงค์/ไม่มีความประสงค์ ให้ผู้วิจัยส่งเทปบันทึกการสัมภาษณ์ให้ข้าพเจ้า

ข้าพเจ้า ยินยอม/ ไม่ยินยอมให้ผู้วิจัยสังเกตกิจกรรมในชีวิตประจำวันของข้าพเจ้า

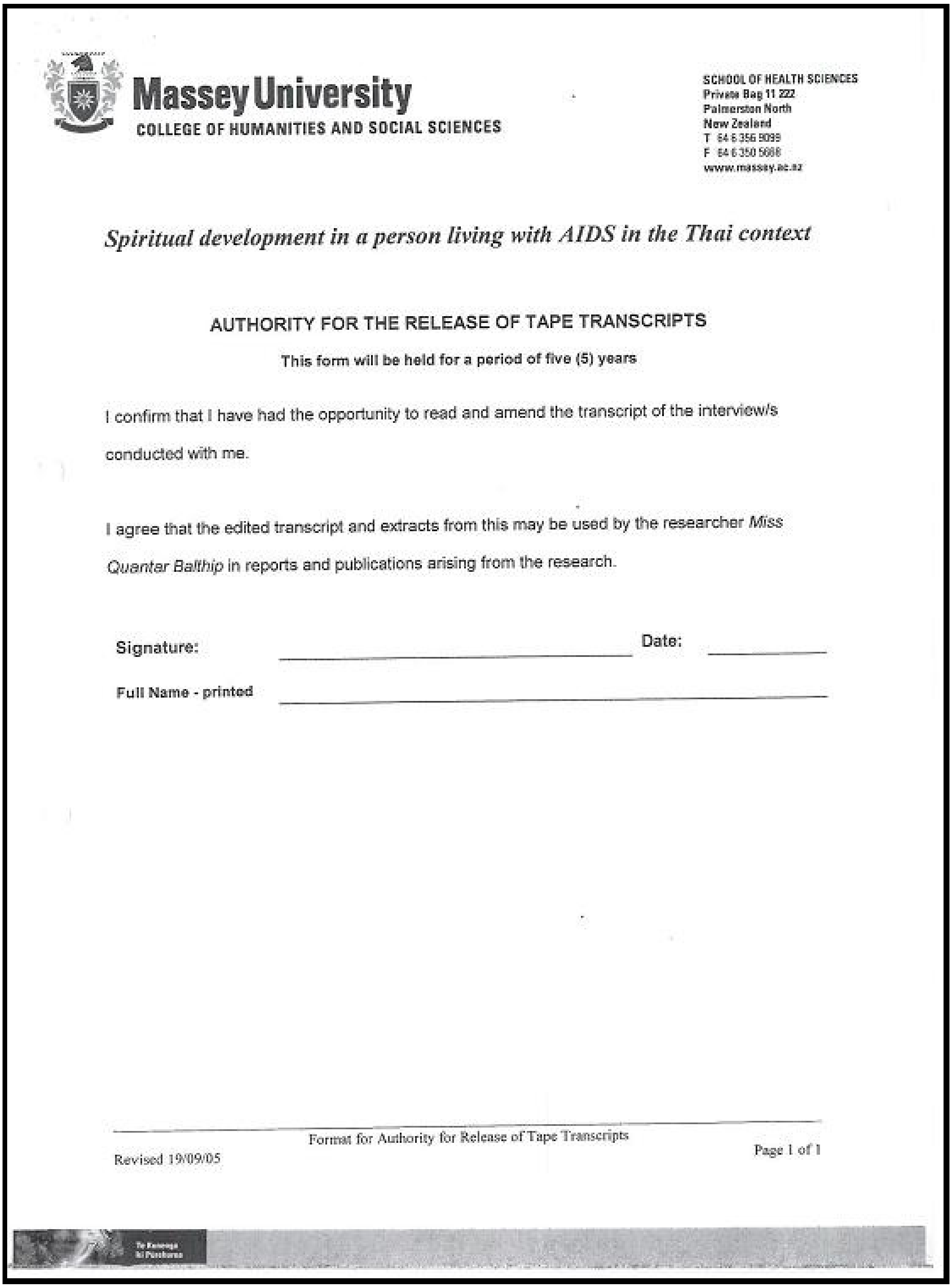
ข้าพเจ้ายินยอมเข้าร่วมการวิจัยนี้ภายใต้เงื่อนไขที่ระบุในรายละเอียดข้อมูลการวิจัย

