

**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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School of Nursing and Midwifery

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

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ขอบพระคุณแม่ ที่แม่ประคับประคองลูก 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

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I will 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

Chapter One

Introduction

My background

I was born in Udonthanee Province, Isan which is in North East Thailand. My nursing undergraduate degree and my post graduate Master's Degree in Child Health are from Khon Kaen University. Thai is my first language and I have used the English language for the last ten years. I work as an academic at Khon Kaen University, Faculty of Nursing in the Community Health Department. I was fortunate to receive a four year scholarship from Khon Kaen University which allowed me to continue my education at PhD level. I enrolled as a Higher Degree candidate in the School of Nursing and Midwifery at the University of Newcastle, Australia. I commenced this inquiry in July 2007 having completed a compulsory 15 weeks of English tuition at the English Language Intensive Courses for Overseas Student (ELICOS).

Beginnings

I was born in 1976, the youngest of three children. Mother and father had a small grocery store. In July 1981 my father died suddenly of a heart attack. I became an 'orphan' when I was five years of age. I recall the funeral very well and that my brother and I were playing a 'game', we did not really understand. At 32 years of age my mother was a widow and had to bring up three children by herself. She decided to return to Roi-Et province where her brother lived and she sought his support. With assistance from her brother, she set up a small food shop.

My memory of my mother is that she worked long hours in her food shop every day, from the early morning until late at night. In the first twenty years she did not have one day holiday. Our circumstances were satisfactory only because my mother worked so hard to sustain her family. Being an 'orphan', a term I will define as being without one or two parents, was a problem when growing up. It seemed that other families were perfect; my friends had both their parents. I had a few toys whereas my friends had many. As a family we pulled together and we are still very close. It was also difficult financially but we survived. There were no government services that could step in to support single mothers. I felt more responsible than my friends the same age. I often helped my mother in the shop and had less time to play with friends. I was not entirely without friends, my uncle's children were close by and we lived as an extended family.

Education was valued

My mother is the youngest daughter of a traditional Chinese family. My grandparents migrated to Thailand in the 1940s. At that time it was not usual for girls to have an education, whereas boys were sent to school. Nevertheless she completed four years of primary school. Working in her family's grocery store was how she spent her young adulthood. She deeply regretted her lack of formal education and she did not have a chance to go back to school. However, she wanted to make sure that her three children had the education she desired. I recall her saying to me on one occasion when it was raining outside and I wanted to stay home: 'Education is the key for having a better life'. Of course I went to school without really comprehending her advice at that time. In the 1980s the schooling in Thailand was an expense mother could barely afford but she managed to send all three children to school and pay the tuition fees. School vacations were spent in the shop helping mother to make extra food, so that additional finance could be accrued for the next semester's fees. She said to us; 'If you work hard at your studies I'll find a way to support you'. My sister and brother both have PhDs, thanks to the effort my mother put in those early years. Both siblings inspired me to continue with my education.

In April 2005, I gained an award to attend the English Intensive Courses at Massey University, Wellington, New Zealand. I returned to Khon Kaen University in June 2005, I talked with my mother about doing a PhD. She was concerned that I would live overseas by myself but she said go ahead and make your dream come true.

My interest in this topic

Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) has become increasingly common around the globe. HIV/AIDS was first identified in Thailand three decades ago. Some of the families impacted by HIV/AIDS in the first twenty years are still alive and have a story to tell. It was not until the early 2000s that Antiretroviral (ARV) treatment became universally available in Thailand. Hence there are quite a few Thai orphans today. My enduring interest in health has been with children and the community. After completing my Master's Degree in Child Health, and already working at the university, I was involved in a project with orphans. It was a community development project which aimed to engage children who were living with HIV. Three university departments were involved; Faculties of Fine Art, Nursing and Medicine. We had a small grant from UNICEF. The project was called 'Who am I, why am I here?' Children from the Isan Region (North East Thailand)

were invited to join a youth camp. We recruited 26 children aged ten to sixteen to take part in this project. All were 'orphans' infected with HIV. For one week, at the camp, accommodation and meals were provided, and they were given emotional support and were able to 'play' alongside faculty staff. If they had a parent or close relative they also boarded with the child at the camp.

Each child was encouraged to be creative: to draw or take a photo of something that was important to them, to make music, or write a poem or play. One camera was supplied hence we were presented with photos of the Temple, the Crematorium, the river at dusk, the ocean, and one child wanted to take a photo in the hospital. They were given art materials such as crayons and paint brushes. One of the project team members would accompany the children wherever they wanted to go. Other children drew pictures of trees, birds, sunflowers, candles, faces, eyes. Under the supervision of the art therapist, children were asked to write some words to match their creative work. Children were asked to tell a story from their point of view and encouraged to dwell on their thoughts. Nam, a 12 year old girl, was able to draw and tell her story. Her drawing was selected for the book cover (Figure 1, see below). In telling her story she said that she often felt discouraged at school. She felt the stigma associated with HIV. Her mother has the HIV infection too. Mother and daughter gathered support from being in the camp. When Nam returned to school she decided to do something about the negative attitudes toward her. She had attended the HIV clinic with her mother and had good information about infection. She realised that ignorance about the infection had stimulated stigma and discrimination among her peers. She started an education program at her school. Education, she believed, might reverse some of the prevalent negative attitudes. She took the initiative to write HIV facts on the black board for all to see. Her mother has since joined up as a community volunteer to provide information about HIV.



Figure 1: Who am I, why I am here?

Many children drew sunflowers, similar to Nam's drawing shown above. A sunflower represents hope but note that in her drawing some of the petals are falling. The candles are lit but eventually they burn down and their life is extinguished. This Buddhist doctrine 'Tam Dee Dai Dee' meaning what goes around comes around may be significant here. Four sunflower stalks are held together and Nam emphasises that as children living with HIV they can understand each other if they join hands. Together they have a voice. It seemed as if children were empowered by being in the group. A twelve year old boy, Keng, wrote in Thai that the group's task was: 'Working together, building the history of the world in order to transform the world toward a better understanding'.

Children were brought together as a group, they shared their experiences through creative art, they were given a voice and they appeared to thrive. In addition to the empowerment of the children, the outcomes of this project were numerous and included the production of: a book with the drawings the cover of which is shown above, each child's effort has been included in the book in photos, drawings and words. In addition, the project team organised the printing of postcards of individual drawings and words. The children collaboratively wrote and staged a play. Its performance including music was presented to the public, alongside an exhibition of drawings and photos. This was held in 2007 in the grand Convention Hall in Bangkok. It was an

exciting journey for the 26 children, travelling to Bangkok, and having an opportunity to present their work. Fundraising from the sale of postcard prints raised money which provided further financial support for these children.

Why this project was important

Being involved in the project team was a significant journey of understanding for me. I knew that there were many 'AIDS orphans' as they were called when I first commenced this journey. But prior to this project, their voices had not been heard. As far as I know, this was the first attempt in Thailand to see the world from the perspective of children who were living with HIV. It was amazing that their experiences portrayed in art shared many common themes. They wrote about being an outsider and being on the periphery of social life. They drew pictures about their isolation and wanting friends. It may be a truism to say that children want to belong; clearly they felt they did not belong. Although they did not use the words 'stigma' and 'discrimination' they felt being excluded with excruciating pain. Their experiences conveyed in art showed that they had been wounded at all levels: socially, emotionally and physically, as many talked about being sick and taking medications. For one child taking a photo of the Crematoria was related to his parents dying. The hospital visit was to show what happened to them when they visited the HIV clinic. Yet, there were pictures of hope; the sunflowers were a good example. It was also the case that children felt empowered being together and they wanted to change the world around them so that they could be better understood. They identified that education of those around them was a good way to proceed.

I knew that I wanted to continue this type of study in some way. I observed the power of bringing people together, its therapeutic effect and the potential for empowerment. It was also important to realise that these voices had not been heard and, through listening, we gained a better understanding of their situation. I felt the principles e.g. collaboration, working with participants, listening to their point of view and bringing people together, to be congruent with my own philosophy. And I really wanted to work with orphans; their art work and stories had touched me. I felt I could make a difference if I could research alongside children and their families. I recognised the potential for reform.

Community development

Community development projects have always interested me. As an academic I was involved in another project with staff from the Pralab Primary Care Unit. These community health nurses are guided by Alma-Ata primary health care principles which are congruent with Participatory Action Research (PAR), which I was later to find out. The project involved providing evidence to local government that provision of milk made of soya bean instead of cow's milk would improve the nutritional status of some school aged students. We had identified that many students were undernourished and discovered that they had lactose intolerance. We had gathered data on students' intolerance and their body weight. This project meant involving parents, the community health nurses and the children. Together we were able to persuade the local government to provide soya bean milk for those with lactose intolerance. Children's nutritional status improved in subsequent years.

I now realise that community development type projects have prepared me for working alongside families that live with HIV/AIDS. The principles identified above are similar to those I will embrace for this inquiry. Families living with HIV/AIDS are the group selected for this inquiry. I want to hear what they have to say and what can be done to assist them.

Research question and objectives

My research question is: What can be done to assist Thai families whose lives have been affected by HIV and/or AIDS? The objectives are:

- Identify and understand how families accommodate to a situation in which they are providing ongoing care for children of relatives who have died of HIV/AIDS.
- Provide a means of registering the effects of widespread societal changes on the family when HIV and AIDS interrupt people's lives and the traditional Thai family structure.
- Plan for action and, where feasible, act on issues raised and prioritised by families caring for orphaned children of family members to assist them in this changed situation.

Based on my experience in community development, I selected a collaborative inquiry approach, Participatory Action Research (PAR), for my methodology, and I will discuss the reasons for its selection in subsequent chapters. Meanwhile it is important to state that PAR:

- Takes place in collaboration with participants
- Participants determine the agenda
- Participants drive the research
- Participants decide on actions

Significance

Since 2002 I have been working as an academic alongside community health nurses in the rural area of Khon Kaen province. I became acquainted with the rural population in several of the villages surrounding Pralab Primary Care Unit. Isan is one of the poorest regions in Thailand, and I observed hardship and poverty in these small villages. I realised that other dimensions would impact on those living with HIV AIDS in such poor rural circumstances. I knew that I wanted to research with these villagers out of a sense of social justice. I was motivated to find out more about the way in which these rural families were able to provide the care for orphan children who have lost their parent(s) due to HIV/AIDS. I had been amazed by the *Who am I, why I am here?* project, its art and stories and wanted to see how these families could live in their problematic circumstances not only the health related problems, but also the stigmatisation experienced, and the effect of being discriminated against by the community. In my involvement in the project with children who were infected with HIV, it occurred to me that something needed to be done to assist families.

Ethics approvals from (1) the University of Newcastle and (2) Khon Kaen University were gained in 2008 and 2009 respectively. I left Newcastle and returned to Thailand for a period of 12 months to implement the research process.

In chapter two I will describe the context for this inquiry. Starting with the Alma-Ata Declaration, which is the philosophy underpinning Thailand's community health program I will connect with The Millennium Development Goals (MDGs) Declaration. The MDGs were built on the Alma-Ata philosophy to reach health goals around the world by 2015, and one goal in particular is pertinent to this inquiry, MDG 6. The MDG 6 aims to reduce HIV/AIDS by 2015 and I will explain the way in which Thailand has responded to this global goal. In this chapter I will describe Thailand's Health Care system focusing mainly on its reforms and ways it has reduced HIV/AIDS. I will provide a picture of the Khon Kaen Province and Pralab sub district which is the setting for this inquiry and its primary health care services. Pralab Community Health Unit (Pralab sub district), the framework for delivery of care is based on the Alma-Ata

primary health care principles. Pralab Primary Health Care Unit (PCU) provides a service to nine villages in its surroundings, and it is from these villages that recruitment of families took place. I will also talk about Khon Kaen and the Comprehensive Continuum of Care Centre. In this inquiry the Comprehensive Continuum of Care Centre refers to the HIV/AIDS clinic at Khon Kaen Regional Hospital. I will mention some Thai cultural features that may have relevance in this inquiry, particularly the democratic processes of governance at local level.

In chapter three the literature on the topic of HIV/AIDS will be reviewed. Included is a review of research papers on HIV/AIDS that have taken place in Thailand identifying key research centres. When researching relevant literature, it appeared researchers have not focused on the stories of family members caring for children orphaned as a result of HIV/AIDS. However, the number of families carrying out this extended family role is increasing. There is a significant gap in the published research, a gap which results in little being known or understood about how families manage. It is not known how families incorporate new roles into their daily lives. My inquiry seeks to address this gap in the literature. Depending on what participating family members tell me in the course of my data generation, the significance of this inquiry is that it will provide insight into family relationships and roles.

I will review the literature around orphans and their families in order to explore the way in which these units accommodate providing ongoing care and the impact of registering the effects of societal changes on the family. I am interested in the concept of stigma and how this is defined in the literature, the impact of stigma on people living with HIV/AIDS and the influence of stigma in everyday life of families

In chapter four I locate suitable principles to guide this inquiry, I refer to my background in community development, and I focus on Participatory Rural Appraisal (PRA), which I have used in community projects. The point I wish to make is that these projects share similar principles. I provide a reason for selecting a particular Participatory Action Research (PAR) methodology for this inquiry (Koch & Kralik, 2006) which embraces a participatory world view. I have identified the principles I would take into my inquiry: they are democratic principles, social justice, social equity, freedom of speech and human rights. I will argue that it is important to listen to people who have been voiceless, in this situation those people whose lives have been interrupted by HIV/AIDS. I discuss evaluation in co-operative inquiries and provide rigour criteria by which this inquiry can be considered as trustworthy.

In chapter five I will explicate the PAR process undertaken for this inquiry. I will describe the actual process of this inquiry including the research setting, gaining ethics approval, the recruitment process, researcher roles, data generation and data analysis. A detailed analysis process will be discussed. There were two distinct phases of this inquiry consisting of one to one interviews and the PAR group discussion. The PAR approach to storytelling and group meetings were sequential and while one led to the other I will talk about data generation and analysis separately. It is important to mention the principles guiding this inquiry and these are discussed as: my belief in democratic principles - social justice, social equity, freedom of speech and human rights. These principles embrace a democratic, collaborative approach to research that equitably involves all persons (facilitators / researchers and participants) in the research process. Moreover, I recognise the unique strength that each person brings to the study, I insist that voices are heard and I attempt to break down the distinction between facilitator / researcher and participants. I describe my role as a facilitator / researcher.

In chapter six I write about being in the field (from April 2009 to January 2010). There were two phases of data generation, storytelling (one to one interviews) which is described in this chapter and PAR group discussions described in chapter seven). I researched alongside five families. My adoption of Koch and Kralik's methodology and emphasis on the importance of storytelling allowed me to invite participants to talk about their experiences. Listening to their stories allowed me to follow the participants' daily lives and to understand the major changes they had had to make in their lives. I was particularly interested in the story telling phase of Koch and Kralik's methodology because I considered it to be important for understanding the way people are managing in their lives. In addition, I was building relationships with my participants and believed that they would be more likely to attend subsequent PAR groups if they felt safe talking with me. Nine stories are described in full in this chapter, followed by an analysis. Fourteen main constructs were identified and their analysis may be found in the appendices.

In chapter seven I communicate what happened in the PAR groups. In the previous chapter I introduced the nine participants from five families. All participants were invited to join the PAR group and the invitation was accepted by all. This chapter describes the group process or stage two of this PAR study. Researching alongside participants in a group, I was guided by the principles of PAR stated above and I followed the cyclical processes of 'looking, thinking, and acting' as an iterative process. Of course the entire research process was conducted in Thai language; I was accompanied by Dr. Kessarawan Nilvarangkul, my field supervisor at every

PAR group meeting. In this chapter I describe preparation, bringing nine participants and community nurses together, setting the agenda, prioritising the items and facilitating the group toward actions.

Chapter eight covers the theoretical discussion. In an effort to answer the research question I continue to explore what can be done to assist Thai families whose lives have been affected by HIV and/or AIDS. I will build on the fourteen constructs resulting from one to one interviews to describe the experiences of nine adult participants as they dealt with the impact of HIV/AIDS in their families. The most striking feature of participants' response to incorporating the consequences of living with HIV in their lives was that they talked about their experiences as a family. Theorising about families' experiences will be attempted as I draw on concepts of Thai culture, transition theories and further develop the notion of stigma, as this influenced the lives of all participants. I will then reflect on the methodology: storytelling and the PAR groups in order to explicate transition. Finally I will talk about ways in which we, as health care professionals, could assist families that are similar to the five families in this inquiry. Given that the 1990s AIDS epidemic has slowed down, I will focus on the next Thai group being infected by HIV, adolescents, and tease out preventive strategies 'we' may be able to use to curb these infections.

In the final chapter I provide an overview of the inquiry. Most importantly I answer the research question in this conclusion chapter. I continue to explore what can be done to assist Thai families whose lives have been affected by HIV and/or AIDS. I build on previous chapters, particularly the fourteen constructs resulting from storytelling (one to one interviews) to describe the experiences of nine adult participants as they dealt with the impact of HIV /AIDS in their families. I demonstrate that I have met my objectives. I reveal the impact experienced by families. It became evident that all my participants had made major changes in their lives. I make a distinction between change and transition: change is what happens to people whereas transition is what people actually experience. My participants' stories show the impact HIV infection had on their everyday life: eating, drinking, bathing, working, walking and talking. Daily life continued as before but with additional hardships. There were changes in daily life, most of these affected grandmothers, in particular. Although grandmothers talked about having a strong commitment to their grandchildren, they explain that many role changes have occurred. I propose that families can adjust and move on when they support each other.

I asked what can be done to assist families and I make several suggestions health care professionals may be able to take into their practice. I talk about key ‘findings’ and their implication for further research, education and practice. I discuss my theoretical contribution or ‘new knowledge’ as I explore the role of Buddhist philosophy in making transitions.

I argue that this PAR approach was the most suitable for this inquiry and highlight its limitations. In addition, I argue that this account is believable as I have adhered to the criteria of rigour agreed on at the outset of this inquiry. Besides, listening to the voices of the nine participants it would be impossible to fabricate these stories, albeit that their translations from Thai to English are products of interpretation. I argue they are legitimate accounts giving great insight in to the lives of families. I talk about the sustainability of the PAR process as the resultant actions are evident in the lives of participants today.

Conclusion

In this chapter I identified how I came to do this inquiry as well as why it is so important to me to conduct it. My involvement in the ‘Who am I, why am I here?’ project was central to my arriving at this inquiry and not only enabled me to understand more about the plight of children with HIV but raised my curiosity about how families care for children who are orphans of parents who have died from HIV, hence this being the topic of my thesis. I have outlined my experience and interest in community development projects which was invaluable in the context of my inquiry and understanding Thai village community life. Also discussed in this chapter are my research question, and objectives as well as the significance of the study. The chapter concludes with a discussion of the structure of the thesis.

In the next chapter I outline the broad and more specific contexts in which the study was conducted. I also discuss global health care policy which drives and impacts health care delivery and distribution of resources in Thailand. I discuss the extent to which goals of these policies are being met and the whole situation of HIV/AIDS in that country.

Chapter Two

Context

Introduction

In this chapter I will describe the global context starting with the Alma-Ata Declaration, which is the philosophy underpinning Thailand's community health program. The Millennium Development Goals (MDGs) Declaration built on the Alma-Ata philosophy to reach health goals around the world by 2015, and one goal in particular is pertinent to this inquiry, MDG 6. The MDG 6 aims to reduce HIV/AIDS by 2015 and I will explain the way in which Thailand has responded to this global goal. Next I will describe Thailand (Figure 2) and Thailand's Health Care system focusing mainly on its reforms and ways it has reduced HIV/AIDS.

I will provide a picture of the Khon Kaen Province and Pralab sub district which is the setting for this inquiry. Isan is a region in North Eastern (Figure 3) Thailand consisting of 20 provinces. Khon Kaen is the province in which this inquiry will take place. I will contextualise Khon Kaen, one of its major cities and the HIV/AIDS clinic which is housed in one of its main hospitals. I will then pay attention to Pralab Primary Care Unit (Pralab sub district) and point out that the framework of Alma-Ata guides the practice of its health care staff. Pralab PCU provides a service to nine villages in its surroundings, and it is from these villages that recruitment of families will take place.

Although it is not possible to describe Thailand's culture in a few paragraphs, I will introduce some traditional cultural features that may have relevance in this inquiry, particularly the democratic processes of governance at a local level. I will identify the village and district group leaders as these are the people I would hope to influence if reforms result as the outcomes of this inquiry. It is necessary to spend a little time explaining the family structure, and emphasise the respect bestowed on its elders and provide a strong case for grandparents taking care of their orphan kin.

Alma-Ata Declaration

The International Declaration of Primary Health Care was signed in Alma-Ata, Russia, in 1978. The Alma-Ata declaration broadly affirmed health as a state of complete physical, mental and social wellbeing. In addition to the social health emphasis, the Alma-Ata declaration challenged health workers to overcome inequalities in the health status of people within the context of the socioeconomic order (Hall & Taylor, 2003). It also established the rights of people to participate both individually and collectively in planning and implementing their own health care. The

Alma-Ata declaration invited nurses in particular to work towards the goal of *Health for all by the Year 2000*. Nurses were challenged to look at the world with a new and critical eye, to note the inequalities in social and health systems and to work together with communities (populations) to tackle these issues (Hixon & Maskarinec, 2008).

The meaning of health promotion shifted from instructing individuals to take up healthy lifestyles to recognising that people's health is part of their social and economic environment. The move was away from a biomedical model to a social model for health and includes wider social, economic and political reform. The Alma-Ata declaration for health promotion thirty years since its inception remains the philosophical impetus for health care reform. The four principles of primary health care are: social justice, equity, community participation meaning working with clients/community and responsiveness to needs referring to having services designed to meet its population's identified needs (Hall & Taylor, 2003). These principles resonate with PAR principles which will guide this inquiry.

Millennium Declaration

In September 2000, world leaders came together at the United Nations in New York. The United Nations Millennium Declaration was agreed upon. Major reforms were required to reduce extreme poverty and a series of time-bound targets were set out for 2015. These targets are known as the Millennium Development Goals. The United Nations Secretary-General Kofi Annan described the MDGs as covering eight key social and economic issues: (1) Eradicate extreme poverty and hunger (2) Achieve universal primary education (3) Promote gender equality and empower women (4) Reduce child mortality rates (5) Improve maternal health (6) Combat HIV/AIDS, malaria and other diseases (7) Ensure environmental sustainability and (8) Develop a global partnership for development. Nurses are well placed to contribute to achieving the Alma-Ata health reform movements with the MDGs, nurses are beckoned to be on the forefront in this social health reform movement (UN, 2010).

The eighth Millennium Development Goal

In the year 2000 the leaders of 189 countries met and were committed to the eighth Millennium Development Goals (MDGs), providing their signature on the declaration and committing to meet designated goals by 2015. After the United Nations General Assembly Special Session on HIV/AIDS (UNGASS Country Progress Report Thailand, 2009) was convened in June 2001,

189 representatives of countries around the world, Thailand included, signed up to the MDGs declaration. Since 2000 many countries have moved forward, including some of the poorest, demonstrating that setting collective goals in the fight against poverty can yield results. (UN, 2010). There are dramatic achievements by many poor countries, such as Honduras (Bussolo & Medvedev, 2007), Laos (Gaiha & Annim, 2010), Ethiopia (Hladik et al., 2006), Uganda (Keane, Kennan, Massa, Cali, & te Velde, 2010), Burkina Faso (Drescher, 2007), Nepal (Poudel et al., 2005), Cambodia (Takahashi et al., 2009), and Ghana (Fobil & Soyiri, 2007). Progress in developing countries includes increased literacy meeting the MDG 2 in education in Guinea and Malawi (Group, 2008; UNION, 2008), and reducing child mortality (MDG 4) in Bangladesh and the Gambia (Osman, 2010), nutrition in Indonesia, Mexico and Tunisia (MDG 1) (Demeke, Pangrazio, & Maetz, 2008), and reducing income poverty (MDG 1) in China (Zhang & Wan, 2006).

Although there are disputes about data collection methods and it is realised that monitoring of MDGs can be done at global and/or country level there is evidence that some countries have gone backwards (Jahan, 2010). Countries that have gone backwards are those which have been devastated by conflict over the last few decades: Afghanistan, Burundi, the Democratic Republic of Congo, and Guinea-Bissau have been at war. Most of the 189 countries fall somewhere in between, some demonstrating solid progress on some indicators and little on others (Clemens, Kenny, & Moss, 2007). Reasons for not meeting MDGs are given as, countries lacking in resources, focus, transparency and/or accountability, and most importantly, lack of commitment. Not meeting the targets was aggravated by the global food, economic and financial crises (Kyrili & Martin, 2010). However, when countries have had adequate funding and political commitment, they have made rapid progress toward the MDGs. In other countries the poorest groups, those without education or living in more remote areas, have been neglected and not provided the conditions to improve their lives (Clemens, et al., 2007; Group, 2008; UN, 2010).

The Global Health Council 2011 (Global Health Council, 2011) writes that HIV infections and AIDS deaths are unevenly distributed geographically and the nature of the epidemics vary by region. Epidemics are lessening in some countries, and some of the most dramatic achievements in reducing HIV/AIDS are recorded in Senegal (Willems, 2010), Uganda (Keane et al., 2010), and Thailand (Punyacharoensin & Viwatwongkasem, 2009). Epidemics are escalating in other countries, for instance in Tanzania HIV/AIDS, tuberculosis and malaria have resulted in

increased morbidity (Mhalu, 2006). More than 90 percent of people with HIV live in the developing world (UNAIDS, 2009b).

Thailand has achieved many of the Millennium Development Goals (MDGs) at a national level well in advance of the 2015 targets (Balisacan, 2009; Bond, 2006; Vapattanawong et al., 2007). Thailand has been recognised for being one of the most successful countries in their responses to the AIDS epidemic (Roberts, 2008). However, since the Asian economic crises during the 1990s Thailand has had to radically reduce funding to HIV/AIDS prevention services and, as a result, the HIV incidence has not decreased (UNAIDS, 2010).

The sixth Millennium Development Goal: Combat HIV/AIDS, malaria and other diseases

My inquiry is related to the MDG 6 (or the sixth goal). Millennium Development Goal 6 targets reducing infections in particular HIV/AIDS, malaria and tuberculosis. Major infectious diseases in Thailand include bacterial diarrhoea, hepatitis, dengue fever, malaria, Japanese encephalitis, rabies and leptospirosis. In this following section I will describe the global and local problems of HIV/AIDS.

HIV emerged as a global health issue in 1981. At that time, an American physician in the San Francisco Bay Area of California began to see a small number of homosexual (gay) men infected with an unusual protozoan parasite identified as PCP (*pneumocystis carinii*) (Volberding, 2008). Since then the global AIDS pandemic has become one of the greatest threats to human health. The human immunodeficiency virus (HIV) and the set of symptoms associated with opportunistic illnesses known as AIDS (Acquired Immune Deficiency Syndrome) is the subject of this section. The Human Immunodeficiency Virus affects the immune system which is the body's protection against infections by micro-organisms (Pratt, 2003).

In the instance of HIV infection, there is often a long, silent period known as the "latency period" (Pratt, 2003). During this period people who are infected may be asymptomatic for seven to ten years. People who are living with HIV will ultimately develop AIDS but when this occurs depends on the antiretroviral drug treatment they receive and how well they care for themselves and are cared for by others. The care required includes, for example the maintenance of good health and nutritional status and prevention from opportunistic infection as well as psychological approaches (Lashley & Durham, 2010).

In order to reduce infections by 2015, several indicators were decided on by the UN and they are: provide universal access to treatment to HIV/AIDS for all the population with advanced HIV infection, with access to antiretroviral drugs by 2015; halt and begin to reverse the spread of HIV/AIDS. The MDG 6 aims to reduce HIV prevalence among young people aged between 15-24 years. In order to reach the targets, young people in this same age group will receive a comprehensive sex education program (Gow, 2008). Condom use is still advocated with high risk groups: Men who have sex with Men (MSM), Intravenous Drug Users (IDUs) and Commercial Sex Workers (CSWs). Orphans and children who are affected by HIV/AIDS should be able to attend school the same as ordinary children (Ina, 2009). Internationally, research studies have sought to identify what factors accounted for substantial reductions in HIV sero-prevalence after several countries deployed "ABC" (abstinence, be faithful, condom use) strategies (Sinding, 2005).

The data in this section are reported by the UNAIDS (UNAIDS, 2009b). In 2009, globally, about 1.8 million people died of AIDS, 33.3 million were living with HIV and 2.6 million people were newly infected with HIV. Although the HIV pandemic is now in its third decade, the number of HIV infected people has shown no decrease. Indeed, globally, there are approximately 33.3 million people living with HIV/AIDS, of which 15.4 million are women and 2.5 million children under 15 years of age. In 2007 there were estimated to be around 2.5 million people newly infected with HIV, approximately 2.1 million adults and 420,000 children under 15 years of age (UNAIDS, 2009b).

HIV/AIDS in Thailand

Thailand was one of the first countries in Asia to launch a campaign to raise public awareness of HIV/AIDS, and recent data confirm the campaign's effectiveness. Thailand has achieved many of the Millennium Development Goals (MDGs) at a national level well in advance of the 2015 targets and it is important to follow its footsteps (UN, 2010).

By 1990s Thailand had been experiencing an extensive HIV/AIDS epidemic for nearly a decade and a need for reforming the health care systems and subsystems of the country had been identified. In 1996, Thailand's Ministry of Public Health started a three-year initiative to reform health care systems to increase their equity in access to health care, quality of services, efficiency of health care subsystems and accountability to the public (Wibulpolprasert & Thaiprayoon, 2008). This country launched a huge media campaign against HIV/AIDS with

warning messages aired regularly and repeatedly on television as part of the national strategy to minimise transmission of HIV (Bowtell, 2007). These *Grim Reaper* messages were frightening, and defined characteristics of people who were identified as threatening agents of infection: prostitutes and drug users were portrayed (Rovin, Young, & Hardee, 2008). Thailand's national policy toward HIV/AIDS prevention was known as "100 per cent Condom Use" (Kerrigan, Moreno, Rosario, & Sweat, 2001; Plipat et al., 2004; Rojanapithayakorn & Hanenberg, 1996) particularly for workers in the sex trade where condom use is required.

In Thailand, HIV/AIDS was presented as a Sexually Transmitted Disease (STD) associated with homosexual contact and unfortunately despite evidence to the contrary, the stigma associated with this has remained a dominant theme in popular culture. The stigma is a significant obstacle to appropriate intervention policies, such as clean needle depots, condom use among sex workers and the Prevention of Mother to Child Transmission (PMCHT) program (Mawar, Saha, Pandit, & Mahajan, 2005). Condom use amongst sex workers has been implemented and the acceptability and feasibility of this practice has been evaluated since the program was introduced in the mid-1990s (Kerrigan et al., 2001). Furthermore, Kerrigan and colleagues (2001) asserted that owners or administrators within the sex industry recognised that 100 per cent condom use would increase business because customers felt safer to visit a STD free environment.

The Prevention of Mother to Child Transmission program for HIV infected mothers, mentioned above, was introduced in 2000 in order to reduce transmissions from mother to child (Kanshana & Simonds, 2002; Phanuphak, 2011; Phanuphak & Lolekha, 2011; Plipat et al., 2007). In 2000, Thailand evaluated this program to assess the efficacy of PCMHT. Evaluation reports were received from 669 hospitals in 65 provinces for the period October 2000 through July 2001. During this period, 93 per cent of 318,721 women who gave birth were tested for HIV; 69 per cent of 3958 HIV-infected women giving birth received zidovudine ¹; and 86 per cent of the 3865 infants born to HIV-infected women received zidovudine and 80 per cent infant formula, through the program (Amornwichet et al., 2002; Kanshana & Simonds, 2002). The results clearly indicate that effectiveness of this program; furthermore, as a successful prevention strategy developed in Thailand, (Chitwarakorn & Tantisak, 2002), these results may encourage other developing countries to implement or expand similar PMCTH strategies (Amornwichet et al., 2002)

¹ Zidovudine (INN) or azidothymidine (AZT) is a type of antiretroviral drug used for the treatment of HIV/AIDS.

Successful strategies to combat HIV/AIDS in Thailand

Two of the most successful strategies introduced were: (1) the 100 per cent condom use and (2) the PCMHT program and treatment for HIV infected mothers and provision of Antiretroviral (ARV) medications through universal health coverage in Thailand (Kladsawad, Plipat, & Rattanasuporn, 2004; Pachanee & Wibulpolprasert, 2006; Plipat et al., 2007; Rojanapithayakorn & Hanenberg, 1996; Sunthrajarn, Wongkongkateph, Onnom, & Amornwichet, 2005). The government funded an antiretroviral drug program and, in September 2006, more than 80,000 people with HIV/AIDS were receiving these drugs. In 2005, ARV treatments were included within a subsidised health scheme of the universal health coverage in Thailand (Lyttleton, Beesey, & Sitthikriengkrai, 2007).

The Thai government introduced universal coverage reforms in 2001. Means-tested health care for low income households was replaced by a new and more comprehensive insurance scheme, originally known as the '*30 Baht project*' (NaRanong & NaRanong, 2006). All Thai people were entitled to visit a doctor or hospital for a flat fee of 30 Baht (about AUD1). People joining the scheme received a gold card which allowed them to access services in their health district or be referred for specialist treatment elsewhere (Séguin, Hardy, Singer, & Daar, 2008). By November 2004 the Thai government had launched a well-funded, politically supported, and pragmatic response to the epidemic. National adult HIV prevalence had decreased to an estimated 1.5 per cent of all persons aged 15 to 49 years (Moving Toward Universal Health Coverage Thailand). Funds were provided to support HIV/AIDS groups for the first time.

In addition, HIV infected persons access to ARV has been brought about through legal and political advocacy. However, when Thaksin Shinawatra (the former Prime Minister of Thailand) was ousted as prime minister following the coup in September 2006, a military-installed Thai government decided to abolish the fees. The new program is known as the universal healthcare scheme and patients are no longer charged any fees for visits to state hospitals. Most of the finance comes from public revenues. Although the reforms have received a good deal of critical comment, they have proved popular with poorer Thais, especially in rural areas (NaRanong & NaRanong, 2006). However, many people, migrants, illegal migrants and refugees, do not have access to this universal cover. Ethnic minority groups without full Thai citizenship have also been denied access to the universal health coverage scheme including ARV treatment (Lyttleton et al., 2007). This is short sighted given the nature of the disease, and the cost to the total community. As discussed, HIV infection does not discriminate along political borders.

New groups with HIV infection in Thailand

Thailand continues to confront the challenge of preventing the spread of HIV/AIDS, which in the early 2000s emerged as the country's leading cause of death. The HIV surveillance data over the past three to four years indicate that the number of new HIV cases has not declined in all groups. One group where HIV has increased is in young people. In addition, the HIV surveillance data show an increase in the level of infection among pregnant women (Keereekamsuk, Jiamton, Jareinpituk, & Kaewkungwal, 2007) and military recruits aged 20 to 24 years. These patterns of the spread of HIV present a challenge for reducing HIV in line with the MDG 6. The number of cases of people with HIV in some provinces of Thailand is increasing. In areas of tourism and provinces bordering on the eastern seaboard and Gulf of Thailand, Phuket, Chonburi, Trad, and Samut Songkram, HIV is on the increase (Press, 2005). In relation to migration, in the late 1990s reported data on AIDS cases in Thailand suggested that laborers and agricultural workers, who are generally the poorest groups and least educated, are most susceptible to AIDS. The largest proportion of AIDS cases were reported in Thailand's Northern provinces, mainly in rural areas (Klunklin & Greenwood, 2006). Migration between the Laos and Burma borders was also cited a problem area (Leiter, Suwanvanichkij, Tamm, Iacopino, & Beyrer, 2006). The Upper North of Thailand experienced the highest levels of HIV. A number of Thai and Cambodian people live in Sa Kaeo province, situated on the Thai, Cambodian border and many of these people move between Thailand and Cambodian areas where a large number of people with HIV are located (Deoisres, 2008).

As discussed, groups at risk of HIV are: Men who have Sex with Men (MSM), Injection Drug Users (IDUs) (Fitzgerald, Lundgren, & Chassler, 2007), and Commercial Sex Workers (CSWs) (Changtong, Muangkleng, Limsiri, Chemnasiri, & Plipat, 2004).

Gender inequality

The wider spread of HIV in women in Thailand reflects their lower status when compared with men. Traditionally, Thai women are expected to be honorable **“Kulasatri”**². Kulasatri means a woman deferring, in all things, to her husband. When a wife defers to her husband in all matters

² **Kulasatri** is the ideal woman who has to trust and believe in her partner's honesty and fidelity even when she has evidence to the contrary

it increases the difficulty in negotiations around condom use. Within a marriage, condom use is unusual so even if the wife suspects that her husband is not faithful, she cannot demand that he use a condom (Aheto & Gbesemete, 2005; Klunklin & Greenwood, 2006; Plipat et al., 2004).

Gender inequality is instrumental in the difficulties women face in negotiating the use of condoms, particularly so for wives. As discussed, condom use or protected sex is unusual in long term relationship between partners (Decker, McCauley, Phuengsamran, Janyam, & Silverman, 2011; Klunklin & Greenwood, 2005; Plipat et al., 2004). Gender inequality prevails in rural Thailand. Women do not have a voice in their sexual relations. Men are generally considered to be the leader in their family and they are more likely to be the breadwinner. Consequently, women are perceived as less powerful than men (Klunklin & Greenwood, 2006).

Furthermore, women who attempt to introduce condoms into their marital relationship are viewed as not trusting their husbands and, indeed, it may even be alleged that they are sexually unfaithful. If women reject having sex with their spouse, even when she suspects he may have an infection, it may lead to marital conflict, domestic violence and divorce. Divorce is stigmatizing for Thai women and further, it can result in a woman's loss of economic security (Klunklin & Greenwood, 2006). Financial security is not something a Thai woman can take for granted; there are no social security systems.

Ongoing reform

Thailand has experienced almost thirty years of the HIV/AIDS epidemic. AIDS is still having an adverse effect on Thai daily life, the health system, and the socio-economic well-being of its people. Numerous public media campaigns have promoted condom use in youth and most-at-risk population groups (Janepanish, Dancy, & Park, 2011; Rongkavilit et al., 2007). When it became clear that nearly 50 per cent of infected people were women, and that this percentage was up from 35 per cent in 1985, three additional prevention strategies were identified in Thailand which focused on gender relations, economics and migration (Chamrathirong, 2009; Ford & Chamrathirong, 2007; Nyunt, 2008).

As discussed, the rate of new HIV infections is increasing among several groups. The government has responded to this by announcing a new campaign to combat complacency regarding HIV/AIDS (Punyacharoensin & Viwatwongkasem, 2009; Sakthong, Schommer, Gross, Prasithsirikul, & Sakulbumrungsil, 2009; Youngkong, Baltussen, Tantivess, Koolman, &

Teerawattananon, 2010). Thailand has set the target to reduce the number of new cases of HIV by at least half of those projected for 2011. Currently, three HIV prevention strategies are (1) public information campaigns (2) strengthening the HIV prevention networks; and (3) finding ways to ensure sustainability at the provincial and local administrative organisation levels to accelerate and take ownership of the HIV/AIDS prevention agenda (UNGASS Country Progress Report Thailand, 2009). The Thai Government has collaborated with many other organisations to meet its target goals, for example, the non-governmental sector (NGOs), Local Government and lobby groups of people living with HIV/AIDS (Pattanaphesaj & Teerawattananon, 2010).

In its most recent plan, Thailand has identified a National AIDS plan and the HIV prevention programs. Most at risk population groups will receive greater attention. In addition to meeting the MDG 6 target, Thailand has a separate policy and plan to reduce new infections by half by 2011 in IDU, MSM, female sex workers, prisoners and migrants in Thailand (UNGASS Country Progress Report Thailand, 2009). The national program will work with all these groups using both domestic and international funding from the Global Fund to fight HIV/AIDS, tuberculosis and malaria (GFATM) (Global Health Council, 2011; Poore, 2004). The plan incorporates the need for people with HIV to access outreach health promotion services and link with hospitals.

In 2007, the Department of Infection Control, Bureau of Public Health, Government of Thailand, published the 4th National Plan for Prevention and Alleviation of the AIDS problems for 2007-2011. There are four main aims, including encouraging the Thai population to become involved in HIV/AIDS prevention in order to contain and reduce the pandemic, enhancing quality of life among people living HIV/AIDS and affected families, stressing family and community values for HIV/AIDS prevention and also to promote anti-discrimination toward people living with HIV/ AIDS (*4th National Plan for Prevention and Alleviation of the AIDS problems 2007-2011*, 2007). Understood are those health service providers having knowledge about sex/gender/sexuality in order to be responsive and to make their services user-friendly to the target populations. In other words, this implies that staff development programs are in place for health care professionals' ongoing education so that they can respond to this different population target for health promotion in line with Thailand's new health plan and policy direction.

Current developments in Thailand

Recently a progress report relating to HIV/AIDS prevention in Thailand between 2008-2009 was published and presented by the United Nations General Assembly Special Sessions of HIV/AIDS (UNGASS Country Progress Report Thailand, 2009). In the section to follow, I will outline the report's decisions. The UN policy makers write that "there is growing recognition that HIV does not discriminate by age, race, gender, ethnicity, sexual orientation, or socioeconomic status" (UNGASS Country Progress Report Thailand, 2009). In the 1990s, groups identified at risk of HIV were: Men who have Sex with Men (MSM), Injection/injecting Drug Users (IDUs), and Commercial Sex Workers (CSWs). However, recently there has been an increase in the number of women and girls infected by HIV and the impact is disturbing. Women and girls now comprise 50 per cent of those aged 15 and older living with HIV. The impact of HIV/AIDS on children and young people is a difficult and a growing problem. In 2009, 370,000 children under 15 years were infected with HIV and 260,000 died of AIDS (UNAIDS, 2009a). At the same time, the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) (UNGASS Country Progress Report Thailand, 2009) Declaration emphasised the importance of collaboration between the various sectors including the government, business, civil society, labour organisations and People Living with HIV/AIDS (PLHA) organisations. In order to monitor implementation in support of the MDG 6 Declaration goals, United Nations Programme on HIV/AIDS (UNAIDS) and partners developed a framework of indicators to assess progress of related programs, and requested the signatory countries to report on these indicators every two years.

As part of the 60th UN General Assembly, convened on June 2, 2006, progress and successes in implementing programs in support of the UNGASS Declaration were reviewed. The issues of concern identified were: the spread of HIV in women, that half of new infections are among people under the age of 25 years, that there are more children diagnosed with HIV/AIDS and finally many countries do not yet have adequate ARV drugs to treat young children with HIV infections.

The HIV/AIDS epidemic is still increasing and the message from government is clear, a major health promotion campaign needs to be delivered across Thailand. As a result, there are major health system reforms in Thailand particularly a movement called '*Triangle that Moves a Mountain*' (Wasi, 2000, p.106) meaning that by creating relevant knowledge through research, social movement of social learning and political involvement, a mountain can be moved.

Nevertheless Thai's political culture is blemished; on the world's corruption index Thailand rates at 3.5, at the rank 78 of the 178 countries in the index score (Corruption Perception Index results 2010). While corruption is not publically discussed, major government reform plans may be delayed as moneys that should be reaching health services and health promotion at grass root populations disappear. Further, moneys intended for primary care and health promotion are still being diverted to curative health services (Hughes, Leethongdee, & Osiri, 2010). There is an argument for transparent economic evaluation (Teerawattananon & Russell, 2008).

Health is a human right

The life expectancy of the Thai population is estimated to be 72 years for women and 66 for men (Karcharnubarn & Rees, 2009). It is recognised that HIV/AIDS is both a cause and consequence of poverty (Alban & Anderson, 2007; Alkenbrack Batteh, Forsythe, Martin, & Chettra, 2008; Balaile, Laisser, Ransjö-Arvidson, & Höjer, 2007). The Thai Government was convinced that the important elements of resolving the AIDS crisis were that policy improvement and strong leadership were important in addition to being steadfast in the commitment to the Millennium Declaration, full participation of all sectors and adequate resources for effective strategies. A fundamental principle is that people living with HIV/AIDS have access to ARV drugs. Three major policy interventions meant to address poverty are; to deliver a health care system to poor people through the extension of health insurance to the formal and informal sectors; (2) the extensive geographical coverage of health care infrastructure and; (3) the provision of mandatory rural services by all medical, nursing, pharmacist and dental graduates (Limwattanonon, Tangcharoensathien, & Prakongsai, 2008). In 2006, UNGASS stated strongly (for the first time) that health was a human right incorporating basic freedoms.

The speed with which Thailand has scaled up public provision of ARV has been unprecedented through Thailand's National Access to Antiretroviral Programs for people living with HIV/AIDS (Chasombat et al., 2009; Over et al., 2007). Universal access to antiviral drugs has been included since October 2003 (Pachanee & Wibulpolprasert, 2006). The Thai government has recognised that inter-sector collaboration is important and they have scaled up care and treatment services nationwide. Today, most people living with HIV can access treatment and efforts are shifting to care for previously excluded populations (Ford et al., 2009). Until recently, medical treatment of people with HIV/AIDS was focused on ARV treatment but did not provide psychological support. However, current policy now includes clinical treatment,

psychological and socio-economic support which can be accessed through many dedicated HIV/AIDS clinics spread around Thailand.

In addition, the Thai Government has collaborated with many other organisations to meet its target goals, for example, the non-governmental sector (NGOs), Local Government and lobby groups of people living with HIV/AIDS and collaboration between the sectors e.g. service infrastructure, human resource development, civil society, community services, integrated HIV/AIDS care and treatment services are organised (UNGASS Country Progress Report Thailand, 2009). The Thai Network of PLHA mutually works with the AIDS Access Foundation and NGOs such as Médecins Sans Frontieres. Together, they aim to support PLHA participation in care and treatment through 'one stop' centres called 'Comprehensive Continuum of Care Centres'. There is joint collaboration between PLHA and health care providers in the centres. Health care professionals working in these centres have major roles in providing full care coverage information about the ARV treatment, counselling, group activities, home visits to provide support for those taking ARV and health promotion in general. It is also possible for people living with HIV/AIDS to take advantage of a free interest loan through micro-finance policies. In Thailand, there are now 367 Comprehensive Continuum of Care Centres providing services to 42,763 clients. In 2011, the National Health Security Office (NHSO) will provide budgetary support for 400 centers, seven regional offices and 1,014 ARV facilities nationwide (UNGASS Country Progress Report Thailand, 2009). Khon Kaen regional Hospital is one of the 'Comprehensive Continuum of Care Centres'.

Thailand has an excellent HIV/AIDS treatment and care monitoring system through the Bureau of AIDS, Department of Disease Control and this has ensured that new policies have been implemented. Evaluation includes monitoring, surveillance of HIV drug resistance and treatment of children using a tool to measure their quality of life. In addition, NHSO has supported the development and implementation of a national monitoring and evaluation system for the ARV program and the strengthening of PLHA networking. The HIV/AIDS treatment for migrants and those who are not eligible for universal coverage scheme has been supported by the GFATM. The NHSO introduced *the National AIDS Program (NAP)* Database in 2007 which is a paperless system to monitor PLHA care and treatment throughout the country. This organisation management framework for the NAP program consists of two parts: a benefit package and support system for people living with HIV/AIDS.

Results from the NHSO monitoring system show that 50 percent of people living with HIV who commenced ARV medication in 2008-2009 were diagnosed when their disease had already progressed. HIV diagnosis and result notification among PLHA are delayed for a number of reasons. Having access to information about HIV/AIDS may be one of the problems. Other possible factors for a delay in diagnosis are lack of knowledge about access to treatment services, or not being referred by health care providers. Other reasons may be that the person is not supported by health insurance as the person is a migrant with limited language or financial means, although there is a communication network facilitated by the Thai government on HIV/AIDS. Additionally, the Comprehensive Continuum of Care Centres are located in the government hospitals where people living with HIV/AIDS (PLHA) can go to obtain, treatment, support or advice, but it is not clear whether all PLHA are reached through these information centres.

Current situation of orphans

My interest in the inquiry stemmed from understanding more about ways health care professionals can assist AIDS orphans. High AIDS mortality has resulted in a substantial orphan population (Kuo & Operario, 2009). Authors Kuo and Operario (2009) write that survey data collected from 17 African countries revealed orphan-hood among children younger than 15 years. In a report by Operario et al., (2007) a national household study in South Africa revealed that 27% of youth between 15 and 24 years experienced parental death. Caring for the estimated 15 million children orphaned by AIDS will constitute a significant challenge for communities across the world for generations to come. That means millions of children are growing up without their parents and also many children are living in households with family members who are sick and dying (UNAIDS, UNICEF, & USAID, 2004). In Thailand, there is also an 'Orphans and Vulnerable Children' (OVC) program monitoring system being trialled. Currently, the OVC monitoring system is still fragmented. A national system is not yet operational. It is very difficult to use monitoring data to monitor progress of the national response on OVC. More discussion about orphans will be incorporated in the literature review in the chapter to follow.

One of my strong interests is the way stigma is pervasive and the damage this continues to have on families. United Nations General Assembly Special Session on HIV/AIDS (UNGASS) acknowledged that stigma associated with HIV/AIDS was still a major concern, and the

eradication of stigma and aversion toward people living with HIV/AIDS is the foundation for effective solutions.

Thailand, Khon Kaen Province and the Pralab Sub-district

In the context of this inquiry I will provide a description of Thailand, Khon Kaen province and the Pralab Sub-district. The geographic data, physical environment and population of Khon Kaen province and Pralab Sub-district will be described.

Thailand

Thailand is situated in South-East Asia. Thailand, where the inquiry took place, is located between the Gulf of Thailand, the Andaman Sea and south-eastern Burma, now known as Myanmar. It is shaped like an axe and its neighbours are Burma (Myanmar) in the North West, Laos in the North and Northeast, Cambodia in the East, and Malaysia in the South.

Isan is a Region of Thailand located in the North Eastern part of the country. It comprises 20 provinces. Agriculture is the main activity of people living in these provinces and 70 per cent of its population are involved in growing food (Mishra, 2010). The rainy season is from June to August. At other times of the year the climate is usually hot and dry and the sandy soil is of poor quality. The Chi³ river is the main water way but there are many tributaries which flow through the villages, and these are the main water supply for its inhabitants. Water used for washing and cooking comes from this river, canals, rivers, ponds or communal wells.

Sticky rice is the staple food of the region and is the main agricultural crop. This rice thrives even when grown in poorly drained paddy fields. Some of these fields flood from the nearby river so that two harvests are possible in one year. Recently, villagers have started to grow cassava and sugar cane. The main animals raised for food are cattle, pigs, chickens and ducks.

³The Chi River is the longest river in Thailand. Its length is 765 kilometers and it runs through the central Isan provinces

Figure 2 Map of Thailand



Retrieved from <http://www.maps-thailand.com/maps-thailand-files/map-thailand.gif> 29 May 2011

Khon Kaen

Khon Kaen is a large province which lies in the northeast part of Thailand. It comprises of 26 districts (see map below) 198 sub districts and 2,307 villages, four of which are the setting for this inquiry. The population of Khon Kaen is approximately 1,7000,000 (Wong-Asa, 2006). Khon Kaen has one Regional Hospital in the east of the province and the Khon Kaen University Hospital in the west.

Figure 3 Map of Khon Kaen Province



Retrieved from <http://www.thailandmaps.net/khonkaen/images/khonkaen.gif> 29 May 2011

Khon Kaen Comprehensive Continuum of Care Centre

The Khon Kaen regional hospital has a Comprehensive Continuum of Care Centre for people living with HIV/AIDS. Participants in this inquiry are probably familiar with the centre as this is where HIV/AIDS services, medical attention and support are provided.

