Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.
FROM EXPERIENCING SOCIAL DISGUST

TO PASSING AS NORMAL:

SELF-CARE PROCESSES AMONG

THAI PEOPLE SUFFERING FROM AIDS

A thesis presented in fulfillment of the requirements for the degree of

Doctor of Philosophy

In

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2008
AIDS is a chronic disease that seriously affects health, emotions, social relations and household economy. People living with HIV/AIDS experience great suffering, stigmatisation and discrimination from other people around them because they know that it is incurable, contagious, evokes social disgust and is a complex disease requiring life-long self-care. This researcher explored ways people with HIV/AIDS take care of their health and manage their lives in the context of stigma and discrimination. A grounded theory study was conducted with 30 participants with HIV/AIDS, in Mahasarakham Province, Thailand. Participants were recruited from an HIV/AIDS day care clinic and by snowball sampling. Data were gathered through in-depth interviews, participant observations and field notes made during home visits. Interviews were tape recorded, then transcribed verbatim.

“From experiencing social disgust to passing as normal” was generated inductively from the data as the basic social psychological process of Thai people living with HIV/AIDS. From experiencing social disgust to passing as normal comprised four categories: being HIV/AIDS, making choices, keeping well and feeling empowered. The category “being HIV/AIDS”- discovering the meaning of having HIV/AIDS, comprises four concepts: being diagnosed with HIV/AIDS, being stigmatised, suffering, and learning about HIV/AIDS. The category “making choices”- to live a normal life, involves three concepts: avoiding unhappy situations, getting remarried and seeking support. The category “keeping well”- maintaining emotional and physical health, includes eight concepts: religious practices, keeping a cheerful mind, self-treatment, taking care of the body, keeping the environment clean to prevent getting germs, healthy behaviours, getting healthcare services, and attention to, and concern about, medication. The last category “feeling empowered”- personal and social acceptance of illness, includes eight concepts: being encouraged, acknowledging the disease, social acceptance, tamjai, feeling proud of self, feeling good about life, feeling lucky and having hope.
In the context of northeastern Thailand, successful management of HIV/AIDS was underpinned by participants making a transition from “experiencing social disgust” to “passing as normal” within their communities. The desire to live a normal life despite having HIV/AIDS motivated participants to undertake effective self-care in order to remain symptom free (thus avoiding visible signs of the disease), and to selectively disclose their illness to avoid the ongoing risk of stigma and discrimination.

The findings of this study are useful in that they will provide Thai health professionals with a clearer conceptualisation of self-care among the Thai population. An inductively derived theory of self-care among Thai with HIV/AIDS can be applied and integrated by health professionals into the self-care models for people living with HIV/AIDS including models used in nursing education, research and practice.
I would like to acknowledge first, the participants and their families who shared their experiences with me and gave insights regarding their self-care managing of their lives with HIV/AIDS. I would like to thank the health professionals, especially the nurses at the HIV/AIDS day care clinic, Mahasarakham hospital, particularly, Ms. Kasemukda Chansiri, the head nurse in this clinic, who helped recruit the participants and facilitated access to health records and other information during this study. Thanks to Mahasarakham hospital for allowing me to conduct this study. Without the participants and Mahasarakham hospital this research could not have been completed. I hope that the results from this study will benefit people living with HIV/AIDS in managing and living with the disease; also that the model can be used in nursing education in Thailand.

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

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

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

## ACRONYMS

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

Thai

A

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

Amphur: District

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

B

Baan rom yen: Cool shade house

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

Bai nard: The name of a leaf

Bai yuow: The name of a leaf

Bouw waan: Diabetes mellitus

C

Cham: An old man chosen as a spirit medium

Chan: I, myself, oneself

Changwat: Province

Chue ra nai parg: Oral fungus

D

Dakie: The name of toothpaste (a particular brand)

E

Ethon: Pity

F

Faa tha laai jone: Name of plant

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

G

Gue sawat: Herpes

H

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

I

Isaan: Northeast

J

Jai berk ban: Cheerful mind

K

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

Karma khow: Old karma

Ka ra oo kae: Sing a song

Khon leaw: Bad person

Khum lung jai: Encouragement

King amphur: Minor district

Kin poa: Enough eating

Kuam done lo hid sung: Hypertension

Kun: Itchy

M

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

Matahayom seuksa: Secondary school

Mee kah: Valuable

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

Mor dau: Fortune teller

Mor ngau: Snake healer

Mor naam man: Oil healer

Mor pern ethon chan: Nurse took pity on me

Mor paw: Blow healer

Mor tham: Magic healer

Muang: City

Mubaan: Village

Muu dip: Raw pork
N

Nah kluu: Fearful

Nah la ay: Shameful

Namjai: Spirit

Nam ya buan parg: Antiseptic solution

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

Norn poa: Enough sleeping

Nue dip: Raw beef

O

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

P

Pah pan phae: Bandage

Phii: Spirit ghost

Phii paa: The spirit of the forest

Phu ying ha gin: Sex worker or prostitute

Plong: Accepting situation

Ploy mun pai: Let it go

Prathom seuksa: Primary school

Puad tong: Abdominal pain

R

Roke AIDS: AIDS disease

Roke tid tor: Communicable disease

Roke tid chue chuey oo gard: Opportunistic disease

Ron nai: Glossitis

Ruk sa bor souw: Incurable

Rungkiat: Disgust

S

Sa aad: Clean

Sabai jai: Easy mind, healthy mind
Samoon prai: Herbal medicine
Samson: Promiscuous or promiscuity
Samson tang pase: Promiscuous sex
Sa tha nee a na mai: Health centre
Shampoo: Hair cleaning
Sok ka pok: Dirty
Suad mon: Praying
Sungkom rungkiat: Social disgust

T
Tad: The four elements includes earth (din), water (naam), wind (lom) and fire (fai)
Taay wai: Expect to die (die soon)
Tambon: Sub-district
Tam boon: Making merit
Tam jai: Make mind up
Tiffy: The name of medicine (anti-cold)
Tod pah pa: Robe-giving ceremony to the monks
Tong kin suk: Eating cooked food
Tong taay nae: Must die for sure
Ton ta krai hom: The name of a tree
Tum: Papulae
Tum chua dai chua: Do evil will receive evil
Tum dee dai dee: Do good will receive good

U
Ugsape: Inflammation

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

W
Wan na rok pord: Pulmonary tuberculosis
Wat: Temple

Y

Yaan taay: Afraid to die

Ya: Medicine

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

Ya muad gaae puad: Anti-ache by rubbing

Ya pa ra: Paracetamol medicine

Ya pong guun laee ruk sa: Preventive and curative medicine

Ya samoon prai Thai: Thai traditional herb medicine

Ya taan virus: Antiretroviral medicine

Yay: Grandmother

Z

Zap Zap: Very delicious
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