ลายเซ็นต์: ______________________ วันที่: __________

ชื่อ สกุล - ตัวบรรจง ______________________

Te Kunenga ki Pūrehuroa

Appendix H



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Spiritual development in a person living with AIDS in the Thai context

AUTHORITY FOR THE RELEASE OF TAPE TRANSCRIPTS

This form will be held for a period of five (5) years

I confirm that I have had the opportunity to read and amend the transcript of the interview/s conducted with me.

I agree that the edited transcript and extracts from this may be used by the researcher *Miss Quantar Balthip* in reports and publications arising from the research.

Signature: ______________________________ **Date:** ____________

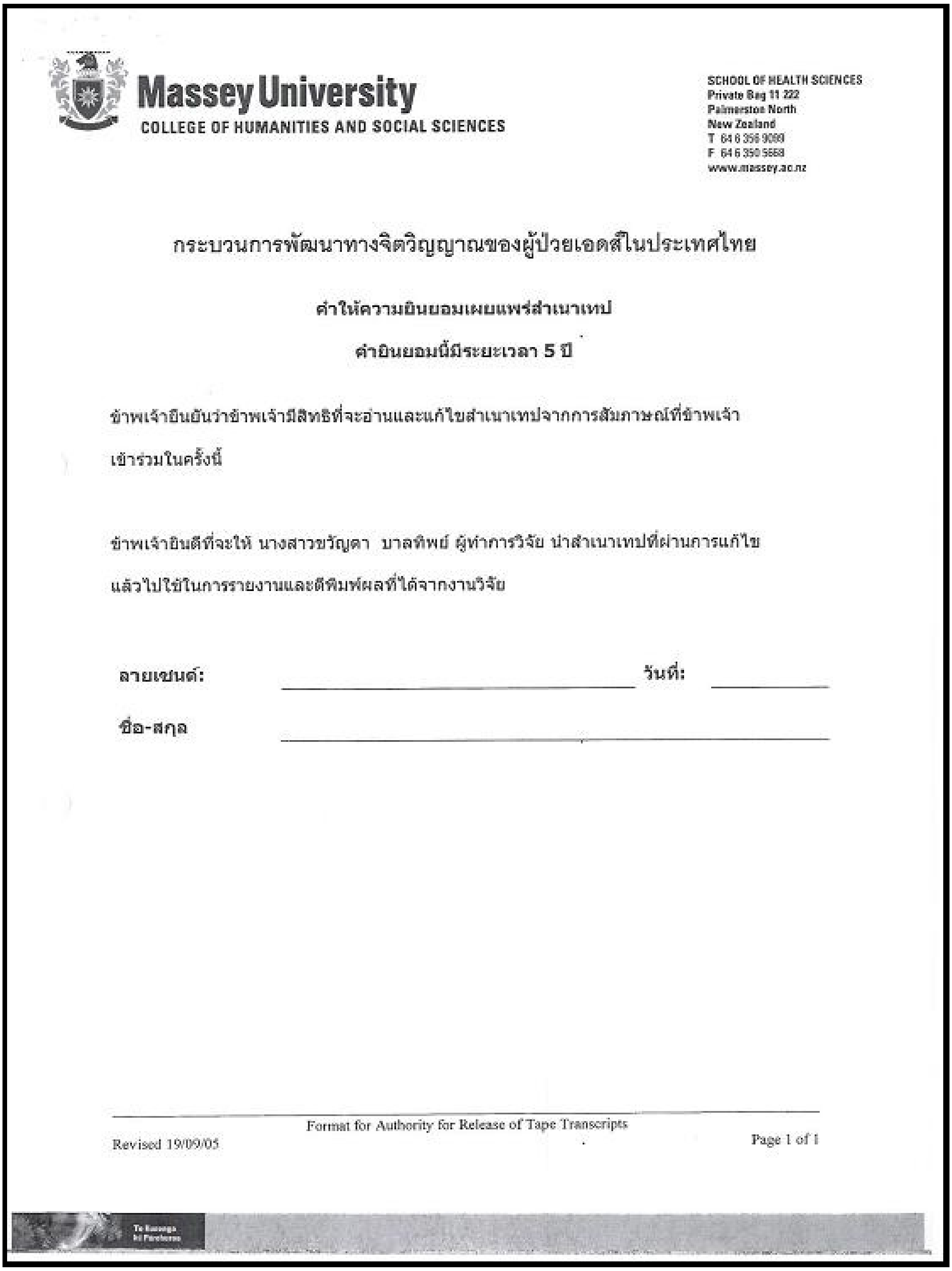
Full Name - printed ____

Format for Authority for Release of Tape Transcripts

Revised 19/09/05

Page 1 of 1

Appendix I



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กระบวนการพัฒนาทางจิตวิญญาณของผู้ป่วยเอดส์ในประเทศไทย

คำให้ความยินยอมเผยแพร่สำเนาเทป

คำยินยอมนี้มีระยะเวลา 5 ปี

ข้าพเจ้ายืนยันว่าข้าพเจ้ามีสิทธิที่จะอ่านและแก้ไขสำเนาเทปจากการสัมภาษณ์ที่ข้าพเจ้าเข้าร่วมในครั้งนี้

ข้าพเจ้ายินดีที่จะให้ นางสาวขวัญดา บาลทิพย์ ผู้ทำการวิจัย นำสำเนาเทปที่ผ่านการแก้ไขแล้วไปใช้ในการรายงานและตีพิมพ์ผลที่ได้จากงานวิจัย