The Comprehensive Continuum of Care Centre at the Khon Kaen regional Hospital collects data on all registered HIV/AIDS clients using its services. These data are part of Thailand's health recording system. When registered as a client of the centre, the local government is authorised to distribute a special benefit for people living with HIV/AIDS. In Thailand, the Ministry of Social Development and Human Security subsidise these budgets. The special benefit provides a monthly payment (500 Baht or AUD17 per person).

Pralab Community Health Unit

The four villages from which my participants were recruited are located in Pralab sub district which is approximately ten kilometers from Khon Kaen city. The population of Pralab sub district is 12,529 (Pralab PCU census 2009). Villagers travel to Khon Kaen for emergency hospital treatment but primary health care is provided at the Pralab Primary Care Unit (PCU). There are seven registered nurses in Pralab PCU. These nurses provide the community care for the entire Pralab population regardless of age, gender and health status of patients. Primary health care principles based on the Alma-Ata declaration drive the practice of these Community Nurses. Staff are well informed about social justice, equity and health promotion.

Health promotion is carried out by the Community Nurses who are Registered Nursing staff and they are assisted by Village Health Volunteers (VHVs). Village Health Volunteers have a prestigious position in the village community. They are not paid for their services but they are the backbone of this health care delivery. It has been recognised that VHVs have excellent knowledge about preventative health (Kauffman & Myers, 1997). In fact, Youngkong et al. (2010) revealed that VHVs and people living with HIV/AIDS both had good knowledge about HIV/AIDS interventions in Thailand.

Although health promotion plans are decided on at a national level, they are undertaken collaboratively at a local level. Recently the outbreak of Influenza A (H1N1) Virus meant that the entire community comprising many villages was the recipient of a major health promotion program. Using Primary Health Care principles to undertake health promotion in the village, Community Nurses and VHVs rolled out the prevention program. Prior to the H1N1 epidemic, HIV/AIDS was the major issue in many villages. Service provision included that Community Nurses and VHVs were able to visit people at home, provide community education programs and act as consultants for people living with HIV/AIDS and their families. However, the focus of the Pralab PCU has changed; in addition to responding to epidemics, the priority has become

Chronic Illness Disease management. Health promotion and education programs on HIV/AIDS are no longer gaining public attention. Campaigns to prevent HIV infection have almost stopped. There is an increase in the number of people with HIV infections, mainly young people and women, but this has not resulted in increased health promotion about HIV prevention.

In 2007, the Pralab PCU established a clinic that offered alternative health services including traditional Thai massage, meditation therapy and Thai herbal medicines. The aim of this new clinic was to provide villagers with a choice between Western and traditional / alternative health care options. Unfortunately, external budget constraints meant that the Pralab PCU alternative health service was not able to proceed with this alternative clinic but some local people were trained in giving Thai massage at that time. In 2010, the Pralab PCU received funding within their budget to recommence this program and reopen this alternative health service. Community Nurses compile Family Folders which contain villagers' health records. These records include the demographic data of each family and each individual family member's health records. Unless someone has permission from the Pralab PCU's Director, only the Pralab PCU staff are permitted to access these family members health records.

A little about Thai culture

I will introduce some geographical, social and traditional cultural features that may have relevance in this inquiry. The Isan area of Thailand is one the poorest. The average wage in Isan is the lowest in the country (Jongudomkarn & Camfield, 2006). Many Isan people seek higher paying work outside the region, particularly in Bangkok. Men in particular, travel to and from villages to big cities for work. Some have settled permanently in the bigger cities. Rather than relocate to the city as a family, couples tend to leave their babies and school aged children in the care of relatives.

There are primary (elementary) schools in the larger villages offering programs to Grade nine and secondary schools to Grade 12. Many children of poorer families leave school after Grade six (age 12). There are four public schools in this Pralab sub-district including three primary schools and one secondary school. Since 2007, Thailand's government has introduced a new regulation for primary school aimed at improving their services up to year nine. Each primary school provides free education from year one to year nine, which is congruent with the MDG 2

(Achieve universal primary education). I will discuss schools that orphans attend in chapters six and seven.

Family is considered to be the basic unit of Thai society. It is common that extended families consisting of several generations live in one house or have several dwellings in one compound. Courtships and marriage in Isan tend to follow strict tradition in rural areas. Most young women are married by the time they are 20 years old. The extended family system is still very much the traditional social structure in Isan, with newlywed couples often living with in-laws or building a home on the family compound or farmland. However, a few women remain single. Tradition demands that the youngest or only daughter continues to live at home to take care of her parents. Elders are greatly respected in the community.

Buddhism is the national religion of Thailand. It incorporates a complex system of beliefs and traditions and is a fundamental influence in Thai society and culture. Traditional village life in Thailand is influenced by villagers' Buddhist beliefs. This influence is less evident in big city life in Thailand for a number of reasons including globalisation. Nevertheless, the majority of Thai people's lives are underpinned by Buddhist philosophy. This philosophy values simplicity in living, tolerance and peace, and these values appear to diminish the levels of stress experienced by Thai city dwellers when compared to residents of cities in other countries.

It is important to understand the principles of the Buddhist religion as these relate to child rearing practices. This understanding may explain why grandparents would see it as their duty to take in orphans to care for them. Understood is that children need protection. Avoiding conflict and fostering a good relationship (harmony) among family members and relatives is essential. Principles are about rearing a child with love, care and kindness. It is imperative to teach children to be generous, dignified, well-mannered and display courteous behaviour. Good behaviour includes good manners, tactfulness, diligence, honesty, frugality, helpfulness and selfless.

The Buddhist Temple is the main feature in most villages. The population is almost entirely Buddhist. Theravada Buddhism is the main religion and has become Thai way of life and the basis for a moral philosophy I share. The temple or *wat* is the focal point of the village. Monks are highly revered and often enjoy more prestige than the head person. A monk may be consulted first if a villager needs support or counselling.

Furthermore, the Buddhist monks offer a school education program for a child which is an alternative to government funded institutions. It is 'free' and used by some villagers who are not able to afford the formal education schools which are provided by the Ministry of Education. Although the Thai education system is promoted as 'free', associated costs can be prohibitive for some families e.g. school uniform, books, travelling expenses and food.

Democracy at village level

A village has between 150-200 households. A *Phu-yai-ban* or the Village Head Person is elected by the villagers every four years. This person has the role to preserve social harmony in the village, through settling disputes and making sure all parties are satisfied with the outcome and that no one has lost face. This person also maintains birth and death data. The head person can be a woman or a man and is the spokesperson for the village community in negotiations with the government bureaucracy. Neighbouring villages are organised administratively in groups called a *tambon*, and village headpersons elect a *kanman* or commune headperson. The *kanman* is the chairperson of a committee which usually comprises a health professional, an agricultural extension person and a school teacher/headmaster. This committee is responsible, among other things, for deciding which villages should have health services. This is one of the committees I would have needed to consult if reforms in health care had been advocated by participants. The provincial governor appoints a district officer or *nai amphoe* who is the *Kanman's* immediate supervisor.

The local government administration system

The local government administration system or Tambon Administrative Authority has been established since 1994. Thailand's government aimed to decentralise the management into local government. Since then, the Tambon/ District Administrative Organisation (TAO) has the ownership of all community plans e.g. projects implementation, local budget management and oversight of the services provided including administration of funds to villagers (Leekpai, 1994). The local government administrative staff collaboratively work with *Phu-yai-ban* or the Village Head Person in six main areas (Leekpai, 1994) to:

1. provide water for consumption and agriculture;
2. provide and maintain waterways and land routes;
3. provide and protect drains and keep the roads, waterway, paths and public places clean and provide garbage and night soil removal service;

4. protect, look after and maintain natural resources and environment;
5. promote employment, and
6. protect vulnerable populations e.g. children, youth, older people and persons living with disabilities.

Conclusion

My interest in the inquiry stems from a desire to understand more about ways health care professionals can assist AIDS orphans and families who care for them. In this chapter, I have described the global context starting with the Alma-Ata Declaration, which is the philosophy underpinning Thailand's community health program. The Millennium Development Goals (MDGs) Declaration built on the Alma-Ata philosophy to reach health goals around the world by 2015, and one goal in particular is pertinent to this inquiry, MDG 6. The MDG 6 aims to reduce HIV/AIDS by 2015 and I explained the way in which Thailand has responded to this global goal. I then described Thailand's Health Care system focusing mainly on its reforms and ways it has reduced HIV/AIDS. I have introduced some Thai cultural practices that might be relevant for this inquiry. In the chapter to follow I will review the literature on the topic of HIV/AIDS.

Chapter Three

Literature Review

Introduction

In this chapter, I will review the literatures on HIV/AIDS research that has taken place in Thailand. It is important to assess current work and to identify how this inquiry is positioned. I will then explore the research literature around orphans and their families. I will be researching alongside families and I need to explore whether other research can deliver some answers about the way in which family units accommodate providing ongoing care for orphans. At the same time, I will check these literatures to assess how units have registered the effects of societal changes within and on the family. I am interested in the concept of stigma and how this is defined in the literature. I will also explore research literatures about the impact of stigma of people living with HIV/AIDS and the influence of stigma in the everyday life of families. In the effort to search for similar research being done elsewhere around the globe, I will seek articles that cover these topics. It is acknowledged that many papers are published only in the Thai language and I have made a decision to read only research studies that are written in English. English is the international language for communicating research results.

Search strategy and terms

I decided to confine the research article dates to 2003-2011 to ensure that I covered only the most recent research papers. The field of HIV/AIDS is prolific, so I had to make a cutoff date decision. The exceptions to these dates were classic theoretical accounts of stigma, mainly the work of Goffman, which were published in the 1960s and 1970s. Search keywords were HIV/AIDS and orphan, caregiver, children, impact of HIV, stigma and I specifically explored HIV/AIDS research in Thailand. Relevant papers and abstracts were transferred into a reference manager: Endnote version 14. This created the reference list. The review of the literature was ongoing throughout the inquiry. I used several search engines including CINAHL, MEDLINE, Proquest, Pubmed, Mosby's Index, PsycINFO, Scopus, Emerald Plus, SAGE Journals online, Science Direct, Springer Link, Google Advanced Scholar and Wiley Online Library. I focused primarily on peer reviewed articles, research reports and research higher degree theses. My Endnote library contains 807 documents and while not all will be used to support this thesis, included are Thai government, WHO and UNAIDS reports which support the context chapter. In addition, there are many methodological references.

What is HIV/AIDS?

Acquired immune deficiency syndrome (AIDS) is a disease of the human immune system caused by the human immunodeficiency virus (HIV). People with AIDS are much more likely to get infections, including opportunistic infections, as the illness interferes with the immune system. HIV is transmitted through anal, vaginal or oral sex, blood transfusion, contaminated syringes (often used by illegal drug users), exchange between mother and baby during pregnancy, childbirth, and breastfeeding. It can be transmitted by any contact of a mucous membrane or the bloodstream with a bodily fluid that has the virus in it, breast milk, vaginal fluid, semen and pre-seminal fluid and blood from an infected person. The virus and disease are often referred to together as HIV/AIDS. Although treatments for HIV/AIDS can slow the course of the disease, there is no known cure or vaccine. Antiretroviral (ARV) treatment reduces both the deaths and new infections from HIV/AIDS. ARV drugs are expensive and the medications are not available in all countries. Preventing HIV infection in the first place is the chosen strategy; hence, health organisations promote safe sex and needle-exchange programs in the effort to slow the spread of the virus. Education campaigns are on the rise.

HIV/AIDS research in Thailand

What research on HIV/AIDS is being conducted in Thailand? The AIDS Research Centre in Chiang Mai has been active for many years and is the main Centre for research in Thailand, so it would be safe to say that providing a brief overview of their research programs answers the question of what is being researched in Thailand (and published in English). Over 70 papers around the subject of HIV have been published since 2009. It is important to understand the main research fields currently under investigation. The majority (about 95 per cent of published papers) are biomedical research studies and most are scientific / technical papers at molecular level that are not able to be reviewed precisely because this requires specialist knowledge and as such, is beyond the scope of this inquiry. Nevertheless, it is important to assess what is happening in the field and scope the main topics of inquiry.

As people with AIDS are much more likely to get infections, including opportunistic infections, it is not surprising that biomedical research has focused on this area. As discussed previously, Thai people have access to ARV treatment, unlike many other countries where these treatments are denied, and sixteen studies investigated retroviruses and opportunistic infections such as meningitis, pneumonia and fungal and reported latest treatment modalities. Researchers have

identified their program HAART, which stands for highly active antiretroviral therapy (B.Lee & Oberdorfer, 2009; V. S. Lee et al., 2010; 2010; Sungkanuparph et al., 2011) in the TREAT Asia HIV Observational Database (TAHOD) and several papers explored virologic failure, ARV treatment and DNA resistance mutation.

In addition, a large research team at the Centre is working on children who are prescribed ARV (Aurpibul, Puthanakit, Sirisanthana, & Sirisanthana, 2010; Aurpibul, Puthanakit, Taecharoenkul, Sirisanthana, & Sirisanthana, 2009; Lao-araya et al., 2011). The AIDS epidemic of the 1990s and early 2000s has created a large population of children with HIV infections as the epidemic time frame would suggest this was before ARV was freely available to their parents, hence the availability of subjects and prolific research on children. Eighteen papers have been published in the last two years, usually in pediatric journals and key researchers are Lao-Araya, Puthanakit and Sirianthana. Research on children covers a variety of topics, but my assessment of the biomedical literature on children is that most relate to infections e.g. hepatitis B, measles, rubella and mumps (Aurpibul et al., 2010) or other problems children experience when living with HIV (Puthanakit & Sirisanthana, 2002). The Centre is part of an Asian Pediatric Observational Database on children.

Since HIV/AIDS is still an untreatable disease, a new HIV vaccine would bring a new hope to people. It is not surprising that Thailand had the highest number of volunteers to trial HIV-1 vaccine (Newman, Roungrakphon, Tepjan, & Yim, 2010). HIV vaccines are expected to be routinely given as preventive treatment to high risk HIV populations such sex workers, injecting drug users (IUDs), homosexual as well as heterosexual (Nagelkerke, Hontelez, & de Vlas, 2011). Lao-araya et al., (2011) recommended a children's vaccine called 'hepatitis B antibody (HBV) vaccination' which involved giving a 3-dose HBV vaccination to HIV-infected children with immune recovery while receiving the Highly Active Antiretroviral Therapy (HAART). The result illustrated that HIV-infected children had increased their immune response to hepatitis B.

Vaccines and their development is a popular focus of research activity (Chariyalertsak et al., 2011; Gilbert et al., 2011; Leelahavarong et al., 2011; Nagelkerke, Hontelez, & de Vlas, 2011). Most of this research is undertaken at an international level and another Research Centre in Bangkok fosters this type of research. The hopes of populations around the world are with the discovery of a vaccine.

By comparison, very little social health research is being carried out by the Chiang Mai Research Centre. I will provide an overview of social health research being conducted as I suspect this will inform my discussion chapter when data for this inquiry have been generated. In addition, these authors will be the team with whom I may collaborate when this PhD study has been concluded as we share similar research concerns. The social health research team has a strong youth research program but this largely involves quantitative research and qualitative research is non-existent at this Centre. The work of Oberdorfer and colleagues identified the prevalence and patterns of disclosure of HIV/AIDS diagnosis for HIV-infected children and these articles will be useful for comparison with this inquiry's discussion (Oberdorfer et al., 2006).

Oberdorfer and colleagues (2006) examined risk-taking behaviours and HIV self-disclosure among HIV-infected adolescents in northern Thailand. They found that rates of substance use and sexual activity were low in this population. In addition, STI knowledge was poor and diagnostic self-disclosure was infrequent. These authors concluded that improved sexual education and self-disclosure skills were needed among these Thai adolescents (Oberdorfer et al., 2006). Some work on stigma and HIV has been reported by the Chiang Mai group (Maman et al., 2009) although several countries took part in this inquiry including Sub-Saharan Africa, Tanzania, Zimbabwe, South Africa and Thailand. Authors found that factors that contribute to stigma and discrimination associated with HIV are fear of transmission, fear of suffering and death, and the burden of caring for someone with AIDS. Again, as part of an international HIV awareness program, Renwick's study focused on young people and investigated the impact of HIV/AIDS on health awareness and education for Thai young people (Renwick, He, & Gu, 2011).

Continuing with social health research at Chiang Mai's Research Centre, social welfare received by orphans was studied by Huang (2008) and this work involved a secondary analysis of orphan statistics gained from six provinces in Northern Thailand. Social, demographic, health, caregiver support and educational data were collected about orphans and vulnerable children. It was found that orphans and vulnerable children need more support at government, family and community levels. This inquiry demonstrated that Thai citizenship, living arrangements, household wealth, parents' socio-demographic characteristics, medical, material, educational support, and the orphan's disability were significantly associated with orphans and vulnerable children is education and health status. Among all the orphans and vulnerable children, double orphans, maternal orphans and disabled children were most vulnerable. It is suggested that

Thailand needs an improved social welfare system to bring fragmented efforts by multiple people into one domain. I will discuss this further in the section to follow.

One study that may be relevant for this inquiry is the work on quality of life conducted by researchers at Chiang Mai's Research Centre (Ichikawa & Natpratan, 2006). These researchers write that the numbers of Thai children whose parents are living with HIV or have died from AIDS are quite large, and these children are often discriminated against by their peers. In their study, children's attitudes towards HIV and AIDS were investigated. Using questionnaires and focus group discussions with primary school children, it was found that most children overestimated the risk of HIV transmission through casual contact. Classes were provided with education about HIV and its transmission and attitudes post educational intervention were more supportive toward children with HIV. They provide evidence that educational intervention at primary school level assists with changing attitudes more favourably for children living with HIV.

In summary, most of the funding for HIV/AIDS studies is from the Thai government, although there is significant input from three external countries: The HIV Netherlands Australia Thailand Research Collaboration (HIV-NAT) (Ruxrungtham, 2008). Thailand's Ministry of Health provides grants for HIV/AIDS research. As discussed in the context chapter, another significant body, the Thai Network of People with HIV/AIDS, is funded through the ministry. However, most research activity with people living with HIV/AIDS takes place through the Thai Health Promotion Foundation and this organisation fosters a preventive approach to research. There is yet another organisation that provides small grants: the Population and Community Development Association (PDA) is a non-government organisation utilising a participatory and community-based approach of research. Its main focus is HIV/AIDS prevention and it is well known for its grass roots efforts involving rural villagers. PDA's success story in family planning and HIV/AIDS prevention has attracted much international attention (Ford et al., 2009). The primary health care principles that support this NGO are appealing to me.

Research studies at 'home': Khon Kaen University

At Khon Kaen University there is some research activity and a few studies may be pertinent to my inquiry. Abel et al., (2010) write that research is required at the local level, particularly in the northeast region of Thailand where there is a rapidly growing HIV/AIDS epidemic, particularly among rural people. How well prepared are doctors and nurses in district hospitals

and health centres to deal with the increase in HIV infections, is the question asked by these researchers (Abel et al., 2010). A self-administered questionnaire was given to all 120 local nurses and interviews were held by health care managers e.g. Directors of Nursing, supply officers, nurse counsellors, and medical doctors. Their findings show that subjects had a fear of becoming infected in the workplace, and of being themselves stigmatized for looking after people with HIV. Who should have access to information about the patient's HIV status was debated; generally, health care staff believed they should know the status so that they could better protect themselves. In service education and improved planning to deal with the future onslaught of patients with HIV was recommended. Most research from my geographical area has been written in Thai and only a few articles have been translated. The above is a paper only published digitally in 2010 but the research was carried out in 1995. The study design and reports of its findings are minimal considering vast sources of generated data, but it clearly identifies the preoccupations of health care staff at that time. I have included this inquiry to demonstrate the difficulty in finding research in North Eastern Thailand.

In North Eastern Thailand, there is recent work from Sridawruang, Pfeil, & Crozier (2010) who explored the attitudes of Thai adolescents and parents. Their main question was to find out the barriers that prevent parents providing sex education to offspring. Focus groups were conducted with 30 parents and 36 youth. Thai parents had given their children sex education and recommendations were provided about ways to improve the situation.

Thailand's future research

As discussed in the previous chapters, the Thai government implemented a wide reaching population health education program and demonstrated reduction in HIV statistics (UNGASS Country Progress Report Thailand, 2009). By 2005, approximately one third of the new infections in Thailand were in married women who were probably infected by their spouses (Gouws, White, Stover, & Brown, 2006). However, a recent and disturbing trend of HIV/AIDS is that a large percentage of new infections are occurring in people considered to be at low risk of infection, for instance heterosexuals, married women, young people (Nguyen et al., 2008; Pattanaphesaj & Teerawattananon, 2010).

I talked about Thailand's response in chapter two, but I reemphasise that the positive side of this story is the government's rapid response to combat HIV/AIDS which included identifying and implementing a range of prevention strategies (Roberts, 2008). Thailand has successfully

implemented several comprehensive national HIV prevention strategies including encouraging people to practise safe injecting techniques, syringe exchange programs, media campaigns e.g. printing and broadcasting HIV/AIDS education messages to people in the cities and rural communities. The message was advocating 100 percent condom use and prevention of infection from mother to child being transmitted (Plipat et al., 2007; Rojanapithayakorn & Hanenberg, 1996; Vuttanont, Greenhalgh, Griffin, & Boynton, 2006). This multi-faceted HIV/AIDS prevention campaign resulted in Thailand being one of the first countries to decrease HIV prevalence by the mid-1990s, and as argued previously, it had met the millennium targets.

Despite the success of the HIV/AIDS prevention campaigns, the infection and its ramifications has resulted in physical and psychological consequences for those infected and their loved ones (Nyamathi, Covington, & Mutere, 2007). ARV treatments were commenced in 2000 and some of the groups missed out on these treatments e.g. migrants. Gouws et al., (2006) point out that the prevention strategies need to change. They argue that the education campaign should change direction and be given to regular partners, sex workers and their clients in order to reduce the HIV transmission. These authors claim that regular groups e.g. heterosexuals were underestimated to be at risk for HIV infection.

Living with HIV/AIDS: What are the main problems identified in the literature?

What are the problems identified in the literature? As stated previously, people diagnosed with HIV/AIDS often experience opportunistic infections and cancer (Kaposi sarcoma). Literature suggests that those living with HIV and their families are often fearful, possibly a result of misunderstanding the infection (Renwick et al., 2011). The literature suggests that people are still vague about ways to prevent it and how to avoid some of the complications (Alban & Anderson, 2007). Foster and colleagues confirm that people are not well informed and they highlight discrimination, stigmatisation and social isolation as a consequence, sometimes resulting in suicide (Foster & Pamela, 2007). Crampin and others (Crampin et al., 2003) state that when people realise that they have contracted HIV, they are often shocked and can become emotionally unstable, or become deeply worried and apprehensive about the disease. Newly diagnosed people may experience sleeplessness, loss of appetite and become depressed (Crampin et al., 2003). Foster (2007) writes that all of these potentially negative consequences continue to affect people living with HIV and their family members, including their children, parents, extended family members and significant others.

The impact of HIV/AIDS experienced by families who have been infected and/ or who have died is not well known (Jongsthapongpanth & Bagchi-Sen, 2009; Richter, 2004; Safman, 2004). Safman's (2004) study explored the social impact of HIV/AIDS on these orphans and their caregivers. Safman (2004) found that the experiences in the lives of orphaned Thai children mirror the lives of orphans in East and Southern Africa in terms of emotional and social impact. Safman (2004) concurred that family members, usually grandmothers, often become the main caregivers of orphans. He found that the role of the extended family caring for the orphan occurred more frequently in Thailand than in East and Southern Africa. This author found family members, especially grandparents, were anxious about a number of things including who would care for the orphan if they died. Grandparents were particularly concerned if the orphan was young and if they were in financial distress including having to juggle finances within the family in order to provide for the orphan.

As discussed earlier in this chapter, Huang (2008) conducted a study in Thailand and found that orphans of parents with HIV/AIDS were still living without social benefit support. Most of the Thai literatures encountered suggest that we must focus on the generation of orphans who have been left behind since their parents had died of AIDS. The literature revealed that HIV/AIDS orphans are in a precarious situation and further assistance is required (Currie & Heymann, 2011; Heymann, Earle, Rajaraman, Miller, & Bogen, 2007; Kuo & Operario, 2009; Pharoah, Richter, Killian, Foster, & Germann, 2004).

Definition of orphans

It was suggested earlier (chapter one) that an orphan is someone who has lost one of both parents, but it is important to turn to the literature to strengthen this definition. The Oxford Dictionary of Literary Terms (Baldick, 2008) defined an orphan as a child whose parents are dead. Nyamukapa and Gregson (2005) identified three different groups of orphans; maternal orphans: children under the age of 18 years whose mothers have died, paternal orphans children under the age of 18 years whose fathers have died, and double orphans: children under the age of 18 years whose fathers and mothers have died. UNAIDS, UNICEF and USAID (2004) also identified orphans as fitting into these three groups except that they additionally described children under the age of 18 years who had lost both parents as 'double' orphans.

Worldwide, various groups have provided definitions of 'orphan'; for instance a child having one or both parents who have died of AIDS (Atwine, Cantor-Graae, & Bajunirwe, 2005).

However, Bhargava (2005) defined the orphans in his study as maternal orphans despite having recruited children who had lost both parents. Likewise, Pelton and Forehand (2005) defined orphan as a child whose mother died of AIDS and Sarker, Neckermann and Müller (2005) defined orphan as a child under 18 years who had lost father or, mother or both parents.

Sherr et al., (2008) conducted a systematic review to identify a definition of an AIDS orphan. Using the search terms 'orphan' and 'AIDS', they found 383 studies. Two hundred and seventy three (71.3%) of these did not provide a definition of an orphan. Only 16.7 % (64 studies) defined orphan as being a child of whom one or both parents have died. They focused on the instances this had been mentioned, what determined a child to be identified as an orphan and the effects of being an orphan as well as the outcomes of this. Altogether 188 of the 383 papers reviewed contained descriptions of psychological outcomes and 67 of these also described physical outcomes. As a result of their systematic review these authors concluded that "the overriding finding of the research is that very few studies clearly define the term orphan..." (Sherr et al., 2008, p. 531). Nevertheless, they were able to determine a number of negative outcomes surrounding orphanhood, but they did not present a definition of an AIDS orphan as a result of their review.

After reviewing the studies discussed above, the definition of orphan in this inquiry is inclusive of: a maternal orphan who is a child aged under 18 years whose mother has died, a paternal orphan who is a child aged under 18 years whose father has died, and a double orphan, a child aged under 18 years who has lost both parents. The definition in this inquiry is the accepted definition of orphan used by UNAIDS, UNICEF and USAID (2004).

Impact of HIV/AIDS

In the following section I will discuss the impact of HIV/AIDS infection on orphans and then on families who care for orphans of parents who are family members and who have died of AIDS. In 2007, there were an estimated 15 million children who had lost one or both parents to AIDS, including nearly 12 million children in sub-Saharan Africa (Unicef, 2009). Millions of children are growing up without parents. Millions more are in households with family members sick or dying from AIDS; children in sub-Saharan Africa have been hardest hit.

Children on the Brink 2004 (UNAIDS et al., 2004) presents the latest statistics on historical, current and projected numbers of children under 18 who have been orphaned by AIDS and other

causes. According to this report after losing parents and caregivers, children have an even greater need for stability, care and protection. Family capacity, whether the head of household is a widowed parent, an elderly grandparent or a young person represents the single most important factor in building a protective environment for children who have lost their parent(s) to AIDS (Knodel & Saengtienchai, 2005).

The impact of being an orphan

Children who lose their parents through HIV/AIDS are orphans, no less than children whose parents have died in automobile accidents or war, and the responsibility of their care falls on their relatives, if they have them. Internationally, the orphan crisis caused by the human HIV/AIDS pandemic remains a serious issue with long-term social consequences (Birdthistle, 2004; Crampin et al., 2003; Kuo & Operario, 2009; Safman, 2004; Zhao et al., 2009). Children are directly affected by HIV/AIDS when they are orphaned as a result of their parents' AIDS related deaths (Sherr et al., 2008).

There are three major aspects on orphan-hood discussed in the literature: physical health issues; psychological issues and social issues.

Physical health issues

Orphans may also be HIV positive, as a result of mother to child transmission, or as a consequence of other ways of transmission, such as open wounds. In the early 2000s, many HIV infected children came from poor families, and did not have access to adequate health services and they may not have been able to afford ARV therapy, which is important to improve their physical health (Janjaroen & Khamman, 2002; Smith et al., 2010). These orphans are reaching adolescence in 2011, and, if they are still alive, these infected children are likely to become sick more often. Furthermore, children who are HIV positive may succumb to opportunistic infection. As a result, they may require additional health care resources which increase the already great burden of the cost to families, who have already lost the parent(s) of these children.

Pancharoen & Thisyakorn (2003) wrote in the Stuart Gan Memorial Lecture 2002 that children who were infected with HIV often have impaired development, multiple and prolonged hospitalisation and early death. According to the National ARV policy for Thailand, some of

these vulnerable children do not have a birth certificate, and immigrant children cannot access the Thai National ARV programs through the Thai National Health scheme (Pannarunothai, Patmasiriwat, & Srithamrongsawat, 2004; UNGASS Country Progress Report Thailand, 2009). Moreover, family financial stress forces children to be at risk of malnutrition and to lack basic items like clothes, medicines and accommodations. Similarly, the report of “Children on the Brink 2004” by UNAIDS (2004) claimed that when children become orphaned, they may also experience increased vulnerability. Without the care of parents or an appointed caregiver, children may face malnutrition, poor health, inadequate schooling, migration, homelessness, abuse, become child headed households and may be in the position of having to bring up younger siblings.

When researching the effects of being orphaned on health and nutrition in the highly affected HIV endemic areas of Africa, Sarker, Neckmamm and Mülle (2005) reported findings from a cross-sectional survey on orphan health status and health and nutrition parameters of urban Uganda. They compared the nutrition status between three groups of children, including non orphan, non AIDS orphan and AIDS orphan (Akwara et al., 2010). They found that orphaned children were sick more often during the previous two weeks than non-orphaned children. The higher morbidity in the orphan group could well be attributed to a higher morbidity in AIDS orphans, as some may have succumbed to opportunistic infections or AIDS disease. However, there were no differences in the prevalence of malnutrition between orphaned and non-orphaned young children in this inquiry. The researchers suggested that children in this inquiry who were looked after by one of their grandmothers seemed less likely to be undernourished. This inquiry emphasised the central role of grandparents regarding nutrition for the orphans. Moreover, the researchers also pointed out the quality of care which the extended family provided for young orphans in their study field in Uganda.

Psychological issues

Orphans who experience the loss of their close relatives and/or parents are at risk of psychological problems (Tulloch, Ananworanich, Cardiello, & Morsbach, 2004;. Zhao et al., 2010). It is hard to imagine seeing, little by little, the child’s parent becoming sicker and sicker and dying. This must be a dreadful memory for orphans. These are experiences which have not yet been studied. Perhaps through contact with older carers, such as the children’s grandparents, it may be possible to gain insights that will inform future care strategies, policies and practices.

Children of parents living with HIV may experience many changes in their lives after one or both parents die. However, the reports from UNAIDS, UNICEF, & USAID (2004) revealed that approximately 90 per cent of orphans were living with biological families or their relatives; unfortunately, 10 per cent were homeless. For that reason, orphans are often taken care of by one of their relatives. Yet, the same relatives have also experienced huge losses in their family as a result of morbidity and mortality caused by HIV/AIDS (Safman, 2004).

In China, Zhang et al., (2009) revealed that children affected by AIDS had to play a significant role in responsibilities for housework. Furthermore, those children not only were caring for themselves and younger siblings but also for parents with illness and elderly grandparents. These duties resulted in negative consequences for orphans, including physical fatigue, psychological fear and anxiety and suboptimal schooling (dropping out from school, repeated absence from school and inability to concentrate in class).

Likewise, in Zimbabwe, Nyamukapa et al., (2008) measured psychosocial effects of orphanhood in orphans living in a sub-Saharan African country. These researches surveyed 5321 children aged 12 to 17 years. Their findings revealed that the orphaned adolescents suffered greater psychosocial distress than non-orphaned, non-vulnerable children. The children in this inquiry were living in various circumstances, including low socioeconomic environments where they often experienced extreme poverty and may have become head of the family.

Cluver, Gardner and Operario (2008) conducted research in South Africa with 1,025 adolescents who completed self-report questionnaires comprising five different standardised scales: (1) Child Depression Inventory, (2) Children's Manifest Anxiety Scale-Revised, (3) Peer problems and conduct problem subscales of Strengths and Difficulties Questionnaire, (4) Child Post Traumatic Stress Checklist and (5) delinquent subscale of the Child Behaviours Checklist. These data were analysed by chi-squared and one-way analysis of variances (ANOVAs). The researchers found that AIDS-orphaned children experience significantly more stigma than other orphaned children ($P < .001$). Moreover, the orphans from this inquiry illustrated higher levels of psychological problems than non-orphans. Findings from this inquiry emphasised that AIDS orphans are affected by social impact.

Social issues

Safman (2004) reported the preliminary findings of a longitudinal study of the circumstances and welfare of Thai youth who have lost one or both parents to AIDS-related causes and the families who care for these orphans. The researchers used three qualitative methods to collect data in their study: semi-structured interviews with key representatives from the public health system, group discussion with caregivers for AIDS orphans and unstructured interviews with the familial caregivers. The study aimed to identify the circumstances and welfare of Thai youth who have lost one or both parents to AIDS-related causes. The results showed that orphans were experiencing significant financial hardship which might have implications for the children's long-term well-being and stability and for their opportunities for educational advancement.

Orphans are witnesses to changing family structures. According to Oburu (2005), writing in a context of Kenya, orphans in that country were more likely to experience problems, such as homelessness through lack of alternative accommodation, and forced to work or engage in hazardous labour in order to survive.

Being stigmatized by society adds to the difficulty experienced in the daily lives of people living with HIV/AIDS and their family (Rao, Pryor, Gaddist, & Mayer, 2008; Sandelowski, Lambe, & Barroso, 2004). Sandelowski et al., (2004) found even that when they did not report any specific occasion of stigmatisation, women in their study nevertheless anticipated or perceived themselves to be stigmatized. Referring to Goffman's (1963) work, these researchers found women in their study attributed "...potentially discrediting physical signs of HIV" as being attributable to other illnesses (Sandelowski et al., 2004, p. 127). They feared the impact of their disclosure of their HIV status should they choose to disclose it, on their children, including how this might result in stigmatisation of these children (Sandelowski et al., 2004, p. 126). This resulted in the women being cautious about how much they disclosed to others.

In Thailand, Ishikawa et al., (2011) explored children's attitudes towards HIV/ AIDS using questionnaires and focus group discussions with children in grades three to grade six in five primary schools in a northern province in Thailand. There were 513 children (274 boys and 239 girls) taking part in this inquiry. The five focus groups were structured. The findings described a strong positive correlation between children's belief that HIV could be transmitted through casual contact and their negative attitudes towards their HIV-affected peers. Most children overestimated the risk of HIV transmission through casual contact and this made their attitudes

less tolerant and less supportive. Consequently, affected children from HIV/AIDS were more likely stigmatized and discriminated by their peers.

The impact of caring for orphans

In the following section I will demonstrate the impact of caring for orphans on the family. First I will discuss the literature related to the role of older parents when they become a caregiver for orphans. I also describe the situation of Thai grandparents who take on the responsibilities of caring for orphaned children of their relatives. Finally, I will review the literature about the impact of caring for orphans on families.

The role of grandparents

In many countries, research revealed that the world-wide spread of HIV/AIDS has been a major contributing factor in the increase in number of grandparents who are taking on the caregiving role of their grandchildren (Backhouse, 2006; Knodel, 2006; Nyasani, Sterberg, & Smith, 2009; Schatz, 2007)

Thampanichawat (2008) conducted a grounded theory study to describe how primary caregivers managed problems when caring for children with HIV infection in Thailand. Grandparents in this inquiry had willingly taken on the care of their orphaned grandchildren because of a sense of responsibility and duty, feelings of love, attachment, sympathy, fear of losing the child and a desire to raise the child in an environment of hope. However, the grandparents had suffered as a result of the stigma of AIDS while providing care for children with HIV. Furthermore the grandparents experienced increased levels of anxiety and fear of loss, bore much of the burden for care, and faced many difficulties because of limited resources. The results suggest that psychosocial care and informational support are needed to enable these caregivers to provide better care for children with HIV infection. This inquiry is similar to the study by Oburu (2005) in that it too found all grandparents were challenged by several difficulties since they became the foster parents for orphans.

Schatz (2007) investigated the circumstances of South African older women who were providing care for orphans. These older women were experiencing financial, physical, and emotional burdens related to the morbidity and mortality of their adult children. There were many family circumstances which lead older women to care for grandchildren left behind, for

example their offspring's mortality, migration, (re)marriage, and unemployment. In this inquiry, Schatz (2007) pointed out the considerable responsibility that older women take on when caring for family members who are sick with HIV/AIDS and the children left behind. These duties extend beyond normal household duties and discussion of their responsibilities clearly identified that older women face enormous burdens for 'taking care of their own blood'. Schatz (2007) therefore strongly suggested that these older women might need further physical, emotional and financial support as the HIV/AIDS epidemic escalates and they continue to be 'bound' to take on increasing responsibilities. This inquiry demonstrated similar circumstances experienced by grandparents when they committed to care for orphans to those identified by Ssengonzi (2007), and they also pointed out that these older women in particular have increased responsibility and face enormous burdens. On top of that, the respondents were also influenced by feelings of psychological distress including worry, crying, depression and a sense of hopelessness not only about the state of things now but also about the future.

The role of caregiving grandparents in Thailand

In Thailand, the traditional extended families are still the norm (Vithayachockitikhun, 2006). Older generations contribute to the care of the family and, in the circumstances discussed in this paper, provide dedicated care for those with AIDS (Knodel & Chayovan, 2008; Knodel & Saengtienchai, 2005; Safman, 2004). A number of authors have published widely on older people caring for orphans, including Knodel, Vanlandingham, Saengtienchai and Im-em (2001), Knodel and Im-em (2003), Knodel, Watkins, and VanLandingham (2003), Foster (2006), Knodel (2006), Knodel (2008). Knodel has conducted many studies on this topic and his findings are relevant to this inquiry. Older people in Thailand, and probably many other developing countries, are extensively impacted by the AIDS epidemic through their involvement with their infected adult children. They are also most likely to provide care for surviving grandchildren, once their sons and daughters have died. This may have important implications for public health programs that address caretaker education and social and economic support.

The literature suggests that older people not only play an important role in providing support for HIV/AIDS family members in Thai society, but they also suffer a "burden of care", including providing physical care, assisting with activities of daily living, child care, cooking, giving medicine, wound care and providing basic care for general symptoms for example fever,

headache, oral ulcers, cough and diarrhoea. Moreover, they are also providing important emotional support (Knodel & Saengtienchai, 2005; Orbach, 2007).

When a family member becomes infected with HIV, it has an impact on the family, particularly the adult's parent who is the key person assigned for looking after the home, including care of the sick. The older women often play a huge role in the care of adult children who live with HIV/AIDS, in some cases it is the older man who takes this role if his wife is already dead. Richer et al., (2009) revealed that most migrants who are living with HIV/AIDS return to their hometown, a sign that they are looking for parental care during the final stages of the illness.

As stated earlier, traditional extended families are still the norm in Thai society. Older generations contribute to the care of the family and, in the circumstances, provide dedicated care for those with AIDS. Older people in Thailand, and probably many other developing countries, are extensively impacted by the AIDS epidemic through their involvement with their infected adult children (Knodel & Saengtienchai, 2005; Kuo & Operario, 2009; Ssengonzi, 2007). They are also most likely to provide care for surviving grandchildren, once their sons and daughters have died. This may have important implications for public health programs that address caretaker education and social and economic support (Kuo & Operario, 2009; Wakhweya, Dirks, & Yeboah, 2008). This inquiry aims to address a significant gap in the research literature, as very little is known about the way in which older family members cope with this load and difficult situation.

Impact of HIV/AIDS on families

In the last three decades, more than 25 million people have died from HIV/AIDS. It is known that it is a debilitating illness. It is well known that families and communities have been devastated by the impact of HIV/AIDS (Kandala, Brodish, Buckner, Foster, & Madise, 2011). Richter et al., (2009) comment that, in southern Africa, where there is a very high prevalence of HIV/AIDS, this is recognised as a 'family disease' thereby indicating how commonly it impacts on families as a whole. This author also provides some indication of the level of impact on families when he points out that they have to play the fundamental role in caring for their family's members who are living with HIV/AIDS, their children and other members directly affected by the epidemic. In addition, these families may be living in poverty, a situation that has been identified as retarding meeting the MDG 6 (Bussolo & Medvedev, 2007; Zaidi, 2010). This is because a person with HIV/AIDS has a diminished ability to provide or work for his or

her family, and treatment and health care costs related to HIV/AIDS often impact negatively on already meagre household incomes and further impoverish families (Tawfik & Kinoti, 2005).

Moreover, it is often women in families who are most impacted upon by having one or more family members infected by HIV. For example, women have a greater risk of infection because they have limited control over safe sex practices such as condom use (Decker et al., 2011). When HIV/AIDS impacts on families, women are more likely to have fewer options for providing income, food, and access to health services and to experience restrictions obtaining ARV treatment.

Children also are frequently impacted on there being HIV/AIDS in the family. It is not unusual that children are made responsible for assisting families financially or for taking on the role of caregiver for sick parents with HIV/AIDS (Heymann & Kidman, 2009; Zhang et al., 2009). Some children may also be infected with HIV/AIDS by their mother, experience more frequent bouts of illness than ordinary children and, as a result, miss more of their schooling (Wakhweya et al., 2008; Wijngaarden & Shaeffer, 2005). There are four factors that particularly impact negatively on parents of adult children who are living with HIV/AIDS. These are health problems; psychological issues; financial distress and stigmatisation discrimination. Each of these issues is addressed separately below.

Health problems

The vast majority of Thai older people taking care of adult children living with HIV/AIDS have been found to be aged 50 or more and many of these are aged 60 or older (Knodel, 2006; Knodel, 2008; Vithayachockitikhun, 2006). Furthermore, older people who care for their adult children living with HIV/AIDS are more at risk of health problems due to possible exposure to infectious diseases, such as tuberculosis (TB) or infection more generally, for example, infected wounds (Knodel & Saengtienchai, 2005). Older carers of adult children in the family who have HIV/AIDS may also suffer because of the physical strains associated with providing this care, for example, they may experience physical exhaustions from caring for these children (Rotheram-Borus, Flannery, Rice, & Lester, 2005).

Ssengonzi (2007) conducted a qualitative study in ten communities in rural and urban cities of Uganda. This researcher used focus group discussion and in-depth interviews to gather data. His research findings included that the greatest impact on older people caring for people infected

with HIV/AIDS was on their physical well-being. The study demonstrated that older female respondents experienced more physical ailments such as chest pains, leg pains, backache, pressure, and hypertension than younger respondents, which they attributed to the frequent changing, lifting, and washing of their adult offspring. More importantly, female participants in this inquiry reported sleep deprivation and weight loss because of the constant caregiving needs; they also felt fatigued and frail. Older parents, although willing to care for orphans (whether suffering from HIV/AIDS or not), also ensured they were lovingly cared for. Nevertheless, they found that 'AIDS orphans' were harder to care for than 'non- AIDS orphans' because they fell sick more frequently and hence required much more medical attention. Moreover, in most cases, they had lost both parents when they were still very young and therefore required more care from the carer because this could not be shared with a surviving parent. This differed from non-HIV/AIDS affected orphans because often these orphans still had one parent who could continue to provide parental care for them.

Psychological distress

The literature identified several emotional stresses experienced by older carers, including feelings of grief, loss and guilt toward their offspring. People living with HIV/AIDS are more likely to become severely ill and are then not able to care for their children. Several studies highlighted that older parents raised this issue (Mudavanhu, Segalo & Fourie, 2008; Oburu, 2005; Schatz, 2007). Oburu (2005) highlighted from a quantitative survey that the grandmothers reported higher levels of stress than the biological mothers ($p < 0.001$). Moreover, older parents may also suffer illness and grief following their adult child's death (Knodel, 2008). This may be compounded if the surviving child (orphan) is also HIV positive and also dies, leaving this older person, perhaps, with no-one to look after them as they become very old (Safman, 2004).

Thampanichawat (2008) used grounded theory to explore primary caregivers' experience of providing care for children with HIV in Thailand. He found that most Thai grandparents concealed an HIV diagnosis from the child they were caring for, because they feared that the child might not accept it and would worry about it. He found that these grandparents only told the child that he or she had a chronic condition such as pneumonia, allergies, or heart disease.

Financial impact

The economic impact of HIV/AIDS has been identified by tracing through its effects on households, firms and the government and thus on measures of overall economic activity. Numerous studies that were reviewed during my inquiry showed that high prevalence of malaria is correlated with low rates of economic growth; with particular reference to HIV/AIDS, it is fair to say that it has a trenchant or impoverishing effect on economies (Knodel & IM-em, 2003; Mhalu, 2006; Rodsom & Tangjareansatean, 2005; Twumasi, 2011). The costs of HIV/AIDS come in the form of reduced growth, declines in savings and investment rates, and huge health care costs. Those studies that were sampled have been extremely valuable in improving or sharpening our understanding of the threat posed by the epidemic. The young people in their most productive years are more at risk of HIV infection than any other demographic group (Knodel, 2008; Knodel & IM-em, 2003). This has had the effect of sharply reducing life expectancies across the continent (Knodel, 2008). Ghana is considered as one of the countries with low HIV/AIDS prevalence rates, yet the annual number of AIDS deaths was 17,058 and prevalence is high among the 40 – 44, and 45 – 49 year groups (Twumasi, 2011).

The older parents may not be able to earn an income for their families because they are often juggling the role of caregiver, looking after adult children and raising grandchildren. In addition, loss of the “breadwinner” adult child from the workforce may contribute to the families’ financial crisis. Finally, the financial drain of health care expenses also makes the financial situation more complex (Knodel, 2006). Likewise in Uganda the economic implications were categorised as loss of remittances from the sick relatives, loss of income and/or time to garden or work, and loss of savings and/or personal belongings (Ssengonzi, 2007).

Heymann et al., (2007) conducted research in three locations in Botswana including Gabarone, Lobatse and Molepolole. The researchers employed quantitative methods to gather data including a face-to-face survey. The research findings from this inquiry demonstrated that caregivers in Botswana face a challenge in balancing fulfilling the demands of a job, which would bring in income, and meeting the health and well-being needs of their children and older or disabled family members. Furthermore, those families who were caring for orphans had the challenge of needing to take on increased responsibilities including working overtime and evening and weekend shifts in order to provide for them.

In Thailand, it is apparent that there are economic difficulties encountered by HIV/AIDS families (Janjaroen & Khamman, 2001; Knodel & Center, 2006 ; Knodel & IM-em, 2003). Wijngaarden and Shaeffer (2005) revealed that people known to be living with HIV and/or their family members are frequently forced to quit their jobs or they find their business is negatively impacted because of decreasing numbers of customers leading to increasing financial distress. Moreover, people living with HIV/AIDS are burdened with medical costs coupled with a reduced income producing capacity, further adding to their financial distress (Epstein, 2004).

When discussing HIV/AIDS issues in relation to African countries, Tawfik and Kinoti (2005) identified that HIV/AIDS has the potential to have a severe economic impact. Two key factors are, first, the loss of young adults in workforces due to HIV/AIDS infection and, second, the increased cost of care, for example, expenditure for medical care, funeral expenses, lost working time due to illness and the cost of caring for orphans.

Kitajima and colleagues (2003) revealed that, in Thailand, the average cost per outpatient visit, including cost of supplementary medicine, laboratory test and ARV drugs, amounted to US\$ 294.2 for patients who need the ARV treatment and US\$ 26.1 for those who do not require such treatment. This expense is a significant problem for governments where HIV/AIDS is prevalent and also individuals living with HIV. It is thrown into sharp contrast when it is recognised that the average annual Thai family income stands at US\$ 876⁴ (Steinbrook, 2007).

The impact of stigma in the everyday life of families

In the following section I will review stigma and some definitions and perceptions about stigma, Goffman's (1963) work on stigma and stigma in relation to its impact on people and families living with HIV/AIDS.

Stigma

It is argued that stigma and discrimination are barriers to seeking care, ARV treatment, prevention effectiveness and counseling and the person may resist being tested. I was interested to read that Genberg et al., (2008) had developed scales to measure stigma. Genberg and colleagues have developed an HIV/AIDS-related stigma scale with strong psychometric

⁴ The original article speaks of Thai Baht, but I have converted it into USD, as a universally recognised currency.

properties. The interest is not so much the scale but the main factors related to stigma these authors have identified: (1) shame, blame and social isolation; (2) perceived discrimination; (3) equity.

It is important to discuss stigma and I will refer to classic texts written by Goffmann. Burrell and Morgan (1979, p. 190) note that Erving Goffman "...established himself as the foremost exponent of the 'dramaturgical' approach to symbolic interactionism". They suggest that Goffman's main focus has been on showing how "...individuals shape and influence their social reality" (Burrell & Morgan, 1979, p. 190). Goffman's (1963) focus on stigma discussed in his work "Stigma: Notes on the Management of Spoiled Identity" is consistent with this orientation. In it he explains stigma as "... the situation of the individual who is disqualified from full social acceptance" (Goffman, 1963, p. 9). He notes that the term 'stigma' originated from the Greek and "refer (red) to bodily signs designed to expose something unusual and bad about the moral status of the signifier" (Goffman, 1963, p. 19). Suggesting that the term is still widely used, Goffman (1963, p. 11), however, suggests that its meaning, although still reflecting the original concept, "...is applied more to the disgrace itself than to the bodily evidence of it". A similar orientation is reflected in Haug, Ytterhus, and Almvik's (2009) work in which they discuss stigma in the context of parents living with a mental illness and their children, and suggest that not only might both live with health issues but also endure negativity from others because of stigmatisation arising from being perceived as 'different' by others.

I will now turn to other authors who have described stigma. Haug Ytterhus, and Almvik, (2009, p. 462) state that the purpose of their article is to increase knowledge about "what it is like to grow up with parents with mental health distress by examining how children who live with parents suffering from this health issue present themselves so as to avoid stigma and self-stigmatisation and to be viewed as 'normal'" (Haug et al., 2009). Given that a number of explorations about stigma suggest that stigmatisation is about being identified as different (Goffman, 1963, p. 12; Haug et al., 2009, p. 462), it is important to consider what is considered 'normal'. Goffman (1963, p.11) identifies 'normative expectations' as the "attributes felt to be ordinary and natural for members of each category (of persons)". He suggests that people in everyday social situations interact with others without any particular attention or expectation of them being 'different' to how they anticipate them to be (Goffman, 1963) and that we unconsciously categorise people, establishing their social identity on first meeting them. This assessment is a taken-for-granted process that is only interrupted when anticipated categories and attributes (or normative expectations) are not fulfilled (Goffman, 1963). This results in an

awareness of difference in the other and he or she "...is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma...." (Goffman, 1963, p. 12). In addition, he also suggests that whatever others say, the stigmatized person may recognise that he or she is not accepted by the 'normals' and may experience shame because of recognition that an attribute of him or her is considered by others as tainted in some way.

