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Achieving Harmony of Mind

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

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

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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 (kwarsa-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.
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
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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.

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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-n gob: 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.
Learn 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.

**Precept:**

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,

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

R

\textit{Ru pa}: Body, matter or physical phenomena (Sutheravut, 2007)

S

\textit{Sa buy jai}: The state of mind where you are happy and relaxed.

\textit{Sa-ngob jai}: A peace of mind

\textit{Sa thi}: Mindfulness

\textit{Sia jai}: Sadness

\textit{Sin wang}: A mind that feels a sense of hopeless

\textit{Su}: A mind that feels strong and able to face challenge and face with any situation or fight with any situation.

\textit{Suk jai}: A happiness of mind

T

\textit{Tam Jai}: To accept, to calm down

\textit{Tam dee dai dee, tam sure dai sure}: If people do a good deed, they will also receive a good deed in return.

\textit{Tao kae}: A rich person. Normally, it refers to Chinese people who are rich or have a business.

\textit{Tor jai or Toe tare jai}: A feeling of distress or giving up that relates to a feeling of hopelessness.

\textit{Tuk jai}: The mind experiences the feeling of giving up and/or wanting to give up, distress, and suffering.

U

\textit{U bek kha or u pek kha or epeksha}: Equanimity

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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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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.