ลายเซนต์: ______________________ **วันที่:** __________

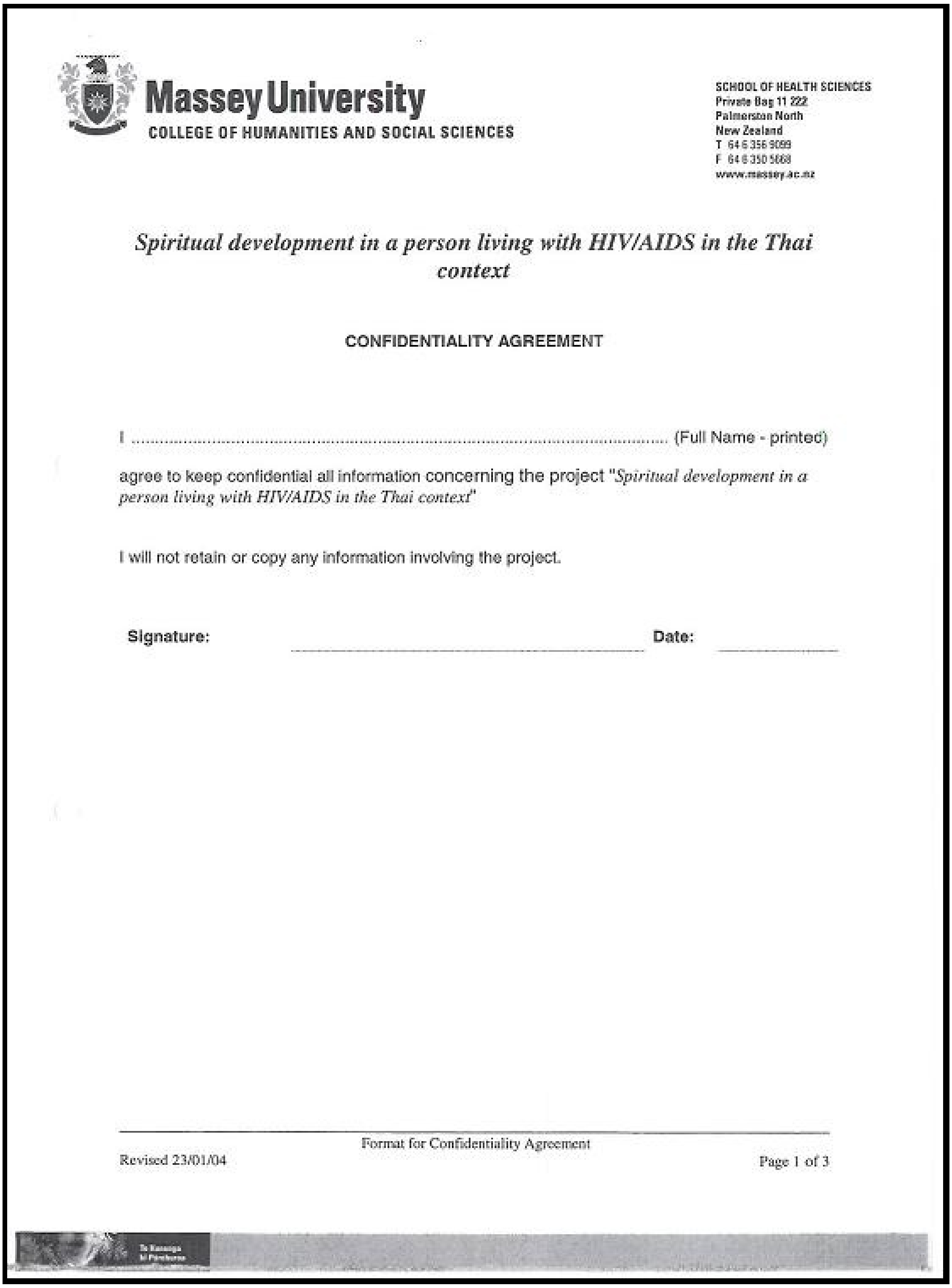
ชื่อ-สกุล ______________________

Format for Authority for Release of Tape Transcripts

Revised 19/09/05

Page 1 of 1

Appendix J



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Spiritual development in a person living with HIV/AIDS in the Thai context

CONFIDENTIALITY AGREEMENT

I .... (Full Name - printed)