Definition of stigma for this inquiry

Goffman (1963, p. 13) states that "the term stigma, then, will be used to refer to an attribute that is deeply discrediting". Haug et.al., (2009) explain this further by suggesting that "the discredited person could be read as being alienated from 'the normal'" and therefore perceived as different. However, Goffman (1963) warns that the detection of whether or not a person is discreditable does not rely on attributes but rather relationships', suggesting that it is a comparative process guided by what is considered 'normal'. He further states that "a stigma, then, is a special kind of relationship between attributes and stereotype" (Goffman, 1963, p. 14). He further suggests that there is a difference between the discredited and the discreditable. Huang (2005, p. 462) explain this difference, suggesting that "the discredited could, for example, be a person who has been open about his or her suffering from (his or her health) problems (while) the discreditable person could be a person marked by a societally devalued, but invisible and unknown, sign. The person is able to control her or his potential stigma and may choose to hide the information". From the above then, Goffman's (1963) definition of stigma pertains to someone who is excluded by society because of having attributes perceived as different to the norm and unacceptable to it.

Link and Phelan (2001) highlight that Goffman's work on stigma aroused researchers' interest in this topic, causing them to research it in numerous contexts. These authors base their critique of stigma on a sociological perspective, questioning several factors including the way it has been defined (Link & Phelan, 2001, p. 364). Addressing stigma, they (Link & Phelan, 2001, p. 364) suggest that frequently those writing about it provide no 'explicit' definition, preferring to use a dictionary definition, while others use Goffman's (1963) definition. They say arriving at a definition requires careful consideration of the context to which it is being applied and the background discipline of those discussing it, because "...different frames of reference (lead) to different conceptualisations" (Link & Phelan, 2001, p. 365). It is this that makes it important for me to clearly consider and express the way that stigma is being conceptualised in my inquiry.

Link and Phelan (2001) highlight that, because of the complexities in stigma, the important thing is that those who focus their work on this phenomenon are clear about the meaning they attribute to it when using it. Focusing on the many factors that need to be considered when seeking to define stigma, they identify that from their sociological perspective they "...apply the term stigma when elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold" (Link & Phelan, 2001, p. 367). They recognise, however, that this conceptualisation is more about "...the nature and consequences of stigma than its sources" (Link & Phelan, 2001, p. 364). Reviewing the idea that stigma is a persistent predicament, Link and Phelan (2001, p. 381) question this and suggest "...two principles in considering how to really change stigma". The first of these is that approaches to this change must be "...multifaceted and multileveled" and second, and of primary importance, that the:

approach to change must ultimately address the fundamental cause of stigma – it must either change the deeply held attitudes and beliefs of powerful groups that lead to labeling, stereotyping, setting apart, devaluing and discriminating, or it must change circumstances so as to limit the power of such groups to make their cognitions the dominant ones (Link & Phelan, 2001, p. 381).

Angermeyer and Matschinger (2005, p. 391) found Link and Phelan's (2001) conceptualisation of stigma "...applicable to all kinds of stigma not only mental illness". Restating of this conceptualisation as a conceptual framework for their research into stigma associated with schizophrenia resulted in the propositions that: "1) people distinguish and label human differences; 2) dominant cultural beliefs link labeled persons to undesirable characteristics that form the stereotype; 3) labeled persons are seen as an out-group, as 'them' and 'us', and 4) labeled persons experience status loss and discrimination that lead to unequal outcomes (Angermeyer & Matschinger, 2005, p. 391). However, Burris (2008) critiques Link and Phelan's (2001) ideas to the extent that he suggests that their definition of stigmatisation "...narrows Goffman's definition of stigma, or at least adapts it to apply more usefully to the social problems posed by stigma like HIV"(Goffman, 1963, p. 3).

In conclusion, the definition of stigma that I will adopt for this inquiry is an attribute that is deeply discrediting, distinguishing and leads to labeling a stereotyping.

Stigma among people and families living with HIV/AIDS

The following section discusses research that has focused on stigma experienced by people with HIV/AIDS.

Herek and Glunt (1988) discussed stigma of people and families living with HIV/AIDS in the early HIV/AIDS epidemic. The stigmatisation has been accompanied by intensely negative public reactions to persons presumed to be infected by the human immunodeficiency virus (HIV). They also demonstrated some of the social and psychological processes that contribute to AIDS-related stigma and offer suggestions for eradicating stigma through public policy and individual education.

Noting the strong association of stigma with people with HIV/AIDS and that “women are presumed to have a distinctive experience of the HIV-related stigma” (Sandelowski et al., 2004, p. 122), these researchers conducted a qualitative metasynthesis on stigma in HIV positive women. The sample contained 114 research study reports, of which 93 contained findings relating to stigma. These researchers identify the central finding of their study to be that “...stigma is virtually synonymous with the experience of HIV infection in women” (Sandelowski et al., 2004, p. 124). They also found that women expected that they would be stigmatized even though they had not experienced any specific manifestations of this. They suggested that stigma management largely involved efforts to control information in the service of preserving social relations and maintaining moral identity.

Castro and Farmer (2005) described stigma as a social process and part of a complex system of beliefs about illness and disease which is similar to Sandelowsky’s study (2004). They suggested that stigma management largely involved efforts to control information in the service of preserving social relations and maintaining moral identity. Castro and Farmer (2005) described stigma as a social process and part of complex systems of beliefs about illness and disease. Stigmatisation is often grounded in social inequalities. Indeed, stigma is often just the tip of the iceberg; because it is visible and generally accepted in public health discourse without further qualification, the term has frequently served as a means of giving short shrift to powerful social inequalities.

Kittikorn, Street & Blackford (2006) conducted a longitudinal ethnographic case study in Thailand and found that AIDS stigma disrupts families as a whole. The study demonstrated that,

although some participants disclosed their infection status to their family members, their concern about being stigmatized influenced whether or not they chose to disclose their infection status or still conceal it as a secret. Furthermore, the Thai women often reported that they were afraid of experiencing disgust from others in their social network because they were HIV positive.

Stigmatisation and discrimination is frequently apparent in communities who are responding to HIV/AIDS sufferers living in their midst. Visser, Makin & Lehobye (2006) used a quantitative method to assess the extent of social stigmatisation of people with HIV/AIDS in a South African community. The study demonstrated that 17 per cent of respondents had a high stigmatizing attitude towards these people. However, 42 per cent of the respondents perceived a high level of stigmatisation by others in the community. These results demonstrate that more than one half of people living with HIV/AIDS and their families are affected by stigmatisation from their community.

Steward et al., (2008) examined whether a multi-component framework, initially consisting of enacted, felt normative and internalised forms of individual stigma experiences could be used to understand HIV-related stigma in Southern India. The study showed that enacted and vicarious stigma influenced felt normative stigma; that enacted, felt normative, and internalised stigma were associated with higher levels of depression; and that the associations of depression with felt normative and internalised forms of stigma were mediated by the use of coping strategies designed to avoid disclosure of one's HIV serostatus.

Cluver et al., (2008) conducted a study in South Africa, which resulted in a clear description of the social effect of AIDS on orphans, especially their mental health. The orphans in this inquiry explained their experience of AIDS-related stigma, for instance, depression, post-traumatic stress, conduct problems and delinquency. They suggested that intervention programs aimed at the reduction of stigma for orphans should be utilised.

Conclusion

In this chapter, I have provided an overview of research in Thailand. It was important to establish the knowledge being generated in the Thai context. I then reviewed the current literature, particularly research based literature relating to orphans and their families in order to explore the way in which these units accommodate providing ongoing care and the impact of

registering the effects of societal changes on the family. I have also reviewed literature concerning the role of older parents who provide care for orphans of parents who have died with HIV/AIDS and the impact of this on their lives. Given that the literature points out that stigma is frequently experienced by those with HIV/AIDS, I have examined the meaning and definitions of this in order to broaden my understanding of it and how it impacts on and or is experienced by people living with HIV/AIDS as well as its influence on the everyday life of families caring for people with HIV/AIDS.

As can be seen, almost all of the literature focuses on the negative impact of HIV/AIDS on society, communities and people living with HIV/AIDS. The literature emphasises the burden of care, yet there may be situations where families take pride in their care relationships and we can learn from them. Little is known about any more positive factors relating to families with HIV/AIDS. A further gap in the research literature is that it appears researchers have not focused on the stories of family members caring for children orphaned as a result of HIV/AIDS. Yet, the number of families carrying out this role is increasing. This is a significant gap in the published research, a gap which results in little being known or understood about how family members caring for these orphans experience this situation and incorporate it into their daily lives.

Much of the research discussed in this chapter identifies that it is research conducted *on* the participants. However, in my research, the use of PAR principles is not only congruent with my research question but will also enable me to research *with* participants, in order to together identify what can be done to assist Thai families whose lives have been affected by HIV and AIDS. Given that my participants will be family members caring for orphans of parents with HIV and AIDS, my expectation is that, rather than identifying only negative experiences, I may also capture positive ones. In addition, by working *with* participants and building on their existing strengths, I am hopeful that I may ensure that they are willing and able to continue to address issues and strategies they identify to assist them in their role as caregivers after I have left the field.

Chapter Four

Principles Guiding the Inquiry

Introduction

In the effort to find suitable principles to guide this inquiry, I refer to my background in community development and I focus on Participatory Rural Appraisal (PRA), which I have used in community projects. The point I wish to make is that these projects share similar principles. I provide a reason for selecting a particular Participatory Action Research (PAR) methodology for this inquiry (Koch & Kralik, 2006) which embraces a participatory world view. I identified the principles I would take into my inquiry: they are democratic principles, social justice, social equity, freedom of speech and human rights. I will argue that it is important to listen to people who have been voiceless, in this situation those people whose lives have been interrupted by HIV/AIDS. I discuss evaluation in co-operative inquiries and provide rigour criteria by which this inquiry can be considered as trustworthy.

In this inquiry, the research question is: 'What can be done to assist Thai families whose lives have been affected by HIV and/or AIDS?' The three main objectives of the research were to 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, to 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 and to plan for action. Where feasible and taking the direction from my participants, I will facilitate their actions on issues raised and prioritised. In chapter one I identified my affiliation with collaborative approaches and community development projects. It is therefore entirely consistent that I would seek a PAR approach for this inquiry to help me answer the research question and meet the set objectives.

Background

In chapter one I talked about community development type projects carried out with community health nurses and others as part of my role as an academic. I referred to the 'Who am I, why I am here?' project with orphans living with HIV and pointed to major reforms that were a consequence of these collaborative endeavours. Orphans were given a voice through art. I am not an art therapist nor would I be able to research with minors as I would have trouble gaining the ethics approval from Committees in the University of Newcastle and in Thailand, considering that I was a novice in the field. However, I could see that researching alongside families might be the best option. These projects were the motivation to pursue this inquiry.

I have used PRA for a project with school children to explore the way we could improve their nutrition. Participatory Rural Appraisal in primary health care is used throughout Thailand. I was familiar with one participatory action approach and understood the principles that guided PRA (Chambers, 1994a, 1994b). These principles were facilitation, relationship building, letting participants make the decisions, equity and democracy. Facilitation was seen as handing over the baton to the participants, giving people time to build relationships, and giving people time to consider their options and make decisions. Participants were acknowledged as decision makers. Equity is seen when people's equality of worth is acknowledged. Children with lactose intolerance were given soya milk and their nutrition improved. When local rural people were given the baton and time to analyse their situation, they felt empowered. This was a collaborative project which involved all participants: rural people, local governments, academics and health care providers. Democratic principles underpinned all discussion and decision making.

Further, in 2003-2006 I gained a grant from the Thai Health Promotion Foundation (100,000 Baht) for a project called '*Tra Pra Roun Jai*'. Roun Jai translated means strengthening the community; in other words this was also a community development type project. The aim of this project was to work alongside youth in an effort to reduce their tobacco and alcohol consumption. The setting for this project was in the village of Tra Pra, 15 kilometres from Khon Kaen University. We invited 32 adolescents and their parents to attend a camp where health promotion was the focus. We also visited a Drug and Alcohol Rehabilitation centre and one person who was recovering from alcohol abuse volunteered to tell his story, the story resonated with the youths and they asked many questions. The project was an awareness raising exercise. One of the activities youths were invited to do was to compete for the best slogan for a public 'stop smoking or stop drinking alcohol' media campaign. The winning slogan was distributed widely throughout the Tra Pra area and posters found a place of pride at the community hall and the village gate. This is another good example of cooperation between families.

I have already said that Alma-Ata principles underpin most of these community development projects. However, I would not describe these participatory action or community development projects as research. None were published in English but reports were written in the Thai language. At the core of these community development projects was the promotion of health through education, early identification of disease, and working with entire families rather than solely with individuals.

As discussed, the International Declaration of Primary Health Care was signed in Alma-Ata, Russia, in 1978. The Alma-Ata (Declaration of Alma-Ata International Conference on Primary Health Care, Alma-Ata, 1978) declaration broadly affirmed the World Health Organisation (WHO) definition: health as a state of complete physical, mental and social wellbeing. In addition to the social health emphasis, the Alma-Ata declaration challenged health workers to overcome inequalities in the health status of people within the context of the socioeconomic order. It also established the rights of people to participate both individually and collectively in planning and implementing their own health care.

In reading the Bangkok Charter for Health Promotion in a Globalised World (The Bangkok Charter for Health Promotion in a Globalized World (11 August 2005), 2005), organised by WHO, and its conference proceedings, it is clear that the meaning of health promotion has shifted from instructing individuals to take up healthy lifestyles to recognising that people's health is part of their social and economic environment. The move is away from a biomedical model to a social model of health and includes wider social, economic and political reform. As my inquiry will be guided by these principles, it is important to discuss the Ottawa charter (The Bangkok Charter for Health Promotion in a Globalized World (11 August 2005), 2005) which is to:

1. Build healthy public policy. This refers to advocating a clear political commitment to health, and equity in all sectors.
2. Create supportive environments. This means paying attention to the environments in which people live and work. This includes promoting healthy living and working conditions that capitalise on resources and are safe, stimulating, satisfying and enjoyable.
3. Strengthen community action. At the heart of the process of strengthening community action is the empowerment of communities. This is achieved through developing a sense of ownership and control over individual endeavours and destinies.
4. Develop personal skills. This refers to being committed to health promotion that supports personal and social development through the provision of information and education for health.
5. Reorient health services. This statement evolves from a view of the health sector as moving increasingly in a health promotion direction, beyond its responsibility for providing clinical and curative services. This reorientation includes expanding the health service mandate to one that is sensitive and respects diverse cultural needs.

These are the principles that have been identified as guiding Thailand's public health policy.

The concept of community participation continues to capture the attention of international health policymakers and analysts nearly a quarter of a century after it was formally introduced at the Alma-Ata Conference (Declaration of Alma-Ata International Conference on Primary Health Care, Alma-Ata, 1978). I am aware that primary health care principles being applied in Thailand are about working with people in communities. However in this inquiry I describe these as: social justice, equity, community participation and responsiveness to needs (services are designed to meet identified needs). Guided by these principles I have been motivated beyond the individual and the medical and/or nursing diagnosis of HIV/AIDS to view the larger social picture of people in the context of their socioeconomic, cultural and political environment, to consider the way in which the context affects health and to act on this information. This means exploring the impact of inequality when health care is not affordable or when access to health services is denied. These questions shape the objectives for this inquiry.

Having decided that I have an affinity with participatory action approaches, I realised that I needed to understand the research component. My Thai field supervisor (Dr Kessarawan Nilvarangkul) completed her PhD using a cooperative approach to her inquiry, which was the development of a community-based care program for people with HIV/AIDS in Rural Thailand (2002), so I knew I would be in safe company when in the field for my data generation phase. I learned from my field supervisor that her philosophical discussion was influenced by Habermas. However, I realise that not all PAR facilitators share this 'critical' background in critical social theories (Habermas, 1971, 1979). I expected to read about his theory, stating that valid knowledge can only emerge from a situation of open, free and uninterrupted dialogue. I connected his thinking to my role as facilitator and creating a safe space for voices to be heard. I intended to read more about critical theory upon my arrival in Newcastle.

When I arrived at the University of Newcastle, I wanted to expand my knowledge about PAR; I wanted to understand the research component. My principal supervisor (Professor Diana Keatinge) has expertise in PAR; in fact, she supervised my field supervisor. Fortunately my third supervisor (Professor Tina Koch) had done extensive research with participants using cooperative inquiry methodologies. One text in particular, written by Koch and Kralik (2006) became my handbook to PAR. I quickly understood that storytelling was a component of their PAR methodology and this resonated with my desire to listen to the stories of families.

However, I realised that this serendipity in finding supervision that was congruent with my methodological aims would be short lived if I did not understand the philosophy underpinning this and other action research approaches.

What is Participatory Action Research (PAR)?

The PAR approach is one in which the researcher/facilitator works alongside participants to reform, improve, remodel or restructure a situation and/or practice that is impacting on their wellbeing and/or that of their community. It is certainly the case that I would like to facilitate change for people and families who provide care for orphans of HIV/AIDS. Koch and Kralik (2006), when unpacking the methodology write that PAR 'is participatory where participants decide the agenda and actions. However, there are many levels of participation as Arnstein shows in her ladder of citizen's participation (Arnstein, 1969). Participatory action research usually results in action and this may be personal development and/or at group reform level. Participatory action research is research, demanding a systematic and rigorous data generation/analysis process, responsive reflection and a documented account of the PAR process whilst researching (Koch & Kralik, 2006).

The literature suggests that most PAR facilitators are in pursuit of socially and culturally responsive, community capacity building, social justice oriented work that is meaningful in practice e.g. it makes a difference (Baum, MacDougall, & Smith, 2006; Dick, 2004; Maguire, 2001; Minkler & Wallerstein, 2003; Reason & Bradbury, 2001).

The research process attempts to be in tune with the specific cultural practices. In this inquiry, I will research alongside Thai people, I am Thai born and I was raised in the same area. Cultural sensitivity demands that the facilitator spends time in the field to ascertain the nature of these specific cultural practices. My plan was to be 'in the field' for storytelling with participants and group activity for one year (depending on Ethics clearance). In this inquiry I wished to pursue a process of research that is democratic, culturally sensitive and reciprocal (facilitators and participants share experiences and learn from each other).

Often people ask me if the PAR group is the same as a focus group. Whilst focus groups are static, the PAR process is dynamic and allows the facilitator to observe movement over time (usually several sessions). Participatory action research aims to demonstrate a culturally sensitive way to working with people and seeks to change the social and personal dynamics of

the research situation. The approach is non-competitive, non-exploitative and seeks to enhance the lives of those who participate.

My attraction to PAR is because its process has been shown to be equitable, transformative and liberating for participants (Stringer, 2007; Stringer & Genet, 2004). The PAR process can be liberating, empowering and educative and can set the agenda for reform and validate the knowledge of participants. It can be a challenge to authentically embrace and practice principles of participation when working within the boundaries of hierarchical organisational structures where information and decision-making is centralised (Reason & Bradbury, 2006).

In chapter two I described the context, so that operational and local government systems are visible and I suggest that democracy processes of local government are working at village level. While participation must be central to the research process, it is important that the construct be understood and practiced as a genuine process. Participatory action research principles express participation as the central core of health practice as we move from a philosophy of doing things to clients and on subjects in our research, towards working with people to assist them to identify their own needs and formulate their own strategies to assist in meeting those needs. Reflection increases self-knowledge and prepares people to make deliberate, well- informed choices (Schön, 1991).

Philosophical underpinning

Participatory action research approaches differ in terms of philosophical underpinnings, theoretical, ontological and epistemological orientations, shared understandings and purpose. Guba and Lincoln's Fourth Generation Evaluation text guided my understanding of these terms: Ontology refers to the nature of reality and asks the question; 'What does it mean to be a person?' What is it like? Epistemology refers to 'What counts as valid knowledge?' or to the philosophical question: 'How do we know what we know?' Methodology refers to the philosophical framework, the assumptions and characteristics of this participatory world view (Guba & Lincoln, 1989).

I will share my philosophical understandings. I struggled with dense western philosophical texts e.g. Habermas, and found my ability to grasp and apply these ideas to be wanting. I realise now that is partly because as a Thai person I was not educated in western philosophy, rather my background is Buddhist. Even my niece aged three is learning to meditate at kindergarten. I

took my rich Buddhist upbringing for granted. I now realise that it would have been suitable to explore the tenets of Buddhism as I believe there is considerable congruence with some of its teachings and PAR. Buddhism can be a religion and/or a philosophy but I refer to it as a philosophy. In chapter eight, I will connect some of its teachings with my findings.

In Thailand most research is quantitative. The scientific method informing biomedical research and the assumptions underpinning this paradigm reigns unchallenged in the Chiang Mai Research Centre. I am familiar with the scientific approach. In quantitative research, the process of measurement involves deciding what to measure, how to measure it and determining the reliability and validity of the instrument. I view the terms 'scientific method', 'scientific approach', 'positivistic approaches' and 'quantitative methods' interchangeably. They refer to a general orientation to research that implies the world can only be known if observable entities and regularities may be demonstrated and general laws verified through their measurement and verification. It relies on the positivist assumption that an objective reality exists: objectivity is the key term. The notion of value neutrality is accepted as critical in carrying out quantitative research.

In learning about the philosophical underpinning of PAR, I had Koch and Kralik's (2006) text to guide me on this inquiry not only methodologically but also philosophically. I am aware of PAR's critical social theory background and I refer to Habermas (Habermas, 1971, 1979), but, as stated I, was not able to grasp the complexity of his ideas. My research focus will be to listen to (and hear possibly for the first time), the voices of the families living with HIV/AIDS. The dominant ethical issue emerging is social justice and in that sense I am aware that there is stigma attached to the label of HIV/AIDS. I can see that having a critical stance may be congruent with my ambition to challenge the assumptions underpinning stigma.

Koch and Kralik's (2006) PAR methodology is guided by the work of Paolo Freire, (1970). Following these authors, I read Freire's work carefully. I decided that I would try to shift my theoretical learning from Habermas to Freire. My reason is that the movement he inspired in South America (Brazil) was appealing to me. Freire, who was one of the world's leading educationalists, in his classic text *Pedagogy of the Oppressed* broke with the tradition of gathering data on oppressed people and instead researched with participants placing capabilities in the hands of disenfranchised people, so that they could transform their lives for themselves. I believe that it is only through awareness of the way in which people contribute to their own oppression that people can begin an empowerment process. Empowerment of people is a

desirable outcome through the process of constructing and using their own knowledge. This version of PAR has emerged from their world view identified as a participative world view. I have embraced this participative world view.

In terms of researching, the key aspect of this philosophy is participatory: researching with people. Guided by the principles of PAR, a potentially democratic process is enabled that is equitable and liberating as participants construct meaning during facilitated, group discussions. The cyclical nature of the PAR process promotes reflection and reconstruction of experiences that can lead to the enhancement of people's lives, either at an individual or community level or both. My position is that a participatory ethos drives PAR; I now recognise that it was present, as a motivator, for my community development projects. At last I have a 'label' to describe my position; I hold a participatory world view.

Defining action research

There are many versions of PAR (Altrichter, Kemmis, McTaggart & Zuber-Skerritt, 2002; Bray, Lee, Smith & Yorks, 2000; Dick, Stringer & Huxham, 2009; Kemmis, 2006; Kemmis & McTaggart, 2005; Maguire, 2001; Reason & Bradbury, 2006; Stringer, 2007; Swantz, 2008; Wadsworth, 1998). When the multidisciplinary journal Action Research was launched, a definition thought to be encompassing was proposed by its editors; Peter Reason and Hilary Bradbury (2006, p. 10):

A participatory, democratic process concerned with developing practical knowledge in the pursuit of worthwhile human purposes grounded in a participatory world view, which we believe is emerging at this historical moment. It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities.

I particularly like the idea of doing research that can stimulate human flourishing. The action research 'family' includes a whole range of practices and approaches and the assumptions unpinning these are diverse in political, psychological and philosophical orientations. Rationale for the selection of the most appropriate PAR approach is often settled by the research question asked. I wished to listen to the stories told by families when living with HIV in their midst, so I had a strong preference for adapting Koch and Kralik's PAR approach (2006).

The PAR approach for this inquiry

I have become familiar Koch and Kralik's (2006, p. 27) PAR as a process in which 'we', researchers and participants, systematically work together in cycles to explore concerns, claims or issues that impact upon or disrupt people's lives. Collaboratively, we reflect on ways that may change situations or build capacity. We act according to self-devised plans to bring about social reform on a macro level or continuity into individual lives on a micro level. The systematic approach to data generation and analysis, validating cycles as we collaboratively decide what counts as data, and clear auditable documentation makes it a research approach. The cyclical nature of the PAR process promotes reflection and reconstruction of experiences and story that can lead to the enhancement of our lives, either at an individual and community level or both. Together 'we' decide on the shape of the outcomes that may be a resource, research report, a web site, a book for public readership, published papers and ideas for further research.

Reason's and Bradbury's earlier definition referring to human flourishing is quite close to Koch and Kralik's interpretation.

As discussed, the process of PAR is generally thought of as spirals of self-reflective cycles. Look, Think and Act describes this cycle, however, this cycle is described differently by various participatory action researchers. In the Action Research Planner, Kemmis and McTaggart (2005, p. 563) do not incorporate a story telling phase into their PAR process. These authors talk about cycles as overlapping stages as:

- planning a change;
- acting and observing the process and consequences of the change;
- reflecting on these processes and consequences;
- replanning;
- acting and observing again; and
- reflecting again and so on.

Regardless which PAR methodology used, e.g. Koch and Kralik (2006) or Kemmis and McTaggart (2005) or others, each of the steps is best taken collaboratively (facilitator and participants). In this way, PAR is a social process of collaborative learning. Building relationships is central, otherwise data generated may be fraught or minimal. Focusing on participants' lives makes them accessible for reflection, discussion and reconstruction. The

learning process can be observed in what people do, how people interact with the world and with others, what people mean and what they value and the language which people use to describe their world.

Koch and Kralik's PAR research approach

I read around the topic of PAR, in particular Koch and Kralik's (2006) version and what follows are my understandings. Their methodology consists of two distinct phases. Phase one is storytelling (one to one interviews), feedback, construction of a short story, finding commonalities and constructs. I realised that this methodology would allow me to privilege the storytelling. Storytelling appears to be the best way to proceed with this inquiry because HIV is a sensitive topic and people may be reluctant to talk in a group. I believe it is important to hear the stories from participants themselves. The second phase is the PAR group discussion. I was not sure at this stage whether participants would agree to join a group, given the stigma surrounding HIV. Besides, participants may have confidentiality concerns. If participants agree to meet, I would facilitate PAR group sessions and the second phase of this inquiry would be generated. My understanding was that phase two of this methodology involved group discussions which meant researching alongside participants, guided by the principles of PAR and following the cyclical processes of 'looking, thinking, and acting' as an iterative process. I came to the conclusion that Koch and Kralik's (2006) PAR approach would be the most suitable for this inquiry, but I need to explain further.

Storytelling is followed by group meetings where consensual and participatory procedures enable people to set the agenda for discussion by prioritising issues that are important for them, to reflect on their experiences, and devise actions that they perceive as being both possible and meaningful within the context of their lives. I am attracted to commencing this inquiry with storytelling. Storytelling has been used for centuries as a powerful vehicle for communication.

Looking

The process of Look, Think and Act describes a systematic, cyclical action process. Stringer (1996) used this cyclic process in 1996 and Koch and Kralik have used the process since that time. The looking process starts with creating the space for the person (or group) to have a voice, tell a story or describe a situation. Creating the space for voice involves ensuring a comfortable environment, safety, authentic listening, allowing people time to talk and respond

without judgment. When looking, in Koch and Kralik's methodology, I will ask the person to tell me a story about an aspect related to my research question e.g. what is it like to live with HIV? What is it like to care for your grandson? There is a strong possibility that narrating one's experience can help people make sense of their lives. My role as a facilitator researcher is in developing ways to enhance listening, seeing and writing. People live stories, and in their telling of them, reaffirm them, modify them, and create new ones. Constructions of experience are dynamic and new understandings emerge as we begin to make sense of our complex social world. The looking phase means that the group (or individual) observes the setting or the situation, gathers information, defines and describes the context. We make a distinction between listening and hearing by suggesting that listening is active and hearing is often passive. I am keen to observe that listening is an act of participation and manifests itself as an 'existential presence' whereas hearing implies that words are heard but not necessarily with full appreciation of what matters or what is important to people. Creating a story, as well as attending to one, is an active and constructive process. The reason to focus on storytelling is to better appreciate the value of each person's unique way of attaching meaning to the experience of living with HIV or looking after a grandchild. I would like to explore the potential of really listening to the stories I am told through 'looking'.

Thinking

Thinking is stimulated when the facilitator/researcher asks the participant to reflect. This is not only a validation process but usually requires the participants to reflect about their situation. In the PAR group discussion process, the facilitator provides feedback about the group's engagement in a summary statement, and then encourages participants to engage in discussion and dialogue, so as to develop mutually acceptable accounts describing their experiences. In this way participants can learn from the experiences of others, yet, at the same time, each person has an opportunity to be heard. Further thinking is stimulated when facilitators and participants collaboratively attempt to make sense and create meanings through conversation. Together 'we' compare and contrast our various interpretations. Stories and analysis occur concurrently, which enables identification of emerging understanding from early data to guide the subsequent group discussions. Feedback to participants will be ongoing. In terms of rigour, critical to validation of the data generation process (or the story line), the main constructions from the previous group session are presented and confirmed at each gathering or conversation. In short, thinking refers to exploring, analysing, interpreting and explaining events, story lines and interpretations.

Acting

When contemplating action, participants query what is important and what matters in their lives and they are facilitated to dwell on options or choices available to them. Story analysis occurs concurrently with successive individual interviews or when the groups are in progress. Constructs, issues, concerns and strengths are extracted, shared and discussed collaboratively. Involvement of participants ensures constructs are congruent with their life experiences and as such, enhances the rigour of the inquiry. The simplicity and order of the Look, Think and Act process motivates people and clarity about an issue emerges. I read that enduring friendships often develop between participants. Most importantly, the group often continues to meet after the researchers have left the inquiry.

The PAR process translates knowledge into action (Park, 2001). Central to this process is a cycle of critical reflection and learning. Reflection is about learning to understand our human situation and ourselves as we try to construe meaning in experiences and situations of which we are a part. The idea is of learning and sense making through dialogue. Chinn & Kramer (1999, p. 171) used the term “personal knowing”, which is “an unfolding process that is grounded in the context of everyday experience, in relationship with others”.

Look, Think, Act and potential outcomes

There is a conceptual difference between the Look, Think and Act elements. However, Koch and Kralik (2006) write that these conceptual differences begin to dissolve and merge. They suggest that people engage in many cycles of reflection on action, learning about action, considering possibilities and then devising new informed action which is, in turn, the subject of further reflection. During conversations, people absorb new ways of seeing or thinking in the light of their experience, leading to new actions. With practice, these become the focus of discussion, further reflection and group self-understanding. Change from action often does not happen at ‘the end’ of a PAR inquiry, but rather it happens throughout (Wadsworth, 1998). During the PAR process it often occurs that the focus of what needs to change will shift over time as people refocus their understandings about what is really important to them.

Participatory action research evolves from people reflecting and theorising about their lives. It helps if participants are inquisitive about understanding the relationships and forces between circumstances, action and consequences in their lives. Reform and change are the usual

outcomes of PAR, but change processes can occur slowly, hence the impact of engaging with a PAR process can resonate long after a researcher has left the field. Koch and Kralik (2006) write that they have found that it is important that the outcomes of PAR are not judged in terms of the magnitude of the change achieved or the action undertaken, because PAR often makes its impact as a process of ongoing learning and awakening.

Although not always feasible, the main aim is to involve participants in every phase of the research process. In this inquiry, I will facilitate a process that encourages participants to set the agenda. In order to make quality assessments, participants validate findings in cycles of reflection and action. Participation in the entire process promises that the findings are relevant, believable and useful. Participant ownership of the research inquiry may sustain action processes into the future. Outcomes, in terms of human flourishing, continue to impact on the lives of those involved in the inquiry (Reason & Bradbury, 2006).

Role of the facilitator

Working principles of PAR include building relationships, communication and inclusive participation (Stringer & Genet, 2004). These principles are based on the assumption that people are self-determining authors of their own action, who can and do learn to reflect on their world and their experiences within it. Everyone involved in the research inquiries should be able to contribute to collaborative thinking, decision making and idea generation. I refer also to the notions of reciprocity which is a key Buddhist belief with mutual respect for each person.

I understand that the role of facilitator should not be underestimated. As a facilitator, I will help families to work together to answer the research question ‘What can be done to assist Thai families whose lives have been affected by HIV and/or AIDS?’ I will use the term facilitator as it correctly describes the way I see my role. My role as facilitator will be to create a safe space for voices to be heard, in this inquiry it will be families who live with HIV in their midst. While a participatory action approach to working with people may appear to be fundamental, it is a complex undertaking. As discussed, assisting the process is an understanding of the working principles of PAR, which are based on building relationships, open communication, equal participation and inclusion of all people.

The skilled role of the facilitator is crucial in PAR. The facilitator who is congruent with the principles of PAR contributes to the lives of the people with whom they research. A facilitator

needs to maintain neutrality within the group. Principal qualities of facilitation are ensuring that relationships are equal, harmonious, accepting, cooperative and sensitive. Ideally, good facilitation is attentive, accepting, comprehensible, truthful, sincere, appropriate and advisory rather than expert. Stringer's (2007) guidelines on the role of the facilitator are particularly useful. A researcher, within the traditional paradigms, is an 'expert' doing research, whereas PAR has evolved to a point where the researcher is a 'resource' person and referred to as facilitator, associate or consultant. The PAR facilitator acts as a catalyst to assist participants to define their concerns clearly and then support them as they find solutions. When the participants have selected an option, it is the facilitator's role to assist with the implementation of the plan by identifying the pros and cons and then helping to locate the necessary resources. It is recognised that the ultimate responsibility for the success of the process is with the participants. Encouraged is a feeling of 'ownership' and thus motivation to invest time and energy to make changes in their lives.

The facilitator leads the group where participants want to go; the outcomes of the PAR process cannot be predicted. People engaging with the PAR process may find themselves on a route that takes many twists and turns; they may travel along unexpected pathways. I understood that I had to learn to live with uncertainties. Participatory action research relies on an interactive process between researcher and participants, and the nature of this interaction should be described. Participatory action research emphasises approaches such as openness, self-disclosure, group interviews and negotiation of interpretations. Here, the divide separating 'researched' and 'researcher' dissipates. I grasped that, when using this approach, the facilitator / researcher must be able to accept that research may not produce reassuring answers. Ambiguity and doubt are primary features of PAR because it takes its direction from the participants. The most important feature is that participants set the research agenda. Further, Stringer (HIV /AIDS Policy Lessons: Learning from Thailand) suggests that a facilitator:

- acts as a catalyst to bring about change;
- maintains flexibility in the PAR process;
- negotiates with the group about the role of the facilitator;
- understands the cultural and social issues involved in facilitation;
- is an inquirer, a clarifier and creates a safe place for discussion;
- maintains the focus of the group; and
- stimulates people to change by addressing issues that concern people now.

I had to research alongside participants but they would decide the 'rules' or norms beforehand or prior to the group meeting. There are several suggestions from Stringer (2007) I took on board.

- Be good listeners without judging others. Support and inclusion of everyone within the group is very important.
- One person speaks at a time. Wait for the other person to finish speaking before you start.
- Be mindful that others, who want to speak, have the opportunity to do so.
- Ensure the privacy of group members. What is said within the group stays in the group.

It was useful to understand what the needs of participants are, asking PAR group members what they wanted to gain or achieve from participating in the group. This is one way of setting the 'agenda' of the issues that the group may address. Checking with group participants regularly about their perceptions of the group progress is part of the process evaluation. That means we can talk about issues before they reach a level of conflict and discuss ways to move forward.

Discord or conflict can be anticipated as not every person has developed the skills to participate in a group. Discord is a disagreement resulting from individuals or groups that differ in attitudes, beliefs, values or needs. It can also originate from past rivalries or perceptions of difference. Conflict may also arise when people perceive their needs or the needs of the group are not being met. People may perceive differences in the severity, causes and consequences of the issues being focused upon.

Conflicts can arise when people try to make others change their actions or to gain an unfair advantage. Values are beliefs or principles we consider to be very important. Serious conflicts arise when people hold incompatible values or when values are not clear. When one party refuses to accept that the other party holds something as a value rather than a preference, the result is most likely discord. Conflict can also occur because people ignore their own or others' feelings and emotions or when feelings and emotions differ over a certain issue.

Power relations can cause discord within groups. Developing and regularly reviewing and revising group norms or ways of working together can help to counter conflict. Participatory action research is about bringing people together for a period of engagement, it is about learning

to listen and hear the voices of others. The root of conflict is often that people feel they have not been heard.

Rigour and evaluation

The term process or formative evaluation refers to the provision of short loop diagnostic feedback about the quality and implementation of – and immediate responses to activities generated by PAR group participants. Participatory action research participants and groups shape process evaluation as feedback cycles are concurrent to the research. Cycles of PAR with concurrent feedback means that ‘process’ data generated are immediately validated. In PAR groups, short loop feedback ensures that problems and issues identified during the research process are communicated quickly so that refinements and improvements can be planned and implemented. Systematic recording and analysis of actions, feedback and responses provide process evaluation data. Participatory Action Research and process evaluation share evaluation criteria.

During the PAR process, I examined what happened whilst researching; I recorded and analysed my reflections and these constituted a data source. Analysed reflections were reported and documented; their transparency determines whether the reader can follow decisions made whilst researching. I suggest that, based on reported reflections, the reader will decide if he/she can trust the research process.

The aim of collaborative inquiry is to construct meaningful, practical knowledge from the experiences of the participants. The group process enables enriched insights into the experiences of others, from which the group engages in making meaning of these experiences. Collaborative, reflective discussions are helpful in generating deeper insights and understandings.

It is important to consider ways in which PAR work may be read as a rigorous approach. At the same time it seems important to ask whether PAR work is accessible, makes a difference and is sustainable. These are questions about quality. I agree with Koch and Kralik (2006) who argue that rigour and quality of PAR practice are co-dependent.

More importantly, rigour in PAR may be evaluated by the willingness of participants to act. Evaluation criteria demonstrating success are when participants express a strong sense of self

development and evolution in their practices (lives), and demonstrate an increased understanding of their situation and the group initiates action toward reform. The core validity claim is focused on the workability of the actual social change activity engaged in. I am interested in the practical accomplishment of participants making sense of their lives and its relation to social action.

In summary, criteria for rigour are (1) all data are co-constructed with participants, (2) feedback is ongoing (3) participants drive the research process (4) their voices will be incorporated into the text with a claim that a multi-voiced text is believable (5) stories will be presented in their entirety – I will not privilege certain aspects of their story over others (6) translation of data from Thai into English will be validated by my field supervisor (7) my reflections will be incorporated into the text making the research process transparent (8) I will provide analysis protocols and an example of analysis in the appendices (appendix H) (9) social action as an outcome is deemed valuable to participants. Making a difference is PAR's goal and outcome.

Principles underpinning this Participatory Action Research inquiry

This PAR approach has an emphasis upon working with people rather than on people. The principles of PAR proposed in Koch's and Kralik's work (2006) are that the process is relational, democratic, culturally sensitive and reciprocal. I agree with those principles. I have traced principles as they apply in my previous community development studies and I have argued that they are congruent with the Alma-Ata Declaration and principles of Primary Health Care (PHC) (Declaration of Alma-Ata International Conference on Primary Health Care, Alma-Ata, 1978) which focus on social justice; equity; community participation and responsiveness to needs. The main principles I took into my inquiry are: democratic principles, social justice, social equity, freedom of speech and human rights in that they enable the facilitator and participants to work alongside each other in a cyclical reflective process. It is important to listen to people who have been voiceless. I believe that these principles will guide this inquiry in researching alongside families. This PAR approach embraces a participatory world view.

Conclusion

This chapter has focused on the methodology and method used in my inquiry as well as the reasons for its congruence with my research question. Participatory action research allowed me to work *with* my participants as they reflected on their situation, told their stories, and sought to

address issues they raised. The chapter noted the suitability of Koch and Kralik's PAR approach largely because of its focus on storytelling and the detailed analysis of stories that this approach enables. The principles which underpin this approach, data analysis processes used within it, the role of the facilitator and how rigour is assured was also discussed. In the next chapter I describe the process through which I undertook my inquiry.

Chapter Five

Participatory Action

Research Approach

Introduction

In chapter three I identified a gap in the research literature about how orphans and their families (usually their grandparents) integrate their experience of HIV/AIDS into their daily lives. In chapter four I surveyed cooperative research approaches and I gave my reason for selecting Koch and Kralik's (2006) PAR methodology for this inquiry. In this PAR approach, storytelling and group meetings were sequential and while one led to the other I will talk about data generation and analysis separately. In the previous chapter I identified the principles I would take into my inquiry. I was guided by these throughout the storytelling and group data generation and analysis. There were two distinct phases of this inquiry consisting of one to one interviews and the PAR group discussions.

In chapter two (context of study) I talked about the influence of Buddhism on my world view. I made the distinction between Buddhism as a religion and a philosophy and I have emphasised the latter. I have internalised these beliefs and not yet made connection between them and philosophies underpinning PAR.

In the previous chapter I summarised the principles to guide this inquiry as my belief in democratic principles - social justice, social equity, freedom of speech and human rights. These principles embrace a democratic, collaborative approach to research that equitably involves all persons (facilitators/researchers and participants) in the research process. In principle, I recognise the unique strength that each person brings to the study, I insist that voices are heard and I attempt to break down the distinction between facilitator / researcher and participants. When researching alongside people collaboratively, I work toward building sustainable relationships, I recognise the PAR group as a community and I build on strengths and resources within that community. As a facilitator / researcher I help this community to work together to improve their lives (reform).

In this chapter I will describe the actual process of this inquiry including the research setting, gaining ethics approval, the recruitment process, researcher roles, data generation and data analysis. After I had secured ethics approval from the University of Newcastle, I returned to Thailand for a period of 12 months to implement this process and research alongside its participants. Before commencing data generation in Thailand I gained ethical approval from Khon Kaen University.

Setting

This inquiry took place in the Pralab district just outside the city of Khon Kaen. I had already built relationships with staff at the Primary Care Unit (PCU) in the sub district of Pralab. Prior to starting this research inquiry I had worked as a Lecturer in Nursing at Khon Kaen University. Part of my role as lecturer was to work in the PCU and I had met Pralab's PCU Community Nurses. In chapter one I talked about working alongside these community health nurses in community development type projects. As discussed in chapter two, there were seven registered nurses in the PCU. These Community Nurses provided primary health care and promoted health for the entire Pralab population in nine villages serving approximately 25,000 inhabitants. The Community Nurses are assisted by Village Health Volunteers (VHVs). I relied on the Community Nurses at Pralab PCU to assist me with the recruitment of participants. In addition, the director of the PCU facility offered me the use of a small private interview room for one to one interviews and a larger meeting room with an oval table for people to sit around for the PAR group meetings. This room was equipped with a whiteboard and tea making facilities.

Ethical approval

This inquiry was approved by two Ethics Committees. The first was the University of Newcastle Human Research Ethics Committee (appendix A) and the second the Human Research Ethics Committee of Khon Kaen University (appendix B). Although all documents approved by the University of Newcastle's Human Research Ethics Committee were in English, the information letters to staff and to participants approved by Khon Kaen University's Human Research Ethics Committee were in Thai language. Initially, I wanted to research directly with orphans; however there were many ethical reasons why I could not pursue my ambition to recruit minors.

Recruitment

I recruited families fitting my definition of family which was a unit of people who share a dwelling or compound over time and are biological family members. I sought families in which adult family members were caring for child/children who had lost one or both parents due to HIV/AIDS. Children were excluded from this inquiry. Inclusion criteria were:

- participants who spoke fluent Thai;
- family members who were adults (usually grandparents) whose families had a history of HIV/AIDS; and
- families who currently cared for children who had lost their parent(s) to HIV/AIDS.

The recruitment process was assisted by the Pralab PCU Community Nurses. I spent time with PCU staff and gave them an information session. I discussed who would be eligible for recruitment. I explained that those people who were clients visiting the PCU for a health check or other appointments were eligible if it was known that the person has a relationship with an orphan whose family were living with HIV/AIDS. I requested that these Community Nurses invite eligible people to take an information package (appendix C and D originally in English but distributed in Thai translation) which provided details about the study. A potential participant was then able to make an informed decision about whether or not to participate. If a person was interested, he/she could complete the expression of interest found in the information package. This expression of interest could be posted to me at the Pralab PCU where a special letter box was provided. The information package also contained contact information about Dr. Kessarawan Nilvarangkul who was my field supervisor, should potential participants have any complaints or queries.

My contact details were provided in the information package. If potential participants required further information about the study, the interested person was able to contact me. There was a stamped envelope in the package addressed to me for the return of the study consent form, or potential participants could contact me via mobile phone. If interest was shown I said that I would meet with the potential participant at a time and place suitable to them. If the person agreed to meet me, I provided a verbal account of the study and made sure that the person understood the time commitment and expectations. I then asked the participant to sign (or apply their thumb print by way of signature) to the formal consent letter (appendix E and F originally in English but distributed in Thai translation). All participants signed their consent.

Recruitment was flexible in terms of the number of families but at least five families were to be sought as volunteers to the study. I estimated that there would be three to five members in each family, although some Thai families are much larger than that. I expected that there would be two or three family members who were willing and able to participate. The first person to be interviewed was likely to be the grandmother of the child because in Thai families it is generally the grandmother who is the main caregiver for children. In reality, the exception to this was

Lee's family (from family one). Lee is the mother of Pete (a paternal orphan); she had lost her husband due to AIDS and she was the first person that I interviewed in family one. I recruited five families and indeed the first people interviewed were grandmothers.

In an effort to maintain confidentiality of participant information, pseudonyms were selected. I asked participants to select a name but for the purpose of the English version I gave a fictional name to all participants. One participant, Noi, was the only person who specifically requested that his own name was to be used.

The benefits of researching with participants

When reflecting on appropriate methodologies to facilitate a study, not only is congruence with the research question consideration but also the possible benefits for its participants. Based on my readings of PAR, I understood that relationship building was my primary task. I would be able to build relationships with my participants as I would be in the field for 12 months. I assumed that this would give me time to 'walk' alongside families. I would invite the person to tell me their story. I suspected that giving voice to a person whose life has been impacted by HIV/AIDS could be experienced as therapeutic. I imagined that storytelling (one to one interview) might be the first time that a participant had openly talked about their experiences. It was likely therefore that the person might become distressed or uncomfortable and I had an ethical responsibility to ensure the availability of support for her/him if this occurred. I responded to this by ensuring I could offer counselling support should this occur. However, despite this, a possible benefit from participant's involvement in storytelling is that it usually enables people to reflect on their lives and build their self-esteem and confidence (Hyden, 1997).

Being able to join a group (in this instance a PAR group) may give the person support where previously she/he had been managing alone. Previous research shows that if the support people give each other in a group is meaningful, the group may continue to operate once the research has been completed. Again from my reading (Dick et al., 2009; Koch, 2006; McTaggart, 1994; Stringer, 2007), I understood that a group formed in this way may continue to meet when the researcher has left the field. Participants may decide to meet with each other, regardless if they find the support they give each other is beneficial. Although, we cannot know in advance the actions participants will take, research in this tradition shows that reforms participants have initiated are likely to be sustained. Most importantly, I speculated that this group would

stimulate reform and although I could not predict what shape this would take, it seemed highly probable that the group would be strengthened and individual lives improved in some way.

Participants were reimbursed for travelling costs when these were incurred at approximately AUD \$5 per time for travel to the Pralab PCU, where the one to one interviews and PAR group meetings were held. In Thai culture it is important to share food and drink as this shows the kindness of the host and respect for participants. Fortunately, I was in receipt of money from the University of Newcastle. I was able to provide light refreshments at approximately AUD \$5 per interview. Participants were provided with light refreshments during the storytelling interviews and group discussion should they go ahead.

Data generation

My inquiry was guided by the approach to PAR as articulated by Koch and Kralik (2006). My adaptation of their methodology consists in two distinct phases. Phase one is storytelling (one to one interviews), feedback and construction of a storyline. Phase two is researching alongside participants in a group, guided by the principles of PAR and following the cyclical processes of 'looking, thinking, and acting' as an iterative process.

I briefly describe four data generation sources: one to one interviews, PAR group data, my reflective journal noting both context and what was going on whilst researching, and the discussion with supervisors and my learning process. I conducted this inquiry in the Thai language but translated most documents into English in preparation for writing this thesis document. Further explanations of data generation and analysis will be discussed later in this chapter.

One to one interview data was digitally recorded with the consent of each participant, and I made verbatim transcripts of those interviews. In order to preserve confidentiality, I transcribed all interview recordings myself. After transcription, I analysed and developed a story line reflecting on what I had heard. Participants were given this storyline. This was not only a validation process, but it supported the principle of a collaborative approach to research that equitably involves all persons. Participants could claim ownership of their own story. Of course they were invited to make changes to their story and make corrections.

For the purpose of this inquiry, I translated the Thai interview transcripts and stories into English for the production of this document. In the translation process I worked with my field supervisor, as we moved from ‘spoken’ Thai, to ‘spoken’ English: moving backwards and forwards between these to obtain the closest possible accurate and meaningful translation of the interview. My field supervisor, Dr. Kessarawan Nilvarangkul, who is bilingual, was able to ensure the validity of the translation process.

I recorded and transcribed the group process in both Thai and English, giving feedback to participants in Thai. The way in which the data was generated and the analysis process will be discussed in detail in the section to follow.

In collaborative inquiry it is important to note the context in which the research takes place. I observed village life. I noted what was happening during the interview process and these observations were documented in field notes and used for process evaluation.

Interview data were digitally recorded and verbatim transcripts of those interviews, field notes and my research journal were analysed concurrently. ‘Look, Think and Act’ was used as the interpretative framework to guide analysis. Look, Think and Act also shaped the concurrent analysis in the researcher’s reflective journal.

The data analysis was divided into two separate phases, first of all the one to one interview data were analysed using the storytelling guide in Koch and Kralik’s (2006) methodology and the PAR group discussion were analysed using Look, Think and Act protocols established by Koch 2010. The PAR group data involved considering how participants looked at each of the seven constructs that they had placed on the agenda; their thinking about their experience of each of these and the actions they devised together to address them. Consistent with any group discussion, these processes did not take place in a linear way. Rather, the discussion moved to and fro over the course of meeting over four PAR sessions. These movements are described as cyclical processes; some of the actions were completed while others were still being worked on, needing further adjustment and discussion within the group.

My role as researcher

My role as researcher/ facilitator was considerable. Central to the PAR process is building relationships. In the first place, I spent time with each participant. Listening to their story and

talking with them about it, incorporating their feedback and sharing with them what I believe to be their strengths appeared to go some way toward building a close relationship with each person. I am Thai and I have been living in Khon Kaen Province for a long time and I believe speaking Thai and having common cultural sensitivity / understanding enhanced relationships with my participants. But building a relationship required continuous effort. One of the principles I took into the study was my interest in the lives of others and ways I could facilitate change. I showed an interest in their story and my participants seemed to feel that I was listening and that I had an authentic interest in their life. Being a good listener is a powerful way to build a relationship (Atkinson & Delamont, 2006; Bruner, 1991).

Most people are very capable in telling their own story. It is their life after all. I trusted their knowledge generating abilities. I trusted their version of events even if they contradicted mine (Atkinson & Delamont, 2006). When listening to the story, I tried to be patient and give the person the time to talk. Even if the story sequence did not follow the way I thought it could, I expected that eventually the story would emerge (Bruner, 1991; Bury, 2001).

I recognised that the HIV/AIDS topic was sensitive and that the participant might feel distressed. Sensitivity was required. One way to gain understanding was to be empathetic: I tried to place myself in the person's shoes. The principle of reciprocity required me to share some of my life or disclose some aspect of my life that indicated that I could relate to what they were saying. Whenever possible I reminded the person what had been achieved, I provided my perceptions of their strengths, and pointed out steps they had taken (action). These gentle reminders, I believe, are capacity and confidence builders. I am aware that the process of 'Look, Think and Act' facilitates movement. I was in continuous conversations with my participants and used my gentle reminders to show that they were achieving (building on strengths). In this way, I expected that the person would be encouraged to reflect on their life. In addition, my feedback on storylines stimulated action.

