

**THE IMPACT OF HIV/AIDS:
A PARTICIPATORY ACTION RESEARCH
STUDY TO EXPLORE WHAT CAN BE DONE TO ASSIST
THAI FAMILIES WHEN CHILDREN ARE ORPHANED**

JURAPORN TANGPUKDEE

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STUDY TO EXPLORE WHAT CAN BE DONE TO ASSIST
THAI FAMILIES WHEN CHILDREN ARE ORPHANED**

Submitted by

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Qualifications

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Faculty of Health

The University of Newcastle, NSW, Australia

Statement of Originality

The thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to this copy of my thesis, when deposited in the University Library, being made available for loan and photocopying subject to the provisions of the Copyright Act 1968.

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Statement of Authorship

I hereby certify that the work embodied in this thesis contains the published papers of which I am a joint author. I have included as part of the thesis a written statement, endorsed by my supervisors, attesting to my contribution to the joint publications.

Signature of Candidate

Date 7 December 2011

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Dedication

ฉันขออุทิศความดีงามจากการศึกษานี้ให้ คุณแม่ อารยา แซ่ต่าง
ผู้ที่เฝ้าพร่ำสอนฉันเห็นคุณค่าของการศึกษาและกล่อมเกลาให้ฉันเป็นผู้มีความคิดรู้ด้วยความรักที่ไม่มีเงื่อนไขใครมีแ
ก่เพียงพันธุการแห่งรักของแม่ที่มีต่อลูกเท่านั้น

ขอบพระคุณ ที่แม่เป็นแม่ผู้ให้มาทั้งชีวิต

ขอบพระคุณแม่ ที่แม่มอบชีวิตทั้งดงามให้แก่ฉัน

ขอบพระคุณแม่ ที่แม่เป็นทุกสิ่งทุกอย่าง ในชีวิตของลูกคนนี้

ขอบพระคุณแม่ ที่แม่ประทับประคองลูก ในทุกวันที่เหนื่อยล้าและท้อแท้ใจ

ขอบพระคุณแม่ ที่แม่เชื่อมั่นว่าลูกสาวคนนี้จะสามารถร่ำเรียนจนถึงปริญญาเอกได้

ฉันจะรักแม่ตลอดไป

I dedicate this dissertation to my mother who taught me about unconditional love:

Thanks mother for being there for me

Thanks mother for giving me peace of mind

Thanks mother for being all that you could be for me

Thanks mother for being there when I was feeling down

Thanks mother for believing that I can do a PhD

I will I always love you

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Abstract

I commenced this inquiry by describing the global context referring to the Millennium Development Goals (MDGs) Declaration to reach health goals around the world by 2015. The MDG 6 aims to reduce HIV/AIDS infections by 2015. I made connections to Thailand's Health Care system which is guided by the same principles underpinning the Alma-Ata Declaration. The overall purpose of this PhD study was to research alongside Thai families whose offspring had lost their lives to HIV/AIDS. Literature was prolific around stigma, orphans and caregivers, but none had woven these topics together to explore what was going on in families affected by HIV. My research question was: What can be done to assist Thai families whose lives have been affected by HIV and/or AIDS? The objectives were to: (1) identify and understand how families accommodate a situation in which they are providing ongoing care for children of relatives who have died of HIV/AIDS (2) provide a means of registering the effects of widespread societal changes on the family when HIV and AIDS interrupt people's lives and traditional Thai family structure (3) plan for action and, where feasible, act on issues raised and prioritized by families caring for orphaned children of family members to assist them in this changed situation.

Using Koch and Kralik (2006) participatory action research methodology I researched alongside five families who live in rural communities near Khon Kaen in Thailand. I was in the field for 12 months. The methodology comprised storytelling with nine participants followed by group sessions. The democratic principles guiding this inquiry are: social justice, social equity, freedom of speech and human rights.

So how did families accommodate this situation? I have presented their stories in their entirety albeit they are translated versions from Thai to English. Fourteen (main) constructs arose from my one to one interviews with family members who were participants in my study. Reflecting on participants' stories and these 14 constructs I observed that constructs 1-7 were about the dramatic events that happened nearly a decade ago for five families. Yet their experiences of those harrowing times were recalled as if they happened yesterday. Participants talked about the shock surrounding the diagnoses of HIV/AIDS. They explained about upheavals experienced with changing houses and moving back 'home' to the village. Grandparents described complex nursing care they had to learn to give to their offspring, including understanding the principles of universal precautions. They provided care and comfort to five extremely ill daughters of whom three daughters died of AIDS. Grandparents felt the weight of additional responsibilities as they took on the major role in caring for the children of those who were sick or had died of AIDS. The family grew in size when the orphan came 'home' to live with his grandparent(s). Major restructuring of families occurred out of necessity. Relationships changed, the family was often reliant on extended families for housing, financial and emotional support. Families were forced to adjust to new ways of living. It was interesting to note how they managed major interruptions in their daily routines. There was no preparation for these crisis events. Moreover,

dire economic circumstances meant that often there was no choice but to reconvene as a 'new' family.