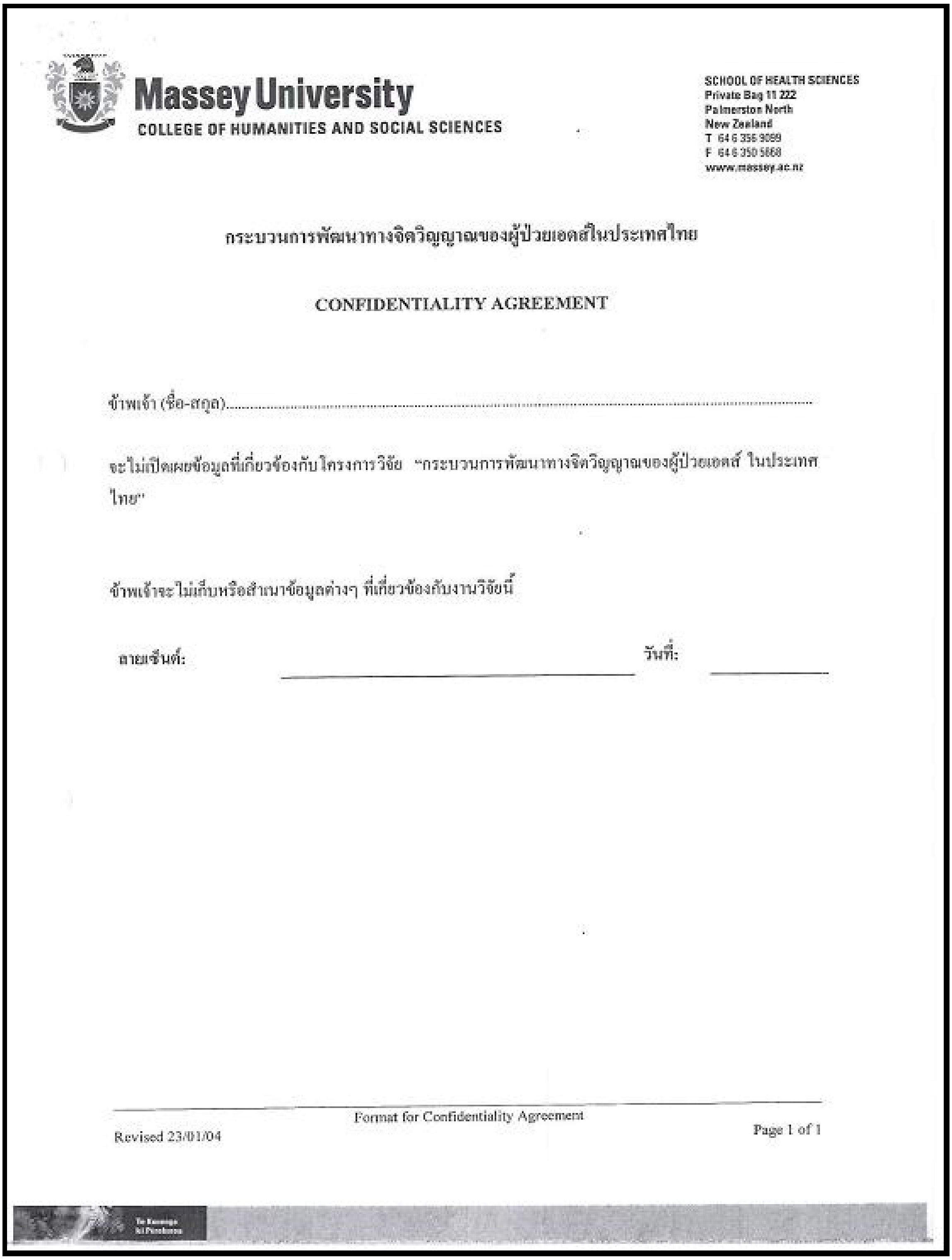
agree to keep confidential all information concerning the project "*Spiritual development in a person living with HIV/AIDS in the Thai context*"

I will not retain or copy any information involving the project.

Signature: ______________________________ **Date:** ______________

Format for Confidentiality Agreement
Revised 23/01/04 Page 1 of 3

Appendix K



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กระบวนการพัฒนาทางจิตวิญญาณของผู้ป่วยเอดส์ในประเทศไทย

CONFIDENTIALITY AGREEMENT

ข้าพเจ้า (ชื่อ-สกุล)..

จะไม่เปิดเผยข้อมูลที่เกี่ยวข้องกับโครงการวิจัย "กระบวนการพัฒนาทางจิตวิญญาณของผู้ป่วยเอดส์ ในประเทศไทย"