In my reading around the topic of PAR research, it is usually the case that when people feel heard or being listened to, they feel empowered. Sharing a story in a safe, comfortable environment with someone tends to bond people. Storytelling is often therapeutic. In fact, telling one's story may facilitate 'moving' on and I needed to be aware of my facilitator / researcher role in this movement.

I realised that I might be asked for health or life style advice. I had decided that it would be best not to offer advice; rather I sought someone who could answer their questions. But I took notes about advice requested or I listed all the questions asked, and with the participant's permission, offered to seek answers for them. As it turned out, the Community Nurses' attendance at the PAR group, requested by participants, greatly assisted me in responding to questions about health issues. Both these nurses and I also were obliged (by health authorities) to take the opportunity to correct any incorrect health information voiced by participants in the group and to take the opportunity to build on participants' information about (Swine Flu) which was of grave concern to the villagers, and people in Thailand more generally, at the time of my inquiry.

Storytelling

There are many versions of PAR but the appeal of Koch and Kralik's (2006) methodology is the storytelling component which in my inquiry preceded the group activity. I view storytelling as a vehicle for human encounter and communication. We tell stories with the guidance of our memories of the past and hopes and fears of the future.

Storytelling allowed me to invite participants to talk about their experience. In listening to their stories it allowed me to follow the participants' daily lives and to understand the major changes they had had to make in their lives. I was particularly interested in the storytelling phase of Koch and Kralik's (2006) method because I considered it to be important for understanding the way people have made transition in their lives.

Look, Think and Act describes the PAR cycle where looking can be facilitated through asking participants to tell their story (Koch and Kralik 2006). I asked the person to share their own experiences and tell their story about their past experiences, their current situation and what they envisage for the future. This was achieved during one to one interviews conducted in a private / safe place at the PCU. I said 'Tell me your story...' I waited and if the story was not forthcoming I used some prompt questions prepared for use during the interview, including:

- Could you please tell me your story about your life and family since the HIV infection entered your life or your family member's life?
- Tell me about your family?
- Can you describe your family as it is today?

- What has happened to you in the last ten years or when this infection first made an appearance in your life?
- What changes have you experienced or had to make since HIV came into your life?
- What matters most to you today?

And after the interview session I asked:

- Do you think anyone else in your family might be willing to talk with me?

I asked the participant to tell their story in whichever way he/she wanted to. I tried not to interrupt and instead let the conversation flow. Then I asked the question: ‘What really matters to you today?’, as a way of identifying the most important things to them at the time of my inquiry, and concerns that they may possibly want to consider further either one to one with me or in the PAR group. I believed that most people talk about what really matters to them, so if I was patient, I believed I would learn what that was. I realise that sometimes people talk about the same thing over and over again. I assumed that if they did this, what they are saying was really important to them.

Reflective journal

I maintained a reflective journal and analysed my observations as data. In ensuring that the research process was transparent, I also recorded what I was thinking as I researched and my insights about doing research. These data also constituted the substance of the process evaluation. This reflective process was ongoing throughout the study and my observations are written into chapter six and seven. I used the prompts (appendix G) to guide my observations, journaling post interview.

Developing the story line

I recorded my reflections in the researcher’s reflective journal. I needed to be aware of my own expectations/prejudices. As discussed in previous chapters, I have cultural and professional expectations and assumptions and it was important to be constantly monitoring these. It was also important to note my position, interest and values as these were operating in the study environment and I needed to be able to record their influence on my inquiry.

Process evaluation

There were two main evaluation processes in this inquiry consisting of the formative evaluation and the summative evaluation. The formative evaluation occurred concurrently with the data generation process. Koch and Kralik (2006) suggest several ways to assist with this process evaluation and I referred to and responded to these after each interview when my reflections, post interviews, were guided by these prompts.

They write: *‘When you have completed the interview ask if she/he has anything further to say’*:

- *Ask the participant about her experience of being interviewed. Is it difficult to talk about her experiences? Does it help to talk? If so, in what way?*
- *Remind the participant that counselling is available if the interview subject reawakens bad memories.*
- *Renew your pledge promising confidentiality.*
- *Inquire whether the participant was able to open up. Did she feel ‘safe’ to tell her story? When the person ‘really’ opens up it is more likely that you have quality (good, in depth experiential) data.*
- *Ask the participant if there are ways to improve your interviewing. Make sure that you tell her that you welcome her suggestions and will take her advice on board subsequently. Remind her of the purpose of the study.*

The summative evaluation process was achieved by the last PAR group discussion. During this discussion I asked all participants to tell me about their experience of being involved in this research. They told me that this inquiry was the first time they had been invited to share their experiences about problems and issues they were facing in an ongoing way, and to be involved throughout the study. They contrasted this to other research in which they had been involved and were asked questions but given no feedback or further involvement. They said that being involved in my inquiry had given them a way in which they could continue to address problems and issues in their lives with the support of others whom they had grown to trust. They also expressed satisfaction that the research had encouraged and enabled them to identify strategies to act on problems and concerns by implementing these strategies. They told how they had been able to share some of the outcomes of their action and, on the basis of these outcomes, to adapt or further develop strategies as required.

Data analysis: Developing a story line

The story as told by the participant was transcribed verbatim. I read through the entire transcript to get the sense of the whole. I asked: ‘what is happening in this story?’ What has the participant chosen to talk about?’ and ‘what is important here?’ I read each transcript several times to gain further familiarity of the interviewee’s tone. I noted the choices the participant made in telling this story, its chronology (or not), what the participant had decided to include in their story and I pondered about what could have been excluded.

There are numerous ways to analyse storied interview data but this was how I developed the storyline for each participant. I realised what was spoken rarely follows a neat sequence of events. Storied data were analysed concurrently. I did not proceed with further interviews until the previous one had been storied and feedback given to participants. These interviews were ongoing for several months or until the story had been told. I provided a written storyline (in Thai language) as it evolved in order to encourage participants to read their own story and take ownership. This feedback process triggered reflection about their situation. And the story telling went on and on ‘in cycles’ until participant and researcher were satisfied with the ‘end’ product. For the purpose of the research, my involvement with participants was mutually agreed upon, although in my situation, closure was dictated by the time line of the study. Each storytelling episode (interview) lasted 60-90 minutes of digital recording, resulted in 20-30 pages of transcript and varied between 3500-4500 words.

I will describe how the transcript was abridged into a storyline that was an acceptable account to be confirmed by the participant. Capturing the tone and voice was paramount, so using actual sentences uttered by the person woven together into the storyline provided a way to achieve this.

In the first level of clustering, I closely read the transcript again and using the cut and paste function of the word-processing software, I attempted to sequence events or time lines. I clustered aspects of identity, relationships, social context, events, opinions, perspectives, feelings, experiences, similar content and similar phrases under temporary headings. I paid attention to repetition, I clustered when the participant had repeated certain events, made mention of certain people/relationships, or emphasised particular words or phrases. I pondered about their significance. Perhaps the participant had repeated these meaning to emphasise its importance to her. Perhaps she was beginning to find her voice. I paid attention to words

selected, particularly the verbs which relate to 'looking, thinking and acting'. I asked what is going on (look coded in red), what is being reflected on here (think coded in orange) and what action is proposed (act coded in green). When clustering, I asked what really mattered to the participant, what was important to her? I asked what the participant's strengths were in this emerging storyline so that I could mention these to the participant next time we met.

At the second level of clustering, text was coloured into Look, Think and Act colour codes. Then I clustered text around strengths, self-identity, relationships, social context, events, opinions, perspectives, feelings, experiences, similar content and similar phrases, deleted repetitions, noted images and metaphors. I grouped these into paragraphs and condensed text. I asked what is the most significant thing happening in each paragraph? In this way I determined significant statements. I then rewrote the paragraphs with the most significant statement at the helm. Using the significant statement as the first sentence of the paragraph, I then reordered the paragraphs into a storyline. This story line was further condensed by gathering the first lines of each paragraph (significant statements) and joining them together to make a short story version. Depending on the situation, I could then select whether to return the long or short version of the story to the participant. I selected to give the longer story line in Thai of course.

When I met with the participant, this storyline was given to the participant for discussion and I incorporated any changes. Feedback also mentioned the person's strengths. The final story was a co-construction between facilitator / researcher and participant. Storytelling continued until the participant was satisfied with his/her story. Ongoing validation of the story enhanced methodological rigour.

In subsequent interviews, I monitored any actions the participant had implemented between discussions by asking him/her specifically how they were going in relation to their actions, What was working and why? What was not working and why? What were the challenges? These are process evaluation questions and I often observed that the opportunity to tell their story heightened participants' consciousness of their situation and resulted in them making small modifications in, for example, their living situations over the period of the interviews taking place. They also learnt and understood more about their 'New families' circumstances'. Furthermore, when I had completed the interview cycles, I invited the person to join a PAR group. The actions from the PAR group discussions were identified by the person as discussed in chapter seven.

Commonalities or constructs

Nine people were interviewed: five grandmothers, one grandfather, two aunts and one mother living with HIV. The interview, analysis process and storyline writing was repeated for each transcript. I then compiled a list of all significant statements from each of the stories. In my own words, I then wrote up the commonalities based on these. In other research, clustered text might be called “findings”. Fourteen constructs are identified in chapter six all referring to commonalities in experience.

Creating a common story line

I recognised that at least some of the nine participants volunteering to join the PAR group might not have wanted to share their personal lives about the impact of HIV/AIDS in the public domain of the group. In the attempt to start a group conversation, I created a short summary of the seven agenda items which were selected by all participants to be discussed in the PAR group. These summaries were written on the whiteboard and presented in the first PAR group by me at the first session.

Preparation for the group meetings

After conducting the one to one interviews, I conducted the PAR group meetings. It was important to be organised and prepared before each PAR group discussion. Preparation consisted of: personally inviting participant and their family members to a PAR group meeting as per the information letter for the study, organising a suitable, accessible and familiar venue (the Pralab PCU), ensuring that the timing of the meetings was appropriate to their availability, ensuring all participants had transport to meetings, negotiating an agenda for the meetings with participants or building agenda items based on discussions from the previous meetings, creating a comfortable and safe environment, arranging seating around the oval table before starting group meetings, providing suitable and/or appropriate refreshments for participants particularly for those grandmothers living with diabetes, checking the functioning and battery power of the digital recorder, recording my reflections immediately after each meeting and writing these into my journal after each group meeting.

In setting up the PAR groups there were some additional points to consider; confidentiality, privacy, safety (feeling safe to share one’s experiences) and comfort (seating, refreshments,

room, temperature). Setting the norms for acceptable behaviours within the group was important.

Prior to starting the PAR group discussion I met participants from each family in order to ensure that all participants understood the PAR group discussion and to ensure that they were free to say 'no', that joining the group was not compulsory. Therefore I invited the nine participants to join in this PAR group discussion. I explained that participants would be invited to set the agenda for discussion and that they would decide if they wished to take action and which strategies they might like to implement. Surprisingly, they all agreed to participate in the PAR group, however, all of them preferred to share only some concerns within the group, since they still wanted to keep some concerns confidential. Consequently, I was allowed to present the seven agenda items on behalf of them in the first PAR group discussion.

The group PAR process

In Koch and Kralik's (2006) participatory action research, 'Look, Think and Act' describes a systematic approach which can be articulated as follows: participants set the agenda, initiate and determine the salient questions, co-create the findings, determine voice and the representation(s), decide on the actions they wish to take and decide how reforms will be communicated.

The PAR group discussions were conducted in the Pralab PHC. Participants all agreed that it was an ideal setting to have the group meeting. I was accompanied by my field supervisor at these PAR group meetings, of which four were held. At the beginning of the first PAR group, I read the seven agenda items for all participants instead of participants telling their own stories because all participants preferred to share their stories as a group rather than individually. Besides, all participants felt that to speak out in the group of new people with whom they were not familiar might not be cultural appropriate. Eventually, all participants increased their confidence to talk and share their concerns in the group.

Conversations during the PAR group sessions were recorded and data generation and analysis were both systematic and collaborative. Conversations were digitally recorded with participants' consent. Group sessions were described verbatim in Thai language. My field supervisor attended the four PAR group meetings. Conversations with my supervisor, ideas and reflections

about the process were recorded straight after the PAR group had met. This was the debriefing session. The language was Thai.

As discussed in the previous chapter, I used 'Look, Think and Act' to guide data generation and analysis, 'looking' means observing the setting or the situation, gathering information, defining and describing the issue. People will offer different perspectives, reflective of their culture and their life experiences. 'Thinking' was stimulated as I asked participants to reflect on the emerging storyline and to think about 'what is happening here?' and 'why are things as they are?' Analysis followed the pre-established protocols using the look, think & act framework (Koch & Kralik, 2006). 'Acting' was decided by participants and referred to their achievement to improve their lives. Analysis focus was on actions generated by the group and these were closely monitored, documented and returned to participants as feedback. At the subsequent PAR meetings, the 'findings' from the concurrent analysis were provided as feedback to participants for reflection, discussion and validation before we moved on. 'Findings' were shaped collaboratively. This is an important rigour consideration.

Researcher as Facilitator

The researcher is a 'resource' person and referred to as a facilitator. A key to facilitating a PAR group is that the researcher does not lead the group but instead she gives of herself when facilitating the group and the following criteria should be considered (Koch, 2009). I was aware that I was a catalyst to bring about change, that I maintained flexibility, which I acted as an inquirer, a clarifier and a space maker. I did not often have to refocus the group, they organised themselves.

When researchers, community nurses and participants first met, we introduced ourselves to the group. Prior to the first group meeting, I had asked each person to suggest agenda items and I had these ready to place on the whiteboard. The concept of collaborative relationships in participatory research was introduced and discussed and group norms established by group members. Group norms are discussed in chapter seven.

One aspect amplified in the PAR group is that participants set the agenda for discussion. It is the researcher / facilitator's role not to change the direction or course of the discussion unless it becomes repetitive or when there is conflict. Skilled facilitation was required. Reducing the authority of the facilitator was the aim. My facilitator's skill was tested as I observed group

interaction and I tried to analyse whether participants were judging and/or controlling. Group dynamics is a critical factor in group performance (Forsyth, 2009). As facilitator, I constantly analysed whether the group was 'looking, thinking or acting' and thought about ways in which I could contribute to the group. I understood that the PAR facilitator acted as a catalyst to assist participants to define their meanings as they talked. Facilitators encourage participants to engage in discussion and dialogue, so as to develop mutually acceptable accounts describing their experiences. In this way, participants could learn from the experiences of others, yet at the same time, each person had an opportunity to be heard. Facilitators play an important 'manager' role in the PAR process. If someone talked too much or was too dominant he or she was reminded of the norms established when the group first met. This reminder was rarely necessary.

As researcher/facilitator, I acted as a catalyst to assist participants to define their strengths and their concerns clearly. When the participants had selected an option, it was the facilitator's role to assist with the implementation of the plan by identifying the pros and cons of suggested actions (individual or wider reforms) and then helping them to locate the necessary resources. It was recognised that the ultimate responsibility for reforms instigated were owned by the participants. I believed that participants needed a feeling of 'ownership' and thus motivation to invest time and energy to change the status quo.

Rigour in PAR research

During the PAR process, the facilitator / researcher examines what happens whilst researching. I recorded and analysed my reflections. These constitute a data source and my reflections are woven into chapters six and seven. Their transparency will determine whether the reader can follow the decisions made whilst researching. For the outcomes of the research to have credibility and for the findings to be meaningful to others, the research pathway needs to be transparent and available for scrutiny. For both validity and reliability of the findings to be achievable, the research needs to demonstrate a clear audit trail of evidence. The research trail is a set of reasoned decisions about the questions to explore and those to abandon, what to include and what to leave aside, what direction to take and not to take (Koch & Kralik, 2006).

In addition, this inquiry's credibility was established through the adequate representation of the participants' voices. In chapter six, nine stories will be given. Commonalities in participants' experiences will be drawn to the reader's attention showing identification of the 'common

features' in their stories. I was mindful of the need to accurately record all data and observations in a way that was accessible to outside appraisal, hence the 'audit' decision trail. More importantly, this research process relied on constant validation of stories and group matters *with* participants, so I would argue that a cooperative or collaborative inquiry such as this establishes its own trustworthiness. The most desirable outcome was that the group would continue to meet after I had left this research study and that actions and reforms generated by participants had sustained.

Conclusion

In this chapter I have discussed the process of my inquiry including gaining ethics approval, participants' recruitment processes, data generation and analysis. I have also discussed my role as researcher working *with participants* and as well demonstrated how rigour was assured in my inquiry.

In the next chapter, I describe each of the five families in my inquiry, including the family members within each family. I next relate the stories participants in each family shared with me and my reflections during the process of talking and working with them. From these stories I was able to identify 14 constructs, seven of which were selected by participants for discussion in the PAR groups.

Chapter Six

One to one interviews with family members and storytelling

Introduction

I will restate my research question and the relevant objectives here to focus this chapter. My research question is: What can be done to assist families whose lives have been affected by HIV and/or AIDS? The objective for this section of the inquiry is to 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 (objective 1).

As discussed, my inquiry was guided by the approach to PAR articulated by Koch and Kralik (2006). My adaptation of their methodology consists of two distinct phases. Phase one is storytelling (one to one interviews), feedback, construction of a short story, finding commonalities and constructs and these aspects will be covered in this chapter. In this chapter I will privilege storytelling. Participants' stories will be heard in their own voice. I researched alongside five families. Phase two is PAR group discussion which is researching alongside participants in a group, guided by the principles of PAR and following the cyclical processes of 'looking, thinking, and acting' as an iterative process. The PAR process will be discussed in the chapter to follow.

I was interested in the notion of storytelling and the cyclical processes of 'Look, think, and act'. My adoption of Koch and Kralik's method and emphasis on the importance of storytelling allowed me to invite participants to talk about their experiences. Listening to their stories allowed me to follow the participants' daily lives and to understand the major changes they had had to make in their lives. I was particularly interested in the story telling phase of Koch and Kralik's method because I considered it to be important for understanding the way people have managed in their lives. In addition, I was building relationships with my participants and believed that they would be more likely to attend subsequent PAR groups if they felt safe talking with me. I was in the field from April 2009 to January 2010.

Setting

I confined my research to take place in one district just outside Khon Kaen. I have described this district in the context chapter. My inquiry has been supported by staff working in the Primary Care Unit (PCU) in the district of Pralab. The primary health care staff, at this PCU, are registered nurses working in their community and supported by village health volunteers who roll out some of the preventive strategies relating to HIV/AIDS.

The Pralab sub district consists of nine villages each with a population varying between 2000-3000. In each village a Village Head Person makes decisions in collaboration with local government personnel. These villages are situated about 10 kilometers from Khon Kaen, the capital city in this province. Khon Kaen has almost two million inhabitants and a large 800-1000 bed tertiary hospital, including the Comprehensive Continuum of Care Centre (HIV/AIDS clinic). There is a good road and bus transport from Pralab sub district to Khon Kaen City.

I was invited to recruit participants by staff working in the Pralab PCU. I had worked as a lecturer in this area before and so I was familiar with this environment. My inquiry enabled me to observe village life as it connected with participants and I report my observations and reflections in this chapter.

The digital recorder

Prior to each interview I asked informant's permission to use a digital recorder to record our discussion so that I did not forget anything. Nevertheless, I told them I would turn off the recorder at their request if they did not want me to record something, or they became distressed because our discussion stirred up sad memories. I also advised them that I would take some notes during the interview to remind me about things, like where the interview was taking place, what was going on around us and their non-verbal responses to our discussion. Most of all, however, I emphasised that I was interviewing them because I was really interested in listening to their story.

Preparation

In preparation for this inquiry, I attended a three day seminar series called 'AIDS UPDATE' in Khon Kaen about the latest research, treatment and programs for People Living with HIV/AIDS (PLHA). I learned about the latest HIV/AIDS statistics, current treatments and more about opportunistic infection prevention. In one seminar, a woman who worked as a village health volunteer talked about her own diagnosis. She shared her experiences working with people diagnosed with HIV/AIDS in the village. She was a good example of working alongside people in her community. She was recognised for her work by the Department of Public Health as the best village health volunteer in Thailand in 2008. This woman was an inspiration to me.

I also spent time in Khon Kaen Regional Hospital and was able to see the way in which this hospital's Comprehensive Continuum of Care Centre supported people living with HIV/AIDS. This centre works under the umbrella of the National Access to Anti-retroviral Program for people with HIV/AIDS (NAPHA) in Thailand. It was interesting to note how clients were followed up once they had been seen by centre staff. The most important aspect of this service is that this is a One-Stop-Shop for PLHA. This helps ensure their privacy because clients do not have to go elsewhere in the hospital. Part of the program offered to service recipients is an intensive education program. This program includes learning about Universal Precautions and antiretroviral medication information, and how drugs should be administered. Social welfare support is another service provided. It is also possible for clients to access micro loans should they wish to start a small business. Social workers are able to assist the centre's clients to access social welfare benefits. People attending this clinic are able to attend self-help groups.

Recruitment of the participants

I met with the Pralab Head of the PCU and talked with the community nurses. I knew most of the staff as I had worked there before because I was supervising my nursing students in this village during 2004-2006. I talked about my inquiry and gave staff the information as described in Chapter 5 and in the ethics submission for my inquiry (see appendix D and F). The community nurses agreed to recruit people visiting the PCU. The nurses understood the selection criteria to be participants who provided care for children who have lost parent(s) due to HIV/AIDS. HIV status disclosure is a sensitive issue in this rural community and these nurses understood the implications. I arranged a post box in the PCU, where potential participants could return their expression of interest if volunteering in my inquiry.

I will now introduce the participants from five families. Family One: Sandy is a grandmother. Lee is her daughter living with HIV/AIDS and her nine year old son is called Pete. Family two consists of Nancy who is the maternal grandmother of two boys, Kenya and Golf. Family three is made up of husband and wife, Tracy and Noi, who are grandparents to Lula. Family four comprises Grace, a grandmother, her daughter Mary and Feat, Mary's brother's son. Finally, family five consists of Grandmother Sue, her daughter Norris and Ron, who is Norris 'sister's son.

In most of the five families, grandparents were the main caregivers. Most current caregivers were grandparents. Three families shared the characteristics typical of a Thai village population

in terms of their low education, difficult socio-economic circumstances and predominance of blue collar workers. Their main occupation was worker. In the rainy season, they found employment in the rice fields; in the dry season it was time to harvest the rice. As well as rice, several other crops are grown during the dry season, including spring onions, herbs and green vegetables and this sometimes provided work for grandparents. Grandparents also caught fish if they were living near the Chi River. Income generated from selling fish complemented their financial situation. Others, Sandy, Kenya, Grace and Mary's husband worked as construction labourers, lifting huge blocks of concrete in the building industry. Two families had adequate income; Tracy and Noi had their own land and a small grocery shop, whereas, Sue's family bred frogs and this gave them a reasonable income. The five families lived in four villages in the Pralab district. Grace (family four) and Sue (family five) lived in the same village.

'Orphans' cared for by these families were five boys and one girl. All these children except one, Kenya, attended school. Kenya had recently started work as a labourer. Only one of the six children, Feat, was infected with HIV through maternal child transmission.

One to one interviews with grandmothers

In the first family, I interviewed Lee whose partner died of HIV/AIDS leaving her with their son Pete. Lee was the first person to consent for interview in this family. Then Lee introduced me to her mother 'Sandy'. Sandy is Lee's mother and grandmother of Pete and she agreed to participate in my research. Pralab PCU Community Nurses introduced me to families two, three and four. The fifth family was introduced to me by Grace (family four), the only family recruited through a snowball technique. I started off by interviewing the first person who volunteered in each family. Eventually, I invited be interviewed other members of that family. Unfortunately, Nancy's husband having agreed to participate died suddenly. Noi was the only grandfather who participated in my inquiry. Pseudonyms were used for all participants, except Noi who requested that I use his real name.

Building relationship with the participants and listening to their stories

At the beginning of every conversation with my participants, I expressed my interest in listening to them and their story and in trying to understand their situation. I utilised several strategies during the interviews including active listening which is an effective communication skill, and I tried to avoid being judgmental, blaming or upsetting to participants in any way. I found that by

listening actively to participants, I encouraged them to relax and discuss their situation openly with me. I remained alert throughout the interview and the use of active listening helped me to generate rich data. The interview data and field notes that I made during interviews assisted me to gain a deep understanding of participants' stories and their situations.

My field supervisor, Dr Kessarawan Nilvarangkul, who is an experienced focus group facilitator, supported me as I worked alongside my participants in their village context and helped build my facilitation skills. I reassured all participants that their stories were confidential, and that only my supervisors had access to them.

The translation of Thai interview data into English

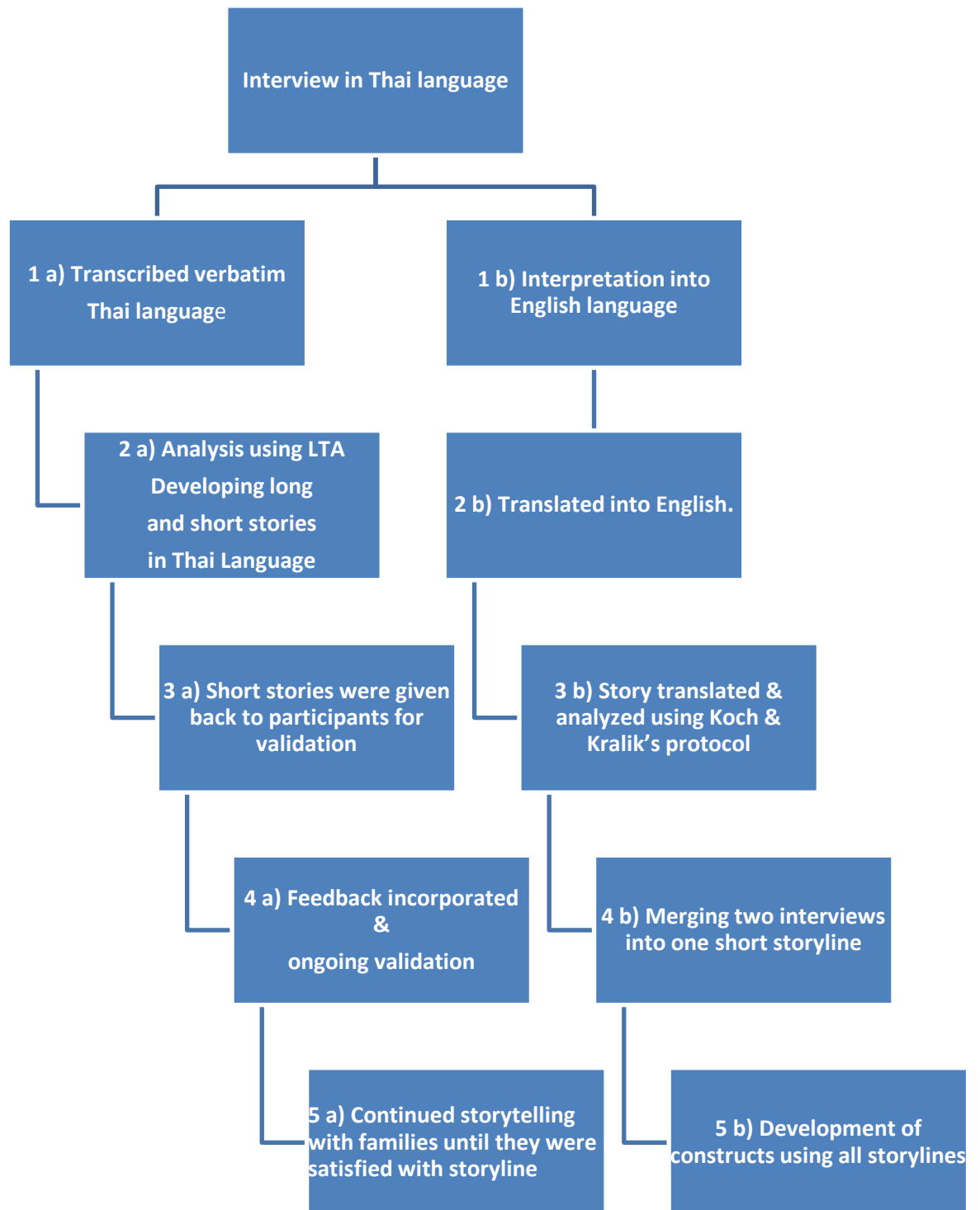
Using the following flowchart (Figure.4) I now describe the data generation and analysis process. As a researcher, I worked with Thai participants who did not have English as their first language; therefore, I conducted the research process in Thai language. However, the requirement that I produce this PhD document in the English language led to data generation and analysis taking place in both languages concurrently.

I transcribed all of the Thai interview recordings myself (1a) and analysed them concurrently (2a) to the data generation process using Koch and Kralik's (2006) cyclical analysis processes of 'look, think, and act'. Each interview transcription was developed into a short story (3a). Then all participants were given their own short story prior to the second interview. Before starting the second interview, the participants validated and gave feedback on the short stories of their interviews (4a). This process provided participants with the opportunity to edit or delete any part of their story and also prompted further discussion. The advantage of this process was that participants could verify their stories or make changes as they wished. This validation process is an important consideration for assuring methodological rigour. The next interviews continued storytelling with families until they were satisfied with the storyline (5a).

At every stage identified in Figure 4, I worked with my field supervisor in the interview translation process. We moved from "spoken" Thai, to "spoken" English: moving backwards and forwards between these to obtain the closest possible accurate and meaningful translation of the interview. Being bilingual, my field supervisor also read and commented on my interpretation and the accuracy of my translation process (1b-2b). I then shared the English

version of each interview transcript, its analysis and the emerging short story arising from it with my Newcastle University supervisors who provided further feedback (3b-5b).

Figure 4 Interview and analysis flow chart in both Thai and English



In the following section, I present each participant's short story which has been compiled by merging the two interviews I had with him or her. First, I outline the details of each family. This is followed by a timeline of significant events experienced by the participant's family. A detailed introduction to each participant follows before the presentation of his/her short story. Following the story, I outline first my observations and next my reflections about the participant's situation as I came to understand it from the story and the time I spent with him/her.

Family One: Lee's family

Sandy: Grandmother (interviewed twice and joined the PAR group)

Lee: Sandy's daughter (interviewed twice and joined the PAR group)

Lee's husband: Died of HIV/AIDS in 2006

Pete: Grandson (Lee's son)

Sandy: Sandy's other daughter married and living elsewhere

Timeline of significant events for Lee's family

1999 Lee married and moved to Bangkok. Sandy was independent and living alone.

2001 Pete was born.

2006 Lee's husband died. Rumour held that AIDS was the cause of death.

2007 Lee became sick and was received back home to be cared for by Sandy.

2007 Sandy, Lee and Pete now live together in Sandy's house.

2007 Lee diagnosed with HIV/AIDS. Lee started ARV medications.

2007 Lee lost her job and her financial security.

2009 Pete received a school scholarship.

Introduction to Lee

I was introduced to Lee by the staff at the Pralab Health Care Unit. She agreed to participate in this inquiry and our first meeting was in this centre. I organised a private space where she could attend without being noticed. I interviewed Lee twice then she introduced her mother (Sandy) who also agreed to be interviewed. Before convening the PAR group, I discussed it and its purpose with Lee and Sandy and gave them the option of attending and discussing the concerns they had raised in their interviews with others at the group. Alternatively, I said that if they

preferred I would convene a further discussion with them on their own, to discuss and plan, to address some of these issues. They chose to attend the PAR groups.

Lee is thirty seven (37) years of age. When I first saw her she appeared tense and she looked gaunt. Her appearance was possibly due to her condition living with HIV/AIDS. Later I heard that she had endured several episodes of opportunistic infections.

I learned from Lee that two years ago her husband had died of HIV/AIDS. She was not only shocked by his sudden death but also that she had been infected by him. Her immediate concern on receiving her diagnosis was about her son, Pete, aged eight, particularly what would happen to him? She lost her job when she became ill herself and experienced significant financial difficulties; she moved in with her mother-in-law. Unfortunately, her mother-in-law was inconsiderate, even brutal. Whilst living with her husband's family, Lee experienced being discriminated against. Lee decided to ask her own mother if she could move in with her. Lee's mother, Sandy, aged sixty-nine (69), offered her support and accommodation. Lee and Pete travelled 70 kilometers to Sandy's village. Not only had Pete lost his father and his home, but he had to leave his familiar environment, his school and his friends. When Lee arrived at her mother's small house, situated at the edge of the village, she had a raging temperature and was very sick. She had not disclosed to her mother that she had HIV/AIDS; she was admitted to Khon Kaen Regional Hospital because she was too ill to be cared for at home. Thinking that Lee may not survive on that occasion, the doctor at the hospital told Sandy about Lee's diagnosis. Sandy was heartbroken and shocked. Nevertheless she declared her commitment to care for both Lee and her grandchild Pete regardless. Sandy offered ongoing emotional and economic support. Three people now share her small living space. Lee recovered and was commenced on ARV medication. Gradually, her physical, emotional and economic situation improved.

Before Lee became ill, she worked in a laundry and earned 100 Baht a day. However, her illness interrupted her wage earning capacity and she became unemployed. Knowing that Sandy's financial circumstances were limited, Lee tried to find some work and working from Sandy's home, she began to earn money from cutting up galangal. This was one way she could contribute towards the family's living costs.

I talked with Lee on numerous occasions after this first interview. Interviews were recorded on two occasions resulting in three hours of recorded conversation. These conversations took place

in Thai language. A short version of Lee's story in Thai was returned to her. She asked her son to read it to her. Several months after meeting Lee, I started to ask Lee if she thought Sandy might like to volunteer to participate in my research. Lee felt quite sure that Sandy would like to participate. Nevertheless, she reminded me that the interview timing needed to be flexible because Sandy worked long hours.

Lee's short story

Two years ago I became sick and I was admitted to hospital. I then found out that I had the HIV infection. My dreams were shattered; I had hoped for a perfect family life. But I was very ill, and my husband thought I would die. He sought the support of his family. We moved from Bangkok to live in his hometown in Chum Pae district ⁵ with his family. Then we both became very ill at the same time but while I survived my husband died. When it became known that I had the HIV infection it made many people show their prejudice. I felt they discriminated against me. I was very upset. I sat alone and cried. I asked why life is so difficult. I was often sad. But I survived that severe illness episode. The reason I wanted to continue to live is for my son. The last time I was ill I thought I would die. I asked my mother to look after my son if I should die. The doctor told me that I now have full blown AIDS so I have to take the ARV.

My main concern when I was first diagnosed was about my son. When we were in Chum Pae district some people did not allow their children to play with my son. The worst experience was when his school friends taunted him by saying "Like mother like son, your mother has HIV so you are bad boy too". My son was victimised. He found that he was blamed for instigating fights when playing with other children. He has since made a choice not to play with those friends. He avoided their company.

We now live in Khon Kaen with my mother. My son is doing well at school. His school performance is excellent: he came first in his class and won a scholarship to pay his school books for the next year. He is good boy. And he will be in grade five in the next school year. He tells me he loves me.

We worry about each other. I have told him about his father's death from AIDS so that he knows should something happen to me. Pete is worried about me and reminds me to take

⁵ Chum Pae district is a district in Khon Kaen province approximately 70 Km from Khon Kaen.

my medications. I sometimes tell him “I don’t know when will I die, I could die soon but I want to be alive until you grow up”. I am disappointed that I cannot provide for all his needs. I do prepare his school uniforms. And I cook food for him except breakfast because that is rush time. We don’t have a meal together because I worry that he might be infected eating with me. I earn only 30-60 Baht a day how can I save some for our future?

I work at home. Initially I was employed in the laundry shop downtown but because I was ill so often I had to quit the job. I work when I am not too tired. Fortunately I have financial support from my mother and the government.

Introduction to Sandy

Sandy was born in the Pralab sub- district where she still lives today. Her husband died many years ago. Sandy has worked all her life and is independent financially which means she can provide for her own everyday needs. Her work is as a manual labourer shifting concrete at building sites. In addition, she is employed by farmers on seasonal work in the rice fields when the crop needs harvesting. Occasionally she peels galangal for the local market, so creating another small income. Her house is very small, just one room, 16 square meters, and she has an outside eating area protected by a large tree and shade cloth.

Diagnosed with Diabetes Type II several years ago, she self manages this chronic illness with oral hypoglycaemic medication. Already she has visual impairment, cataracts in both eyes and hypertension. She is in regular contact with the community nurses at the Pralab PCU. While her medical expenses are covered by the Universal Health care scheme, money is required for transport to and from the Health Centre. A visit to the clinic often takes all day and she is unable to earn her income on that day because of the travelling. A welfare system pension while highly desirable is yet not a reality for Sandy; she has to provide for herself.

Sandy has two daughters, Lee and See. See lives in Bangkok with her husband and children and she is aware of the family’s situation and supports emotionally and financially when she is able to. Financial support is especially valued when Sandy and/or Lee require urgent medical attention.

I arranged the first interview appointment with Sandy at the weekend, as this did not interfere with her busy weekday work schedules. I talked with Sandy several times, both formally

(interviews) and informally. Interviews were recorded on two occasions resulting in three hours of recorded conversation. These conversations took place in the Thai language; transcription was completed in both English and Thai. A short version of Sandy's story in Thai was returned to her. Sandy read her own story and validated its content. The story to follow is a merger of two interviews and the version validated by Sandy.

Sandy's short story

I am Lee's mother and Pete's grandmother. I agreed to provide care for Lee and Pete but I knew that my life would change. When Lee arrived from Chum Pae district I could not look after her in my home. She was too sick with a high temperature, nausea and vomiting and I noticed weight loss and that she did not have an appetite. Although I could see that Lee was very sick, I was not aware that she had contracted HIV/AIDS. So I took her to Khon Kaen Regional Hospital. Pete had to come because I could not leave him home alone.

I was shocked when the physician gently advised me that Lee had contracted HIV and had developed AIDS. My daughter then realised she had to confess to me. She told me "Mare (mother) I have contracted HIV infection from my husband". I felt my heart break. I was very upset and angry. I was angry because Lee's husband had given her this illness. Upset because I had not been taken into Lee's confidence, and I could not believe that my daughter had this illness. I felt my life was in chaos. I realised that it would be very difficult to care for both my daughter and my grandson because Lee was so sick and Pete is so young. I felt very responsible. It is believed in my village that this illness is related to promiscuous behaviours. I was immediately worried about stigma associated with AIDS and the impact this would have in our life with the neighbours.

When Lee was hospitalised it was very difficult for me to deal with her illness. She had tuberculosis and meningitis and I thought she was going to die. I saw Lee crying. I thought she may be in pain or uncomfortable. So I asked her what is happening. Lee said "I don't know when I will die; I could die soon and then who will care for my son". This was the first time we talked together about Pete. I said 'don't worry I will care for Pete as long as I can. I promise'. Pete was present at the bedside for this conversation. Although Pete knew that his father had died of AIDS he then became aware of his mother illness.

I think Pete is good boy. He does the housework and takes care of his mother when she is not well. Pete reassures us that when he is older he will look after both of us. I still worry about my grandson's future. I am old, my daughter is sick and my grandson is young. Pete is already doing well at school and I wish for him to have a very good education so that he can have a better future.

I have always been able to look after myself but now I am the breadwinner for this new family. My daughter is often sick and cannot work. Every Baht that I earn, I use for our living expenses; electricity, water, food, Pete's school books and Lee's health related expenses.

Two years ago (2007) I had received massage training under the scheme provided by Pralab PCU. However I had not been able to secure appointment as a massager because I am 'too old' and I could not attract customers. Now I have to be a wage earner to support this new family, however, job opportunities are scarce. The uncertainty about future employment is a worry to me. I do everything; I work in the building industry, lifting concrete as a construction labourer, and in the season for rice harvesting I work the field. However in some seasons there are few jobs. Now it is rain season so the job in the construction field is not available. I am now employed cutting the ginger root into small strips. I do this at home. I really hope that someone would like to employ me.

I call HIV/AIDS "Sum Het diseases⁶" because HIV is spread through unprotected sex. If a man does not use the condom with other sex partner then he could pass on an infection to his wife. My daughter concealed her diagnosis from me. But I am sure that my son in law passed on the infection to my daughter. It was my opinion that AIDS is a promiscuous disease and untreatable like the plague. I believed those who got AIDS often end up dead. I did not have confidence in AIDS medications. I believed that there were many people in my village who are infected with HIV but they did not disclose their health status because they would worry that they would be discriminated against.

When Lee was in hospital, I was taught by nurses how to care for Lee. I learned about disposal of waste products and wound management (universal precautions). I now understand how to look after Lee when she is sick. I know more how HIV/AIDS can be

⁶ The definition of HIV/AIDS understood by local people because they believe that HIV is spread through unprotected sex.

prevented and how to be safe when providing care for Lee. I learned about regular hand washing, how to avoid making contact with Lee's blood and her secretions. I know more about separating sharps like razors, hygienic use of food utensils and taking care with food preparation. Now I am no longer worried about living with my daughter. I feel confident about taking care of her.

My everyday life is still the same as before. But now I have enormous responsibility to care for my daughter and my grandson. I know my daughter is very sick. When she can't work I have to care for her. I understand that HIV/AIDS is untreatable and that she may never get well. People who have HIV/AIDS have low immunity and they are high risk for an opportunistic infection. Therefore my daughter is likely to be sick again.

I am still angry about the way that my daughter was treated by her mother in law. When my daughter was sick, she did not care for my daughter. I understand better now the way stigma of HIV/AIDS works in small communities and how people are discriminated against. I think villagers do not accept people who are living with HIV/AIDS. They (my daughter and Pete) were often being discriminated against. My daughter disclosed her infection status and consequently some of the villagers are not willing to be friends with her. However she still has some good friends who are accepting of her. Being discriminated against, I believe is one of the reasons why some people do not disclose their infection status.

My grandson still has friends even though many villagers know his mother has contracted HIV/AIDS. My grandson is wise beyond his age; he seems to know how to make friends despite his circumstances. He helps his friends to understand their homework or prepare for an exam. He is good at school and he is clever so is able to help others. I think his friends accept him. I am very happy that my grandson is a good boy. He is the top student in his class. This year he is awarded the scholarship for 1000 Baht. I will spend this money for his school expenses.

What happened whilst researching?

When I first talked with Lee I was conscious that this was my first interview. I arranged the seating in the private room so that my participant would be comfortable and feel safe. I arranged a lunch box and refreshments. I explained about the recorder and that I was going to turn it on

because I did not want to forget anything that she was going to tell me. I reminded her that everything that she said would be in confidence. Most importantly I told her that I was really interested in listening to her story.

I was aware that the conversation could bring back sad memories. If I noticed her distress I made the decision that I would turn off the recorder before moving on with the interview. There were occasions where Lee broke down; once when she was talking about Pete's uncertain future she shed tears, and she became distressed when she recalled the moment her mother first found out that she had AIDS. I felt this emotion and I wanted to comfort her so I touched her hand lightly. I was surprised when she recoiled. At this point I had many questions I would like answered. Why did she recoil? Did she object to me invading her private space? Was she worried about passing on the HIV infection to me? Although I know that HIV cannot be transmitted through touching, Lee was not sure that I knew this. I reassured her that I was well informed about HIV/AIDS risks, touching had very little risk.

Lee experienced full blown AIDS more than two years ago. At the beginning, she was critically ill, she said and this is literally translated from Thai: *"I could die by doctor, according to me previous believe that doctor could kill people living with HIV/AIDS (PLWH)"*. This meant that she thought that doctors would kill her. She had no knowledge about HIV/AIDS except that people died from it. I was really shocked when she shared her fear that she would die at the hands of the doctor. She later learned about universal precautions and that the hospital staff were kind and gentle in trying to explain about HIV/AIDS. She changed her opinion about doctors and came to see them as helping her to live. She survived severe tuberculosis and meningitis. Lee learned to live with her health conditions and she knows about safe management of her HIV infection. She has adapted well to living with Sandy and Pete. Lee practices universal precautions every day. She carefully disposes of her blood, elimination products and secretions. Lee has good hygienic practice when sharing food with Sandy and Pete. She uses her own utensils.

When Pete was young, he experienced a difficult situation with his friends. He was rejected by his friends. He used to tell his grandmother that his friends taunted him by saying 'your parents are infected by AIDS'. Furthermore, his school friend died of AIDS which had been passed on to him maternal to child. Pete felt sad for him because none of his classmates went to the funeral. He has learned about living with a mother who has physical limitations. This boy

appeared to be more mature than his friends the same age. Pete had big responsibilities in this household; he did the housework and sometimes worked to earn extra money.

Since Lee returned home to live with Sandy, their lives have changed forever. Sandy was the family breadwinner and she cares for Lee and Pete. Instead of looking after just one person, she was now responsible for three. That meant increasing living costs and Sandy had to work even harder for the three of them. Lee was often sick and required much attention. Sandy's life was on the brink. When Lee was well she tried to assist Sandy as much as she could. Lee looked after herself and was very concerned to prevent opportunistic infections.

Being short of money to live was a constant problem. It made the family worry about their future. When I listened to their future plan for Pete's schooling and their desire to see him well educated I felt concerned on their behalf. This older woman was doing her best to hold the family together. But her health was compromised by her chronic condition. How long will she be able to work so hard? How long will she be able to care for Lee and Pete? Have they saved money for the future? Sandy is portrayed as strong but she had to maintain this strong face to care for her new family. Their income was small and uncertain, their lives were on edge. Lee and Sandy received 500 Baht per month each from local government. This financial support was provided by local government to people who are living with HIV/AIDS and older people.

Life changes

Life has been full of changes since Lee's diagnosis with HIV. There were numerous events: losing her husband to AIDS, being treated unkindly by her mother in law, her medical crisis and its aftermath, learning that she has full-blown AIDS, the need to shift house on three occasions finally ending up at her mother's humble house, her reduced financial circumstances and lack of opportunity to find suitable work. Although being on antiviral medication had made a difference, she was still vulnerable to opportunistic infections and she was often sick. Her main concern through all of this was for her son, Pete, and his future.

Prior to Lee's life changing so rapidly, Sandy, despite living with a chronic illness, was employed in several jobs and this made her financially independent. The space in her house was adequate for just one person. Sandy then had to deal with her daughter's HIV/AIDS diagnosis. The major impact her daughter's new situation had on her previous life was dramatic. She became the responsible person for the family, both financially and emotionally. She had to share

her small living space. She was worried about the stigma attached to HIV/AIDS should her neighbours find out. She had to earn enough money to feed and support the entire family. Once she accepted that being the main breadwinner in the family was her new role in life she got on with it. She showed determination and strength. Her main concern was about Pete. It was extremely important that he should have a good education and she was very pleased that he was doing so well at school. However, this family totally relied on Sandy to hold things together. Sandy's ability to hold the family together relied on a cotton thread. Sandy said in her own words 'I am old', and given that she has Diabetes type II, the ravages of which are already with her, her ability to continue working as hard as she did to secure the income this family needs were uncertain.

Pete was the centre of attention for both Lee and Sandy. They were very happy and relieved that he was doing so well at school. They recalled how he had been exposed to a hostile discriminatory environment several years ago and that he had been jeered by his class mates. But in the Pralab sub- district he had made friends. I was not able to interview him as he was a minor and I did not have the approval of the Ethics Committee, but I could observe him as he always accompanied his mother or grandmother. Lee had not kept the truth about her husband's cause of death from Pete but he learned at the same time as his grandmother that his mother also had HIV/AIDS. One of the most remarkable events in this inquiry was when he was asked by his mother to read her story. Afterwards he told her that he understood her position more clearly.

Personal reflections

In listening to Lee's story I sensed that she had learned to live with HIV/AIDS. I carefully listened to her story without interruption. Lee's emotions matched her tone and her facial expressions. When Lee recalled the moment that she became severely ill, she displayed feeling sad. She looked troubled when she thought her friends were talking about her behind her back. In contrast, when she told me about her son's declaration that he would care for her and his grandmother when he is older, her face lit up with happiness.

Personally, I perceived that this family is very nice and gentle. Talking about Pete, I felt Lee and Sandy were proud of him, I think because Pete was a good boy and well understood his family situation. However, there was some sadness when Lee said 'I won't live very long', her facial expression was very solemn. Their family story is like being on a roller coaster: they go up and

then rapidly came down. However they had considerable strengths between them to bolster their lives.

During the interview I felt sad many times. I wanted to help, find them a job, give them money and help them in other ways. I knew that those actions would be totally unacceptable as a researcher. But my heart went out to this family who has found themselves in dire poverty. I was also dismayed by the attitudes of children Pete's age and that they would not play with him.

Family Two: Nancy's family

Nancy: grandmother (interviewed twice and joined the PAR group)

Katie: Nancy's daughter (died of HIV AIDS in 2001)

Kenya and Golf: grandsons (Katie's sons)

Timeline of significant events for Nancy's family

1996 Katie 'ran away' with her partner (Kenya was born five month after).

1999 Golf was born.

2000 Nancy's diagnosed Diabetes Type II.

2001 Katie died, two months later Katie's husband died.

2001 Children, two boys, under the care of Katie's mother-in-law.

2001 Katie's mother-in-law died.

2002 Nancy took Kenya (8) and Golf (3) into her care.

2009 May: Kenya started work.

2009 August: Nancy's husband died.

Introduction to Nancy

I met Nancy, who is aged 65, in May 2009 for the first interview, in June for the second interview, in August when I attended her husband's funeral and then continuously when she joined the PAR group in September of that same year 2009. Since her husband's sudden death of leptospirosis⁷, she now carries the sole responsibility for her grandsons, Kenya aged 14 and Golf aged 10. Their mother and father died of HIV/AIDS eight years ago.

⁷ Leptospirosis is a bacterial disease of humans and animals. It is caused by *Leptospira* bacteria that are found in infected animal urine and animal tissues

Nancy lives with a chronic illness; she was diagnosed with diabetes ten years ago, and claims that she is managing this condition very well on hypo-glycaemic medications and regular attendance at the Primary Health Care Clinic at Pralab sub district. Since her husband died she is troubled by insomnia and the practice nurse is able to prescribe diazepam 2mg to help her sleep.

Despite living with diabetes Nancy, like Sandy, is another hard working woman. She is able to earn a living and she has several sources of income. Leaving breakfast ready for the two boys, she travels on her motorbike to the Temple to provide food for the monks. Her son is a monk and, as a deeply religious woman, she gains spiritual strength from talking with him. In the morning, she cleans the Temple; washing dishes, sweeping the floors and other maintenance tasks. She earns 30 Baht from Temple donations. In the afternoon, she goes to her rice field. Being a land owner is significant as she can make money from her land. In the rice field she burns wood for charcoal, gathers water vegetables and morning glory to sell and uses some for the meal she will prepare later that day. She had two cows, another source of independent income, but these were sold when her husband died. Another source of income to support her grandsons is from their mother's house which is in another village but earns them rental moneys. Nancy is eligible for financial support from the government, but as her daughter did not declare her HIV/AIDS status prior to her death this source of income has not been granted as it relies on being registered.

Nancy talked openly about her daughter, Katie, who died eight years ago in Nancy's house. Both Katie and her husband were critically ill at the same time. Nancy agreed to look after Katie and Katie's mother in law looked after her son in a neighbouring village. Nancy confided that when Katie first came to stay she was horror-struck when she saw her daughter's emaciated face and in translation from Thai language the expression '*death warmed up*' described her physical appearance. Her voice was soft when she talked about her daughter's tragic death. Her voice raised when talking about her son in law, she was still angry that he had given her daughter the infection.