However, families adjusted to new ways of living, as was shown in constructs 8-14. They managed interruption to daily routines. Financial difficulties were experienced by three families whose poverty worsened. All families made comments about changes they had to make to secure income for their newly composed family structure. In the village, rumours disturbed families; being discriminated against was brought to my attention in all stories. Most families were preoccupied about disclosure, whether a child should be told about their parents or about their own HIV health status.

There were seven agenda items which all participants agreed to discuss in the participatory action research group discussion. Participants set the agenda: (1) Financial problems (2) Rumours and their impact (3) Access to social welfare payments (4) Discrimination and verbal abuse (5) Care of orphans when grandparents are ill or die (6) Services provided by Primary Care Unit (7) Prevention of HIV and health promotion. Participants commented that by working together to share their experiences they were able to address some of the concerns in their lives. Empowerment of participants was evident; awareness was created about common concerns they faced and increased confidence, amongst them, were the key benefits participants had gained from the group process. In terms of sustainability, participants have become a social network for each other.

When researching alongside families, I worked toward building sustainable relationships. There were considerable strengths within families as shown by their resilience and ability to move on, I suspect assisted by their strong beliefs in Buddhism. Transition was possible despite emotional upheaval, financial hardships and social injustices experienced living in a culture where HIV is stigmatized. This participatory action research methodology was transformative in that families were able to accelerate their transitions to incorporate the consequences of living with HIV/AIDS into their lives.

This inquiry has shown that participative problem solving in communities is effective. My future aim is to work toward greater participation in health care, so that people can contribute their ideas, plan and partake in effective action. I believe that by working together alongside community members we can make a difference. In this inquiry my ability to facilitate people to make changes in their lives has been the major driving force. I strongly believe that social justice and equity are enhanced when democratic principles guide our practice and research. Moreover, participation is a political imperative because it affirms the fundamental human right of persons to contribute to decisions that affect them. My thesis is that people have a right to have a voice about decisions that affect their lives, and in this situation all matters related to HIV/AIDS, and that a participative world view fosters these democratic actions.

Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
AUD	Australian Dollar
CSWs	Commercial Sex Workers
GFATM	The Global Fund to fight AIDS, tuberculosis and malaria
HAART	Highly Active Antiretroviral Therapy
HBV	Hepatitis B antibody Virus
HIV	Human Immunodeficiency Virus
HIV-NAT	The HIV Netherlands Australia Thailand Research Collaboration
IDUs	Injection/injecting Drug Users
MDG 6	Millennium Development Goal number six
MDGs	Millennium Development Goals
MSM	Men who have Sex with Men
NAP	National AIDS Program
NAPHA	National Access to Anti-retroviral Program for people with HIV/AIDS
NGOs	Non-Governmental Sector
NHSO	The National Health Security Office
OVC	Orphans and Vulnerable Children
PAR	Participatory Action Research
PCU	Primary Care Unit
PDA	The Population and Community Development Association
PLHA	People Living with HIV/AIDS
PMCHT	The Prevention of Mother to Child Transmission
PRA	Participatory Rural Appraisal
STD	Sexually Transmitted Disease
TAHOD	TREAT Asia HIV Observational Database
TAO	Tambon/ District Administrative Organization
UNAIDS	United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
UNICEF	United Nations Children's Fund
VHVs	Village Health Volunteers

Glossary of terms A-Z

AIDS orphans	A child under 18 years who had lost father or, mother or both parents
Alma Ata	Alma-Ata declaration broadly affirmed health as a state of complete physical, mental and social wellbeing
Chum Pae district	Chum Pae district is a district in Khon Kaen province approximately 70 Km from Khon Kaen
Comprehensive Continuum of Care Centre	The centres which provide the National Access to Anti-retroviral Program for people with HIV/AIDS
Double orphan	A child under 18 years who had lost both parents
Facilitator	to assist communication, discussion, decision making, action
Grim Reaper messages	A frightening characterisation of people who were identified as threatening agents of infection
Kamnan	A commune headperson
Kulasatri	The ideal women who has trust and belief in her partner's honesty and fidelity even when she has evidence to the contrary
Millennium Development Goals (MDGs) Declaration	The Millennium Development Goals (MDGs) Declaration built on the Alma-Ata philosophy to reach health goals around the world by 2015
Maternal orphan	A child under 18 years who had lost mother
Nai amphoe	The provincial governor appoints a district officer
Paternal orphan	A child under 18 years who had lost father
Phu-yai-ban	A village head person
Sum Het disease	Thai villagers term for HIV/AIDS which incorporates their belief that HIV is spread through unprotected sex
Tam Dee Dai Dee	Meaning what goes around comes around
Tam Jai	Common expression for the feeling of dispassion when something has happened that cannot be changed.
Tambon	A district
The Chi River	The Chi River is the longest river in Thailand. Its length is 765 kilometres then runs through the central Isan provinces

The Millennium Development Goals 6 (MDG 6)	The Millennium Development Goal (MDG6) 6 aims to reduce HIV/AIDS by 2015
Wat	The Buddhist temple
Who am I why am I here?	A community development project which aimed to engage children who were living with HIV
Zidovudine (INN) or azidothymidine (AZT)	Type of antiretroviral drug used for the treatment of HIV/AIDS