ข้าพเจ้าจะไม่เก็บหรือสำเนาข้อมูลต่างๆ ที่เกี่ยวข้องกับงานวิจัยนี้

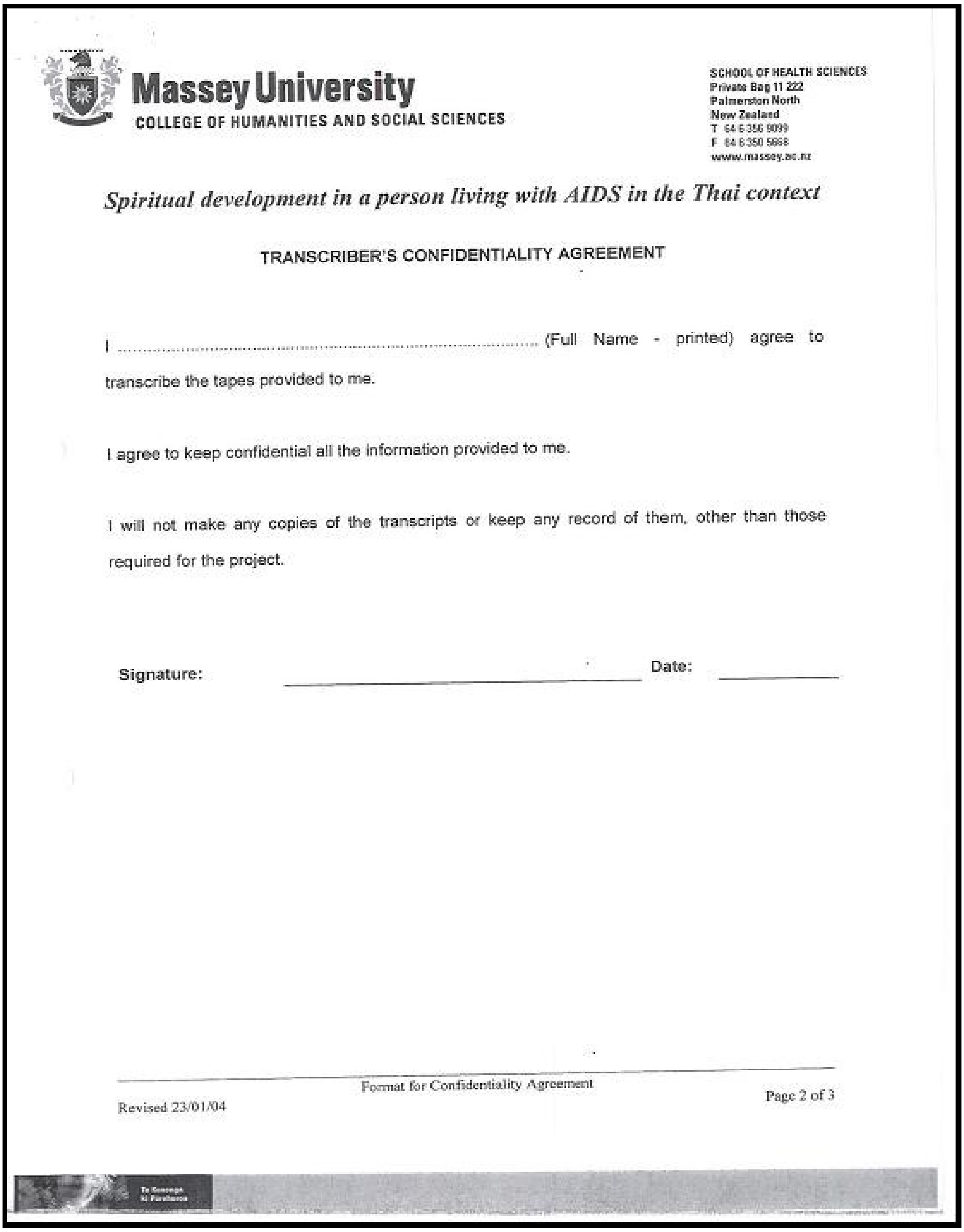
ลายเซ็นต์: ______________________ วันที่: ____________

Format for Confidentiality Agreement

Revised 23/01/04

Page 1 of 1

Appendix L



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Spiritual development in a person living with AIDS in the Thai context

TRANSCRIBER'S CONFIDENTIALITY AGREEMENT

I .... (Full Name - printed) agree to transcribe the tapes provided to me.

I agree to keep confidential all the information provided to me.

I will not make any copies of the transcripts or keep any record of them, other than those required for the project.