It became clear that Nancy did not like her son in law at all. Apparently, he was a womaniser and had seduced her daughter when she was only 15 years old, enticing her to run away with him. Being unmarried was a great shame to Nancy's family, and their marital union was negotiated before Kenya was born. Katie lived with her husband's family. Nancy believed that Katie was not cared for very well when she was pregnant and that she had been given unsuitable

food while breast feeding. Although there is no evidence to support her claim that Katie had been neglected, she attributed Katie's vulnerability to HIV/AIDS to lack of care given at pregnancy and birthing. Nancy still carried that anger.

The boys joined their maternal grandmother aged three and eight. Kenya had already commenced work as a construction worker, he did not like school, and Golf is not doing well at school work. According to Nancy the boys have not experienced discriminations in village life but there was an obnoxious neighbour, who, when he was drunk, hurled abuse at the family. His public abuse was about their mother's AIDS and his nasty comments instigated great shame within the family. Nancy said that when he was drunk they would avoid him by taking the back streets.

Nancy's short story

I have been living with diabetes for ten (10) years. Once a month I visit the Pralab Health Care Centre where my blood sugar is checked and I am told that it is under control.

My son in law was a womaniser; he flirted with many women in the village and I did not like him at all. When my daughter was only 15 years old he seduced her to run away with him. Being unmarried was a great shame to my family, and so their marital union was negotiated before Kenya was born. This was to overcome the shame associated with this situation and to retain my family dignity. But it was a dilemma for us to support her marriage to him because we knew he was a not good person. Nevertheless, we could not let my daughter be an unmarried pregnant woman.

When Katie married she lived with her husband's family in a neighbouring village but I think that she was not well looked after by her husband's family. When she was pregnant she was given unsuitable food while breast feeding she did not 'Kalum'⁸. I still carry that anger about Katie's neglect by her mother-in-law because I believe that receiving inappropriate food during breastfeeding increased Katie's risk to HIV/AIDS.

⁸ Kalum is a verb which means food taboo for example during pregnancy or breast feeding

Eight years ago Katie and her husband were critically ill at the same time. When I first saw Katie, I was frightened, she was emaciated and she looked like 'death warmed up'. I did not understand what was happening. I took Katie back home to my house to look after her.

However Katie was too ill for me to care for her at home. I was not able to cope with her diarrhoea, loss of appetite, nausea and vomiting. I took Katie to receive treatment in Khon Kaen Regional Hospital. It was the first time that I was told about Katie's diagnosis HIV/AIDS. The physician told me that my daughter had contracted HIV and her current condition turned to AIDS. I felt very upset. I was shocked and it seemed it was the end of the world. We did not know what to do next. I searched for a reason why this should happen. Perhaps my daughter is paying for her sins by having premarital sex. Premarital sex is unacceptable and breaks with good Buddhist belief. My husband consoled me. He reminded me about Buddhist doctrine 'Tam Dee Dai Dee' what goes around comes around. I could only Tam Jia⁹ because we could not do anything. I understood it had already happened and there was nothing we could do about it but be comforted by 'Tam Jia'.

I was still grieving over the loss of my daughter when I was faced with another big decision about the grandchildren. A few months after my daughter died my son-in-law died also. I did not go to his funeral nor did his neighbours. This showed me that nobody liked him. After his death I lost contact with his family. We did not have a good relationship with Katie's in-laws. However our grandchildren were still under Katie's mother-in-law's care. Nine months after Katie's death her mother-in-law died, leaving Kenya and Golf without custodial care. My husband and I volunteered to care for the boys. Kenya was eight (8) years of age and Golf was just three (3) years of age when they came to live with me.

When Kenya and Golf came to live with me my life dramatically changed. I had not raised my grandchildren, as they had been living with their other grandparents. I believed I was too old to start with a new family; I was already sixty years of age. However there was no choice for us but to take our grandchildren in under our care. There was no one else to care for them.

⁹Tam Jia is a common expression for the feeling of dispassion when something happened and can not change.

Let me tell you about all the changes in my life. My new family meant I had many extra responsibilities. Golf was only three years old and he needed mothering and I had to give him total care; feeding, bathing and toileting. Kenya had to learn to trust me. I was worried about him starting school. I was still grieving the loss of my daughter and this made me sad. I realised there was a lot more work in looking after two grandchildren. My life was easier before they arrived. I did not have support to look after my grandchildren from my husband. I missed support from my husband but he was still angry with our daughter, therefore he could not contribute toward the care of our grandchildren.

One of the things that helped me was my faith: I am a practicing Buddhist. I have held strong beliefs in Buddha all of my life. I believe in the circle of life of Buddhist doctrine. I think this belief helped me cope with the grief and loss of my daughter and also to care for grandchildren who were under my care for the first time. I became used to this new role guided by my Buddhist faith and soon my husband revised his outlook and began to approach our grandchildren. Then my husband shared this new role for caring for Kenya and Golf. I felt less stress once my husband gave me his support.

My husband and I made a decision to tell Kenya and Golf about their parents HIV/AIDS and that they died from the disease. So they know the truth right from the start. The grandchildren now understand why they have to live with us.

I would like to tell you about my financial status. I have regular financial support from my eldest daughter who married an English man and has lived in the United Kingdom for three years. Fortunately my daughter transfers money to us every three month. It is for 10,000 Baht, and this is enough for the new family expenses. I also earn 1500 Baht every month from Katie's house which is being rented out.

One of the things that have disturbed our peaceful life is conflict with an abusive neighbour. For the last seven years my family has experienced the verbal abuse of the neighbour. He was often drunk and then I hear him say: 'Hi boys! Don't you know your parent died of AIDS, ha-ha your grandma may not tell you, listen to me I will tell you the truth about your parents, they had AIDS you know'. I felt really ashamed about this abuse because it was a public insult to my family for all the neighbours to hear. What I really worried about was that my grandson would hit this man. Kenya has grown enormously in the last few years and now he is man size. Therefore when this man was drunk, we would

avoid him by changing the route when walking back home. Often we had to sneak out of the back door. I wanted to avoid further conflict but Kenya was not easily convinced, he still wanted to kick him.

Golf is not doing well at school; Kenya finished his schooling in the ninth grade when he was fifteen years old. Kenya already commenced work as a construction worker. I did not anticipate that Kenya would start to work because there is no need for him to earn money. We have enough financial support. However Kenya told me that he did not like school; so he would rather assist his family by starting work at this early age.

Kenya is physically bigger than his age (15) so he is able to do the hard work as a construction laborer. I have never heard him complain about hard work. He is very satisfied that he is financial independent. I think Golf is also waiting to finish his ninth grade and commence work as soon as possible because he is the same as his brother; he does not like school. I blame their father, Katie's husband; he was not good at school. I think 'like father like son'.

What happened whilst researching?

I had already met Nancy and we had several interviews when suddenly her husband died. Just before we convened the PAR group, Nancy told me that she has had difficulty with sleeping. Nancy met with the community nurse at the Pralab PCU to discuss her insomnia. The community health nurse prescribed sleeping pills for her. She is sleeping and gradually recovering from the emotional shock. A further difficulty in Nancy family is loss of the family's breadwinner: her husband died suddenly. Now Nancy plays the major role earning the family's income.

Nancy agreed to schedule her interviews with me at ten o'clock on weekdays because this fitted in with her schedule practicing her Buddhist activities in the Temple. Nancy rides her motorbike to the Pralab PCU so I arranged parking for her in the shade. I arranged the seating in a private room so that my participant would be comfortable and feel safe. I arranged a lunch box and refreshments. I explained about the recorder and that I was going to turn it on because I did not want to forget anything that she was going to tell me. I reminded her that everything that she said would be in confidence. Most importantly, I told her that I was really interested in listening to her story.

I was aware the conversation could bring back sad memories. If I noticed her distress I made the decision that I would turn off the recorder before moving on with the interview. There were occasions where Nancy recalled her anxiety; once when she was talking about her daughter's married life and she became anxious when she recalled the moment her daughter confessed to her that she had contracted AIDS. Her voice softened when she talked about her daughter's tragic death. In contrast her voice raised and her face expressed angry emotions when talking about her son-in-law, she was still angry that he had given her daughter the infection.

I recognised that thinking about her daughter and her son in law's life reawakened Nancy's emotions. Nancy said "*my daughter too young to die*". Every times Nancy talked about her daughter she shed a tear. This did not happen when she talked about her son in law's family. Then she expressed angry emotions in a strong voice and sometimes she grasped her hands together. Nancy considered her daughter was neglected by her mother in law and this made her daughter's ill health worse.

Life changes

It was not in Nancy's plan to provide care for two grandsons then aged three and eight years old. But there was no one else to care for them. Nancy and her husband made the decision to take them in. Their lives completely changed when the two boys entered into their family. The youngest boy (Golf) was only three and he needed a 'mother'. Kenya, who was a little older, had not met Nancy before he went to live with her and her husband and he found it difficult to build a relationship with them.

Nancy and her husband tried their best to accommodate their new circumstances. Furthermore, Nancy's son who is a monk always gives her great mental support. Nancy's strong religious beliefs helped her to manage her new role. Nancy appeared to have achieved some harmony in sharing her life and her home with her grandchildren.

When Nancy's husband died suddenly in 2009, her world was turned upside down. It happened suddenly, she was not prepared for the loss of her beloved husband. I recognised Nancy was extremely sad. Nancy invited me to her husband's funeral. Nancy frequently cried when I visited her. Nancy told me she and her husband always had a good marriage. They were together more than forty years. Nancy had strong support from her husband in every situation of her life including trying to cope with the changes associated with being a principal carer for her

grandchildren. Nancy was still in shock and needed time to accommodate the loss of her beloved husband. Luckily Nancy's children supported her even though they were living somewhere else.

Personal reflections

Thinking about my interview with Nancy I reflected on how much more confident I was feeling about generating stories using the one to one interview process and with analysing these concurrently so as to have them ready to feedback to participants. I was becoming skilled using prompts and relaxed enough to allow the participant to tell her story in her own way. I avoided directing the interview in certain directions. I was alert to non-verbal expression. I could see that attentive listening meant that Nancy could see I was really interested in what she had to say and she talked openly.

I also reflected on Nancy's description of how she found solace in dealing with her husband's death by practicing Buddhist meditation. She told me how she regularly practiced Buddhist activities and visited the temple every morning. Furthermore, Nancy's son is a monk in the village temple; he shared the Buddhist philosophy with Nancy. The essential message of this teaching was that all of us will pass away eventually as a part of the natural process of birth, old-age and death and that we should always keep in mind the impermanence of life which clearly brought her comfort at a very sad time in her life. Her deep faith seemed to have helped Nancy to gradually accept her loss and to see death as another phase of life.

Nancy's husband died suddenly from Leptospirosis which is a communicable disease caused by rats, ever present in Thai rice farms. Nancy's husband suffered severe leg pain and high fever and he was in hospital for nine days before he died. He died on the 28th of August 2009. Nancy was broken hearted.

Part of being in the field and researching alongside families is that you become caught up in their lives and involvement may be perceived as building relationships. When I went to Nancy's husband's funeral I brought a bunch of flowers and a basket of fruit as a gift. I dressed in a black dress as is customary. I noticed Nancy saw me at the funeral and she cried with me. I gave her a big hug. I met her grandchildren Kenya and Golf. Kenya looked bigger than his age and he seemed more mature than his friends. Nancy's trust in me and her openness towards me increased significantly, I believe, because I went to her husband's funeral. Thai funeral customs

comprise complex beliefs and practices. Attending the funeral enabled me to show my sincere respect for her husband and her family. It gave me the opportunity to comfort Nancy.

Family Three: Tracy's family

Tracy: Grandmother (interviewed twice and joined the PAR group)

Noi: Grandfather (interviewed twice and joined the PAR group)

Lily: Tracy's daughter

Lula: Granddaughter (Lily's daughter)

Timeline of significant events for Tracy's family

1990 Tracy and Noi became village health volunteers.

1997 Lily began living with her partner.

1998 Lula was born and her grandparents took her home (with Lily's permission).

2005 Lily's husband died from HIV/AIDS.

2006 Lily became ill (opportunistic infection) and started ARV. Lily was looked after by her parents (Tracy and Noi) for a few months.

2006 Noi stopped drinking and started a grocery stall to secure finance for his 'new' family.

2007 When Lily recovered she moved out to another town and found another partner. Lula remained with grandparents.

Introduction to Tracy and Noi

I will talk about three family members: Tracy who is a 56 year grandmother, her husband Noi who is 58 years old, and twelve year old Lula (granddaughter), she is a paternal orphan. I interviewed Tracy twice and then her husband Noi agreed to talk with me on his own in a one to one interview. Over several months and after some conversations, both Tracy and Noi attended the PAR groups.

Villagers Tracy and Noi, who are both in their 50s, are married and together they have bought up their granddaughter Lula since she was a baby. Lula was twelve years of age when I first talked with her grandparents, whom she calls her mother and father. Lula is not exactly estranged from Lily, her real mother, but she sees her only twice a year; at the beginning of the school term with uniforms, books and other gifts.

Lily, her mother and her husband were living in Bangkok until four years ago. Parents on both sides were surprised by their separation, each returning to their village of origin. Lily came to live with her parents and was soon admitted to hospital. She confided to her parents that she had contracted HIV. This was the first time her parents learned that she had HIV/AIDS and they were disappointed that she had kept her diagnosis a secret. Certainly Tracy and Noi were even more stunned when they learned that Lily's husband died of AIDS a few weeks after arrival in his village. Tracy and Noi went to his funeral in the neighbouring village. Fortunately, Lily survived this critical illness episode and at that time commenced with ARV. As soon as she recovered, she left home once more and her daughter remained in the care of her parents. She has since married again and lives in Khon Kaen 20 kilometers from the village.

Tracy and Noi have been respected village health volunteers for twenty years. Once they found out that their daughter was infected with HIV they sought additional information including understanding the principles of universal precaution. It was unusual for a man to provide personal care for his daughter but Noi provided all nursing care for Lily when she was critically ill. Tracy was less sure about her role as caregiver but she was eventually convinced by Noi that she should help. Nevertheless, the relationship between mother and daughter was tense. Tracy feared her neighbourhood would find out that her daughter had AIDS.

Discovering that Lily had contracted HIV was a turning point in Noi's life. He was determined to change his life so that he could be a responsible guardian for Lula. He stopped drinking alcohol, and made wise financial investments in his village grocery shop so that his family would be financially secure. This family has a comfortable life with few financial worries.

Lula has not been told about her parents' HIV/AIDS health status. Her grandparents' main concern is to keep this information hidden from her as long as possible. Tracy was interviewed twice, and Noi once. Together they created over four hours of digital recording. Of course we had many other conversations when they joined the PAR group. The stories to follow are given separately: Tracy's story is the merger of two interviews.

Tracy's short story

My family has a comfortable life because we earn enough money for family living expenses. I am fifty six (56) years old and I am healthy. My family life is very good. My husband (Noi) is a great support for me. Lula (granddaughter) respected me as a mother and is a good girl. Noi and I were elected to be village health volunteers for a long time. I

am trusted by villagers because I was elected to the position of village health care volunteer at Pralab Primary Health Care Centre.

My daughter (Lily) lived with her first husband without our permission. I was angry with Lily because she ran away with him. I could not do anything because they moved to live in Bangkok. I was very angry and felt 'Saie Nha Saie Tha'¹⁰. We have to Tam Jai her poor behaviour.

Lily returned to Khon Kaen and gave birth to a baby girl. My husband and I considered bringing up my granddaughter (Lula) because we thought (Lily) and her husband were not able to care for their child given their poor financial circumstances.

Four years ago, Lily returned home without her husband. We were surprised that Lily broke up with her husband. A few weeks later, we learned her husband had died. My husband and I went to his funeral but Lily did not. Lily was ill at the same time as her husband died. Some villagers started a rumour that Lily's husband died of AIDS. We still did not know this. However we learnt from Lily that she knew about this and she broke up with her partner because she was so angry about it.

Lily became seriously ill so I took her to Khon Kaen Regional Hospital. My husband and I had just realised that our daughter was diagnosed as having AIDS. We were shocked because we had not believed the rumour about Lily's husband. However when Lily was discharged from hospital, we took her home to be cared for.

At the beginning, I did not want to provide care for Lily. I was worried I could lose face with villagers because of Lily's HIV/AIDS status. Lily was cared for by Noi. When I realised how tenderly Noi was caring for Lily I reconsidered and I decided to share this responsibility.

A few months later Lily recovered from this particular severe illness, she immediately moved out of our house. She went to Khon Kaen and found a new job. Lily is on ARV treatment at Khon Kaen Regional Hospital. Recently Lily has a new partner; he is a friend

¹⁰ Saie Nha Saie Tha is a Thai proverb meaning to lose face or feel disgraced

from the HIV/AIDS clinic. Lily told me that her partner helps her to work with him. Lily and her partner deliver goods to a grocery shop near Khon Kaen city.

Our family life has changed since we learnt Lily has HIV/AIDS. We are concerned about Lula's future. Fortunately we earn enough money for day to day living. Together my husband and I planned how to manage Lula's future. My husband committed to stop drinking alcohol. He took part in the Pralab community campaign for the prevention of alcohol consumption. We have a small grocery shop in the village market. I am satisfied with my life at the moment.

Lula has blossomed into a young woman. We have looked after Lula since she was born and now she is twelve years old. We love and worry about her. I attempt to care for Lula as well as I can.

Lula does not see her mother often, perhaps twice a year. I want to protect Lula. We have not disclosed her mother's HIV/AIDS status to her. Lula's other family still keeps in touch with us. Lula's paternal grandfather provides 500 Baht every month for Lula's expenses. I suspect Lula may worry about her mother. I really worry about Lula finding out about her mother's health problems. I worry that she would be ashamed if her friends find out. I also don't allow anybody to tell Lula that her mother had AIDS. I know I would be ashamed if Lily's HIV/AIDS status was known in public.

The most significant thing in my life is being a village health volunteer. I have been elected by villagers to hold this role for more than 20 years. I was trained in universal health precautions and HIV/AIDS transmission so I am confident to share this with villagers. I have seen many teenagers in our village are intimate with a number of partners in the village park.

I think nowadays the teenagers are not listening to their parents. Teenagers are likely to have unsafe sex. My husband provides free condoms for teenagers and he also educates them, for example, about the reasons for using condoms including the prevention of diseases and unwanted pregnancy. However, we no longer provide free condoms for adolescents and villagers. The Pralab PCU staff said they have a shortage of free condoms and the supply from Khon Kaen Regional Hospital has ceased.

Noi's short story

I have stopped drinking for almost three years because I considered it was good for my life and my family. Since I stopped drinking alcohol I feel healthier because my stomach ache is gone. I turned 58 years of age this year.

Working as a village health volunteer taught me valuable life skills. I have been involved with several community health promotion projects: basic health care, stop drinking, health education for villagers, and monitoring communicable diseases. I also benefitted from being a village health volunteer because I was taught about universal precaution. It was useful knowledge and practice when it came to providing care for Lily when she was ill.

This has created many tensions in my life. Tracy's initial reluctance to care for her daughter caused me concern. Lily was critically ill; an infectious episode meant that I had all the responsibilities to care for her. And more recently, I have been worried about disclosure. I want to avoid disclosing Lily's HIV/AIDS status to Lula. When we brought Lily home Tracy did not provide care for Lily. I understood her unwillingness to provide care because she was ashamed and wanted to avoid the villagers finding out. Tracy did not want to lose her status as a respected person in the community. But our daughter had AIDS and Lily needed care. I cared for Lily when she was bedridden. I changed her nappy, provided her hygiene care, and helped her to eat. It was a hard time for me as a man and head of family to do these duties.

I hoped that Tracy would rekindle her love for Lily so she could forgive Lily's mistake. Eventually Tracy found forgiveness. I was so pleased when Tracy shared the responsibility to look after Lily. However Lily recovered from this infectious episode, she moved out from my house and is living in another town. Lula has not been told about Lily's health problem. I try my best to care for Lula. I am now acting as her father.

When Lily was diagnosed with AIDS my life changed. Previously I was always drunk and I was not a good family man. Lily returned home with full-blown AIDS, and then I realised my daughter could die any time. So I stopped drinking. I saved money. I rented a shop and started a small business in the village market.

We (Tracy and I) try to fill the gap in Lula's life because she is growing up without her parents. I have looked after Lula since she was born. I provide a comfortable life. My wife

prepares the meals. I also encourage Lula to do exercises every morning; we go jogging from our house to the village park for about 30 minutes. I pay attention to cleanliness in our house.

We worry that Lula might contract the HIV infection from Lily. We don't know how long Lily will live. If I could make a wish I hope Lula will not get the infection. Yet I would like to know her HIV status. I will not take her for testing now. I cannot think what I would tell Lula why she needs to have an HIV test. We are keeping Lily's infection status as a secret. If she has contracted HIV we expect that she would have some symptoms soon.

Lula still keeps in touch with her paternal grandfather's family. They are paternal grandfather, uncle, aunt-in-law and their daughter who is the same age as Lula. I allow Lula to visit her paternal grandfather once a week. We have a good relationship even though my daughter broke up with their son.

Meanwhile my daughter, Lily, is reasonably healthy. She has been on ARV treatment since she became seriously ill in 2005. When she was first diagnosed I advised Lily to take ARV. I said that if she wants to be there for her daughter when she grows up she needs to start treatment.

Lily visits us twice a year which is enough for her to keep in touch with Lula. I am aware that I don't want Lula to know about Lily's HIV status. But it is very difficult for me to conceal Lily's story with Lula.

I am committed as a village health volunteer. I willingly carry out all duties. As a village health volunteer I am a trainer for the safe sex campaign in the village. As you know, teenagers are most at risk of sexually transmitted disease and HIV/AIDS. However the Pralab PCU is not able to target these at risk groups. Unfortunately government money for these health promotion projects has ceased. I believe that teenagers are at risk of contracting HIV/AIDS and I want to be involved in health education and prevention.

What happened whilst researching?

This was my third participating family in this inquiry. When the community nurse informed me that one of my potential participants was a village health volunteer, I was a bit excited because

this person was likely to have a different perspective because of their health promotion background.

Tracy told me she agreed to participate in my research because she wanted to share the great changes she had experienced in her family's life. We agreed to meet for the interview at a time that suited her new small business venture. Tracy and I met late morning. I arranged the seating in a private room at the Pralab PCU so that Tracy would be comfortable and feel safe. I arranged a lunch box and refreshments.

Prior to interview, I reminded Tracy about the recorder. I told her I did not want to forget anything that she was going to tell me. I confirmed with her that everything that she said would be in confidence. Most importantly, I told her that I was really interested in listening to her story.

I was concerned that she might recall painful memories that would stir emotional distress. I made the decision that I would turn off the recorder before moving on with the interview if this should happen. Tracy was not emotional; she coped with this interview situation very well.

I was astonished when Tracy introduced me to her husband, Noi who said that he was interested in participating in my research. I did not expect a man to volunteer. This couple is well-known in this village as village health volunteers. I was thankful that they took part in my research. Noi spoke openly with me. I appreciated that he felt comfortable to share his alcohol addiction and recovery program with me.

Life changes

The realisation that Lily was HIV positive changed Tracy and Noi's lives. Noi became aware that he needed to provide financial security and to become a parent rather than a grandparent to Lula. Noi and Tracy were not in a close relationship to Lily. They did not like her partner. Once Lily returned home with full blown AIDS, Noi and Tracy provided all the care for Lily because she was critically ill. Tracy was reluctant to care for Lily. However she noticed that Noi was providing a good example in caring for his daughter. Tracy reconsidered and began to share the responsibility of caring for Lily when she was ill and physically compromised.

When Lula was born, Noi and Tracy were aware that Lily's mothering skills were not adequate. This situation triggered Noi and Tracy's plan to care for Lula. In addition, Noi decided to stop drinking. Having the responsibility to care for a new born baby was a turning point in their family. In order to improve their economic situation, they started a micro business in a small grocery shop in the village market place. Since Noi stopped drinking, family life has improved: there are fewer family arguments. Instead this couple focuses on caring for Lula and her future, their family's financial security and they save money for any unplanned situations. This family could be described as comfortable, in financial terms.

Personal reflections

I noticed Tracy and Noi appeared proud to share their achievements in their life. They took pride in providing care for Lula. They also took pride in their work as village health volunteer. Lula is their beloved granddaughter and she respects them as parents.

I noticed Tracy and Noi are a respected couple in this village. They have collaboratively worked with Pralab Health Care Centre for 20 years. As unpaid community volunteers, they have made valuable contributions to this village. Their commitment to their community gave them status and satisfaction. However their grandchild Lula's infection status was not known. She had not been tested for HIV and Tracy and Noi also worried about Lily's HIV positive status and her health problems. The issue of when to disclose HIV to Lula caused tension between the couple.

Family Four: Grace's family

Grace: Grandmother (interviewed twice and she joined the PAR group)

Mary: Aunt (interviewed once and she joined the PAR group)

Feat: Grace's grandson

Timeline of significant events for Grace's family

2000 Grace's husband was diagnosed with Type II Diabetes.

2001 Grace's son married.

2002 Feat was born and four months later Feat's mother died.

2002 Grace and her husband asked to care for Feat. Feat came to live with them.

2002 Two months later Feat became sick and was diagnosed with HIV/AIDS. He started ARV.

2002 Mary built a house in the compound (next door to Grace).

2003 Grace registered Feat's HIV status with the local government to receive the HIV cash benefit.

Introduction to Grace and Mary

I was involved with this fourth family for six months. I undertook one to one interviews with mother and daughter and subsequently, many informal conversations later, they joined the PAR group. There are three key family members in this fourth family: Grace who is 65 years old and grandmother (paternal side) to Feat, a boy who is aged eight, and his aunt Mary who is 35 years of age. Mary is the sister to Feat's father. Both Grace and Mary have husbands but they have a limited role to play in Feat's life; they provide financial assistance.

Pha, Feat's mother died of HIV/AIDS nearly eight years ago when he was only four months old. Feat's father has been disinterested in his son's welfare, leaving him initially in the care of his own mother, who said that she was too old and too poor to provide care for him. She begged Grace to take him. Grace did not have much choice but to agree to care for this underweight baby, her daughter Mary also offered to lend a hand.

A rumour circulated that Pha had died of HIV/AIDS. Although it was suspected that mother to child transmission of HIV infection may be a possibility, this was not confirmed until Feat was eight months old when he became ill with pneumonia. He was admitted to Khon Kaen Regional Hospital, diagnosed with AIDS and immediately commenced ARV medications. When the hospital physician told Grace about HIV/AIDS she was deeply shocked. She was unprepared to care for a baby; let alone a sick baby. Her age, lack of adequate housing, necessity to earn an income and work hard in the rice fields, and the fact that her husband had diabetes made the additional demand of looking after a sick baby seem too much for her to deal with. Mary offered to help.

Mary lived with her mother and father and helped with Feat; his hygiene, his feeding and toileting and the entire family learned about universal precautions. Mary married when Feat was two years old but she elected to live nearby so that she could continue to support Grace in Feat's care. Mary and her husband have since had two sons, and the three boys (including Feat) are growing up together as brothers. Although the family lives in separate houses, they eat and share family life together and this includes sharing their combined income.

Grace's family borrowed money to build a new house for the 'new' family. This house was on the same site as their rambling old shack, and it was close to the Chi River. Living close to the river meant that an income was more easily produced from its surrounding land which supported rice and shallot crops throughout the year. These crops and fish caught from the Chi River could be sold for income. Working on the land was a reality for all adults except Mary's husband who worked as an electrician's assistant. Money to pay back the house loan was one of the main problems, requiring 1500 Baht of their combined income per month.

The way finance could be acquired so that the family could afford to live was a common topic for conversation. Feat had been registered as diagnosed with HIV/AIDS and 500 Baht per month is made available by the local government to families who are affected. The way in which this money is accessed is different for each village. In Grace's village, the Village Head Person had made a decision that recipients of this finance have to physically collect the money envelope from his office. The person's name and HIV status was written on the envelope for all to see. Grace was easily identifiable in this small community and visibly standing in the queue for her money. She feared the negative impact should Feat's health status be disclosed and she was very scared that her neighbours would find out that Feat had HIV/AIDS. She was worried about his wellbeing and wanted to keep this a secret for as long as possible.

Feat had not been told about his diagnosis, he was too young to understand, his grandmother said. Feat's HIV status had been disclosed to his teacher, as he needed to take his ARV medication twice a day and this coincided with school hours. According to Grace, Feat was leading a normal boy's life; he was not good at school but he loved football. Much of the family and his teacher's concern were about injuries he could sustain while he was kicking the ball on school grounds. Together they developed some 'safe' strategies. On one occasion Feat drank water from another boy's bottle and such an event required explanation. Feat took on board that he should not share his utensils with anyone and promised not to do this again.

Grace's short story

I am sixty five years old. My husband and I are getting old. My husband was diagnosed with diabetes more than ten years ago. He regularly visits Pralab PCU. Recently I have problems with my eye sight; the doctor tells me that I have cataracts in both eyes. I need to have an operation, but I am really worried about that. I may not have enough money to pay for the cost of surgery. I hope my eye sight does not get worse, because I do not know how I will manage.

We have been looking after our grandson, Feat, since he was very young. Feat's mother (our daughter-in-law) died when he was four months old. We went to her funeral in a neighbouring village. I heard rumours at the funeral. Some villagers gossiped about my daughter in law dying from AIDS. I was not sure if it was true or false. Feat was living with his maternal grandmother when her daughter died but she is old and poor and she begged me to care for him 'please take Feat home with you; I am not able to care for him'. Really I had no choice. So we took him to our home and we have been caring for him ever since.

In the first few months of his life, Feat was often hospitalised. When he was eight months old, he became seriously ill; he was very hot to touch, he could not breathe easily, and his bowels were running loose. Feat was admitted in Khon Kaen Regional Hospital. I was shocked to find out that Feat was HIV positive and even worse, the physician told me he had pneumonia and that it had turned to AIDS. When the doctor told me I collapsed. My husband lifted me up and consoled me. I remember looking at Feat, he was so small. He was smaller than my arm. I thought that he was too young to die. I was very upset that my grandchild was so ill with AIDS.

I did not know how I would manage this sick child. My husband reminded me that we promised Feat's maternal grandmother that we would care for him. We had to learn fast how to manage a child with HIV/AIDS. The physician prescribed Feat the ARV treatment. Feat commenced the ARV. When he was a baby I used a disposable syringe to feed ARV to him twice a day.

When Feat was a little older we became the subject of a village rumour. Our neighbours noticed that Feat was taking ARV medicine. I was worried that neighbours would know Feat was HIV positive. I discussed my concern with the nurse at the Khon Kaen Regional Hospital. I told her that I would like to remove the label but that I would write the medication times on the bottle. I was allowed to tear off the label. Although everybody can see he has to take medication, no one knows what the medication is for because the label has been removed. Feat does not know himself what it is he just knows he has to take it twice a day at eight o'clock in the morning and at night.

Mary (my daughter) is living nearby so she helps me to look after Feat. Mary regularly cooks for us. She provides food for Feat. Now that Feat is older he shares the table

together with her sons. Mary's sons and Feat look on each other as brothers. Mary takes Feat to school. I occasionally forget to give Feat his ARV medicine when he goes to school. Mary offers to take it to him at school.

Feat sometimes asks me 'why do I have to take these medicines everyday whereas my younger brothers (Mary's sons) do not'. I tell him 'it is a vitamin to increase your appetite'. I am worried he will find out. I want to keep it a secret. I don't know how to tell him the truth. I need money from the government to support Feat. That means I have to disclose Feat's HIV infection status with the local government in order to access this money. We need money to cover the costs. Yes, I am worried that disclosing Feat's HIV status will have negative impact on him. But I have no choice; I need the aid to support our living expenses. I am anxious about the way the Village Head Person gives me the money. Every month Feat has to be present at the Village Head Person's house to receive this money in an envelope with his name on it. It also has Feat's HIV status on the envelope. I think this is a risky practice. I don't want Feat's HIV status exposed, should someone see the envelope. Mary met with a Village Head Person and she told him about our concern. We requested that Feat's health status is removed from the envelope.

Feat is much healthier now. I take him for health checks at Khon Kaen Regional Hospital every month. I also manage his ARV. Sometimes I will ask Mary to give ARV to him. Feat's teacher knows he is HIV positive. We told the teacher for safety reasons. Feat is a good football player. We thought that he might have an accident or injury while playing football. We were worried about contamination if he should bleed as we know that we must obey taking precautions. We told the teacher about universal precautions and said she should not touch Feat's blood with her bare hands. We also teach Feat not to let anybody touch his blood. Feat knows if he bleeds he must clean it by himself.

Once Feat played football and he absent mindedly drank his friend's water. His friend's father observed this and responded by throwing the water bottle in the bin. Feat was very upset; he asked me why his friend's father did this. I was very angry about Feat being treated in this way. Besides I knew there was little chance for HIV transmission by sharing drinking water. But I understand that villagers are scared about contacting HIV. So now when Feat plays football with his friend, I make sure he has his own water supply.

Mary's short story

I am a mother of two sons; one is four years and the other two years old. My house is located next to my mother's. My mother has looked after Feat since he was very young. So I have always helped her to care for my nephew. I know it is very difficult to care for Feat because of his AIDS problem. I assisted my mother to care for Feat even before I married and had my own children. After I married, my husband and I decided to live next door and we are a sort of an extended family.

When Feat was very young, he was often sick. Feat looked so sick and he was smaller than babies his age. I cook for my sons and Feat. I am very aware about providing nutritious food. Our financial circumstances are limited but I cook as well as I can. I try to minimise food expenses by catching fish from the Chi River, and I gather papaya fruit and look for green vegetables such as morning glory growing wild on the river banks or bamboo, and I forage for sweet potato. It is fortunate that we live so close to the river. But children become bored eating fish every day. When I can afford it I buy meat, eggs or chicken to cook for them.

The three boys share everything. In my eyes they are equal as brothers. I care for Feat as if he is my son. I let Feat play with my sons, they eat the same meal and I take them to school together. I don't care that some villagers perceive that I shouldn't let my sons live with Feat because he has contracted HIV. The villagers tell me that my sons would be at risk of contracting HIV from Feat. I don't worry.

I know how HIV/AIDS is transmitted. I organize individual eating utensils; bowl, plate and glass for my sons and Feat. I do this because I know about universal precaution. The nurse at Khon Kaen Regional Hospital, HIV/AIDS clinic, taught me all I know about HIV/AIDS.

I am concerned about Feat's emotional wellbeing. Children need other children to play with. Villagers refuse to let their children play with Feat. He is continually rejected in the playground. Feat has only a few friends but at least he has my sons as play mates.

I was worried that Feat has to be present to collect the aid money every month. I understand the Village Head Person would like to be transparent with their payment

method. I negotiated with the Village Head Person not to write Feat's name and his infection status on the money envelope.

Grace (my mother) sometimes asks me to look after Feat so I give him his ARV medications. When I first took charge I noticed that the ARV labels were taken off the medication containers. I did not understand why my mother did this. But now I understand it was to maintain his privacy and conceal his HIV status. However that meant I did not always know how many tablets to give him.

My sons asked me why Feat has to take tablets every day. I told them because Feat needs extra vitamins. I don't know any other way to tell my sons about Feat's infection status. They are too young to understand.

My husband is concerned about Feat; he has lost his mother and he is infected with HIV. My husband has agreed that Feat and our boys can grow up together. Feat has been neglected by his father; my brother has never looked after Feat. He works in Bangkok. He comes back home to see him once a year but more recently he doesn't come back home at all. I think Feat's father seems to be scared of Feat's HIV condition.

What happened whilst researching?

This is the fourth family in my research. I felt increasingly confident in conducting one to one interviews. Grace had been very talkative in her interview. She had shared her story openly with me. Nevertheless, sometimes, when she talked about her grandchild I noticed tears in her eyes especially when she talked about Feat being rejected at school and in his village. Mary provided transport for Grace to join me at the interview venue. Mary then said she was interested in participating in the inquiry. Mary and I arranged a meeting time during the day as she had to be around for the three boys after school. Mary was even more determined to care for Feat and she had claimed vehemently that she was not concerned about the rumours about Feat's HIV positive status. I was impressed with her commitment to advocate on Feat's behalf and she was a role model in allowing her children to live, play and eat with Feat. Despite, her determination to fight against discrimination, I felt her sorrow when she talked about Feat being rejected at school. This outburst of emotion led me to suggest we take a break in the interview, and enabled me to comfort her.

I had not anticipated that Mary or any of the other participants would be so willing to share information with me so early on in our relationship. I was relieved that Grace and Mary were able to demonstrate universal precautions when caring for Feat. They told me that they had been trained about universal precautions by the Khon Kaen Regional Hospital nurse at the ARV clinic. When Grace and Mary described universal precautions it was clear that they understood how to prevent HIV transmission. They appeared confident about caring for Feat. Mary seemed happy to bring up her sons and Feat together.

Grace seemed to really value Mary's support in caring for Feat. It would be difficult for Grace to care for Feat without Mary's help. It was clear that Feat needed a lot of specialised care including taking his ARV medications, and that Grace and Mary were constantly aware of adhering to the universal precautions.

Life changes

Life has completely changed since Grace and her husband agreed to care for Feat. Feat was very young when he first joined the family. Grace was not well prepared to be a parent for Feat however she had no choice. Agreeing to care for Feat caused a major transition in the life of Grace's family. Grace became a 'mother' again at sixty years of age. Life had become even more complicated when Grace and Mary were informed by a physician that Feat was HIV positive.

Feat was critically ill and under nourished when he came to live with Grace. Fortunately Mary offered to assist Grace. Later when Mary married she still supported Grace to care for Feat. Grace and her family and Mary all had to acquire new knowledge about universal precautions in order to keep Feat, themselves and those who Feat was in contact with healthy. These life style changes brought new dilemmas. Although Feat was too young to realise his living environment was different to that of other children he would become curious. And when he should be told about his HIV status was the main problem. Grace and Mary claimed that they were not yet ready to tell Feat about his HIV positive health status.

Personal reflections

I could see that Grace had a strong relational bond with Feat. Grace and Mary had raised Feat since he was very young. They both ‘mothered’ Feat. Feat called both Grace and Mary ‘Mum’.

I was surprised to hear that Feat was HIV positive because I knew that in the year 2000 Thailand had promoted free access to prevention programs called Preventing Mother-to-Child Transmission of HIV (PMCTC). I therefore was dismayed that Feat had fallen through the gap in health care delivery. Furthermore, I understood it would be very difficult to care for Feat. In addition to bringing up this child, there were several extraordinary tasks to do for him: monitoring and administering ARV medications, monthly visits to Khon Kaen Regional Hospital, and constant vigilance and taking universal precautions into daily life. I appreciated that Grace and Mary were knowledgeable about universal precaution. They were not worried about living with Feat despite his HIV positive status.

Family Five: Sue’s family

Sue: Grandmother (interviewed twice and she joined the PAR group)

Norris: Sue’s first daughter (interviewed once and she joined the PAR group)

John: Sue’s second son

July: Sue’s youngest daughter (died of AIDS 2003)

Ron: Sue’s grandson (July’s son)

Timeline of significant events for Sue’s family

1999 July studied in Khon Kaen city for six months then became a missing person.

2000 Sue is diagnosed Diabetes Type II.

2001 July is beckoned back home to live with Grace. July is four months pregnant.

2001 Two months later July’s partner dies of AIDS and July becomes critically ill.

2002 July gives birth. The baby is named Ron.

2002 July dies 10 months after giving birth to Ron.

2004 Norris’s husband dies. Norris moves in to live with Sue.

2004 Norris opens a small food shop in the village. Norris’s food shop does not thrive.

2007 Ron commences primary school.

2008 John returns to live nearby Sue’s house and becomes the breadwinner for this family.

2008 John opens a street food stall in Khon Kaen. Norris is employed by John.

2009 Ron leaves the village school and attends a school in Khon Kaen city.

Introduction to Sue and Norris

I will write about three family members: Sue who is a 67 year old grandmother and Norris (Sue's eldest daughter), and an eight year old called Ron (grandson). I interviewed Sue twice. Norris was interviewed once. After some informal conversations, both participants attended the PAR groups.

Sue's husband died many years ago. Fortunately, she had land on the Chi River and could therefore continue to support herself from her rice crop, but she had to work hard in the rice fields. She lived in a comfortable house. When I first met Sue she looked exhausted. Her own health had failed, she was frail and she is visually impaired. She cried when she told her story about her daughter's death and all the consequences thereafter.

July, her youngest daughter, was reported as a missing person when she was only 17 years old. Sue was distraught. The entire family searched for July for several years. When John (Sue's second son), her brother, came across her accidentally at the Khon Kaen food market, she looked unwell. She was persuaded by the family to return home, leaving behind the sugar cane fields where she had worked and her poorly maintained hut which was situated on the outskirts of Khon Kaen. Her male partner was also sick but she left him behind too. At this stage the family was suspicious that there was a serious illness but nothing was declared or revealed.

It turned out that July was already pregnant; her vomiting was excused as morning sickness. July was often sick and had diarrhoea, skin rashes and infections; July's symptoms were not ones consistent with normal pregnancy. Sue insisted on a test for HIV and was shocked when she found out her worst fears were realised. She did not recover. July became bedridden and then died peacefully at home under the care of her mother. She was only 28 years old. Just before July died she delivered a son by caesarean section. Baby Ron was ten months old when his mother died.

Again Sue was heartbroken. This time she had the responsibility of a grandchild permanently placed in her care. Norris married and lived in a neighbouring village. She still offered to help

her mother look after the baby. A few years later Norris's husband died in a motorcycle accident. Norris returned to live in a house next to her mother.

In Sue's village rumours were spread that Ron's father had died of HIV/AIDS. Two years ago, Ron first commenced year one in the village's school. Parents of other children in Ron's class went to Ron's teacher and demanded that Ron have a test for HIV. The teacher passed this request on to Sue. Norris had Ron tested and was pleased that he was not HIV positive. He was able to attend primary school. Ron appeared not to be happy at school. Children were not allowed to play with him as the rumours still lingered. For this reason John decided to move Ron to another school in Khon Kaen city.

The rumour was vicious and, consequently, Norris's food shop no longer attracted customers. The economic loss was too much for Norris to bear. John rescued her by offering work at his street market food shop, cooking meals. This food shop was in Khon Kaen and both John and Sue had to travel to work. John also lived near his mother at weekends.

Meanwhile, Grandmother Sue looked after three children; Sue's two great-grandchildren (Norris's grandchildren) were almost the same age as Ron and they all required her daily care. This extended family was quite self-contained; they ate, played, worked, helped each other and lived together. They shared all the financial resources and could make ends meet.

Sue's short story

I am sixty nine years of aged (69). I was diagnosed with diabetes several year years ago. My blood sugar level is good but I have problems with both eyes, I think it is glaucoma. My vision is poor now. I worry about going blind. Now that my vision is poor I feel more dependent on my older daughter. I don't want to be a burden.

I have looked after Ron since he was born. I am his grandmother. It was long story why Ron entered in my life. July (Ron's mother) my daughter studied in Khon Kaen city center. Then she ran away with a man who we did not know. July disappeared and she went missing. We lost contact with her for a year. I was tremendously distressed because she is my beloved daughter. When July did not contact us, I thought I had lost her forever.

I asked John (my son) and Norris to find July. John accidentally bumped into July in Khon Kaen market. John told me July looked unwell and it was obvious that she was pregnant.

We agreed to bring her home to care for her. John and I went together to find her and we travelled about 50 kilometers away from my house.

I was shocked when I saw July. I was dismayed by her poverty. She lived on a sugarcane farm property in a dilapidated hut nearby the sugarcane field where she had been working as a labourer. She looked desperately ill. July was emaciated and weak. She was four months pregnant. I persuaded her to come home with us and she agreed to return with us. She left her male partner in that cottage. I know little about him. We took July back home but July's partner did not visit her. Two months later we heard that he had died.

I looked after July during her pregnancy and she was often ill. I thought she was suffering morning sickness but it lasted too long. When July's baby was due she had caesarean session operation at Khon Kaen Regional Hospital. I was surprised when physician decided to do this operation instead of a normal delivery but I think I understand now. At that time I did not know much about July health's problems. We returned home with baby boy named 'Ron'.

July did not breastfeed Ron, I thought it was because she was under nourished, but now I understand why she did not. I looked after July and Ron in my house. July was severely ill after she gave birth. There was a dramatic weight loss and she looked even more and emaciated.

I took her to Khon Kaen Regional Hospital; finally I realised that she had AIDS. I was emotionally distressed and also extremely angry. I was angry because she had become infected with HIV through 'bad' behaviour and I was sad as I knew that she would die soon.

When July was critically ill she stayed in Khon Kaen Regional Hospital; but as she recovered a little I took her back home to care for her. I cared for July until her last breath. Before she died she asked for forgiveness, she begged me 'mum I am so sorry I have strayed so far, I am sorry that I did not listen to you, mum please accept my apologies'. July died on my bosom. I remember that my heart was breaking. July had disappeared for a year, she had only just returned to the family and then she was dead. I was extremely sad. I just had a new grandson to look after.

Ron was only ten months old when July died. Since then I have been looking after him.

Norris (my older daughter) helps to care for Ron. Norris has two grandchildren. Norris's daughter works in Bangkok so she is not able to look after their children, so these grandchildren are also brought to me to look after. Every day I work in the rice field and I have three small children to look after.

July died almost seven years ago but the rumours of her illness still remain in the village. Norris's food shop was affected by the rumours. Some villagers were scared of us because we cared for July when she was sick and they are afraid they might catch HIV.

Two years ago, Ron commenced year one in our village school (primary school). He was not accepted by his peer's parents. The school teacher asked me to have Ron tested for HIV. I was persuaded to take him to Khon Kaen Regional Hospital for a check up for HIV. I had no choice whether to take a test or not. I was afraid that Ron might test positive for HIV and that the blood result would change my life again. But the blood result was very wonderful because my grandchild did not have the infection. I presented Ron's blood test result to school teacher. Ron has been attending this school for two years. Even when we provided the test result to the school teachers and parents to show them Ron's results, still Ron has few friends. Children are not allowed to play with him. Ron is still isolated from his friends.

John (my son) knew we were in a difficult financial position. Norris was not able to earn an income since customers stopped coming to her shop and business gradually went down, John moved from another province to live with us. John has a street food shop in Khon Kaen city. His business is good. John is now our family's breadwinner. Norris is employed by John. Because Ron did not have friends John decided to change Ron's school. Ron now studies in school in Khon Kaen city and as John has to travel every week for his business, Ron now goes to school there. He is much happier as he now has friends. John has a good job and is able to care for Ron. After school Ron helps John in the shop. I am lucky that John and Norris help me to care for Ron. I am now too old and I often get sick. I am now free from worry about Ron's future because John has promised me he will raise Ron. But at the weekend the entire family comes back to stay with me.

Norris's short story

I am Sue's oldest daughter. I moved back to Khon Kaen four years when my husband died in a car accident. I was living in a neighbouring village with my family. I considered that my mother was too old to be living alone. I felt sorry for my nephew (Ron) because he has lost his parents. So I decided to move back home. It was very difficult decision as I had to earn money. I opened a small food shop in village. However the villagers did not buy food from my shop because they were bothered about a family member who had died from AIDS. Villagers thought they might catch HIV.

I was the breadwinner for my mother and Ron but now my younger brother John has become our head of family. John has a food shop in Khon Kaen city. His business runs very well so his financial status is more stable than mine. We live together in two houses which are located on my mother's compound. We have all built our houses on Sue's land and so we are able to have a family life together.

I now care for Ron (my nephew) and my daughter's children as she lives in Bangkok. Sue is always there to help me. Every morning I dress and feed them and take them to school. During the day I work at John's food shop.

I have struggled to make ends meet. My daughter sends money to me every month for her children's living expenses. I use this money for our family's expenses. I am thankful to my brother because he helps us to care for my nephew. I know Sue is also happy that Ron will be cared for by John if she should die. My brother and I would like to reassure my mother that we will continue to care for Ron. We don't want her to be worried. We are so lucky that Ron is not infected by HIV. I think he is very healthy. He is not often sick. This is the good thing to remember about my nephew.

What happened whilst researching?

I had tears in my eyes when Sue told her story. Sue shared several difficult moments: the disappearance of her beloved daughter when she ran away from home, went missing for a year and then returned home pregnant, and then her daughter's death due to HIV/AIDS. Sue shed tears when we were talking. I sympathised with her because she was an older woman who looked very exhausted and had sadness in her eyes.

Sue's family demonstrated support for each other. Norris and John offered the great help to continue care for Ron. Norris had her own duties to care for her grandchildren. John was living in a neighbouring province. However they were shifting their families to lend a hand to help Sue to care for Ron.

This family symbolised the traditional extended Thai family because there were four generations and numerous family members living together. It consisted of Sue, Norris & John (Sue's offspring), Ron (Sue's grandson) and Norris's grandchildren (Sue's great grandchildren). They brought back memories of when I was young, a Thai's family structure always consists of many generations.

Life changes

Sue's family experienced many changes. When July disappeared for more than a year, Sue lost hope of ever seeing July again. Sue was worried because July was her youngest and most beloved daughter.

When John brought July to Sue's home, they grasped that July was pregnant. Sue provided care for July when she was critically ill. July was not only returning home as a pregnant woman but also she had full blown AIDS. Shortly after Ron was born, July died peacefully in Sue's arms. Sue already knew that July was HIV positive but she still cared for her until she died.

The villagers were not accepting of Sue's family. This family was discriminated against. Norris's small food shop business was bankrupt. Their financial situation became stressful until John lent a hand to provide economic stability. He provided work for Norris which helped her financially.

Personal reflections

I believe Sue was still grieving for her daughter. She often shed tears when we talked about July. I also noticed that Sue was keen to maintain responsibility for her grandchild. She had some visual impairment, possibly a complication of diabetes, but she still wanted to care for Ron.

Discussion

Nine people were interviewed: five grandmothers, one grandfather, two aunts and one mother living with HIV. Lee gave a first person account of being diagnosed with HIV/AIDS and the financial, physical and emotional impact this was having on her life. She had travelled across Thailand and returned to a small abode in her birth village, a shelter which she then shared with her mother and her son, Pete. Five grandmothers and one grandfather talked about major upheavals in their lives when family members were diagnosed with HIV/AIDS and its subsequent consequences. Two siblings of people who had contracted HIV/AIDS, Mary and Norris, described the way in which they support their mothers and with other extended family members managed to hold the family together financially and emotionally. Five boys, Pete, Kenya, Golf, Feat and Ron and one girl, Lula being cared for in families, are the offspring of women who have HIV/AIDS. Lula's mother is still alive but living elsewhere and I also interviewed Pete's mother, Lee. Three mothers have died. I did not have ethical permission to talk with the grandchildren, but the nine people interviewed talked about these six children/adolescents. The interview, analysis process and the participants' short stories were repeated for each transcript in both languages. I then compiled a list of all significant statements from each of the participants' short stories. I wrote up the commonalities between these participants' short stories as constructs based on these. In other research, clustered text, commonalities or constructs might be called 'findings'. This following section outlines the fourteen constructs.

Fourteen main constructs

Fourteen (14) main constructs were identified in the close analysis of nine stories. (1) Being diagnosed with HIV/AIDS was a shock for all concerned. (2) There were major upheavals associated with changed living arrangements. (3) The person with HIV/AIDS was often sick and requiring ongoing support and care. (4) Most interviewees talked about death in the family and a few people were still grieving. (5) Grandmothers in particular 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. (6) Restructuring of families occurred, relationships changed, and there was often reliance on extended families for housing, financial and emotional support. (7) The impact on families as they were forced to adjust to new ways of living and how they managed interruption to daily routines. (8) Financial difficulties were experienced by three families but five families made comments about changes they had to make to secure income. (9) Living in a

close village community meant one's status was at risk if HIV positive status was revealed; there were rumours that disturbed families, judgments were made about 'bad' behaviours associated with sexual mores. (10) Discrimination was brought to my attention in all stories. (11) Disclosure, whether a child should be told about their parents or their own health status, was a problem for a few people. (12) All families used the services of Khon Kaen Regional Hospital. (13) Although I was not able to interview the children, all participants talked about their offspring. (14) One of the actions coming from these participants was their desire to initiate and support prevention of HIV/AIDS programs in their community. All constructs show transition in people's lives.