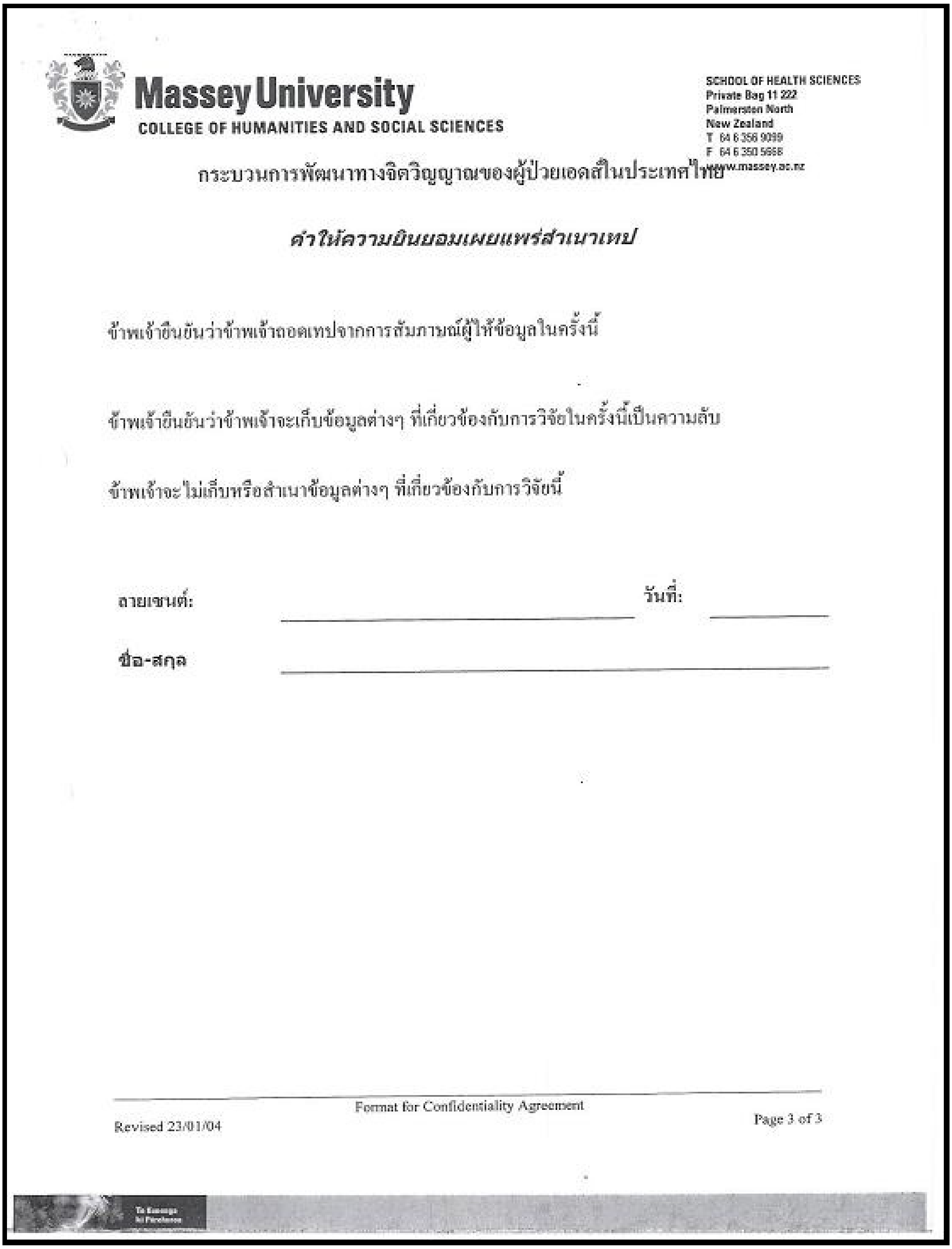
Signature: ______________________________ **Date:** ____________

Format for Confidentiality Agreement

Revised 23/01/04

Page 2 of 3

Appendix M



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กระบวนการพัฒนาทางจิตวิญญาณของผู้ป่วยเอดส์ในประเทศไทย

คำให้ความยินยอมเผยแพร่สำเนาเทป

ข้าพเจ้ายืนยันว่าข้าพเจ้าถอดเทปจากการสัมภาษณ์ผู้ให้ข้อมูลในครั้งนี้

ข้าพเจ้ายืนยันว่าข้าพเจ้าจะเก็บข้อมูลต่างๆ ที่เกี่ยวข้องกับการวิจัยในครั้งนี้เป็นความลับ

ข้าพเจ้าจะไม่เก็บหรือสำเนาข้อมูลต่างๆ ที่เกี่ยวข้องกับการวิจัยนี้

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Revised 23/01/04

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Te Kunenga ki Pūrehuroa

Appendix N (a)

Relationships: a main condition in Finding meaning in life of person living with HIV in a Thai context[27]

Abstract

People living with AIDS are faced with an intensity of suffering such as loss of hope, loss of life, loss of self and loss of significant person that can lead to the spiritual distress. Nevertheless, some HIV/AIDS patients have successfully to overcome life crisis by "finding a meaning in life".

The process of finding a meaning in life is one category of the study "the journey of finding a peaceful in life in person living with HIV/AIDS in a Thai context". Thirty three participants were selected in this study. The study design was following the Grounded Theory methodology in particular data collection and data analysis.

The result illustrates that the process of finding a meaning in life is a turning point between living and dying. The main reason underpins of finding a meaning in life is "having relation" with oneself and others by asking a question such as "who I have to live for?" The consequence of having relationship with oneself and others both receiving support and giving support for others attribute to the increasing sense of self value that lead to finding a meaning in life. Once, the participants perceived their meaning of living, finally, they desire to live or will to live.

Conclusion, this study confirms that having "relationship" play a vital role in person living with HIV in order to find a meaning in life and maintain their life.

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[27] This paper had been presented in 4th International Conference on Spirituality and mental health on April 23 and 24, 2009 at Saint Paul University, 223 Main Street, Ottawa, Ontario, K1S 1C4, Canada.

Appendix N (b)

Living well and dying well: the role of religion in people living with HIV in a Thai context[28]

Abstract

This paper examines the significant role of religion in enabling people living with HIV/AIDS in the Thai context to live with harmony, happiness and serenity or *kwarm sa-ngob jai*. These findings are drawn from a larger grounded theory study that explored the meaning of spirituality and the process of spiritual development in 33 adult Southern Thai participants - twenty-eight were Buddhist and five were Muslim - who had lived with HIV/AIDS for five years or more. Although, participants perceived that HIV/AIDS had "turned their lives upside down", understanding and accepting the truth about life, illness and death or

kwamjingkongcheewit, belief in the law of karma and belief in life after death that was grounded in religion doctrines, enhanced their ability to find real meaning in their lives, thus enabling them to obtain peace and harmony in living.

Keywords*: religion, chronic illness, grounded theory, spiritual harmony, HIV/AIDS*

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[28] This paper had been presented in International Conference on Death, Grief and Bereavement Conference on May 31-June 3, 2009 at Wisconsin University, LaCrosse , US.

Appendix N (c)

Achieving Harmony of Mind: an essential process in living with HIV/AIDS[29]

Abstract

This paper illustrates the process of development of mind in enabling people living with HIV/AIDS in the Thai context to live with harmony, happiness and serenity or *kwarm sa-ngob jai*. These findings are drawn from a larger grounded theory study that explored the meaning of spirituality and the process of spiritual development in 33 adult Southern Thai participants. Twenty-eight were Buddhist and five were Muslim; all had lived with HIV/AIDS for five years or more. Participants initially perceived that HIV/AIDS had "turned their lives upside down" and led them to being unwilling to live. However, over time participants developed an understanding and acceptance of the truth about life or *kwamjingkongcheewit* that is grounded in religion doctrines, and this enhanced their ability to find an ultimate meaning in their lives. Thus understanding and acceptance of the truth about life guided them to live with contentment including living with loving kindness, compassion, and altruism and living with self-sufficiency as promoted by the King of Thailand. As a result, they obtained peace and harmony in living.

Knowledge of this study may help nurses to create a therapeutic exchange with people living with HIV/AIDS by promoting the ways of living which bring contentment; this may include encouraging them to (re)connect with religious teachings. All people can find peace in life and receive the positive outcomes of peace if they know how to live with self-sufficiency, morality, loving kindness, compassion, and altruism.

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[29] This paper had been presented in International Conference on Diversity and Dynamic in Nursing Science and Art" on April 7-9, 2010 at Phuket Graceland Resort and Spa, Phuket, Thailand.