Being diagnosed with HIV/AIDS was a shock for all concerned

Lee was devastated when both she and her husband were diagnosed with HIV. Her dreams of having a good family life were crushed. The most challenging experience was learning that they had contracted a disease they regarded as associated with prostitution. Given the short lapse of time between her husband's death and learning about their seropositivity, Lee was concerned to protect her child. Lee became even more alarmed when she succumbed to an opportunistic infection, and had to seek help from her husband's family. When her husband died and she returned to her village, she did not convey this diagnosis to her mother.

There was silence around communicating seropositivity. Sandy and Nancy found out from the physician in Khon Kaen Regional Hospital only because their daughters were critically ill. Lee had no choice except to confide in her mother that she was HIV positive.

Five grandmothers vividly recall receiving the HIV/AIDS diagnosis. It was a great shock and accompanied by feelings of anger and sadness; anger, because they usually found someone to blame, the women's partners, sad, because they feared losing their child or grandchild. They may have been suspicious when their daughter or grandchild was unwell, or rumours may have reached them, but when they heard the actual words 'HIV/AIDS', they were alarmed. Grace remembered looking at Feat, and that "*he was so small*". Grace collapsed when she heard. Sandy felt her heart break. Sue found her daughter to be desperately ill, emaciated and weak and four months pregnant. Sue's daughter's diagnosis of HIV/AIDS was confirmed at Khon Kaen Regional Hospital. Receiving this diagnosis threw their lives into chaos.

When grandparents were first confronted with the diagnosis, their understanding of the nature, cause and transmission of HIV was limited, as they would seldom have access to information on it, and awareness campaigns typically target the young, not the old.

Realising that shock often accompanies this diagnosis means that there is a potential role for health care professionals to provide support. Open, genuine communication with willingness by the health care professional to listen would be affirming to those receiving this diagnosis. In addition, those hearing for the first time that they have HIV/AIDS will be dealing with raw emotions, and there is so much information that has to be absorbed alongside their anger and disbelief. And then there are questions about life and death that may need to be answered. The counselling role of health care professionals is important, but emphasis should first be placed on improving their wellbeing and their perception of stigma.

Upheavals

There were major upheavals associated with changed living arrangements. Grandchildren Pete, Kenya, Golf, Lula, Ron and Feat all live in their grandmother's house but they probably would not recall the major abode changes their parents had to organise to provide a roof over their heads as these shifts took place when they were very young. However, recently Lee and Pete had to make two shifts, first from Bangkok to her husband's family and, second, when her spouse died, to her mother's one room house in the village. The grandparents have had to make major adjustments. There is evidence that an extended family can absorb these young children, but the effect of these upheavals should not be underestimated. While an extended family rises to the occasion, again we should not assume that taking this responsibility is a matter of choice. Where else would Lee and her son Pete find shelter if not with Sandy? There are few social welfare system resources in Thailand and provision of housing for those impacted by HIV/AIDS is not on the agenda. Nancy said that she volunteered to care for the boys, Kenya and Golf, but what does volunteer mean? Aunts Norris and Mary, as part of the extended family, also accommodated Ron and Feat, as did John who moved back home to assist his mother. Most of these rural families now live in an extended family with at least three generations living in one house, or many houses within the same compound.

Illness and care

The person with HIV/AIDS was often sick and required ongoing support and care. Grandparents had to absorb universal precautions and understand a myriad of things about nursing. It must have been emotionally very difficult to see their son, daughter or grandchild become very ill, sometimes even close to death or dying. When daughters were ill at home, grandmothers had to learn precaution any skills as well as providing hygienic care, assistance with activities of daily living and nourishment. Sandy said Lee had meningitis and 'I thought she was going to die'. Being ill, becoming dependent on others to care for her was Lee's experience. Her mother could not manage her care, but, fortunately, the Khon Kaen Regional Hospital specialist HIV/AIDS unit was on standby for cases just like this. Sue said that: 'July was severely ill after she gave birth to Ron. There was a dramatic weight loss and she looked like death warmed up'. Grace was worried about looking after Feat, he was only a few months old and his grandmother used a disposable syringe to tubal-feed ARV to Feat twice a day. Once grandparents had learned about ARV treatments, hand washing, care of sharps, hygienic use of food utensils and food preparation, they became more confident. Grandparents eventually gained good information about HIV/AIDS and once it was on their radar, they wanted to share this information in the village. Grandparents could see a role for prevention of HIV.

I have used the term universal precautions but I realise this term is used in hospital settings and designed to treat all patients as potentially carrying the virus. The kind of precautions relatives needed to learn about was preventing exposure to blood and body fluids using condoms (not an issue for Grandmothers or family but their use became a subject for prevention). However, all families had limited access to equipment such as gloves and eyeglasses. For example, gloves were no longer available. Families were using plastic bags to cover their hands and protect themselves.

Knowledge that family members acquired was to recognise the potential hazards with blood and body fluids. Grandparents understood responsibilities relating to their personal safety. Using proper hand washing techniques was important and involved washing hands thoroughly with soap and water for five minutes and rinsing under running water, before drying their hands. It also meant knowing that urine, faeces and saliva did not require the same precautions. So there was no reason why families could not eat together. However, Lee still ate separately rather than joining Sandy and Pete. However, Feat was allowed to join the family for meals. It appeared from this response that families had different levels of knowledge about HIV/AIDS

transmission. Grandmother Grace and Mary had extensive knowledge and knew that if Feat was injured at school and had an open wound there would be a possibility of transmitting the virus. *Grace said “we told the teacher that she should not touch Feat’s blood with her bare hands. We also teach Feat not to let anybody touch his blood. Feat knows if he bleeds he must clean it by himself”*. The family’s knowledge about how HIV is transmitted and could be prevented was increased through opportunities to learn about how to recognise symptoms of HIV in a family member and how to care for a family member with HIV which included treating common infections.

Death and grieving

Most interviewees talked about death in the family and a few people were still grieving. Lee lost her husband to HIV/AIDS and then, when she thought she was dying, she was worried about who would care for Pete. Nancy was still grieving the loss of her daughter, Katie, but she had no time to grieve, there were two grandsons who came to live with her and her time was absorbed. Tracy and Noi were already looking after Lula when Lily’s husband died. Sue said her heart was breaking when her daughter died. All participants had been touched by death in their lives. Some of the problems experienced by grandparents included exhaustion, financial hardship, grief and emotional upheaval, lack of knowledge and resources for dealing with adult children with HIV. The strain of caring for people living with AIDS in the final stages of the illness can also be harrowing and tiring, and takes its toll on older people’s own health. In addition to increased care-giving workloads, grandparents can also suffer from feelings of blame, shame and guilt about their children’s situation.

Weight of responsibility

Grandmothers in particular 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. Sandy felt very responsible for her daughter Lee who was not well and often required her mother’s care. And then there was her grandson’s future to consider should Lee’s condition deteriorate. Nancy said that her ‘new’ family meant that she had many extra responsibilities. The burden in bringing up Feat was shared by her grandmother and her daughter Mary. Sue claimed that she has looked after Ron since he was ten months old.

Caring responsibilities also exact economic costs. Grandparents meet the costs of family survival, including the provision of food and shelter. They took their responsibilities very seriously, and often became distressed about not being able to provide enough food and clothes, or being able to meet grandchildren's educational needs.

Relationships, role of extended families and restructuring

Restructuring of families occurred, relationships changed, and there was often reliance on extended families for housing, financial and emotional support. Some relationships were strong, such as between Lee and her son Pete, who looked out for each other. Other relationships were despised, particularly when the daughter or son's partner was seen as the guilty one bringing HIV/AIDS into the family. Sandy was still very angry with Lee's husband, now deceased. Nancy's husband was still carrying anger about his daughter bringing AIDS into their lives and this anger was used as a reason for not helping Nancy share the burden looking after two grandchildren. Even Kenya is blamed for his lackluster achievement at school and Nancy blames his father. She said 'like father like son'.

Making major changes in one's life and adjusting to circumstances appears to be less confronting when marital relationships are good, as is the case for Grandparents Noi and Tracy. Although it was difficult for Tracy initially, between them they were able to sort out their new roles in providing care for their sick daughter and granddaughter Lula. Grandmother Grace felt supported as Mary had taken over much of Feat's care and she includes him into her family as if he is her son and her children are his siblings. She said: "*The three boys share everything and in my eyes they are equal as brothers*". With Mary's brother, this family live in the same compound. As a family, Grandmother Sue, her daughter Norris and son John searched until they found missing daughter July and they travelled about 50 kilometers to bring her home. They had all built their houses on Sue's land and so they are able to have a family life together. These people have carried out remarkable actions to hold families together, to gather strength from each other and to face the future together. They are restructured families.

Changes and interruption to everyday life

Families were forced to adjust to new ways of living and it was interesting to note how they managed interruption to daily routines. Lee, Sandy and Pete do not have meals together because they use separate utensils: there was a fear of contamination. Sandy said that her life was in

chaos learning to care for both Lee when she was so sick and her grandson Pete. Noi and Tracy said our *“family life has changed since we learnt Lily has HIV/AIDS”*. Fortunately, this couple earns enough money for day to day living whereas Sandy’s family was having trouble making ends meet. Noi reported that he no longer drinks alcohol; since taking up the responsibility for Lula, he has abstained and concentrated on making the future secure for her both financially and emotionally. Mostly changes were associated with work, work and more work, as grandparents took on additional responsibilities.

Finance

Financial difficulties were experienced by three families but all five made comments about changes they had to make to secure income. The first family to experience economic hardship was Sandy; she had become the breadwinner for the family. Saving money for a rainy day was impossible for Sandy, all her income had to be divided among three people instead of one. Lee could work occasionally but living with HIV meant she was often fatigued or not well enough to work. She was disappointed that she could no longer provide for her son’s needs. Finding suitable work that provided an income was the priority for Lee and she had recently been able to work from home. An older woman by Thai standards, and living with diabetes, Sandy still laboured in the building industry and when the rice crop needed to be harvested she worked in the fields. This family did not have land of its own; rather they relied on income working on other people’s land. Land was a distinguishing feature about how well a family was able to absorb the additional costs associated with bringing up grandchildren. During the rainy season, building construction stopped, there were no crops to harvest, so, being desperate for work, Sandy was employed cutting ginger root into small strips.

Grandmother Grace experienced financial problems. Gaining access to social welfare funds was a public affair according to Grandmother Grace and Mary. In order to secure money for Feat, they had to queue publicly for government financial support offered for children with HIV. In these restructured families, there were now more mouths to feed; Mary said that it was good to live so close to the river, as the extra income generated from catching and selling catfish could buy meat, eggs or chicken. Grace and Mary foraged for morning glory, a kind of spinach, and collected other vegetables growing on the river banks.

Grandmother Sue and Norris relied on extended family financial support. John, Sue’s son, knew they were in a difficult financial position. Norris was not able to earn an income when

customers rumoured about HIV and they stopped coming to her shop. John intervened and created jobs and an income for the family in Khon Kaen.

Grandmother Nancy had financial support from her offspring and rent from her daughter's house. Grandparents Tracy and Noi were financially secure as they were the local shop owners in the village. Even if grandparents managed to find funds for school fees, they were often unable to provide other essential items such as uniforms, books and transport costs to and from school. Fortunately, Pete won a scholarship. The financial burden on older people who care for grandchildren was immense.

Living in a village – the effect of rumours

It is often said that secrets cannot be kept in small communities. In these small villages, everyone usually knows everyone else's business. Good information about HIV/AIDS was not available and myths surrounded this type of infection, which made people who might have this infection the subject of rumours and discrimination. Living in a close village community meant one's status was at risk if HIV positive status was revealed. Interviewees talked about rumours that disturbed their families, and that judgments were made about 'bad' behaviours associated with sexual mores.

Grace said that villagers gossiped about her daughter-in-law dying from AIDS and when Feat was a little older "*we became the subject of a village rumour*". Feat is in the public attention; in particular his HIV/AIDS infection status is still being questioned. Sue was angry because her daughter had become infected with HIV through 'bad' behaviour and, at the same time, she was sad because she knew that her daughter would die soon. Nancy said that her daughter, being unmarried, caused great shame and marriage was hastily organised before Kenya was born, even when she had no respect for her daughter's partner. Public face was very important in the village and its loss was perceived as a disaster for grandparents. Saving face was on Noi's agenda too, but not to the same extent as his wife. The thoughts village people held preoccupied Tracy to the extent that she could not look after her daughter when she was ill with an opportunistic infection. Tracy was also angry with Lily for bringing public disgrace on the family. She said 'they moved to live in Bangkok. I was very angry. We have to "*Tam Jai*" her poor behaviour. I know I would be ashamed if Lily's HIV/AIDS status was known in public'. Tracy spent a long time declaring her good work in the village as if she had to convince me.

Discrimination

Discrimination was a topic brought to my attention in all stories: in fact it was the most dominant construct. Expressions of strong emotions were detected when participants talked about their anger, shame and sadness.

Lee was very upset and questioned why life had to be so difficult through no fault of her own. But Lee's *main concern* was about her son and that some villagers did not allow their children to play with him. He was taunted at school "*Your mother has HIV so you are bad boy too*". Pete now avoids playing with other children at school, so this has had a major impact.

Sandy was worried that the family would be discriminated against; she said: *I was immediately worried about stigma associated with AIDS and the impact this would have in our life with the neighbours*. Insightfully Sandy said that she understood the way stigma of HIV/AIDS works in small communities and how people are discriminated against and gave this as a reason why some people chose not to disclose being HIV positive.

Nancy was absorbed by her abusive neighbour who threw insults at the family. She felt really ashamed about this abuse because it was a public insult to her family for all the neighbours to hear. The entire family avoided this man by taking back lanes.

Tracy did not want to lose face with villagers because of Lily's HIV/AIDS status and Noi said that the potential discriminatory impact if neighbours should find out, created many tensions in his life. Both villagers, Tracy and Noi had trusted and respected positions in their community and they could not handle gossip and its consequences. They feared losing their status and recognition as respected health volunteers.

Sue said that, although her daughter July died seven years ago, village rumours still prevailed. The impact of the rumours was that customers no longer came to Norris's shop and her business was ruined. Lack of good information about HIV/AIDS and its prevention generated community bias, prejudice and discrimination. As Sue said "*some villagers are scared of us because we cared for July when she was sick and they are afraid they might catch HIV*".

Aunt Mary was able to ignore the bigotry; she was not concerned about neighbours' opinions. She had access to good information about HIV/AIDS; she said "*The villagers tell me that my*

sons would be at risk of contracting HIV from Feat. I don't worry because I know how HIV/AIDS is transmitted".

Disclosure

Disclosure, whether a child should be told about their parents or their own health status, was a problem for a few people. Six interviewees talked about disclosure. I have explained that in the village context, where there was limited knowledge about HIV/AIDS, disclosure to villagers and neighbours was not an option as discrimination would result. Grandparents were mostly concerned about whether their grandchild should be told about the reasons for their parent's death or, in Feat's case, his own HIV status. It had been decided not to tell Feat, the only grandchild who was HIV positive, and already he had started to ask questions about needing to take ARV. While Feat does not yet know, his teacher has been told because *"We thought that he might have an accident or injury while playing football"*. Pete already knows about his father and that his mother Lee is HIV positive. Kenya and Golf know about their parents dying from AIDS and these grandchildren understand why they now live with their grandparents. Lula does not know about her father dying from AIDS and she does not know her mother is HIV positive. Her grandparents are very concerned that she will find out, but at this stage they are acting as her parents and Lula's mother visits infrequently. Noi said *"I am aware that I don't want Lula to know much about Lily's health problem. It is very difficult for me to conceal Lily's story with Lula"*.

Health services provided

All families used the services of Khon Kaen Regional Hospital, which houses a HIV/AIDS clinic. The staff at Khon Kaen Regional Hospital are experts in the field and provide care and education programs. Grace and Mary were confident to look after Feat with the information they gained from the staff at Khon Kaen Regional Hospital. Sandy and Pete were at Lee's bedside when she was ill with an opportunistic infection. Having the hospital 10 kilometers distance from the village was a great resource for those living with HIV/AIDS. Nancy said that her daughter *"Katie was too ill for me to care for her at home. I was not able to cope with her diarrhoea, loss of appetite, nausea and vomiting. I took Katie to receive treatment in Khon Kaen Regional Hospital"*.

Tracy said that Lily returned to Khon Kaen and gave birth to a baby girl 'Lula'. When Lily became seriously ill with an opportunistic infection her parents took her straight to hospital. Within the walls of Khon Kaen Regional Hospital grandparents first learnt that their offspring had HIV/AIDS. Feat is taken for health checks at Khon Kaen Regional Hospital every month. This hospital clinic provides ARV treatments and standby for emergencies if and when opportunistic infections arise.

About grandchildren

Although I was not able to interview the children, interviewees spoke volumes about the five boys, Pete, Kenya, Golf, Feat and Ron and the one girl, Lula. Although they were concerned about their grandchildren they were also proud. Lee and Sandy boasted that Feat was doing well at school, and they provided evidence to support their praise with the scholarship he had acquired. Nancy claimed that her grandchildren were not doing well at school, but she was confident these children would find their way around. Kenya and Gold were keen to help support the family. Lula's grandparents were very proud of her saying that she was blossoming into a young woman at twelve years of age.

Being discriminated against as a child was hard for grandparents. Grace felt sad that Feat had few friends. "*Villagers refuse to let their children play with him so he is continually rejected*". Sue confided that Ron had not been accepted by his peers. Ron's HIV status was checked before he was allowed at school. Fortunately, he was HIV negative; but children are still not allowed to play with him at school. There is still a lot of ignorance about how HIV is 'caught' and misinformation is perpetuated in the village and the schools.

Prevention of HIV/AIDS

One of the actions coming from these participants was their desire to initiate and support prevention of HIV/AIDS programs in their community. This item was placed on the agenda for discussion at the PAR group. Clearly better information is required at village level. Hopefully, a better understanding will reduce the stigma associated with HIV/AIDS, and afford young children inclusivity in their village.

Conclusion

In this chapter I have introduced each family, presented the short version of their stories in English, made some observation and reflective comments about each family unit and after reviewing these stories outlined commonalities between them. The objective for this section of the inquiry was to identify and understand how families accommodate to a situation in which they are providing ongoing care for children of relatives who have died of HIV/AIDS. I found that all constructs demonstrate that families do this bit by bit as in a process of ongoing transition. My participants' stories show the impact HIV infection had on everyday life of all concerned. And they also show the way in which these families had made major transformations in their life. Most relationships were stretched when the family was first confronted by the diagnoses of HIV/AIDS. However, these relationships were reconciled over time. A definition of transition that speaks to my inquiry is from Meleis (2010, p. 72) who said:

Transition is the way people respond to change over time. People undergo transition when they need to adapt to new situations or circumstances in order to cooperate the change event into their lives.

Hence, my interest in the theories of transition or how people have accommodated taking the consequences of HIV/AIDS into their family lives and being able to move on. Meanwhile I believe that this inquiry makes a contribution to transition theory. It is important to understand transition as it is one of the main theoretical constructs in nursing and it is important to understand the transition in families who provide ongoing care for orphans.

Chapter Seven

Participatory Action

Research Groups

Introduction

In the previous chapter I introduced the nine participants from five families. All participants were invited to join the PAR group and the invitation was accepted by all. I will now restate my research question and the relevant objectives as a reminder of the focus of my inquiry and to identify the two objectives that this chapter addresses. My research question is: ‘What can be done to assist families whose lives have been affected by HIV and/or AIDS? This chapter addresses objective two and three: (2) to 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 and (3) to plan for action and, where feasible, act on issues raised and prioritised by families caring for orphaned children of family members to assist them in this changed situation.

This chapter describes the group process or stage two of this PAR study. I will restate that PAR:

- takes place in collaboration with participants;
- participants determine the agenda;
- participants drive the research; and
- participants decide on actions.

Researching alongside participants in a group, I was guided by the principles of PAR stated above; I followed the cyclical processes of ‘looking, thinking, and acting’ as an iterative process. A detailed analysis process was discussed in chapter five. Of course, the entire research process was conducted in Thai language; I was accompanied by Dr. Kessarawan Nilvarangkul, my field supervisor, at every PAR group meeting. In this chapter, I describe preparation, bringing nine participants and community nurses together, setting the agenda, prioritising the items and facilitating the group toward actions.

Preparation: Inviting participants to join a group

After I had completed the one to one interviews with family members from five families, I invited all participants to join a PAR group discussion. I explained that the purpose of the PAR groups was to provide a forum where they could have a voice about things that were concerning them. Other reasons for meeting as a group was that it might help them in identifying common concerns, and that they might like to help each other to improve their lives. I also suggested that they might like to collaborate to make changes in a wider context. I reminded participants that

information about these groups and the option to participate in them had been provided in the Study's Information Statement (appendix D) they had originally received and the Consent Form (appendix F) that was attached to this. Nevertheless, I also explained that participants did not have to join the PAR group if they did not wish to do this. I said that I would be pleased to continue to meet with them on a one to one basis to discuss and possibly plan to act on addressing concerns they had raised in their interview with me, if they would rather do this. All adult participants agreed to join the group, although not all could attend every session. I was astonished that they agreed to attend the group meetings, given the stigma attached to living with HIV/AIDS. We talked about items they might like to place on the agenda for discussion. Participants also asked if two of the community nurses from the Pralab PCU could join the group.

Scheduling the PAR groups – agreeing dates and times

Before setting up the PAR group meetings, we (the facilitator/researcher, participants, Community Nurses and PhD field supervisor) agreed on the time, date, and place. These times and dates were arranged to suite the participants. About two weeks before each PAR group I ensured each participant had been able to make travel arrangements to the PCU where the PAR groups were convened. Then three days before each meeting I confirmed the appointments with each participant via a telephone call. Sometimes, one or more participants could not attend the PAR group because of work commitments, illness or the need for them to take care of a sick grandchild at home or in hospital. These absences were readily accepted and understood. Nevertheless, participants were requested to contact me prior to the PAR group from which they needed to be absent, so that I would know how many participants would be attending each group. We agreed to meet on four occasions:

1. The first PAR group was facilitated on the 6th September, 2009 from 10.00- 12.10 pm.
2. The second PAR group was facilitated on the 18th October, 2009 from 10.15- 12.30 pm.
3. The third PAR group was facilitated on the 21st November, 2009 from 09.30- 11.50 am.
4. The fourth PAR group was facilitated on the 22nd January, 2010 from 10.00- 11.45 am.

The average length of the PAR group discussions was about two hours. There was approximately one month between each PAR group discussion. The time between the third and fourth PAR group was two months because it was harvesting season and Thai people celebrate the New Year holiday during this time. In consultation with participants, I arranged for the last PAR group to take place in the third week of January 2010. In total we had eight contact hours

for discussion but this was increased by an additional four hours for talking with each other informally over food.

Group participants

Nine participants joined the PAR group although not all were able to attend each session:

Family one: Grandmother Sandy and her daughter Lee (living with HIV/AIDS)

Family two: Grandmother Nancy

Family three: Grandparents Noi and Tracy

Family four: Grandmother Grace and her daughter Mary

Family five: Grandmother Sue and her daughter Norris

Table 1: Group participants, facilitator, PhD field supervisor and PCU staff

Person	Group 1 (10 people) September 2009	Group 2 (11 people) October 2009	Group 3 (7 people) November 2009	Group 4 (13 people) January 2010
Sandy	Sandy	Sandy	<u>Absent</u>	Sandy
Lee	Lee	Lee	Lee	Lee
Nancy	Nancy	Nancy	<u>absent</u>	Nancy
Noi	Noi	Noi	Noi	Noi
Tracy	<u>absent</u>	Tracy	<u>absent</u>	Tracy
Grace	<u>absent</u>	Grace	Grace	Grace
Mary	Mary	<u>absent</u>	<u>absent</u>	Mary
Sue	<u>absent</u>	Sue	<u>absent</u>	Sue
Norris	<u>absent</u>	<u>absent</u>	Norris.	Norris.
RNs	Two RNs+	Two RNs	One RN	Two RNs
Head Nurse	Head Nurse	<u>absent</u>	<u>absent</u>	<u>absent</u>
Supervisor	Field supervisor	Field supervisor	Field supervisor	Field supervisor
Facilitator	Facilitator *	Facilitator	Facilitator	Facilitator

*Facilitator / researcher / PhD candidate

+ RN Registered Nurse working in the community / Community Nurse

Table 1 (above) identifies those who participated in each of the four PAR groups. My Field PhD supervisor Dr Kessarawan Nilvarangkul attended each group meeting to offer support and we met straight afterwards to discuss group dynamics.

Community nurses

Participants had requested that two community health nurses from the Pralab PCU participate in the group because they believed that these nurses would be able to offer support and education. Most grandparents had built relationships with the community nurses in the last few years, not because of the orphans but since these older people were self-managing a chronic illness and kept in regular contact with health staff at the Pralab PCU. The Head Nurse had previously been informed about the study (appendix C and D) and supported it taking place in this PCU. She had actively helped to recruit families to the study. I therefore invited the community nurses to attend the PAR groups and to participate. The two community nurses already knew about this inquiry because they had also played a major role in the recruitment of participants and had read the information letter (appendix C and D). Abiding by ethical considerations, I requested that they reread the information letter about the study and thereafter sign a consent form (appendix F). The Head Nurse attended the first PAR group as a courtesy and to introduce the two community nurses.

The community nurses and I discussed our roles prior to the first PAR group. In addition to the information letter, I emphasised that the study would be *with* participants and not *on* participants. I said that participants would set the agenda, drive the research and decide on actions they might want to take. I pointed out that we would not lead the PAR group discussion but that we would encourage participants to talk, share their ideas and experiences. I saw the community nurses' role principally to respond to any questions participants raised in relation to their health or about the health services but not to provide health education unless invited to do so. Nurses were not at the group meeting as 'experts', rather they were in the group to learn more about participants' lives. Listening to participants may require them to review their health service in response to any changes that participants suggested. I explained that my role was one of facilitation, but I did not expect to have a lot to say, rather I wanted the words to come from participants. I also explained that the items to be discussed at the PAR groups were those that the participants had raised with me in their interviews.

Once community nurses were comfortable with the PAR process, I talked about group dynamics. I stressed that the PAR group discussion was intended to be collaborative. 'We' needed to be alert to group dynamics and observe power relations or if one or two people were dominating the discussion. I reminded the community nurses that our role was to listen to participants, and respond to any questions they might ask us, while at the same time ensuring

that participants chose what and how much information and discussion they wanted to share, the actions they wished to take and the plans they wanted to follow to do this.

The setting

Group meetings took place in a Pralab Sub district five kilometers from the major city, Khon Kaen. The venue was a meeting room at the Pralab Primary Care Unit (PCU). As explained in chapter two describing the context, Pralab PCU staff included seven registered nurses who work in this community. Community nurses are supported by village health volunteers who assist them with rolling out some of the preventive health strategies undertaken by staff in the Centre. As previously discussed, Noi and Tracy were both village health volunteers at this centre.

On the day of each PAR group, I went to the Pralab PCU two hours before the meeting started to check the equipment and refreshments. When the PAR group was in progress, I put up a sign stating “*meeting in progress*” on the meeting room door to ensure the PAR group discussion would not be disturbed by others.

Food and refreshments offered at the PAR groups

Food played a big role in the PAR groups. Prior to each PAR group meeting, I organised food and refreshments for all participants. Both were purchased from the village market located near the Pralab PCU. Given that some participants lived with diabetes, the refreshments included ‘healthy’ foods such as fresh fruit (mangoes, oranges and rose apples) but also crackers, cake and fruit juice. Following each of these PAR groups, all participants and the researcher had lunch together, paid for out of the study’s budget. The Thai food provided for the lunches was packed in containers and, as food is a precious commodity in the village, participants were able to take home any food that was left over.

Further support was provided to all participants in the form of an honorarium¹¹ to cover transportation costs and as an expression of appreciation for participants’ time.

¹¹ The honorarium had received approval from both ethics committees who reviewed the study proposal.

Beginning the PAR group process

At the first PAR group, the atmosphere was tense possibly because participants did not know each other. Fortunately they knew the community nurses and I had built a relationship with them. I sensed that being strangers to each other, participants would probably be shy and uncomfortable at first. I had therefore planned an ‘icebreaker’¹² to try to make the group participants feel more relaxed and start to feel a bit more comfortable with each other. I introduced myself and asked them to join in a meditation song that I knew they commonly sang and would be familiar to them. We sang this song together and, when we had done that, I had the impression that they were a little bit less apprehensive. Thankfully, they even laughed a little together and started to chat with each other.

I introduced my field supervisor, the head nurse from Parlab PCU and the two community nurses. Then I invited all participants to introduce themselves. Observing that participants were more relaxed, I asked them if they were ready to start the group discussions. They agreed that they were ready. I started the PAR group discussion by explaining the group process to the participants.

When setting up the PAR groups, I was fully aware of the need to ensure participants’ confidentiality, privacy, safety and comfort. Nevertheless, I also said that I could not guarantee confidentiality because this depended on all those in the group keeping what the group discussed confidential. The exception to this was when the whole group agreed that something (for example a particular action) needed to be discussed with people outside the group. Next, I explained that we needed to agree how we would work together in the group. I knew that it would be novel for villagers to participate in a group where they were expected to take the lead and have a voice. However, I observed that the participants were excited to be in the group. We talked about the norms or rules to guide the group process. Collaboratively we set up the following ‘rules’:

- Confidentiality: keep all talk within the walls of the PCU room.
- Enable everyone to have a voice.
- Listen to each other.
- Do not interrupt when others are speaking.
- Make sure it is ‘safe to talk’.

¹² Icebreakers are techniques used at the first session to reduce tension and anxiety, and also to immediately involve the group in discussion.

Setting the agenda

The process of setting the agenda for the PAR group discussion deviated somewhat from Koch and Kralik's (2006) ideas about how a PAR group should proceed. Using the process identified in their research studies as a guide, I noted that people are invited to tell their own story in the group at the first meeting. Although my participants said they were willing to join the PAR group, most said that they did not want to discuss their own story that they had shared with me or talk about the problems they had raised in their story; individuals did not want to share their private stories in public. I was not surprised, as I thought that they would prefer to keep some of their concerns and experiences confidential, given the sensitive nature of HIV/AIDS in their families.

Being a Thai national myself and used to working with Thai villagers, I understood that they would be unfamiliar sharing their lives with other participants and speaking out aloud with 'strangers'. I use the term strangers because, although participants may have seen each other in their daily village lives, they did not know each other. Indeed, from their conversations with me, I recognised that participants wanted to keep some family matters confidential to their family. I also knew that, because of cultural preferences, my participants were more likely to talk about what they wanted to do in terms of action rather than review their stories in a public space.

Whilst these participants were reticent about sharing their private lives, they were motivated to meet with each other and to discuss ways to address problems. These participants had managed to accommodate significant changes in their lives. Becoming a caregiver to their orphaned grandchildren meant that they were continually problem solving; in fact, they had addressed many of life's problems themselves. I believe they saw this meeting as an opportunity to share ways they had managed their lives and to drive the agenda to collectively solve some common problems.

Summary stories inform participants' selection of agenda items

Prior to the first group meeting, I talked with participants individually about 'what they wanted to discuss in the group'. I reassured participants that I would keep their stories confidential. They were satisfied with this arrangement and willingly identified the agenda items for discussion. The seven agenda items selected by participants did not completely match the fourteen constructs (chapter six) although five were similar. Agenda items that were similar

were finance (construct eight), rumours and their impact / discrimination and verbal abuse (constructs nine and ten), access to social welfare (related to finance construct eight) and health promotion (construct fourteen). Two new items were proposed by participants (1) who would care for the orphans when their grandparents are ill or die? (2) Services provided by Pralab PCU and how they could be improved.

Prior to the first PAR group meeting, I had made short summaries of the seven agenda items selected by participants. I used interview data to create these summaries. The summaries below are translated from Thai to English for the purpose of this PhD document. The seven summaries are mergers of the participants' long stories into seven common stories using 'we' to stimulate group ownership. I read these out aloud in the group so that we could all share common concerns and start the group conversation.

Summary: Financial problems

We share a lack of income and have only just enough to support our day by day living needs. We face the difficulty of trying to earn money to meet our living expenses. Financial distress in our families exists because we have lost the family breadwinners (young 'working age' family members who have died of HIV/AIDS). Because we are older we cannot earn sufficient income to provide a comfortable life for our family members.

The range of income for our families extends from 3,600 Baht (AUD 120) to 9,000 Baht (AUD 300) per month. The average income of our family is different because of the range of jobs which we do. We have tried several ways to earn money, for example, working in the rice field, growing crops, catching fish for sale or opening a small grocery shop. Those who own their own business (Noi and Tracy) are more likely to be able to make more money than others who are wage earners.

Furthermore, Lee and Grace's grandchild (Feat) have monthly hospital visits to the HIV/AIDS clinic. Although ARV treatment is free of charge, the cost of transportation, food and drink in hospital impacts our living expense and costs us at least 100-150 Baht per visit. We plan to accommodate this expense, however, occasionally if we get sick and need to be admitted in hospital we could spend more money than normal. Therefore

some families who have a sick family member have to consider spending money on health related expenses.

Summary: Rumours and their impact

Not surprisingly, the resources and the social connection in our families are limited because of discrimination against our families' members who are living with HIV/AIDS and we who care for them. For example, Lee resigned her job in the laundry shop because she worried that customers would come to know her infection status so they would not come. Norris's food shop suffered when villagers found out that her younger sister died of AIDS. The opportunities for employment are also difficult because some of us who are caring for these orphans are old.

We are experiencing discrimination which emerges in different forms including being ostracised by some in the community causing us to be socially isolated and to experience hardship and children being rejected from attending school and being rejected by other students' parents, verbally assaulted and growing up with few friends.

Stigmatisation is frequently experienced and this is often made worse because it leads to discrimination. Sue's grandchild experienced community stigmatisation resulting in rejection by school students' parents, whose influence resulted in the grandchild's exclusion from school and therefore lack of opportunity for education. It also resulted in Ron's isolation which meant he had few or no friends. These are just some examples of stigmatisation discrimination and abuse that some of us suffer to varying extents.

We have experienced the loss of our beloved offspring and relatives. We are experiencing discrimination which emerges in different forms including being ostracised by some in the community causing us to be socially isolated and to experience hardship, and children being excluded from attending school or rejected by other students' parents, verbally assaulted and growing up with few friends.

Summary: Access to social welfare payments

There are several social supports for people living with HIV/AIDS and their family, for example, the Thai government national health policy for people living with HIV/AIDS.

This provides free access for ARV treatment and social welfare policy for people living with HIV/AIDS and the affected family.

Lee and Grace's grandchild requires ongoing ARV treatment and has access to free ARV treatment provided through the Thai government's health department. Furthermore this service also guides Lee and Grace's grandchild to take part with a group of people living with HIV/AIDS. Adults living with HIV/AIDS are also eligible to access interest free loans from Khon Kaen Regional Hospital in order to establish their small business as a job opportunity. Furthermore, parents who provide care for children living with HIV/AIDS also have monthly support group sessions. This activity aims to assist them to provide care for children.

We can access social welfare from the Thai government which is designed to assist people who are living with HIV/AIDS and orphans of HIV/AIDS. This support provides the following aid to people who are living with HIV/AIDS and families who are living with HIV/AIDS:

- *Local government subsidises funding for people who are living with HIV/AIDS for 500 Baht (AUD 17) per month.*
- *The Social Development and Human Security office provides aid for affected families who are caring for orphans of family members who have died from AIDS to the amount of 2,000 Baht (AUD 66) for each family per year.*

However Nancy's family has not yet received this funding, even though they meet the funding criteria. Nancy is also afraid that she does not have enough information about the Social Development and Human Security scheme for families caring for orphans of AIDS sufferers and therefore has not been able to access this funding.

Summary: Discrimination and verbal abuse

Some villagers choose to abuse us because they know some of our family members are HIV positive. Nancy's family for example is continually verbally assaulted by her neighbours. Their grandchildren are yelled at by a neighbour who accuses them by saying "your parents' die of AIDS". Nancy's family has been verbally insulted by a neighbour for seven years. It is a painful experience for them, particularly for Nancy's

grandchildren, because they are really upset about this situation. Nancy also worries that her grandchild may become very angry in response to this abuse and grow impatient that they have to endure it.

Although distressing, the discrimination against families who care for orphans of parents who have died of AIDS is, we think, gradually getting less. It always hurts us, however, because we think we have not done anything wrong and just try hard to care for our grandchildren. We also try to ignore people who may not be comfortable or want to make friends with us. We cannot change what they think. We also try to teach our grandchild to behave well and ignore this miserable situation.

Summary: Care of orphans when grandparents are ill or die

Another worry we have about caring for these orphans (our grandchildren) is that we are too old and we wonder who will continue to look after them after our deaths. These experiences make us worried, sad and ashamed because we cannot ensure our grandchild's future.

We think providing the care for orphans who have lost their parents due to HIV/AIDS is our duty or responsibility. In these instances we have not only lost our offspring or relatives but we have also gained additional family members for whom we become totally responsible for their care and upkeep. Further, sometimes this involves additional expense and complexity in the care required, because these orphans may be HIV positive themselves, having contracted HIV from their mother. If HIV status is known or suspected they may be discriminated against by others. This need to care for additional family members may also bring increased financial distress to the family.

Summary: Services provided by Primary Health Care Unit (PCU)

We are aware that nowadays the community project on HIV/AIDS prevention is no longer being run. There are limited supplies of free condoms for villagers. The community health promotion project about HIV/AIDS prevention has disappeared.

We are worried that adolescents may miss out on HIV/AIDS prevention information. Thus new cases of HIV/AIDS might happen. Moreover, there is discrimination against

people living with HIV/AIDS and their families. Discrimination may increase if the villagers misunderstand HIV/AIDS.

Noi said “I hear that many teenagers have unprotected sex”.. I tried to provide the free condoms for them. I really want them to learn how to protect themselves transmitting HIV.

Nancy said “I worry about my two grandsons, I always tell them about safe sex practice”. I don’t want them to repeat their parents’ mistake by being infected by HIV.

Summary: Health promotion

In 2009, there was another epidemic; H1N1 or swine flu spread throughout Asian countries as well as Thailand. In fact “we know that H1N1 could be prevented by good hygiene care and personal hygiene, for example, hand washing and using serving spoon with the shared meal”.

We want to talk about healthy living patterns and behaviour in order to prevent some communicable diseases, such as H1N1 or diarrhoea. We want to share our learning experiences about universal precaution knowledge in the group.

The participants prioritise agenda items

After participants had listened to the summaries, I asked them to read the agenda items I had placed on a wall chart. I explained how participants had all contributed to the agenda during their one to one discussions with me. I then asked them if the seven items were still what they wanted to discuss and asked them whether they wanted to make changes or add any further items to the list. They did not want to change items nor did they add any more.

Participants then moved to prioritising agenda items. I had asked those who had raised a particular concern with me during the one to one interviews if she/he would be willing to tell the other participants why it was placed on the agenda. When one participant related why this particular concern had been selected, others in the group frequently identified that they too had similar experiences. Sometimes participants proceeded to describe how they had resolved the

problem and they were keen to share their problem solving with others in the group, particularly when their strategies had been successful.

The participants then prioritised the items as follows, which, coincidentally, was the way in which they were presented as summaries:

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 Health Care Unit (PCU)
7. Health promotion

Although the PAR group agenda identified seven areas, the group talked about all of these under one heading from time to time. The agenda items are all interrelated. In the section to follow, I will tease out discussion and resultant actions under the seven agenda items but there will be some overlap. Even in the first PAR sessions the group worked together to collaboratively solve problems, they were interested in listening to each other and very keen to drive actions that would result in good outcomes.

The researcher / facilitator role

I was alert to group dynamics. Throughout the PAR group discussion, I observed group interaction. I made every effort to avoid being judgmental or controlling of the group process. If someone talked too much or was too dominant, I reminded the participant about the group norms they had agreed to when the group first met. In my observation participants rarely dominated the discussion and none of them appeared to feel embarrassed by the sensitive topics discussed. However, when a participant was quiet, I tried to motivate that person to share something with the group that I had recalled from our one to one conversations and draw the person back into the group. Traditionally younger Thai people respect their elders. Therefore, I observed that often older participants were given permission to have the first word. These older people had considerable life experience to share and their words were appreciated.

In my role as facilitator, I tried to encourage all participants to share their thoughts, ideas and opinions by using an open discussion process. This process was useful in order to gather some

ideas or suggestions. We had agreed that all opinions should be listened to and not condemned as 'right' or 'wrong'. Everyone was entitled to have their own views on issues being discussed. I hoped that by facilitating an open discussion, participants would feel free to express their own opinions and encourage others to do this. I assisted participants to identify participants' strengths and reemphasised the agenda items so that the group could stay focused. When the participants discussed a particular concern and made moves to address an issue, I encouraged them to consider how they could act to make improvements. We also discussed the pros and cons of their plan and the feasibility of implementing their plans toward action. From time to time I made suggestions about how and where they could locate the necessary resources to implement their plan. Nevertheless, I reminded participants that this was their plan and it was up to them how they wanted to go about its implementation.

My field supervisor participated in each PAR group, supporting me, and monitoring and helping me to develop my facilitation skills. After each PAR meeting we debriefed and her advice and experience in facilitating groups was invaluable to me.

Feedback cycles

I recorded each session. When each PAR group discussion was over, I transcribed the entire conversation into the Thai language. I analysed the discussion using Koch and Kraliks (2006) protocol. This required me to read the verbatim transcription and consider how participants 'looked, thought and acted' during each PAR group as these were captured in their discussions. As Stringer (2003) suggests, this is a cyclical process, one readily apparent in the process of participants' discussions relevant to each concern they raise, and their resolutions (plans for actions) the way they decide on actions. I summarised the main points of each meeting so that I could provide feedback. I gave each participant a summary of the discussions stemming from each PAR group at the beginning of the next PAR group. Participants had the opportunity to read, make comments and validate the meeting summary, thus ensuring methodological rigour. This process also ensured that participants were co-constructors in creating the agenda and resultant actions emerging from the four PAR groups.

Actions

Having introduced the agenda items and shared the summaries of their concerns, participants took ownership of the meeting. I will now share the conversations held over four PAR group

meetings about financial problems, rumours and their impact, access to social welfare payments, discrimination and verbal abuse, care of orphans when grandparents are ill or die, services provided by Primary Health Care Unit (PCU) and finally health promotion. Included will be actions group participants suggested to address the problems identified, the resources they would require and the time frame in which it had or was expected to be achieved.

Action one: Financial problems

Lee and Sandy (family one) were the poorest of the three families and in the worse situation as far as lack of finance is concerned. This was because Lee was not well enough to work and she also had limited opportunities to find work because of poor attitudes to people with HIV/AIDS. Furthermore, Sandy was already in her sixties and living with a chronic illness. Besides, she was uneducated and consequently she had few work opportunities. Nancy (family two) was a single grandparent who lost her husband in August 2009. Even though she was working hard, she did not earn enough to provide for her two grandchildren and herself. Nancy was caring for her two grandchildren following the death of their parents. However, she did not receive social welfare from the government to help her with this increased burden on her already meager finances. Her family had come to the rescue and was prepared to provide backup finance: Nancy depended on her daughter for financial assistance. She lacked any certainty about how to sustain an income for her grandchildren and herself. Despite, working hard to provide for an orphaned grandchild, who was frequently ill because he too has HIV, Grace and Mary's finances were stretched. Grace and Mary had raised Feat since he was very young. Grace's husband was diagnosed with Type II Diabetes more than ten years ago; he is unwell and cannot be the family breadwinner. Mary's husband played a major role in providing financial assistance for the whole family.

Table 2 identifies the aims, actions resources and timeline that participants identified to address financial problems discussed within the group.

Table 2: Action one: Financial problems

Participants' Aims	Actions	Resource	Timeline
To increase the family's income to meet financial needs.	Community nurses offered Sandy a job in the Pralab PCU Centre.	The Pralab PCU.	2010 ongoing
	Nancy and Grace offered Sandy and Lee advice to catch fish in the village ponds and to grow water vegetables. Participants advised them how to grow vegetables for themselves using land and water ways that were on Nancy's property. Produce could be bartered or sold.	Permission to use natural resources in their area.	Ongoing
	Participants' suggestion that Lee start a micro finance business making funeral flowers.	Consult staff at Khon Kaen Regional Hospital HIV/AIDS program to explore micro finance.	Micro finance provided.
	Lee and Grace explained to Nancy about her orphan grandchild's right to receive social welfare and how to access moneys.	Consult staff at Khon Kaen Regional Hospital program about benefits.	Result was achieved.
	Recommendation that Grace commence a micro finance business growing mushrooms.	Budgeting advice from group members.	Mushroom growing has started.
	Nancy applied for the social welfare for affected families who are providing care for orphan.	Consult Village Head Person and submit the application to the Thai Social Development and Human Security Department.	Submitted on January 2010.

As discussed in chapter two in 2007, the Pralab PCU established a clinic that offered alternative treatment including traditional Thai massage, meditation therapy and Thai herbal medicines. The aim of this new clinic was to provide villagers with a choice between Western and traditional / alternative health care. The instigation of this new clinic created some employment opportunities for villagers. Sandy had received massage training under the scheme provided by Pralab PCU in 2007. Sandy had not been able to secure appointment as a masseuse because she

claimed that the massage owners said that Sandy was '*too old*' and could not attract any customers.

At the PAR meetings, community nurses suggested that Sandy practice massage on neighbours and relatives and a job may be waiting for her at the centre. When this new employment opportunity was offered to Sandy by the PCU community nurses, she immediately started to practice her massage skills on some of the villagers in order to refresh her skills. Villagers paid her about 40-50 Baht for each massage. At the last meeting (January 2009), Sandy reported her progress to the PAR group. This enabled the community nurses attending the PAR group to offer Sandy a position as a massage therapist in Pralab clinic. Sandy reported to PAR group participants that she was pleased about being offered this new job opportunity in the clinic because it was a permanent job. Her casual job as a construction labourer was not possible during the rainy season. Being able to work as a masseuse, Sandy now had income security.

Participants listened carefully to Sandy and Lee. They offered more advice about creating an income. Other alternative job opportunities suggested by the group included growing vegetables for sale. It was argued that fishing, growing vegetables and salad produce might improve their income. This would be a new project as these participants did not have access to land or the water where they could grow food or fish. Sandy and Lee did not have access to land and water and they were given permission to use the private water ways and land belonging to Nancy and Sue. The idea of fishing to create an income was rejected because neither Sandy nor Lee could swim so both were frightened of water. Instead they started a vegetable garden. Sandy and Lee had grown shallots, chili and basil in pots in their small land area surrounding their one room house. Eventually, they were able to expand their gardening expertise and grow marketable crops. Sue also shared her experiences growing food and bartering her produce with other villagers. The bartering process was new to most participants and they appeared to take this idea on board.

In PAR group discussion, Lee and Grace found out that they could have access to a small interest free loan from a Khon Kaen Regional Hospital program which offered micro finance to their HIV/AIDS clients. The HIV/AIDS clinic at Khon Kaen Regional Hospital provides micro finance to assist people who are living with HIV/AIDS and their family. During the inquiry, Lee and eight other people living with HIV/AIDS signed a contract for a 4000 Baht loan to establish a small business making funeral flowers. Lee and her friends are making the funeral flowers for sale. In the beginning, when Lee had less skill in making the flowers, she only made 40-50

flowers per day and earned about 20-25 Baht. Later, as she improved her skills she reported to the PAR group that she had made more than 80-100 flowers per day and that she earned 40-50 Baht per day. When Lee reported back to the group about her progress in making flowers, Noi and Tracy offered Lee some advice to make even more money on funeral flowers. Noi and Tracy designed a new funeral flower style which was more expensive than the style that Lee made. Lee now makes funeral flowers which cost 1 Baht per flower. In January 2010, Lee told the PAR group about another new job she had negotiated. Lee had returned to the laundry shop where she had worked in 2007 before she was diagnosed with HIV/AIDS and persuaded the owner to let her iron clothes at home. Twice a week the laundry shop owner takes clothes to Lee's home. Lee earns 100 Baht from this job. Lee earns extra from ironing clothes for 200 Baht per week. In the group Lee reported that her health status had improved and that she had increased self-esteem now that she is less dependent on Sandy. Lee is now able to contribute some money toward supporting her family.

Grace applied and received a loan from Khon Kaen Regional Hospital's project moneys and has invested this in starting a small mushroom farm. Grace borrowed a 500 Baht loan from this micro finance project. Grace grows mushrooms in her backyard. Seven weeks after installing the mushroom box, Grace was earning 15-30 Baht per day. Grace said it may not bring in big money but she can sell mushrooms every day. Moreover, she uses the mushrooms to feed her family. Grace is still repaying her loan.

Nancy reported to the group that her grandchildren had not had access to the social welfare moneys available for the HIV/AIDS orphans. The Village Head Person (who was a man) had not registered her daughter's HIV/AIDS death certificate in the local government system. Community nurses helped Nancy understand her rights to receive this income and offered to make contact with the government person on Nancy's behalf to find out current regulations and report back to the group. Nurses reported back that new regulations meant that those affected by HIV/AIDS can be subsidised by 2,000 Baht (AUD 66) for each family per year. These payments come from the Thai Social Development and Human Security Department. Nancy was eligible for this assistance and she now understood how to register for this money. In January 2010 Nancy was waiting for the result of her application for this income.

Action two: Rumours and their impact

All participants experienced the effects of rumours and gossip and there was a long conversation about this in the PAR group, and not so much resultant action. Really the group identified an opportunity to share their fears and experiences. When first diagnosed with HIV/AIDS Lee had resigned from work to avoid being rejected by customers. Ron (Sue's grandson) was expelled from attending school brought on by pressure from other student's parents. Norris's food shop no longer attracted customers because of the rumour about HIV/AIDS travelling throughout the village. Noi and Tracy were careful not to disclose Lily's HIV/AIDS status in the PAR group because they feared gossip, and its associated loss of status in their community. Noi and Tracy did not want to talk about their daughter's HIV status and said that they were in the PAR group as health volunteers. Grace and Mary worried about Feat's HIV status being known in public. Feat was rejected by his friend's parents when playing football with his peers. Some villagers rumoured about Feat's HIV.

Table 3: Action two: Rumours and their impact

Participants' Aims	Actions	Resources	Timeline
To feel more comfortable living in the communities.	Grace and Mary plan to negotiate with the local government about the social welfare payment and ways in which the payment was delivered without identifying the recipient's HIV status (aim to minimise a chance of disclosing Feat's HIV status).	Make contact with the Village Head Person.	Contact made – no outcome yet in Jan 2010.
	Teach Feat how to live with others safely despite not knowing about his own HIV positive status.	Grace's family	Uncertain when Feat will be told about his positive HIV status.

Group participants described the social injustice in being the subject of rumours. All realised that this situation was still a major concern. Grace and Mary still keep Feat's HIV status a secret. Only the Village Head Person, the nurses in the Pralab PCU and Feat's school teachers knew about his HIV/AIDS status. Yet there is gossip, some of the villagers do not allow their children to play with Feat.

Mary told the group that, one day, when Feat was playing football with his friends, he drank water from his friend's glass. His friend's father threw the glass away and said "*do not drink from the glass that Feat used*". Feat cried and asked Mary why his friend's father acted in this way. Mary said she was so sad that Feat had to grow up without friends.

The group listened to Lee who told about Pete's situation. Pete has had several experiences of being rejected by his friends. Lee shared a story with the PAR group about when Pete was young and Lee and Pete lived with Pete's father family at Chum Pae district. The villagers knew that Pete's father had died from AIDS, they gossiped and consequently Pete had no friends to play with.

Mary spent considerable time explaining to the PAR group ways in which she made sure Feat was acting responsibly at school and play. It was recognised that Feat's teacher needed to know about his positive HIV status. Mary shared information given to the teacher about dealing safely with Feat's blood and bodily secretions. When playing football, there were certain things Feat had to learn, he was taught not to let anybody touch his blood or injuries (see table 3). Feat has learned to be independent and to clean his wounds and cover them with a bandage. Mary admitted that although things were going well for Feat in a physical sense, he still did not know about his positive HIV status. Mary and Grace have not told Feat why he has to follow these procedures when other children do not. The reason that they had not told Feat was because she wanted him to have a normal life as long as possible.

Action three: Access to social welfare payments

In 2003, Grace registered Feat's HIV/AIDS status with the Village Head Person (and indirectly local government) in order to receive a special benefit to families. In the PAR group Grace described how the distribution of this funding was made. Every month the Village Head Person announces the list of people who will receive the social welfare. He uses a public broadcasting system which is a loud speaker that can be heard in the entire village. Feat's name is called out. In the middle of the day villagers who have been called by public speaker gather at the Village Head Person's house so that they can collect their social welfare benefits. On the day money is distributed, Mary must take Feat out of school as he must be present to collect the cash in the envelope. The Village Head Person calls out each name one by one and the recipient collects the money with his/her name stamped on the front of the envelope.

In discussion, the group learned that Mary (Grace's daughter) was anxious because Feat does not know his positive HIV status. Feat needs to collect his welfare check each month and will soon ask why he is receiving this aid. When Feat was young, this process was not a problem. But now that Feat is older, he is asking questions. Moreover, the public distribution system meant that Feat's identity and public receipt of cash is under scrutiny. Rumours abound in the village. Some people rumour that Feat might be HIV positive as they know his mother died of AIDS.

Grace and Mary had already made some changes (see Table 4). Prior to PAR group discussions, Mary had spoken with the Village Head Person requesting him not to call out Feat's name in public and not to stamp Feat's name and HIV/AIDS status on the envelope. This was approved but Feat still needs to be present to collect the envelope every month.

Lee shared her case with the PAR group. She also receives monthly social welfare money from her village; however, her method of payment is more convenient and less public. The money is transferred electronically to her account every month. There are obviously different systems working in every village. The Community Nurse said she would explore other possibilities for receiving this specific HIV/AIDS welfare payment (see Table 4).

Table 4: Action three: Access to social welfare payments

Participants' aims	Actions	Resources	Timeline
To able to access social welfare benefits.	Learning from Lee that social welfare benefits can be distributed (electronic transfer) and explore if this is possible for Feat.	The community nurse will follow through and report back.	Ongoing
	Continue negotiations with Village Head Person about the way in which Feat's benefits can be received in private.	Negotiate with the Village Head Person.	Ongoing

While the community nurses offered to explore other ways in which Feat could receive the social welfare payment both Mary and Grace were worried that there would be a backlash. Until the group had met, Mary thought that every village distributed their welfare monies in the same way. She now realised that there were differences from village to village. She was worried because she did not want to ask for further compromises from her Village Head Person. She believed she might be disadvantaged if she caused too much trouble. She said that she might even lose her income if she challenged the Village Head Person again. I realised that the power

difference is the major obstacle for people to pursue their rights. Nevertheless, the PAR group encouraged Grace and Mary to pursue their rights, so progress on the action is forthcoming. The community nurse volunteered to speak with the Village Head Person and local government officers on Grace and Mary's behalf.

Before the PAR group disbanded, Grace, Mary and the community nurse met with the local government officer and the Village Head Person. They negotiated with him about the social welfare payment. Grace mentioned Lee's case (with Lee's permission). Together they achieved a solution about Feat's welfare. In the future, Grace can be the responsible person in receipt of the welfare payment on behalf of Feat. Since January 2010, Feat does not need to be present to collect the money. Grace is relieved. Mary said that she knows Feat will know his HIV status one day, but his knowing about it is slightly delayed.

Action four: Discrimination and verbal abuse

There was an obvious overlap between item two and item four on the agenda, but the participants saw these as separate issues. Being verbally abused was a common experience. The participants shared their experiences in the PAR group. When Lee lived in her husband's village, her mother-in-law was openly cruel. Lee was verbally accused of passing on the infection to her husband (although it was very likely the reverse). Lee was very upset by this accusation and the pain lingers even now, which is why many years later she still felt she wanted to share this event with the PAR group.

Nancy spoke out too. Nancy described the abuse that she and her family had suffered from her neighbour for the last seven years. Her neighbour yelled at her grandchildren and saying 'your parents died of AIDS'. Not only was Nancy exasperated by this continual abuse, but the whole family had had to change the way they entered and left their house but also to avoid his bad language and harassment. In this PAR group, she felt safe to discuss her fears, which she claimed she has never been able to do before. Having her situation broadcast around the neighbourhood, she worried about what the other neighbours would say. Now that her grandsons were older and the neighbour invited violence, she was worried that they would hit him in response. Nancy raised this concern in the PAR group and she asked for other people's opinions (see Table 5).

All participants seriously discussed Nancy's concern. Lee said that it was an infringement of human rights that someone talked about you in this way. Having lived with HIV/AIDS for a while and attending the HIV/AIDS clinic at Khon Kaen Regional hospital had made her more aware of her rights and she was keen to share these with the PAR group. Noi and Tracy empathised with Nancy and advised her to seek help from the Village Head Person. They believed that the Village Head Person would help Nancy to communicate with her abusive neighbour. On the other hand, Grace and Mary encouraged Nancy to report the neighbour's abusive behaviour to police. Sue and Norris said they felt the same pain as Nancy; they told the PAR group that their neighbours refused to buy food from Norris's food shop. Norris reported that her food shop business had totally collapsed. Unfortunately, it was too late for the group to come to Norris rescue with ideas. So instead they focused on ways in which they could help Nancy.

Table 5: Action four: Discrimination and verbal abuse

Participants' aims	Possible Actions	Resources	Timeline
To minimise the verbal abuse from neighbours.	Discuss the possibility problem solving strategies with the group.	PAR group	Nancy felt supported by PAR group and was in the process of negotiation.
	Report to police (this action was not applicable for Nancy).	Policeman	
	Consult the Village Head Person.	Village Head Person	

Nancy took all the PAR group suggestions on board. In the second PAR group discussion she told the group that she had called her daughter who lives in another village. Her daughter suggested that she stay calm and think through each possible action. Nancy also talked with her son who is a monk in the village temple. Her son suggested that she talk with her abusive neighbour rather than report him to the police. Eventually Nancy decided to discuss her concern with the Village Head Person. The Village Head Person offered his help to be a witness with the plan to negotiate a peace settlement with her abusive neighbour.

Nancy arranged the appointment with the abusive neighbour, his parents and the Village Head Person. Nancy gently talked to him; she told him about her suffering. The neighbour felt guilty.

The Village Head Person suggested that Nancy and the abusive neighbour write an agreement to stop all abuse. If the agreement is broken Nancy has a right to report harassment to the police. The abusive behaviour stopped and Nancy reported to the last PAR group that a big stone had been removed from her heart.

Action five: Care of orphans when grandparents are ill or die

In this inquiry, the orphans are looked after by their biological grandparents and additional assistance has been provided by other relatives including two aunts. The grandparents are in their 60s and three older people have Type II Diabetes with complications, hypertension, cataracts or visual impairment. A few of the grandparents told the PAR group that they did not know how long they would be able to continue caring for their grandchild, or how long they would live. As discussed in chapter two, the average length of life for Thai people is 72 for women and 66 for men, so it was not strange that this group would talk about their morbidity and mortality. It was realistic that they would bring this concern into the open. Grandparents were unsure about their health status and living with a chronic illness and they talked about this for one entire PAR group session (see Table 6).

Grandparents shared their plans for their grandchildren. They seemed to really appreciate being able to talk about their situation in the PAR group. Sandy explained that she was the breadwinner of her family. Sometimes when she was sick and thinking that she was going to die, she was really concerned about how her family would survive without her. Nancy had just lost her husband and was worried about her grandchildren's welfare should something happen to her. Nancy had discussed with her monk son that if something should happen to her, he would care for Kenya and Golf. That would mean that both grandchildren would be cared for in the temple "Buch Rean Khean Aun"¹³ and take a Buddhist pathway in life.

Fortunately, her grandchildren are boys as this option would not be available to girls. Noi and Tracy are younger and healthier than the other grandparents; however, they worry about their granddaughter, Lula. Noi and Tracy have made a funeral plan and become a member of private

¹³ "Buch Rean Khean Aun" is a Thai traditional proverb meaning becoming a monk and having a specific education.

health insurance. They have also saved some money and placed this in their granddaughter's account. Grace who lives with Type II Diabetes explained that she depends on Mary to take care of Feat. Mary is already bringing up Feat as one of her own children. Mary has agreed to provide care and is willing to take this responsibility.

Sue told the PAR group that her health is worse than it has ever been. She has impaired vision in both eyes. Sue's children, John and Norris are committed to continue to care for Ron. Sue said she was reassured now that this plan to care for her grandchild has been agreed.

Table 6: Action five: Care of orphans when grandparents are ill or die

Participants' aims	Actions	Resources	Timeline
To plan long term care for orphans.	Discuss the possible strategies with the group and adopt some of these.	PAR group	Ongoing

It seemed that each family had developed a future plan for the care of orphans. Most were relying on the extended family to absorb this responsibility. Their solutions are context specific, depending on resources and commitment of other family members.

Sandy's family situation is precarious not only because of Sandy's health problem but also because Lee lives with HIV/AIDS. Lee knows that she has to look after herself. She regularly takes ARV medication. Lee also avoids opportunistic infections and is very aware that her immune system is compromised. The village funeral organisation will not allow Lee to be a member, so again she is disadvantaged living with HIV/AIDS. Nancy has great support from her son. If Nancy dies, her son who is the monk, will continue to look after his nephews. Nancy said she is lucky to have two grandsons because the boys can study as monks should she die soon. Noi and Tracy have a plan for their granddaughter. Noi said it is good to have a funeral plan. Noi openly admitted that he used to drink too much alcohol, and that since he stopped drinking, their family has more money to save for Lula.

Action six: Services provided by the Primary Health Care Unit (PCU)

Noi placed this item on the agenda. As the village health volunteer, he was concerned about the prevention and health promotion program offered by the PCU, particularly prevention of HIV infection. He believed that it had been a strong program once but that it had deteriorated. All

participants agreed with Noi's concern. Lee in particular agreed with Noi. In her experience she had noticed that community health education had gradually decreased.

Nancy wanted to talk about the free condom program which had been available in the village until recently. Asking the community nurses, she wanted to know if the free condom program would be reinstituted. Nancy claimed that she teaches her two grandsons about the use of condoms in an attempt to ensure safe sex but she had noted that they were expensive. Noi supported Nancy's comment, since he is a village health volunteer. Noi, as the volunteer health worker, always advises young people to use condoms and he said that he regretted that they were no longer freely available.

The community nurses explained that the supply of free condoms sourced from the Department of Health had ceased. It was a cost saving strategy but it had grave consequences. The community nurses said they were aware that the number of infections would increase now that the free condom program had ceased. They agreed with participants in the PAR group that the community education program needed to be restarted.

The community nurses stated the Pralab PCU would no longer be focusing on HIV/AIDS because the government policy direction had changed to people living with chronic conditions. The community health focus would instead be prioritising strategies for self-management by those living with a chronic illness such as Type II Diabetes, hypertension, coronary artery diseases and tuberculosis. They noted that there is no longer a strategic plan to prevent HIV/AIDS in the Pralab PCU.

Table 7: Action six: Services provided by the Primary Health Care Unit (PCU)

Participants' aims	Actions	Resources	Timeline
To increase health promotion programs, particularly HIV prevention.	Discuss revamping the education program.	PAR group	Ongoing negotiations with Pralab PCU and community leaders.
To reinstate the free condom program.	Discuss this concern with the Health Care Providers about services from the Pralab PCU and community leaders.	Pralab PCU staff	

The participants openly discussed this concern with the community nurses. This was one of the reasons the participants wanted to have community nurses in the PAR group, because they knew that they wanted some action on these issues and realised that they could not achieve this without bringing them to the attention of the community nurses.

The community nurses were very enthusiastic to bring about reform as suggested by the participants, but they also stated that they had to consult their colleagues in the PCU. They listened to all comments and then they agreed to take the participants' concerns back to the Pralab Health Care Provider Team.

In the second PAR group discussion the community nurses were able to respond to some of the participants' concerns about the ceased services of free condoms as discussed during the first PAR group. They explained that budget cuts had resulted in Khon Kaen Regional Hospital HIV/AIDS clinic (otherwise known as the continuing care centre) no longer being able to subsidise free condoms. Nevertheless, they noted that the Head Nurse, who is the Director of Pralab PCU, had agreed to report this issue to the Pralab local government in order to seek support. Furthermore, the Director of Pralab PCU agreed to include the HIV/AIDS prevention education in the 2010 Pralab PCU strategic plan (see Table 7).

Noi suggested, as a village health volunteer, he would provide support to help the education program roll out in the community, for example, the program to promote the safe practice on HIV/AIDS transmission and how to prevent HIV/AIDS for the villagers.

Action seven: Health promotion

This concern was placed on the agenda by the community nurses because in 2009 H1N1 or swine flu brought devastation to Asian countries including Thailand. People who live with HIV/AIDS are always immune compromised and the HINI risk added to the burden. Community nurses wanted to increase community awareness focusing on preventive strategies for people who are living with HIV/AIDS and their families.

There was an exchange of information in the PAR group about managing 'universal precautions'. Lee shared her experience about caring for Pete, although Pete has not been infected by HIV, she still needed to maintain caution in her family, especially after she had

tuberculosis in 2007. Lee, Sandy and Pete always use their own utensils to eat and use a separate serving spoon for transferring food from the centre of the table to their plate.

Lee told the PAR group that Pete has developed very good precautionary practice. Pete always takes his own spoon and bowl to school. Therefore, his friends are reassured that they will not be contaminated. Lee also shared her acquired skills regarding her way of practicing universal precaution e.g. use of plastic bags instead of gloves. Lee said that she has to be careful not to get too close to others who have a communicable disease, for example, influenza or diarrhoea. Lee also said that she does not let her family members touch her blood or secretions. She explained that her blood and excretions contain the HIV.

Likewise, Grace shared that she taught Feat not to let anyone touch his blood. If injured, Feat must cover his wound with a bandage. Family members reported that they had been educated by the nurses at the HIV/AIDS clinic at Khon Kaen Regional Hospital.

Table 8: Action seven: Health promotion

Participants' aims	Actions	Resources	Timeline
To improve the preventive practice including universal precautions.	Learn from each other about preventive practice.	Capacity building in the group.	Sustainability post inquiry to be followed through.
	Learn more about preventing opportunistic infection.		
	Work out the best way to stay informed about HIV/AIDS and its prevention.		

During the one to one interviews, I learned that some participants in this inquiry had expertise in universal precautions in the home. The PAR meeting seemed a good opportunity to acknowledge their experiences, so I encouraged participants to talk. Participants were enthusiastic to learn from others in the group. They heard about what to do in the home environment which is quite different to being in hospital even if the principles are the same. Participants grasped the significance of learning to live 'safely' when someone with HIV shares the house and they realised that everyday routine has to be changed. The traditional way of eating food together had to change. Participants were appreciative that they had learned more about 'universal precautions' when living at home (see Table 8).

Lee, Grace and Mary took pride in sharing their acquired skills, knowledge and experiences with the PAR group. I have described this group process as capacity building and I believe it is one of the benefits in doing PAR. People learn from each other and those who are able to share their experiences feel acknowledged and proud of their achievements. Their self-esteem was noticeably improved.

This was an opportunity for the community nurses to offer alternative preventive strategies and resources to the PAR group members. They reminded participants that the Pralab PCU provides disposable gloves and face masks if needed. Participants asked the community nurses to explain about swine flu which was a potential health problem in Thailand 2008-2009. The community nurses communicated specific information about H1N1 swine flu symptoms to the participants. Therefore, the participants understood more about this disease and they were able to self-monitor for symptoms.

Evaluation of the PAR process

In the PAR process 'Look, Think and Act', participants chose to act on seven separate items. 'Action' was the result of PAR group discussions. The process we followed was as follows: participants set the agenda, initiated the discussion and decided on the reform (actions) they wished to make. I facilitated the discussions during the PAR group and assisted participants in teasing out the main issues they wanted to address. Group norms were followed by all participants in the PAR group discussion. None of the participants dropped out from the PAR group discussion process. All participants were given a small honorarium in appreciation of their time and all travelling related expenses were reimbursed from researches for this inquiry.

There were seven agenda items which all participants agreed to bring into the PAR group discussion. All participants received a summary statement of the previous meeting before we started the next session. There was ongoing validation of the research process. I asked them to talk about their experiences in the group and this constitutes the summative evaluation of the process.

They revealed that they had not been involved in this style of research. At the beginning they did not understand why I spent such a long time talking with them in the one to one interviews with the family members. But they acknowledged that it had felt very good to share their stories

because no one had really listened to them before. They said that they felt validated by the storytelling approach.

Being in a PAR group and not being led by one person was new to participants. Once they had grasped that it was their voices I wanted to hear, they could not stop talking. They were proud to participate in this inquiry because they were not passively receiving suggestions but they could actively contribute in the PAR group. Actions were suggested by the participants. The participants appreciated being in this learning process with others. What they had learned from others was invaluable.

The participants themselves confirmed my perceptions about participating in the group. They commented on how helpful it had been and said that through this participation they had learned to share and listen to other participants' opinions, something they had not experienced before. They also commented that they had learned to listen to others in the group and had the opportunity to hear other group participants' opinions.

Participants commented that by working together to share their experiences, they were able to address some of the concerns in their lives. They claimed that they had become more confident. Empowerment of participants, consciousness raised amongst them about concerns they faced and increased confidence amongst them were the key benefits participants had gained from the group process. I will bring these 'findings' together in the discussion in chapter eight. Participants stated that their expectations were met in the group. They said that they could continue working as a group when I was no longer there to meet with them. In terms of sustainability, participants have become a social network for one another.

I would have preferred to meet with this group on more than four occasions but, unfortunately, my time in the field was constrained by factors beyond my control. Nonetheless I was aware that after the four meetings, the participants had gained confidence and appeared quite content to arrange further groups themselves if they wished. By this time, they had established a network between the group members, and had become more confident communicating with each other. Because of this, I was more confident about the sustainability of the group.

Conclusion

Participatory Action Research used in this inquiry was intended to assist people to extend their understanding of their situation so that they could continue to resolve issues confronting them. This inquiry also achieved the goal of working alongside participants, collaboratively planning toward achievable goals and participants felt empowered to act.

In the chapter to follow, I will continue the discussion about the actions suggested by participants and review these to answer the research question on what can be done to assist families whose lives have been affected by HIV/AIDS.

Chapter Eight

Discussion

Introduction

In this chapter I will continue to explore what can be done to assist Thai families whose lives have been affected by HIV and/or AIDS. I will build on previous chapters, particularly the fourteen constructs resulting from one to one interview to describe the experiences of nine adult participants as they dealt with the impact of HIV/AIDS in their families. The most striking feature of participants' response to incorporating the consequences of living with HIV in their lives was that they talked about their experiences as a family. The family was reconfigured when one of its members became infected with HIV, and the orphan joined this 'new' family. I propose that each of these five families acted as a self-contained dynamic unit who came together as a newly constituted family through necessity but showed enormous resilience and unconditional love for its orphans. Theorizing about families' experiences will be attempted as I draw on concepts of Thai culture, transition theories and further develop the notion of stigma as this influenced the lives of all participants. I will then reflect on the methodology: storytelling and the PAR groups in order to explicate transition. It was clear that being part of this research process further enhanced participants' ability to 'move on' as evidenced by actions undertaken. It was obvious that participants raised each other's consciousness about living with HIV in the family, and this process was viewed as empowering. Finally, I will talk about ways in which we, as health care professionals, could assist families that are similar to the five families in this inquiry. Given that the 1990s AIDS epidemic has slowed down, I will focus on the next Thai group being infected by HIV, adolescents, and tease out preventive strategies 'we' may be able to use to curb these infections.

Seven constructs: Crisis in the lives of participants

Arising from the one to one interviews with nine participants, fourteen (14) main constructs were identified. Reflecting on their stories I observed that constructs 1-7 were about the dramatic events that happened a decade ago for four families and two years ago for Sandy's family. Yet, the experiences were recalled as if they had happened yesterday. Participants talked about the shock surrounding the diagnoses of HIV/AIDS. They explained about upheavals experienced with changing house and moving back 'home'. Grandparents described complex nursing care they had to learn to give, including understanding the principles of universal precautions, so that they could provide care and comfort to five extremely ill daughters. Three daughters died of AIDS and their parents relived their sorrow during the interviews. 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 how they managed major interruptions in their daily routines. There was no preparation for these crisis events. Moreover, there was no choice but to reconvene as a 'new' family.

Learning to live in the shadow of HIV/AIDS

Once the dramatic events had been recounted, the conversations in the one to one interviews changed as participants talked about learning to live in the shadow of HIV/AIDS. Learning to live with the spectre of HIV/AIDS in their midst are given as constructs eight to fourteen (8-14). Major changes were made in their lives. Some participants had financial difficulties and I report that this is an ongoing problem in a country where there are few social security or welfare benefits available when families are economically disadvantaged by HIV/AIDS.

In listening to their accounts, I gained a better understanding of small-village family life. There is little privacy in a village. When a daughter and her children return 'home' unannounced, villagers were immediately suspicious. The messages of the Grim Reaper were still in the back of people's minds: the 1990s Thai AIDS epidemic had not been forgotten. Living in a close village community, it was reported that rumours disturbed families and judgments were made about 'bad' behaviours associated with sexual mores. Being discriminated against was brought to my attention in all stories. Disclosure, whether an orphan should be told about their parents or their own health status, was an unresolved current problem. The impact of discrimination and problems conveyed by participants surrounding stigma deserve closer attention and I will contribute to the debates surrounding stigma later in this chapter.

The services of Khon Kaen Regional Hospital Comprehensive Continuum of Care Centre were used by all families. This is the central clinic where all those who were diagnosed with HIV attended. It may be possible to explore ways in which these services can be improved, given the stories told by participants. In the conclusion chapter (chapter 9), I will make some recommendation about improving service delivery.

Although I was not able to interview the children as I did not have approval from the various ethics committees to involve orphans, nevertheless, all participants talked about them. I met all orphans informally as they accompanied participants to the interview or PAR groups in Pralab PCU. Often they played while waiting for participants to reappear from behind closed doors. I will talk about the unconditional love grandparents felt for these orphans.

When the orphan joined a ‘new’ family

I listened to the participant’s description of the most significant events in their journey of caring for a loved one with HIV/AIDS and becoming responsible for their orphan children (constructs 1-7). The most serious crisis was experienced when the person with HIV/AIDS came ‘home’. I refer to this time as the weeks or months that the orphan joined the ‘new’ family. This is the opportunity to assist people with coming to terms with the devastation in their lives. Perhaps some of this support was received at that time from staff at the HIV/AIDS clinic at Khon Kaen Regional Hospital, but it is clear that more assistance is needed at this crucial time.

In a trajectory lasting many years, the peak crisis time for five families happened within two months of the orphan joining the ‘new’ family. I recognise that I can talk about prevention of this crisis in the first place, but here I can show that the peak crisis occurs when the orphan joins the ‘new’ family. This narrow time slot is the most opportune time for additional health care delivery.

I was curious to check current literature to see whether or not a newly constituted family had similar challenges to those experienced in this inquiry. I read Kou & Operario’s (2009) work, and they commented that most research studies assessed the capacity of the extended family to care for orphans, but few examined the caregiving experience in depth. Thampanichawat’s (2008) study was an exception. This author used a grounded theory approach interviewing 27 participants who were predominantly women e.g. grandmothers, mothers and aunts providing care for children infected by HIV. Interviewees’ experiences were heavy with emotions, they described being anxious and were afraid of losing another member of the family. Most of the family members continued to care for the orphan because they loved the child but they also felt a sense of responsibility and duty. The point being made here is that this exploratory study identified the challenges, but was impotent to help these participants make changes in their lives. In contrast, Nyasani et al., (2009) South African study explored options for improving the financial and emotional support for families in which the main caregiver was a woman. In other

words, these authors want action and they also suggest further research is required with men, given that so few take up the caregiving role.

Families

What is a family? For the purposes of this inquiry my definition is that a family is a social group sharing common ancestry and in this situation they are connected biologically. The 'new' family typically consisted of one or two grandparents and grandchildren, occasionally incorporating a parent who was still alive but living with HIV/AIDS. I see this new family as having a long-term commitment to one another. Families usually reside in the same dwelling place (although Mary shares the same compound not the actual dwelling). These grandchildren are all biological offspring. From the perspective of orphans, the reconfigured family served to locate them socially. It is an old adage: 'it takes a village to raise a child' but in these situations villagers could not always be relied on to support orphans, as stigma associated with HIV meant interactions were limited. But in this inquiry, the family members supported each other.

My participants' stories show the impact HIV infection had on their everyday life: eating, drinking, bathing, working, walking and talking. Daily life continued as before but with additional hardships. There were changes in daily life, most of these affected grandmothers in particular. Standing, Musil and Warner (2007) write that grandmothers had mixed feelings about their situation as their household composition changed. These authors reported reduced personal freedom, having to learn to be flexible and accepting that strength to manage their changed lives was attributed to spirituality. These findings were similar to grandmothers Sandy, Nancy, Tracy, Grace and Sue as they adapted to changes in their lives. Although grandmothers talked about having a strong commitment to their grandchildren, they explain that many role changes have occurred. As Huang and Peng (2010) write, the caregiving role (grandparents) transition is a dynamic process of role adaptation. These authors suggest that moving on is promoted when the family has good support.

Some grandparents were still locked in anger. Nancy was still angry with her son-in-law for his 'immoral' conduct and supposedly infecting his wife. Although such anger was easily brought to the surface in conversation, Nancy would wrench her hands and her body language was taut as she talked about her son-in-law. Realising that strong emotions were easily brought to the fore, I was interested in the way families were able to move on with their lives, despite unresolved anger and their overall difficult situation. Most relationships were tested when the

family was first confronted by the diagnoses of HIV/AIDS. However, these relationships were reconciled over time.

It became evident that all my participants had made major changes in their lives. I make a distinction between change and transition: change is what happens to people whereas transition is what people actually experience (Bridges, Pratt, Corp, & OverDrive, 2008). I was interested in the way families were able to 'move on' with their lives in the shadow of HIV. I use the term 'moving on' for transitions families made in their lives and will further explicate these meanings in the section to follow.

I will bring to attention the resilience of these families as they withstood the onslaught of events and the changes they had to make in their lives in order to accommodate the impact of HIV/AIDS. Resilience comes from the Latin '*re-silere*', 'to spring back'. Grandparents battled with serious illness of their offspring, they lost children they loved, their grandchildren were at risk, all participants were the subjects of discrimination or feared stigma associated with HIV. Eventually, participants were able to confront adversity and find hope and meaning in life. In this inquiry, resilience was an interactive process occurring between individuals and their environment. On the whole, participants faced their new realities with dedication toward the family. Most made meaning of hardship instead of crying out in despair. On the creative side, they improvised solutions particularly once they met as a group. Ideas to improve their situation flourished. I believe that resilience is a complex interplay between biology, psychology and environment. I suspect that Thai culture and values profoundly affect a family's capacity for resilience. Despite difficult circumstances, families managed to 'move on', in their own way.

I suggest the best way forward is to look at the movement each family made over the last few years. When talking about: 'moving on', I mean it is "the inner process through which people come to terms with change, as they let go of the way things used to be and reorient themselves to the way things are now" Bridges (2003, p. 1) Families move on over time. In this inquiry, the way families reorient themselves indicating movement can be fast or slow. I suggest that some families have moved on faster than others. My idea is to track movement to answer why some families move on 'faster'. I accept that there is great diversity in each family. No family is alike: "all happy families resemble one another, but each unhappy family is unhappy in its own way" (Tolstoy, 1995, p. 1). But I argue that if we can understand why some families move on 'faster', we may be able to provide an improved response or health service at the most suitable time.

One of the most salient characteristics about these five families is that they worked as a team. Although they came together out of necessity, they pulled together. The most striking feature of participants' response to incorporating the consequences of living with HIV in their lives was that they talked about their experiences as a family. Even ten year old Pete helped his mother on days she was not feeling well. The fifteen year old Kenya wanted to protect his family from further discrimination by challenging his neighbour to fight. Grandfather Noi gave up drinking alcohol so that his/her 'new' family could thrive economically. Kenya was keen to contribute financially to the family. One of the interesting aspects of this 'new' or reconfigured family is that it emphasised its role as the primary economic unit. Sandy and Grace's families did not have their own land and relied on each member of the family to be able to contribute to basic survival: food and shelter. Once basic needs were satisfied, they focused on the orphan's wellbeing and his educational needs. Other families were more fortunate as they owned the ancestral land and they were able to sustain themselves as rice could be grown on their own land.

I explored what participants said about their motivation to move on since HIV interrupted their lives. Lee was motivated to continue living for her son. Nancy felt supported by her Buddhist beliefs. She said "I think this belief helped me cope with the grief and loss of my daughter and also to care for grandchildren". Noi and Tracy were driven by responsibility for their grandchildren. One of the most favourite topics of discussion was about the orphans themselves. Participants spoke about the five boys, Pete, Kenya, Golf, Feat and Ron and the one girl, Lula. Although they were concerned about their grandchildren's welfare, they were also proud. They appeared to show unconditional love for their grandchildren. This appeared to be the most important reason for wanting to move on. In the theoretical section to follow I will explore Thai cultural and family relationships as this may explain why grandparents selflessly absorbed grandchildren into their lives.

I suggest that one way to observe the way in which families have 'moved on' was to pay attention to what they said about the future. Concern about orphans and creating a future for them was a major observation. Lee made the preparation in that should she die that her mother takes care of Pete. Sandy agreed to take on the responsibility should Lee die. Sandy understands that people who have HIV/AIDS have low immunity and she said: "Lee is a high risk for an opportunistic infection ... I know that my daughter is likely to be sick again". In other words, Sandy is better prepared. Noi and Tracy have planned how to manage Lula's financial future. Tracy felt satisfied with her life at the moment. Grandmother Sue is happy that Ron will be

financially supported by her son John if she dies. Norris reassured her mother that she would also continue to care for Ron. All future discussions were about who will care for the grandchild should things change again, and reassurance was required that someone will be around to care for orphans. As discussed, most grandparents are already in their 60s, and while this is not 'old', diabetes had taken its toll. It is not surprising that grandparents want a secure future for their grandchildren.

Theorizing about families and transition

I make a theoretical contribution to the theories of transition or how people have accommodated taking the consequences of HIV/AIDS into their family lives and being able to move on. I believe that this inquiry makes a contribution to transition theory. It is important to understand transition as it is one of the main theoretical constructs in nursing and it is a key to understanding the transition in families who provide ongoing care for orphans.

I was interested in the theories of transition as it was obvious that families in this inquiry have 'moved on'. I wanted to explore the way these families were able to incorporate the consequences of HIV in their lives and I sought clarification from the literature. I turned my attention to definitions of transition. Nursing has held for a long time that transition is a central concept to its discipline. A common definition of transition is:

A passage from one life phase, condition, or status to another...transition refers to both the process and the outcome of complex person-environment interactions. It may involve more than one person and is embedded in the context and the situation. Defining characteristics of transition include process, disconnectedness perception and patterns and response (Chick & Meleis, 1986, pp. 239, 240).

Appealing definitions were from Meleis and Kralik. A definition of transition that speaks to my inquiry is from Meleis (2010, p. 72) who said:

Transition is the way people respond to change over time. People undergo transition when they need to adapt to new situations or circumstances in order to bring the change event into their lives.

Over the years, Meleis definitions of transition have shifted. The definition selected above is my choice as it speaks to this inquiry. Moreover, theories of transition are useful in practice

(Davies, 2005) as they have the potential to identify possible interventions that can be implemented at the time most suitable to families. It is important that nurses understand that transitions are happening every day in the lives of their clients/patients and being aware of the concepts surrounding transition may improve practice (Rasmussen, Dunning, Cox, & O'Connell, 2008; Rowe & Jones, 2008). Kaiser et al., (2009) claim that understanding the experiences of women's health as they learn to mother can be informed by transition theories. In other words, once I am able to identify the way in which transitions were made in the five families, I am better able to communicate these findings to improve practice. Improving our understanding of transition means that we would be more able to facilitate movement in the lives of families, if this is what they require or want. Transition is not compulsory; rather people select which aspects of their lives may be adapted and we, as health care professionals may be able to assist.

Although the definition has been revised several times Kralik, Paterson and Coates (2010, p. 18) said that: "Transition is the movement people make through a disruptive life event so that they can continue to live with coherent and continuing sense of self". In addition Kralik, Visentin and Van Loon (2006) write that meanings of transition are diverse depending on the context. Although there are many definitions spreading across disciplines, one characteristic most share is that transition involves people's responses to events in their life that require them to change. These definitions refer to the individual and my unit of interest is the family. Nevertheless all definitions are about change. However, I agree with Bridges (2003) that transition is not the same as change. When talking about: 'moving on' I mean it is "the inner process through which people come to terms with change, as they let go of the way things used to be and reorient themselves to the way things are now" (Bridges.W, 2003, p. 1). This definition is appealing to me as I can apply it in this inquiry. I can see that internal processes have taken place and mostly participants have been able to let go of their way of living prior to HIV infection and focus on the tasks awaiting them. I will argue that there are obstacles over which they have no control e.g. their financial situation. However, if we as health care professionals can identify those obstacles we can 'fight', such as stigma, we may be able to improve outcomes.

Change and difference are essential properties of transition. Meleis (2010, p. 57) writes:

Although similar, these properties are not interchangeable, nor are they synonymous with transition. All transition involves change, whereas not all change is related to transition. Transitions are both the result of change and result in change.

I agree with Meleis (2010, p. 57) who writes that ‘transitions are complex and multi-dimensional’. Not all the criteria for transition given by Meleis are applicable for this inquiry as they refer to individuals rather than family groups making adjustments, but one criterion that is useful to understand movement of families refers to “the level of engagement” in the process. Engagement is defined as the degree to which a person demonstrated involvement in the process inherent in the transition. Certainly, when participants were involved in storytelling and the PAR process, their involvement increased awareness and confidence generated was instrumental to moving on, evidenced by the number of actions the group initiated.

It is another adage that ‘time heals’. Time is required to adjust and this is another important feature of transition if adaption is to take place. Many of the participants have lived under the spectre of HIV/AIDS for many years. I am confident to state that time passing has helped the process of moving on. Bridges (1991) concurs that transitions are characterised by flow and movement over the time. Transition, when viewed as a time span from the first sign of HIV/AIDS in the lives of participants, can be seen as a critical point or a crisis period when the orphan first joined the new family, followed by a period of instability, confusion and distress to an eventual ending with a new beginning period of stability. This new period of stability appears to be achieved by most families. Stability is fragile, particularly when it depends on the wellbeing and health of grandparents.

I asked how families move on with their lives in the wake of HIV. I read around the topic particular the work of McCabe & Mackenzie (2009) and understood that movement was rarely linear. Rather it is a process of two steps forward and one backwards. I understood that ‘moving on’ does not happen to everyone and it is certainly not mandatory (Minkler & Wallerstein, 2011). It may be a matter of choice or perhaps movement is retarded if there are obstacles placed in the way. I understand that it may be a person’s choice if a person does not want to ‘move on’. I was reminded of Parsons and Shils’s (1951) work on the sick role. If a person grows attached to the label of illness and his/her identity is validated as a ‘sick’ person, there may be a motivation to change. In applying this idea of the sick role to my inquiry, Lee had nothing to gain by adhering to the sick role, rather she wanted to continue as a mother to Pete and assist with the family income for survival. There was one example in the literature where an Indigenous group of people did not want to acknowledge their diabetes (Koch, Mann, Kralik, & van Loon, 2005). Authors report that Port Lincoln Indigenous Australians continued to eat and drink what they desired without paying attention to their diet or exercise. When they met together as a PAR storytelling group, they realised that fear had prevented them from making

changes in their lives. Storytelling helped them to understand they all experienced fear of blindness, losing a limb or impending mortality. Once they acknowledged their fear they were able to change their lifestyle and their diabetes status improved. I believe that families in my inquiry wanted to move on and I can provide evidence to support this claim. Each of the five families closed in on itself and became an independent economic unit. However extended family, brothers and sisters that lived elsewhere, were often on standby to provide additional support.

Participants in this inquiry had change thrust upon them, but they were not pawns. One of the features is that learning occurs as people move on, and this is evidenced by a change in behaviour. I believe that families adjusted their way of living and changed their behaviours providing evidence of transition, but in so doing, grandparents possibly compromised their health. Sandy changed her work schedule when she needed more income; she needed to work extra hours as a labourer on a building site. Inquiring how grandparents self-managed their chronic illness was not the focus of the study, but I suspect their health was affected.

Thai people are moving to a modern and increasingly consumer- driven world. But village life continues as it has for centuries. Thai people still hold onto their strong cultural identity and superimpose it onto an economic and technologically led lifestyle. My participants were often confronted by deep-rooted customs and traditions. I'd like to explore the Thai cultural, religious and relational context where grandparents sacrifice their own lives for those of their kin. I believe family values and cultural beliefs play a big role in the way that grandchildren will learn to make sense of the world in which they live. I will expand on these ideas in the section to follow.

Buddhism and transition

Participants often referred to their Buddhist practices. Practices refer to spiritual beliefs, meditation, herbal medications and massage techniques (Kitsripisarn, Fongkaew, Chanprasit, & Rankin, 2010). I think that their spirituality and the practice of meditation helped them to make sense of their situation. Often, participants changed and corrected their life style through meditation. Researchers (McCabe & Mackenzie, 2009) have shown that practicing meditation regularly – and being more 'mindful', that is, focused on the present moment – has beneficial effects for a range of conditions. These include stress, anxiety, depression, poor sleep and

coping with chronic pain. It also has other health benefits like reduced inflammation, improved immunity and lower blood pressure (Horowitz, 2010).

Perceptions and meanings held by participants influence the conditions under which transitions occur. In this inquiry, I have uncovered the personal and environmental conditions that facilitate or progress toward achieving a healthy transition. Noi said: “I won’t worry about it because I can’t change it”. Being able to let go of things over which you have no control is good evidence that Noi was able to move on. Another expression used by many participants was ‘Tam Dee Dai Dee’ meaning what goes around comes around. This refers to the Buddhist cycle of life and encourages people to understand that suffering and death is inevitable (Ariyabuddhipongs, 2009). Although participants did not talk about suffering as part of life, I suspect that many Buddhist practices are internalised. I will therefore explain that the foundation of Buddhism is based on the Four Noble Truths: (1) suffering (*dukkha*) (2) cause of suffering (*samudaya*) (3) the end of suffering (*nirhodha*) and finally (4) the truth of the path that frees us from suffering (*magga*) (Gunaratne, 2009). Beneath the Truths are countless layers of teachings on the nature of existence, the self, life, and death. Nancy visits the temple every day and talks with her Monk son. She does not only believe in the teachings, but she is encouraged to explore them, understand them, and test them against her own experience. It is the *process* of exploring, understanding, testing and realising that is Buddhism. Sue admitted that she is supported by Buddhism; she visits the temple with offerings regularly. One of the reasons these families have been able to move on is precisely because they practice Buddhism. Understanding the cycle as a part of life is an enduring self-sustaining approach to leaving the past behind, tolerating the present and moving on to the future (Loue, Lane, Lloyd, & Loh, 2010).

As discussed above, my participants held Buddhist beliefs. Meditation and believing gave them the spiritual strength to ‘move on’. In other words, Buddhism was central in their lives, and I suggest, facilitates transitions. My understanding is that believing in the Buddhist Five Precepts (Sila) is reassuring. Because my Buddhism is so much who I am, it is difficult to describe its concepts and philosophy in Thai, let alone in English, my second language. I searched the literature for an adequate explanation of Buddhism:

The moral precepts (sila) overlap to some extent with the Ten Commandments (don't lie, steal, or kill), and embody the Golden Rule (do unto others what you would have others do unto you). Translating sila as morality might create confusion; ethics might be a better choice for this term. The basis for practice and the path to awakening are these ethical precepts. They are done not out of some sense of moral purity but out of

necessity. At their core, the Buddha's teachings are a prescription for ethical conduct in the world. By cultivating wisdom you minimise harm to yourself and the people and planet around you. By embracing meditation, you find a path to find peace in the midst of everyday chaos and a world riddled with uncertainty. Ethical conduct is a foundation for meditation and wisdom, but this is not morality for the sake of morality or social control. You act in the ways because you know that it leads to greater happiness. The Five Precepts are:

- 1. Do not destroy life*
- 2. Do not steal*
- 3. Do not commit sexual misconduct*
- 4. Do not lie*
- 5. Do not become intoxicated*

The Five Precepts (silas), the Buddha also cautioned against another five unwholesome actions, making for a list of ten. This action list of ten things to avoid can be grouped into things not to do with your body (don't kill, steal, harm with sexuality), speech (don't lie, don't be harsh with words, don't gossip, and don't engage in frivolous speech), and mind (don't get lost in desire, don't get lost in hatred, don't get lost in wrong resolve). (Guruge, 2010, p. 89).

A PhD study completed by Balhip (2010), supports my contention that Buddhism provides an important spiritual guide to living with HIV/AIDS. Balhip's grounded theory inquiry sought understanding of the meaning of spirituality and of the process of spiritual development in Thai people living with HIV/AIDS. Some people in her study had made a transition which is described as adjusting their lives to the situation and were able to live with peace and harmony. Her thesis is that achieving harmony of mind comprises two sub-categories: struggling to survive and living life. Categories are further divided into 'encountering distress' or *tukjai* and overcoming distress or *longjai*, and accomplishing harmony in oneself and discovering an ultimate meaning in life. She writes that:

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) (Balhip, 2010, p. 2).

Grandparents in this inquiry often talked about *tamjai* which is similar to *kwarmsa-ngobjai* or in English, 'letting go'. Bridges (2003) talks about being able to let go as part of transition, I repeat he said : "the inner process through which people come to terms with change, as they let go of the way things used to be and reorient themselves to the way things are now". Being able to let go may be one way that my participants were able to move on. Moreover, Chalermnan et al., (2009) support this assertion. Aiming to develop a model on the way in which Buddhist practices could help people with HIV/AIDS, they were successful in showing quality of life had improved when participants received this specific care (Loue et al., 2010).

Obstacles preventing transition

The crisis or peak event, that is, when the orphan joined the 'new' family, presented as an extremely difficult situation. New families had many changes to make in their lives. As argued earlier, change is not synonymous with transition. In this following section I will discuss the obstacles which may have prevented families from moving forward. If we can understand these obstacles we may be able to assist, thus answering my research question. Obstacles identified include: Grim Reaper fear messages from 1990s; shock experienced when HIV/AIDS first disrupts the family; hesitations about disclosure of HIV/AIDS status, stigma, rumours, discrimination and financial hardship (De Moor, 2010). HIV/AIDS has a major socio-economic impact Mhalu (2006), and I argue slows down the ability for families to 'move on'.

The Grim Reaper fear messages from the 1990s

In the third decade of the HIV epidemic stigmatisation remains a core feature of the person's experience living with this disease (Fair & Ginsburg, 2010). This may be a result of the negative messages delivered many years ago, and many people can still recall these. When the HIV/AIDS epidemic was in full flight, the Thai government launched a huge media campaign against HIV/AIDS with warning messages aired regularly and repeatedly on television as part of the national strategy to minimise transmission of HIV (Bowtell, 2007). These Grim Reaper messages were frightening, and defined characteristics of people who were identified as threatening agents of infection (De Moor, 2010). Prostitutes and drug users were portrayed (Rovin et al., 2008). It seemed that these messages were pervasive even today.

Sandy recalled this propaganda and said that HIV/AIDS was the '*Sum Het*' disease. She still believed that HIV was spread through unprotected sex. In addition, in the 1990s, when people

returned 'home', such behaviour was suspect. Villagers immediately thought that the person had contracted HIV. In the 1990s, many people with HIV left the big cities and returned to their villages to die. Participants told me that their families were the subject of village gossip when Lee, Katie, Lily and July arrived back 'home' unexpectedly. Village gossip led to rumour and most likely stigmatizing those returning 'home'. Good information about HIV/AIDS was not available and myths surrounded this type of infection, which made people who might have this infection the subject of rumours and discrimination. Living in a close village community meant one's status was at risk if HIV positive status was revealed. Interviewees talked about rumours that disturbed their families, and that judgments were made about 'bad' behaviours associated with sexual mores. The legacies of the Grim Reaper campaign in the 1990s are evident today. This assertion is confirmed by Scambler (2009) who claims that stigma has a long ancestry. Further, it is suggested by Reidpath et al., (2005) that health care providers may discriminate against their clients when their HIV seropositive status becomes known to them and this is another legacy of earlier fear messages. Stigma is alive and well today as numerous authors point out (Ishikawa et al., 2011; Jongsthapongpanth & Bagchi-Sen, 2009; 2011). As discussed, one of my strong interests is the way that stigma associated with HIV/AIDS continues to batter families and my desire to push toward the eradication of stigma and aversion toward people living with HIV/AIDS is one of my driving motives.

Shock

I argue that participants were not able to move on, or leave their troubles behind them because this peak crisis situation identified earlier in this chapter was too 'shocking'. At family level, when daughters, Lee, Katie, Lily and July returned 'home', their sudden unplanned appearance in the family home alerted parents. At that stage they did not know what was wrong. In these situations there were few options for those with HIV, they had nowhere else to go. Returning 'home' for support and help is not unusual (Knodel & Saengtienchai, 2005). Moreover, support was given generously. Vithayachockitikhun (2006) revealed that Thai families play a major role in support of their kin with HIV/AIDS. Parents were in demand to care for their daughters (Tshililo & Davhana Maselesele, 2009). Sandy, Nancy, Tracy and Sue vividly recalled the moment that their daughters became critically ill. They had to learn to provide complex care. Knodel and Saengtienchai (2005) highlighted that older Thai parents predictably play a central role in caring for and supporting their adult offspring when they are critical ill. The shock experienced when the daughters and grandchildren appeared on the doorstep was shared by grandparents. A little later when it emerged that HIV was the reason for their sudden

appearance, Sandy said she felt her heart break. Nancy thought it was the end of the world as she understood it. Noi and Tracy were upset. They had heard the rumours about Lily's husband but had resisted believing these. Grace was deeply shocked because she was unprepared to care for Feat, he was a sick baby. Sue's fear about July having HIV/AIDS was realised. Participants, as demonstrated in other studies, felt sadness, pain, anger, depression and frustration (Tshililo & Davhana Maselesele, 2009).

Grandmothers

Heymann et al., (2007) reported that 90 percent of the 15 million children orphaned by HIV/AIDS are in the care of grandparents. So it is not surprising that the six orphans in this inquiry are being cared for in a newly reconstructed family with a grandparent at the helm. Five grandmothers were involved in the care of grandchildren; three lived with Type II Diabetes and were attempting to self-manage this condition in these difficult circumstances. No doubt, managing diabetes alongside all the other new activities associated with organising a new family would be stressful. Grandmothers; Sandy, Nancy, Tracy, Grace and Sue felt increased responsibility when the orphan joined the 'new' family. However, a study by Zhao et al., 2010 show that children under the care of grandmothers are better adjusted psychologically than those in orphanages. These findings are confirmed by Hong et al., (2011), who write that orphans cared for in families have the best outcomes in terms of psychosocial well-being. The authors compared this group of children with those in orphanages. As Mudavanhu et al., (2008) report, grandmothers in particular felt the weight of additional responsibilities as they took the major role in caring for those who were sick and dying and orphans. Their study showed that grandmothers found it difficult to resolve the grief of losing their children while engaging in full time grand-parenting in a stigmatizing society. Thampanichawat (2008) concur that grandparents had to deal with the stigma of HIV/AIDS while providing care for orphans. These women had high anxiety, feared loss of their children, bore much of the burden of care, and were in financial difficulties. Schatz (2007) describes rural households in South Africa comprising grandmothers and orphans. Grandmothers face financial, physical and emotional burdens related to their sick or dying children and care for grandchildren who are left behind. This author envisages that, in the future, there will be increased burdens for grandmothers as the HIV/AIDS epidemic takes its toll in Africa. As more prime-aged adults live with these infections, the obligations of grandparents are likely to increase. Although Thailand's epidemic may be declared as less dramatic, in terms of this inquiry, grandmothers still carry additional

stresses. As a result, I suggest that transitions grandmothers are able to make slow down in the light of increased expectations on their roles.

Financial difficulties

Financial security is not something Thai families can take for granted; there are no social welfare or security systems. Participants had difficulties in meeting financial problems associated with caring for the 'new' family. Tshililo & Davhana Maselesele (2009) write that financial problems may add to the shock and insult, increasing sadness, pain, anger, depression, and frustration, as grandparents care for their loved ones within the context of poverty. Grandparents' experiences were perceived as multidimensional; reflecting the physical, psychosocial and financial burden of caring for their daughters, the word burden is used by Vithayachockitikhun (2006, p. 125).

In addition to the emotional impact, there were dwelling problems. Grandparents provided living space for their daughters and their offspring. In the Thai context is not unusual for rural families to live in an extended family with at least three generations living in one house, or many houses within the same compound. But in this situation, the shift to the family home was sudden and there was no planning or preparation. In fact, it was lack of preparation for crisis events that were to unfold that was one of the main obstacles.

Financial hardships were one of the agenda items in the PAR group. Reduced income was a common problem for families who provide care for their offspring living with HIV/AIDS, an effect which has been observed in the literature (Heymann & Kidman, 2009; Knodel & IM-em, 2003). When daughters die, the 'new' family loses the main source of income (Knodel & Center, 2006). Grandparents fill the economic gap and provide additional income to support the family.

Most grandparents were at pensionable age (except there are few social security pensions in Thailand) and they expected to slow down their working lives. Instead, they had to increase the hours spent earning money so that their new family's financial obligations could be met. Sandy and Grace's families lived in poverty. These families did not have land of their own. Land was a distinguishing feature about how well a family was able to absorb the additional costs. Rural workers earn less than 100 Baht (less than three dollars per day). Sandy was prepared to work in

four part-time jobs, evening weekend or night, in order to make ends meet. It is hard to imagine how these families can move on, given their dire circumstances, but they did.

Stigma

There is wide consensus that stigma associated with HIV/AIDS compromises the quality of life of people. Fair and Ginsberg (2010, p. 77), in a study based on interview data from 44 South Africans, write that “the level of felt and anticipated stigma is intense and affects all dimensions of living with HIV/AIDS, particularly disclosure and treatment”. Being discriminated against as a child was hard for grandparents. Grace felt sad that Feat had few friends. “Villagers refuse to let their children play with him so he is continually rejected” Mary said. Sue confided that Ron had not been accepted by his peers. Ron’s HIV status was checked before he was allowed at school. Fortunately, he was HIV negative. But still children are not allowed to play with him at school. There is still a lot of ignorance about how HIV is ‘caught’ and misinformation is perpetuated in the village and the schools.

Stigma is compounded when the woman living with HIV is no longer married. Liamputtong et al., (2009) pointed out that Thai women living with HIV/AIDS still experience stigma and discrimination in their everyday life. This finding is supported by the work of Neely-Smith (2003), who said that women are further oppressed in a patriarchal society. When daughters found out they had contracted HIV from their husband, they returned ‘home’ and sought help from their biological mothers. Although still married at the time, Lee, Katie, Lily and July returned home without their partners because they thought they would die. At that stage, their parents did not know the reason their daughters were coming ‘home’. Katie and July died but Lee and Lily recovered and are still alive. Their recovery was due to ARV treatment and, of course, the good nursing care they received from their parents. Unfortunately, Lee’s and Lily’s relationships with their husbands were irrevocably broken. As single women they were further stigmatized in the Thai village. Divorce and separation are not acceptable in traditional village society. These women had fewer choices regarding their future.

In these small villages, living with HIV associated stigma was a common experience. Interviewees talked about rumours that disturbed their families, and that judgments were made about ‘bad’ behaviours associated with sexual mores. Public face was very important in the village and its loss was perceived as a disaster for grandparents. Tracy was angry with Lily for bringing public disgrace on the family. “We have to “*Tam Jai*” her poor behaviour. I know I

would be ashamed if Lily's HIV/AIDS status was known in public". It was not surprising that families were keen to save face. Once the members of a small community discover the HIV status it is likely to generate negative social response for families (Gonzalez, Miller, Solomon, Bunn, & Cassidy, 2009).

Discrimination was a topic brought to my attention in all stories: in fact it was the most dominant construct. Grace and Mary still wondered when they should tell Feat. More importantly Grace and Mary always questioned about how to tell and approach him.

One of the obstacles to moving on is the constant turmoil about disclosure. Disclosure, whether or not to tell others about HIV in the family or tell the orphans themselves, was one of the most worrying aspects to consider by the adults in the five families. Participants were preoccupied with this subject. Social context plays a significant role in personal decision making. Greeff et al., (2008) write that most people with HIV have disclosed their status to someone, often with mixed responses. Lee openly disclosed her HIV status in her village. Lee said: "I just want to break the silence; I did not have much to lose" Lee disclosed her HIV status to everyone. Decisions about disclosure appeared to be a stressor for people living with HIV (Rodkjaer, Sodemann, Ostergaard, & Lomborg, 2011). These Danish authors researched alongside 16 participants living with HIV and found there were three main disclosure strategies. Lee had chosen the first, to openly disclose. The second strategy was restrictive disclosure and I observe Feat's family to be adherent to this decision as they told school teachers. The third disclosure strategy was to tell no one (being closed) and this could refer to Noi and Tracy. They certainly believed that no one should know and they were fearful about detection. These grandparents were unsure about the best way to tell Lula about her mother's HIV status but they did not want her to know yet. The stress associated with choosing the most desirable strategy depended on the circumstances, but Rodkjaer et al, (2011) claim that all three positions can be evenly stressful. "Disclosure is a sensitive subject requiring careful thought" (Vreeman et al., 2010) and people need to be aware of the consequences. It is a complex question when and how to tell orphans. Oberdorfer et al., (2006) write about six year old Thai children receiving ARV therapy. The most common reason for non-disclosure was the fear that telling them might have negative psychological consequences. Feat is only nine years old, however he takes ARV daily. He questions his grandmother: 'why do I have to take this medicine every day'. Grace and Mary have not been able to answer him but it bothers them. Constant preoccupation with disclosure possibly retards families to move on.

Reflections on methodology

For the outcomes of the research to have credibility and for the findings to be meaningful to others, the research pathway needs to be transparent and available for scrutiny. The key credibility concepts are voice (the creation of a multi voiced text where stories are given in their entirety), involvement of participants (constant ongoing validation of stories and group proceedings) and transferability (a detailed description of the context so that a second researcher can make transfers across a second research context). A second researcher following my footsteps needs to be able to retrace my research decisions and process steps. For all three concepts to be achievable there needs to be a clear trail of evidence and I refer to the audit trail (appendix G). Technically there are four data sources: (1) storytelling, (2) PAR group data, (3) reflections and (4) conversations with supervisors about my learning process. I will attempt to show how this inquiry may be considered trustworthy.

Alongside my field supervisor, I practised the first interview with Lee. Although I had a list of questions and prompts ready, I knew that to really understand about their lives with HIV in their midst was to listen rather than talk. I asked ‘tell me your story...’ I said very little. In all cases, the person I was interviewing had never before openly discussed these sensitive matters. Each interview was in the Thai language and lasted 60-90 minutes. I transcribed the interview in Thai. This text was discussed by both of us (field supervisor and I) and I was asked to justify why I had transcribed verbatim. I argued that meanings and context may be lost if I did not adhere to my ‘credibility’ plan. This verbatim account was later translated into English. My English version did not flow very well so, in conversation with one of my Australian supervisors, I was asked to verbally retell the content of the interviews as I recalled them and together we rewrote the storylines in English. I suspect some meaning is lost in translation from Thai to English, but we strived for the emotional content to be conveyed as accurately as possible.

The interviewing process was both facilitated and constrained by the fact that as researcher I shared Thai culture and language. I was an insider, as I had grown up in the area and I understood that my Buddhist and traditional beliefs systems would be shared. I later understood that this might mean that I took for granted some of its precepts. However, their wisdom about ‘moving on’ guided by their beliefs was so palpable that I did not see it without outside prompting from supervisors. I then realised how much I had taken for granted about my beliefs and I had to reconsider how these might influence the way in which I researched.

In a study such as this one, where the researcher belongs to the same Thai culture as the people interviewed, I recorded my observations in a reflective journal. A major issue in the establishment of rigour is the notion of subjectivity. The difficulty is that subjectivity can both enable and disable. On the enabling side subjectivity allowed me to establish my research domain and that made me alert to traditional, cultural and Buddhist orientations held by my participants. Nevertheless, everything I learned as a researcher was rooted in my personal orientations and precisely because these are also my orientations, they could potentially make me blind. And while I might be aware of the potential to blindness, it could still blur my vision and make me selectively sensitive. I was in tune to the suffering of orphans and over attached to this topic prior to commencing this inquiry. I was incensed by the stigma thrust upon people living with HIV/AIDS and I had many hunches that my participants would be similarly stigmatized. Consequently, I had to monitor my own subjectivity particularly on these two aspects and feel I was only partially able to do this. I sensed that there were many Buddhist beliefs and practices, e.g. meditation, that were connected to the way participants were able to move on, but ,at the time , these beliefs were too close to my personal life for critical scrutiny. I realised I had to be continually alert to the way my interpretations were being coloured - I had to try to see what I was not seeing. I understood that overinvestment in the topic and selective perception was incompatible with the openness required as an exploratory learner. I wanted to open the doors and let the participant talk; to take their story wherever she/he wanted to go.

The topic area, HIV/AIDS, also served as a constraint during interviews but less so in the PAR group. As a 'sensitive topic' located in their private lives, stories were emotionally charged; most of my participants shed some tears during the interview. It is through stories that I obtained a sense of their lives changing. And it is through stories that I was able to obtain a sense of their lives through recent history (past and present); with this understanding they were able to perceive what is possible in the future. Storytelling itself has both therapeutic and untoward elements – being acknowledged was possibly therapeutic. Participants reflected on their own experiences and for the first time in their lives were able to express their feelings and 'relive' their experiences (fifty per cent of their stories were about the crisis period). I noticed that they reawakened their sadness. Participants expressed emotions that were anger, guilt, grief and shame - emotions that may well not have been resolved. Bereavement issues were bound up with the recent loss of a daughter. The stress associated with the interview process had the potential to compromise participants' comfort, so I was alert to discomfort and in my capacity as a nurse I was able to offer support.

Ethically, it would have been difficult to build relationships or achieve closure if I had interviewed just once. Instead, I met with interviewees several times and I was able to follow up how participants were feeling. At the conclusion of the one to one interviews, participants were able to join a group – in which I hoped relationships with other families would be sustained. I envisaged that participants might meet with each other as a support group once I had left the field. This hope was realised as these families are using the same Pralab PCU facility to talk with each other. Participants have greater awareness of HIV and wished to share their new learning outside their group in the wider community. The consciousness raising that took place in the group, even if I did not set out to increase their awareness, was a desirable outcome.

I have left an evidence trail. In this inquiry I have listened to the voices of families and have shared participants' stories in the translated version. I have created a multi-voiced text - nine stories have been given. As described earlier participants were given their stories for verification or qualification. In the group, participants set the agenda and drove the actions. Context has been described in great detail, in chapter two and further in chapters six and seven.

The research process and transition

Storytelling was a novel experience for research participants. This was the first time we have heard stories from those impacted by HIV in their lives. Stories enabled participants to link aspects of their experience through the dimension of time. Storytelling provided the opportunity for them to bring together much of what they had achieved to help themselves during the transition process of accommodating the unexpected situation of having to provide care for orphaned children of family members who have died from AIDS. It provided an opportunity to bring into focus their strengths that had enabled them to cope with their new circumstances and 'move on'. Discussion appeared to help them crystallise some of their most urgent unresolved problems and build their confidence to share these with others in a PAR group discussion; this was an important step in their transition from problem solving in isolation to problem solving within a group.

This inquiry allowed me to understand the sway of HIV/AIDS and what is going on in each of five families over time. This time span stretched over ten years for four families. Family one had two years of experience in dealing with changes in their life. While I understand storytelling is an arbitrary imposition of meaning on the flow of memory, I observed that some events were privileged. Participants talked about the crisis in their lives – most likely a two

month span of time where the major upheavals were experienced. When storytelling, these families had many years to think about the impact of HIV in their lives, yet they vividly recall when they received the HIV diagnosis and the immediate events following this. I considered the role of memory in storytelling and pondered about why participants have selected to talk about specific events in their lives. When given the opportunity, I believe people talk about things that matter to them. I was told about their lives in whichever way they wanted to express it and I think what they said was important. In terms of transition, I asked if time since the crisis made a difference. Sandy, Lee and Pete as a family unit are only now recovering from the crisis events, and Lee has episodes of being unwell and not being able to work, so the impact is ongoing.

Stories are indeterminate (imprecise). There is a degree of ambiguity and uncertainty in all stories. There are often unexplained gaps, inconsistencies and contradictions (very few), rather some events are repeated because they were particularly painful e.g. Nancy and Sue's daughters have died. Withholding aspects of their story was common; Noi withheld some of his story in the 'public' forum of the PAR group. But the actual storytelling is the performance of these texts and that is transformative in participants' lives. In my presence, people lived their stories; authenticity of experience is shared through the appearance of tears, change in their tone, visible trembling and deep sighs. Stories became transformative in their performance (Bruner, 1991).

In this inquiry, the Hawthorne effect is intended (Jones, 1992). I observed changes in people since HIV disrupted their lives. I have shown that participants have 'moved on'. When talking about: 'moving on' I reemphasise that I am referring to the inner process through which people come to terms with change. This is when they "let go of the way things used to be and reorient themselves to the way things are now" (Bridges, 2003). The act of storytelling enhanced transition. The point I make is that the actual process of storytelling facilitated transition. As participants talked, they tended to reflect about their situation. When we met again and resumed our conversations and I noticed that they had left the crisis tales behind, they had changed some of their attitudes or behaviours and were more content with their current situation. Transition had gathered speed. Of course there were ongoing problems about finance, stigma, indecision about disclosure of HIV status, living with a chronic illness but passivity surrounding these had reverted to actively seeking ways to address them. Orienting the way to view problems and address them was particularly evident in the PAR group.

Facilitating transition

I have talked about storytelling as a way to encourage moving on, but it is also important to show how movement is facilitated in the PAR group. In the PAR group, promoting the sense-making processes was the key to facilitate transition. Look, think, and act was a simple approach to assist people in working out what was happening in their life. Looking and thinking focussed on challenging participants' thinking and possibly facilitated a change in their behaviours and stimulated action.

To be invited to work alongside the researcher in every aspect of the study, including being given a voice and setting the agenda is very rare in Thailand. Most Thai people politely sit back and wait for others (those in power e.g. health care practitioners) to talk. It is also very unusual for a group to be 'given permission' to lead the conversations. You would expect that it takes time to understand this democratic process, but participants lost their reserve and almost immediately wanted to exchange ideas, experiences and opinions. They took over the sessions and provided peer support and together built on their existing strengths. The actual research process and my researcher-as-facilitator role, working *with* the participants sped up their transition. Being involved in a PAR group enhanced transition (look at all the actions that were stimulated as a result of being in the group) and built participants' confidence to use this participatory approach as an ongoing process to share and solve problems within a network of others with similar experiences. In this way, the research process not only promoted participants' 'moving on', most obvious and rapid in the year of my research study, but also provided participants with a sustainable, collaborative way of ongoing problem solving and capacity building after I left the field.

Given this transition, the response to my question what can be done to assist Thai families whose lives have been affected by HIV and/or AIDS, in a broad sense appears to be two fold: (1) for health professionals to engage in a supportive process of one to one discussion to enable people to share their concerns, situation and achievements and (2) for health professionals and others to be willing to work with community responsiveness and enhance capacity building. In the context of China, Renwick and colleagues (2011) demonstrated the benefit of working 'with' rather than 'on' as they found that engaging young people in their research ensured a 'bottom-up' approach to policy development. This also contributed to capacity building in the community.

Conclusion

In this chapter I have theorised about (1) Seven constructs that pointed out that there was a crisis in the lives of participants (2) Seven constructs that demonstrated that learning to live in the shadow of HIV/AIDS was possible. (3) When the orphan joined the 'new' family, a crisis situation enveloped all family members. (4) Families worked and lived alongside each other as a dynamic unit and I chose to talk about their transition as a unit. (5) Further theorizing about transition occurred and I was able to show that these families had achieved much to help themselves within individual family groups and moved on despite their hardships. (6) I made a particular contribution to transition literature by suggesting that Buddhist practice, mindfulness and 'moving on' were related. Once I had shown that people had moved on in their lives I asked whether we as health care providers could facilitate transition. Therefore it was important to identify the constraints to transition which I have called obstacles. Obstacles identified were: (1) the Grim Reaper fear messages from the 1990s. (2) Shock experienced around the time of diagnosis (3) Grandmothers and their important role in sustaining the family in the face of many challenges. (4) Financial difficulties experienced by participants (5) Stigma and its pervasive influence. In the following chapter I turn to the research question and explore the study's finding in the Thai context and make connections with the context literatures, MDG 6 and reform.

Chapter Nine

Conclusion

Introduction

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 with Thailand's Health Care system which is guided by the same principles underpinning the Alma-Ata Declaration. On paper there is congruence between Global, Thailand and local primary health care principles. The four principles of primary health care are social justice, equity, community participation (meaning working with clients/community) and responsiveness to needs, referring to having services designed to meet its population's identified needs. These principles resonate with PAR principles which guided this inquiry. Principles taken into my inquiry are: the democratic principles of social justice, social equity, freedom of speech and human rights in that they enable the facilitator and participants to work alongside each other in a cyclical reflective process. I wanted to research alongside families, find out what they wanted/needed, and listen to their voices so that health care providers could respond to their situation.

I came to this inquiry with strong feelings about the pervasiveness of stigma and the damage this has on families. I was also concerned about orphans. There were abundant literatures around stigma, orphans and caregivers, but none had woven these topics together to explore what was going on in families affected by HIV. I read the research literature about orphans, caregivers and their families and found that living under the spectre of HIV was not well understood. I wanted to hear what Thai families had to say about living with HIV in their midst. And I wanted to know how 'we' (health care providers) could respond. Hence my research question: What can be done to assist Thai families whose lives have been affected by HIV and/or AIDS?

Meeting the objectives

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 prioritised by families caring for orphaned children of family members to assist them in this changed situation.

Identifying and understanding how families accommodate a situation in which they are providing ongoing care for children of relatives who have died of HIV/AIDS was the first objective. I appraised cooperative research approaches and I gave my reason for selecting Koch and Kralik's (2006) PAR methodology for this inquiry. Although I recognised that there are many versions of PAR, the appeal of Koch and Kralik's methodology was the storytelling component which in my inquiry preceded PAR group activity. Storytelling allowed me to invite participants to talk about their experience and I could listen and learn how they accommodated this situation. I said 'tell me your story...'. In listening to their stories, it permitted me to follow the participants' daily lives and to understand the major changes they had to make in their lives. In this inquiry participants were given a voice.

I have described the story analysis process and rigour criteria in previous chapters. The storyline was given to the participants for discussion and I incorporated any changes. Nine people were interviewed: five grandmothers, one grandfather, two aunts and one mother living with HIV. Lee gave a first person account of being diagnosed with HIV/AIDS. She described the financial, physical and emotional impact HIV is having on her life. Five grandmothers and one grandfather talked about major upheavals in their lives when family members were diagnosed with HIV/AIDS and its subsequent consequences. Two siblings of people who had contracted HIV/AIDS, Mary and Norris, described the way in which they supported their mothers and with other extended family members managed to hold the family together financially and emotionally. Five boys, Pete, Kenya, Golf, Feat and Ron and one girl, Lula being cared for in families, are the offspring of women who have HIV/AIDS. Lula's mother is still alive but living elsewhere and, as mentioned above, I interviewed Pete's mother, Lee. Three mothers have died. I did not have ethical permission to talk with the grandchildren, but the nine people interviewed talked warmly about their six children/adolescents.

So how did families accommodate this situation? I have given their stories in their entirety albeit translated from Thai to English. Arising from the one to one interviews, fourteen (14) main constructs were identified. Reflecting on their stories 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 the shock surrounding the diagnoses of HIV/AIDS. They explained about upheavals experienced with changing house 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 died of AIDS. Parents relived their sorrow during the interviews. 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.

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 structures. In the village, rumours disturbed families; being discriminated 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 health status. All families used the services of Khon Kaen Regional Hospital. There were ethical reasons (they were underage to give informed consent) why I could not interview the orphans but all participants talked about their offspring. One of the desires coming from these participants was to initiate a preventive HIV program in their locality. As discussed in chapter two, the Thai family, particularly in rural villages, is considered to be the basic unit of society. And although it is common that extended families consisting of several generations live in one house, only one family was reconfigured in this way. Other families absorbed the orphans in their current abode and shared the living space.

Participatory Action Research groups

Participants came together in a PAR group; actions to improve their situation were undertaken. Four PAR group sessions were held in the Pralab PCU. Participants had requested that two community nurses from the Pralab PCU participate in the group because they believed that these nurses would be able to offer support and education. Most grandparents had built relationships with the community nurses in the last few years, not because of the orphans but these older people were managing a chronic illness and kept in regular contact with community health staff.

The process I followed was as follows: participants set the agenda, initiated the discussion and decided on the reform (actions) they wished to make. I facilitated the discussions during the PAR group and assisted participants in teasing out the main issues they wanted to address. Group norms were followed by all participants in the PAR group discussion. None of participants dropped out of the PAR group discussion process. All participants were given a small honorarium in appreciation of their time and all travelling related expenses were reimbursed from this inquiry.

There were seven agenda items which all participants agreed to discuss in the PAR group discussion. All participants received a summary statement of the previous meeting before we started the next session. There was ongoing validation of the research process. Whilst participants were reticent about sharing their private lives, they were motivated to meet with each other and to discuss ways to address their problems. These participants had managed to accommodate significant changes in their lives. Becoming a caregiver to their orphaned grandchildren meant that they were continually problem solving, in fact, they had addressed many of life's problems themselves. I believe they saw this meeting as an opportunity to share ways they had managed their lives and to drive the agenda to collectively solve some common problems. In terms of sustainability, group meetings were continued after I left the field.

Resultant action

Participants planned for action and, where feasible, acted on issues raised and prioritised by families caring for orphaned children of family members to assist them in this changed situation. In the PAR process 'Look, Think and Act', participants chose to act on seven separate items. 'Action' was the result of PAR group discussions. 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 grandparent(s) are ill or die (6) Services provided by Primary Care Unit (PCU) (7) Health promotion. Financial problems were discussed in the group and collaborative problem solving resulted in enabling participants to improve their financial status. All participants experienced the effects of rumours and gossip and there was a long conversation about stigma in the PAR group. This was an opportunity to share their fears and experiences. There was an obvious overlap between item two and item four on the agenda, but the participants saw these as separate issues. Being verbally abused was a common experience. The participants shared their experiences in the PAR group. Nancy said she felt safe to discuss her fears in this PAR group, which she claimed she has never been able

to do before. All participants seriously discussed Nancy's concern and shared their opinions and ways to resolve the problem. These suggestions were acted upon in the group. In Nancy's case, the abusive behaviour had stopped and she reported that a big stone had been removed from her heart. Discriminatory practices were challenged by the group. Access to social welfare payments was discussed and some solutions provided so that people could receive this payment.

As the village health volunteer, Noi was concerned about the prevention and health promotion program offered by the Pralab PCU, particularly prevention of HIV infection. He believed that it had been a strong program once but that it had deteriorated. All participants agreed. The participants openly discussed this concern with the community nurses. This was one of the reasons the participants wanted to have community nurses in the PAR group. The community nurses were very enthusiastic about bringing about reform suggested by the participants. A village health volunteer, Noi suggested, he would provide support to help the education program roll out in the community, for example, the program to promote the safe practice on HIV/AIDS transmission and how to prevent HIV infections. Community nurses wanted to increase community awareness focusing on preventive strategies for people who are living with HIV/AIDS and their families. The PAR group meetings were an opportunity for the community nurses to offer alternative preventive strategies and resources to the PAR group members.

Participants commented that by working together to share their experiences they were able to address some of the concerns in their lives. They claimed that they had become more confident. 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 one another. Although unanticipated, their level of awareness and consciousness was raised to the problems and strengths of living with HIV.

It was clear that being part of this research process enhanced participants' ability to 'move on' as evidenced by actions undertaken.

Grandparents

Concluding comments would not be complete if I did not call attention to the role of grandparents. In this inquiry grandmothers took the main care-giving role for orphans. Elders are greatly respected in the community and it should not be underestimated that the principles of

Buddhist practice influenced child rearing practices. This understanding may explain why grandparents would see it is their duty to take in orphans, to care for them. Understood is that children need protection. Principles grandparents adhered to about rearing a child was to love, care and exhibit kindness. Grandparents taught children to be generous, dignified, and well-mannered and display courteous behaviour.

I recount that orphans were looked after by their biological grandparents and additional assistance has been provided by other relatives including two aunts. Grandparents are in their 60s and three are living with Type II Diabetes and already have complications; hypertension, cataracts or visual impairment. It was not surprising that they would bring this concern into the open. Their ill health was a major 'preoccupation'; they talked about it and their concerns for one entire PAR group session. Grandparents were worried that they might not be able to continue to care for orphans. A few of the grandparents told the PAR group that they did not know how long they would live. As discussed in chapter two the average length of life for Thai people is 72 for women and 66 for men, so it was not unexpected that this group would talk about their morbidity and mortality. However, they were future oriented; grandparents shared their plans for their grandchildren. Each family had developed a future plan for the care of these orphans. Most were relying on the extended family to absorb this responsibility. Their solutions are context specific, depending on the resources and commitment of other family members.

Contribution to transition theory

My participants held Buddhist beliefs. Believing gave them the spiritual strength to 'move on'. Buddhism was central in their lives, and I suggest, facilitated transition. While this will not be 'new' knowledge', it does make a contribution to transition theorizing. Participants often referred to their Buddhist practices. Practices refer to spiritual beliefs, meditation, herbal and massage treatments. I propose that spirituality and the practice of meditation helped them to make sense about their situation. An expression used by many participants was 'Tam Dee Dai Dee' meaning what goes around comes around. This refers to the Buddhist cycle of life and encourages people to understand that suffering and death is inevitable. Thai Buddhists tend to live their life by 'letting go' or 'let it be'. Grandparents in this inquiry often talked about 'tamjai' which is similar to 'kwarmsa-ngobjai' or in English, it means letting go. Bridges talks about being able to let go as a part of transition, as: "the inner process through which people come to terms with change, as they let go of the way things used to be and reorient themselves

to the way things are now”. Being able to let go may be one way that my participants were able to move on.

Answering the research question: What can be done to assist Thai families?

What can be done to assist families can be prioritised. In this inquiry, a crisis point was identified as the time the orphan joins the ‘new’ family. All families recall the events surrounding living in the ‘new’ family. I am able to state that there is a time span of approximately two months when families need particular assistance: additional educational input and/or support from health care professionals. This is a key finding and I am urged to communicate this in the wider health care delivery system so that health care providers can intervene, not only at the peak but preferably, in a preventive way before the crisis occurs.

How can we assist Thai families?

My argument is a call for the prevention of HIV. This is in line with the targets set by Thailand to reduce the number of new cases of HIV by at least half of those projected for 2011. Currently three HIV prevention strategies are (1) public information campaigns, (2) strengthening the HIV prevention networks, and (3) finding ways to ensure sustainability at the provincial and local administrative organization levels to accelerate and take ownership of the HIV/AIDS prevention agenda.

One of my strong interests is the way that stigma associated with HIV/AIDS continues to batter families. In this inquiry, stigma was a major concern for the participants. I would like to push toward the eradication of stigma and aversion toward people living with HIV/AIDS. I firmly suggest that reducing stigma among people and family with HIV/AIDS needs to take place. As discussed, the legacy of the Grim Reaper still campaign holds true for some people and continues to impact on families. Government campaigns should include reduction of stigma. New campaigns should promote a clear understanding about HIV/AIDS transmission rather than create terrifying images of the disease and point blame.

Shock was common and lack of preparation was another key finding. How could we better prepare the family? When would be the best time to assist families and what would this assistance look like? First, families need to be identified before the crisis occurs. I understand that services are fragmented but there is a central service that involves all people with HIV.

The HIV/AIDS clinic in Khon Kaen Regional hospital holds the record of all HIV/AIDS clients. Could it be possible that the information gathered at the HIV/AIDS clinic looks beyond its walls (and its acute care focus) to alert the health care providers that it is known that the clients have children, and have recently moved house. It may be possible to explore the HIV/AIDS database at Khon Kaen Regional Hospital. Confidentiality aside, it may be possible to expand their HIV/AIDS data collection to track clients and include an electronic alert system, when such a system is operational. The alert would register people 'at risk', i.e. not only identifying people with socioeconomic and psychological needs but also the physical, acute cares focus. Tracking clients (with their permission) and improved communication networks between services will no doubt improve continuing care. This obviously needs further research.

Financial difficulties were rife in these families. The national health system is certainly a step in the right direction but much more needs to occur for families to feel safe financially. Micro finance provided by HIV clinics saved Lee and Grace's families; they were able to start a small business. Inroads are being made to relieve families of financial burden but much more needs to be done.

Both storytelling and PAR groups enhanced people's ability to move on. These processes resulted in participants' willingness to not only problem solve alone but also in a wider group. This, in turn, promoted sharing of knowledge and identification of action. It emphasises the values of health professionals working with community members in a genuinely participatory way to support ongoing community development. It was cathartic for people to tell their own story. Storytelling could be part of a nursing assessment in addition to the checklist accompanying the family's annual health survey. Moreover, if storytelling were to be part of everyday nursing practice, additional skills would need to be learned and documented.

In summary, answering my research question, I explored what could be done to assist Thai families whose lives have been affected by HIV and/or AIDS. I built on previous chapters, particularly the fourteen constructs resulting from one to one interviews to describe the experiences of nine adult participants as they dealt with the impact of HIV/AIDS in their families. The most striking feature of the participants' response when incorporating the consequences of living with HIV in their lives, was that they talked about their experiences as a family. The family was reconfigured when one of its members became infected with HIV, and the orphan joined this 'new' family. I propose that these five families acted as a self-contained

dynamic unit who came together as a newly constituted family through necessity but showed enormous resilience and unconditional love for its orphans.

It became evident that all my participants had made major changes in their lives. I make a distinction between change and transition: change is what happens to people whereas transition is what people actually experience. My participants' stories show the impact HIV infection had on their everyday life: eating, drinking, bathing, working, walking and talking. Daily life continued as before, but with additional hardships. There were changes in daily life, most of these affected grandmothers in particular. Although grandmothers talked about having a strong commitment to their grandchildren, they explained that many role changes have occurred. My proposition is that families can adjust and move on when they support each other. Previously, I suggested that one way to observe the way in which families have 'moved on' was to pay attention to what they said about the future. Concern about these orphans and creating a future for them was a major observation. Most grandparents were already in their 60s, and while this is not 'old', diabetes had taken its toll. It is not surprising that grandparents wanted to secure a future for their grandchildren.

Implications for practice

When I commenced this inquiry, I did not know whether participants would join the group given the stigma and discrimination they had experienced in the public sphere. I strongly believe that storytelling was the best way to proceed with these participants. I was able to build relationships, participants learned to trust me and it was this trust and increased confidence that persuaded them to join the PAR group.

Previous projects in community development had set the stage for this larger research inquiry. I had expertise as a facilitator, although in this inquiry, taking direction from participants was more explicit. Participants were not familiar with storytelling or setting the PAR agenda but they did not hesitate. They had many things to reveal in storytelling and much to discuss in the PAR group. In the evaluation, participants appreciated being part of the cooperative process and they took ownership of their stories and actions.

This inquiry throws light on the ways in which people learn to live with uncertainties. I believe that this PAR approach contributed to human flourishing. I sense a need for participative approaches. People should be allowed to participate in the development of their own well-being

and health services. I suggest a movement within health care research to make participation the core of health practices, hence the appeal of human flourishing at individual and community levels. I am a strong believer in principles of democracy and equity.

I strongly believe that family support groups should continue. It was clear that many actions resulted when participants were part of a group and transition was accelerated. Facilitators would need to be trained to understand group dynamics as this skill should not be taken for granted. The staff at Pralab PCU are interested in furthering their understandings of the PAR process, so this could be a good time to work alongside them to enhance group facilitation and the ‘art’ of storytelling. This may be another research proposal in staff development and link in the concept of transition as part of nursing knowledge, and this is particularly relevant in relation to Buddhist practice.

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. Transition was possible, despite emotional upheaval, financial hardships and social injustices experienced living in a culture where HIV is stigmatized. As a facilitator, I was able to build on their strengths through storytelling and collaborative decision making in PAR groups. This PAR methodology was transformative in that families were able to accelerate their transitions to incorporate the consequences of living with HIV/AIDS in their lives. As a facilitator / researcher, I helped five families to work together to improve their lives (reform).

Considering the facilitation of transition, I suggest that the concept of transition should be taught in the nursing curriculum as it is a central to nursing practice. Helping or facilitating our clients and participants to move on is very much what nursing can do in everyday practice. When talking about nurses using transition concepts to inform their practice, transition is possibly best communicated using the CUSP model. Bridges (2004) described a model of transition that is “on the CUSP of change”. It may be useful to expand his ideas as it will help in developing ways health care professionals may be able to facilitate transition. Bridges writes that the CUSP acronym represents four factors of change. A person will be successful in managing a personal transition depending on how they feel about these four factors. The factors are listed in CUSP order and participants could be asked:

Control: Do you feel you have control of the situation?

Understanding: Do you truly comprehend what is happening and why?

Support: Do you have (or can you obtain) the practical and emotional support for what you are going through?

Purpose: Do you have a sense of purpose to give meaning and direction to your experiences and actions?

Implications for policy

In the context chapter I have identified the democratic processes of governance at a local level. These democratic processes may be viewed as limited from an Australian context, nevertheless I have identified the village and district group leaders as these are the people to whom I will give my inquiry report (in Thai language) and talk with about the findings at Pralab Community Hall meetings. The Kanman is the chairperson of a committee which usually comprises a health professional, an agricultural extension person and a school teacher/headmaster. I will share the findings of this research with this committee and hope that these power brokers listen to the voices of families living with HIV/AIDS. In particular, I would like to help them consider the way they distribute the social security payment to families who are eligible to receive AIDS support payments.

I owe it to the participants to have their voices heard. I will provide this short version of this inquiry in the Thai language. It will be distributed to families, and all participant staff at Pralab Health Centre, Khon Kaen Regional Hospital's HIV/AIDS clinic and Khon Kaen University.

Implications for education and prevention

Thailand has achieved many of the Millennium Development Goals (MDGs) at a national level well in advance of the 2015 targets and has been recognised as one of the most successful countries in their response to the AIDS epidemic. However, a new group of adolescents are being infected. It will be timely to turn research attention to this group and explore how HIV/AIDS can be prevented. At this moment in time, Thailand is still dealing with the impact of the HIV epidemic of the last decades, and the immediate problems surrounding orphans was the impetus for this inquiry. My concern for orphans was my motivation for this inquiry, but I also have a strong interest in the way stigma is pervasive and the damage this continues to have on families.

Health care professionals can assist families impacted by HIV/AIDS through prevention of the situation reaching a crisis. We know that a peak event occurred when the orphan joined the 'new' family. If health care professionals are alert to the situation e.g. when a child joins a family, they can intervene before a crisis occurs. This is the first way in which we can help. Secondly, this inquiry and the literature suggests that stigma plays a huge role in retarding access to health care and creating mental health tensions in families. In the effort to de-stigmatise, education, both at national and local levels, needs to be kick started. The Grim Reaper messages need to be supplanted with current information and access to services identified. Most importantly, education at schools may be a good way to commence, knowing that there is a younger group who are currently being infected by HIV and prevention has always been the catch cry of Alma-Ata. This thesis is a call for the prevention of HIV. This is in line with the targets set by Thailand to reduce the number of new cases of HIV by at least half of those projected for 2011. Currently, three HIV prevention strategies are (1) public information campaigns (2) strengthening the HIV prevention networks; and (3) finding ways to ensure sustainability, at the provincial and local administrative organisation levels, to accelerate and take ownership of the HIV/AIDS prevention agenda. Thirdly, health care professionals need to be aware of the shock impact when people are told they have HIV. Access of people newly diagnosed with HIV to counselling services would be ideal, but this will depend on the priorities of the health policy (and budget required to bring expert counsellors on board), although I believe this could be an additional role for nurses working in the community. Fourthly, this inquiry has shown that the person carrying the weight of burden on their shoulders is the grandmother. While the five grandmothers are resilient and managing quite well at the moment, their socio-economic situation is precarious. If one succumbs to illness, or if diabetes takes a further toll on their health, orphans are likely to be affected. Contingency plans need to be in place. Some families may need help with planning, and others may need economic support, realising that the grandmother is the main bread winner. While on the subject of grandmothers, I propose we need to acknowledge the key role they play in keeping the family together and functioning. Fifthly, we already know that one of the major impacts is financial. Health care professionals need to be alert to this problem. It may be outside their scope of practice but the way in which HIV/AIDS services and payments are received may require Health Care service professionals to understand how systems operate.

Evaluation

In the evaluation of group sessions, grandparents said they appreciated being able to talk about their situation in the PAR group. I asked them to talk about their experiences in the group. They revealed that they had not been involved in this style of research. At the beginning, they did not understand why I spent such a long time talking with them in the one to one interviews with the family members. But they acknowledged that it had felt very good to share their stories as no one had really listened to them before. They said that they felt acknowledged and validated by the storytelling approach. The group initiated action toward reform.

For the outcomes of the research to have credibility and for the findings to be meaningful to others, the research pathway needs to be transparent and available for scrutiny. The key credibility concepts are voice (the creation of a multi voiced text where stories are given in their entirety), involvement of participants (constant ongoing validation of stories and group proceedings) and transferability (a detailed description of the context so that a second researcher can make transfers across a second research context). A second researcher following my footsteps needs to be able to retrace my research decisions and process steps. For all three concepts to be achievable, I have left a clear trail of evidence.

My argument for ensuring that this inquiry is trustworthy, believable or, to use another term, rigorous, data was generated collaboratively: both stories resulting from one to one interviews and documents relating to the PAR groups. In the cycles of 'Look, Think and Act', feedback was given regularly. I have described the research process in detail and it should be clear that participants drove this inquiry. I have created a multi-voiced text, participants' voices, indeed their entire stories have been incorporated. Some of the meaning is lost in translation, I accept that this is the case, but I have sought help from my field supervisor to validate translations of data from Thai into English. Besides, she was present at every PAR session and we debriefed after each meeting to discuss activities and group dynamics. My reflections have been incorporated into the text, which I suggest makes this research process transparent. In the appendices analysis protocols and examples of data generation will be found. Finally, success of the PAR process can be evaluated by the willingness of participants to act and seven actions were commenced. In addition, participants expressed a strong sense of self development. Some of the outcomes were practical accomplishments, such as having their AIDS benefit payment redirected.

Limitation of this inquiry

It is my opinion that this inquiry could be improved on several levels. First I think my English language skills are limited, and this was a problem when describing abstract concepts. Often I opted for the most direct way to communicate; simple and straightforward. Although I have read many texts about western philosophy, I was not able to penetrate their denseness. I sought refuge in following Koch and Kralik's methodology and adopted their philosophical stance. This was not only a pragmatic decision but also a wise one, retrospectively, as I believe it was the best methodology for this inquiry. The storytelling component opened communication with participants which may not have happened if I had tried to gain access and trust some other way.

I understand that I may have taken my Buddhist upbringing and my education of eastern philosophy for granted. It would have been worthwhile to pursue Buddhist philosophy to underpin my inquiry: I would have been 'at home' with this world view. Making sense of Buddhism and transition is possibly another research route I could pursue in the future.

If I had had more time in the field, I believe that more could have been achieved. Four PAR sessions with participants limited the inquiry. It is on my agenda to return to this community to follow up and even reconvene or join the group if they are still meeting in 2012.

Further research

As discussed, Thailand has achieved most of the Millennium Development Goals (MDGs) at a national level well in advance of the 2015 targets, particularly MDG 6 which targets reducing HIV infections. Thailand has provided universal access to health care and ARV drugs for the Thai population (excluding migrants and refugees). Today, most people living with HIV can access treatment and efforts are shifting to care for previously excluded populations. Thailand has a new target to reduce HIV infections among young people aged between 15-24 years. I suggest that ways in which we, as health care professionals, could assist families that are similar to the five families in this inquiry. Given that the 1990s AIDS epidemic has slowed down, I will focus on the next Thai group being infected by HIV, adolescents, and tease out preventive strategies 'we' may be able to use to curb these infections. Post PhD, a research study I would like to pursue is a PAR group with orphans who are older than 18. The objective would be to establish a support and working group that could potentially reduce HIV infections in their age group. In collaboration with these adolescents, my aim would be to devise an education

program designed to reach their peers. The envisaged research would be in line with Thailand's three HIV prevention strategies (1) public information campaigns (2) strengthening the HIV prevention networks; and (3) finding ways to ensure sustainability, at the provincial and local administrative organisation levels, to accelerate and take ownership of the HIV/AIDS prevention agenda. Thailand has a separate policy for IDU, MSM, female sex workers, prisoners and migrants and has agreed to work with all these groups using both domestic and international funding from the Global Fund to fight HIV/AIDS.

The Khon Kaen Regional Hospital has a Comprehensive Continuum of Care Centre for people living with HIV/AIDS. Participants in this inquiry are probably familiar with the centre as this is where HIV/AIDS services, medical attention and support are provided. The Comprehensive Continuum of Care Centre at the Khon Kaen Regional Hospital collect data on all registered HIV/AIDS clients using its services. These data are part of Thailand's health recording system. When registered as a client of the centre, the local government is authorised to distribute a special benefit for people living with HIV/AIDS. In Thailand, the Ministry of Social Development and Human Security subsidise these budgets. The special benefit provides a monthly payment (500Baht or AUD 17 per person).

Health promotion is carried out by the Registered Nursing staff who are Community Nurses assisted by VHVs or Village Health Volunteers who hold prestige in the village community. Village Health Volunteers are not paid for their services but they are the backbone of this health care delivery. There is an increase in the number of people with HIV infections, mainly young people and women, but this has not resulted in increased health promotion about HIV prevention.

My thesis

Based on my own personal beliefs, and those of Alma-Ata and primary health care, the principles adhered to throughout this inquiry were guided by democratic principles - social justice, social equity, freedom of speech and a concern for human rights. There had been silence around living with HIV/AIDS. In this inquiry, distinctive, authentic Thai voices have been heard; nine participants were free to speak. However, their stories were told in private and retold anonymously. Public disclosure of HIV status is not yet tolerated in these villages: discrimination against families was still common. It was clear that being part of this research process enhanced participants' ability to 'move on' as evidenced by actions undertaken.

I have used Koch and Kralik's PAR approach to research alongside people who have had HIV as a disruptive event in their lives. I have shown the way families can make transitions through this event and create a sense of continuity in their lives. Underpinning this transition is possibly a philosophy of Buddhism or 'letting go' or being able to leave things behind and move on.

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. My philosophy and guiding principles are grounded in values of democracy, equal opportunities, and education as personal development. I will continue to strive to bring issues voiced by participants to government attention. 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.

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Conference Presentation Abstracts

1. Abstract from the International conference: New frontiers in Primary Health Care Role of Nursing and other Professional, Chiang Mai, Thailand 4-6 Feb 2008.
2. Abstract from the International conference on Health Promotion and Quality in Health services (IHHPQS): Global sharing: People and integration as key to success. Bangkok, Thailand 19-21 November 2008.
3. Abstract from the 8th World Congress Participatory Action Learning & Action Research, Melbourne, Australia, 6-9 September 2010.
4. Abstract from the 10th International Congress on AIDS in Asia and the Pacific (ICAPP10), Pusan, South Korea, 26-30 August 2011.

**Abstract from the International conference: New frontiers in Primary Health Care
Role of Nursing and other Professional, Chiang Mai, Thailand 4-6 Feb 2008.**

**HIV/AIDS in Thailand: Participatory Action with Orphans,
Grandparents and Families**

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By 2005 in Thailand approximately one third of new infections of HIV were married women who were probably infected by their spouses (Gouws, White, Stover, & Brown, 2006). In this study, the group of interest is married women, and their lives within the context of their families. Often infected by HIV, women occupy a central role in care delivery of their spouses. What is not clear about their situation is the impact of HIV on the family, particularly in changes in family dynamics, relationships and roles. This study will explore the living experiences among intergeneration who are living with HIV/AIDS in Issan which a rural area of Thailand. Moreover it will research the way families care for their children and/or grandchildren who are living with HIV/AIDS. Participatory Action Research (PAR) will be the research methodology used in the study because this method will enable the researcher to work alongside participants in finding ways to address or accommodate the issues raised. What can be done to assist families whose lives have been changed by HIV/AIDS?

Aims of this study were: 1) To understand intergenerational family relations when daughters, sons and grandchildren live and die with HIV/AIDS. 2) To provide a means of registering the effects of widespread societal changes on the family when HIV/AIDS interrupts people lives. 3) To identify a reform agenda that is specific to common issues raised by families. 4) To take the 'peoples' agenda to local government to influence policy and planning for future generations.

Co-authors: Prof. Dr. Diana Keatinge, Chair of Pediatric Youth and Family, School of Nursing & Midwifery, University of Newcastle and Prof. Dr Tina Koch, Professor of Older Person Care, School of Nursing & Midwifery, University of Newcastle, Australia.

Abstract from the International conference on Health Promotion and Quality in Health services (IHHPQS): Global sharing: People and integration as key to success. Bangkok, Thailand 19-21 November 2008.

10-011



The impact of HIV/AIDS: A participatory action research study to explore what can be done to assist Thai families when children are orphaned.

Miss Juraporn Tangpukdee 3064883 PhD Candidate

Research Question:

What can be done to assist Thai families whose lives have been affected by HIV and/or AIDS?

Aims of Study

- To 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
- To provide a means of registering the effects of widespread societal changes on the family when HIV and AIDS interrupt people lives and traditional Thai family structure
- To 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

Background to the study:

The Human Immunodeficiency Virus (HIV) and the set of symptoms of opportunistic illnesses known as AIDS (Acquired Immune Deficiency Syndrome) are recognized as a major global health issue. In 2007, World Health Organization and the United Nations Joint Program on HIV/AIDS (2007) indicated that there are approximately 33.2 million people living with AIDS/HIV of whom 15.4 million are women and 2.5 million are children under 15 years. In 2007 there were estimated to be around 2.5 million of people newly infected with HIV, approximately 2.1 million adults and 420.000 children under 15 years of age.

According to almost all of the literature focuses on the negative impact of HIV/AIDS on society, communities and people living with HIV/AIDS. Thus little is know about any more positive factors relating to HIV/AIDS. A further gap in the research literature is that it appears researchers have not focused on the stories of family members caring for children orphaned as a result of HIV/AIDS.

Oral Presentation

8th World Congress 2010

Participatory Action Research and Action Learning 6th - 9th September, Melbourne, Australia

The impact of HIV/AIDS: A participatory action research study to explore what can be done to assist Thai families when children are orphaned

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Prof Diana Keatinge, Prof Tina Koch and Dr Margaret Harris. Assoc Prof. Dr Kessawan Nilvarangkul

ABSTRACT

In 2008 it was estimated that 2.7 million people were newly infected with HIV, approximately 2.3 million adults and 430,000 children under 15 years of age (UNAIDS, 2009). It appears that little is known about the stories of family members caring for children orphaned as a result of HIV/AIDS. This Participatory Action Research study aimed to explore this situation and identify how families' accommodate what effect it has on Thai family structure and to work alongside some of these families to identify action to address issues they raise. The study's method comprised one-to-one interviews with families; PAR group discussion; field notes and a reflective diary. This paper reports on the preliminary findings of the first phase of the study in which its ten participants from five families recounted their stories. The most general concern included that caregivers were elderly, experiencing financial distress and sometimes unable to access social welfare. In addition, the orphans experienced community stigmatization, were often excluded from school and had few or no friends.

Key words: Participatory action research (PAR), HIV/AIDS, orphans, Thai families and Thailand

Abstract from the 10th International Congress on AIDS in Asia and the Pacific
(ICAPP10), Pusan, South Korea, 26-30 August 2011.

Oral Session

Programme, HelpAge International, United States of America

Issue(s): Large numbers of HIV infection are placing the older people and their families in a vulnerable situation. They are becoming poorer as children lose their jobs/die, and are burdened with the role of care for orphaned grandchildren.

Project(s): The project support people infected/affected by HIV/AIDS to form 91 self-help clubs, provides training in community development and access to loans. The income is used to support the clubs' activities, such as paying for health checkup, AIDS orphan schooling, home-visits and funeral services and cash assistance.

Result(s): Provided loans to 2,435 members and created work for 476 PLWHA. Has increased access of healthcare and homecare to the members and allowed the clubs to respond to the various social, health and economic needs in their communities. Has significantly reduced stigma and discrimination. Has managed to support 1,211 PLWHA access to ARV treatment and 1,081 AIDS orphans with education supports.

Lessons Learned: The project has shown that families affected by HIV/AIDS can be resilient and can take lead in mitigating the impact of HIV/AIDS. Therefore, HIV/AIDS programmes/policies should focus on increasing the resilience of the families affected by HIV/AIDS as one of their primary strategy. The project plans to share the project learning to the MOH and donors.

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[SuOE01-03]

Involving Children Living with HIV/AIDS in Community Awareness Raising

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Issue(s): Children are considered as the builder of the nation and every children have right to enjoy their basic needs. But the CABA due to their status are neglected by the society and the community where they are supposed to grow and become responsible person of the nation.

Project(s): The project primarily focused on the awareness raising by the CABA themselves to educate the community about their rights along with the basic information about HIV/AIDS.

Result(s): The project covered 2 municipality and 6 VDC's in Chitwan District, where the CABA facilitated 800 people of the community which included housewives, old aged people along with the job holders, which results to positive change in the community and acceptance to the CABA in the community.

Lessons Learned: Involving CABA in community raising is initiated for the first time with the consent of the CABA themselves, which proved that despite of any age and sex everyone involvement is a major contribution to eliminate stigma and discrimination attached to HIV/AIDS. Such project will provide a supportive environment for CABA to develop them and help them become responsible citizen of the nation and can change the attitude and behavior of the people living in the community.

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[SuOE01-04]

The Impact of HIV/AIDS: A Participatory Action Research Study to Explore What Can Be Done to Assist Thai Families When Children Are Orphaned

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²the school of Nursing, The University of Newcastle, NSW, Australia, Professor, Australia

³Khon Kaen University, Thailand, Associate Professor, Thailand

Background(s): The purpose of study was to research alongside families whose offspring had lost their lives to HIV/AIDS and to reveal the impact these deaths had on families particularly when children have been orphaned.

Method(s): Using Koch and Kralik (2006) methodology which merges storytelling and Participatory Action Research, I researched alongside five families in the Pralab District, Khon Kaen, Thailand for 12 months in 2009.

Result(s): I have identified the way in which families struggled to provide ongoing care for children of relatives who have died of HIV/AIDS. I was able to register the effects of widespread societal changes on the family when peoples' lives are disrupted. The participants' stories demonstrated that family members had little preparation in caring for the orphans because these relatives had concealed their HIV status. Transition to once again parenting children caused numerous concerns for caregivers. I worked alongside participants to identify these concerns into action process.

Conclusion(s): This community development project enabled the researcher to engage with participants to build on their capacity and undertake their new roles as 'parents'. In my presentation I will discuss on the family transitional since the orphans entered into their families.

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[SuOE01-05]

Community Participation in the Treatment of Children on Anti Retroviral Therapy in Manipur, India

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Department of Psychiatry, Regional Institute of Medical Sciences, India

Issue(s): -Increasing Orphans and HIV/AIDS children

-No separate HIV testing centre for children

-High stigma and discrimination

-No Children Counsellors in HIV testing and treatment centre

-Limited access to ARV Treatment

Project(s): -More than 30 community based organisation initiated advocacy program for Free treatment, care & support for children in Manipur since 2006

-Manipur AIDS Control Society and Community based organisation since 2006 have reached treatment services to 9 districts of Manipur and could registered 2578 infected children in Govt ART centre

Result(s): -An assessment done among the 4242 children infected and affected by HIV/AIDS in 6 districts of Manipur reveals that 38% of mothers are widows and 71.8 %among them are HIV positive

-More than 15 Community based organisations have organised World Orphan Day on 7th May 2011 for advocating right of children and their participation in AIDS Program

Lessons Learned: -Since November 2006, more than 700 children received free Paediatric ARV drug

-More than 25 Community based organisations have support free education, nutrition, travel and Psycho-Social to children in Manipur since November 2006 through funding agencies of Clinton Foundation, Catholic relief services, World Vision, HIV/AIDS Alliance

-Govt hospital have come forward for the treatment of children

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[SuOE01-06]

Comprehensive PMTCT Services for Especially Vulnerable Women in Vietnam

Thuy Tran*, Pamela Wright²

¹HIV Team, Medical Committee Netherlands-Vietnam, Vietnam

²MCNV, Medical Committee Netherlands-Vietnam, Vietnam

Issue(s): Comprehensive PMTCT services are important strategies to improve the lives of HIV-positive mothers and their children. However, for especially vulnerable women it has been difficult to access to such services in Vietnam.

Project(s): The Medical Committee Netherlands-Vietnam started a community-based program for HIV-positive women and their children in 12 sites, mainly in remote mountainous areas with large ethnic minority populations, affected by IDU. Support groups of HIV-positive women were established and their capacity built to increase their access to social and economic services. Simultaneously, the existing local health care services were strengthened to provide better quality and more appropriate services for the women.

Result(s): The program achieved good results, especially related to increased self-esteem of HIV+ women and their families, improved access to medical, social and economic services and better adherence to treatment. Nutrition care, access to education for the affected children and income have also been improved because of increased access to income generating activities and fundraising. Furthermore, community events contributed to reducing stigma.

Lessons Learned: Social support groups for women is an effective approach for improving access to and utilization of treatment and care for HIV-positive women, and contributes to a better quality of life including health, social and economic benefits.

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Appendices

Appendix A: The ethics approval from the University of Newcastle Human Research Ethics Committee

Appendix B: The ethics approval from the Human Research Ethics Committee of Khon Kaen University

Appendix C: The English information letter

Appendix D: The Thai translation information letter

Appendix E: The English formal consent letter

Appendix F: The Thai formal consent letter

Appendix G: The reflective journal prompt list

Appendix H: The analysis document 1 - 6

Appendix A: The ethics approval from the University of Newcastle Human Research Ethics Committee

HUMAN RESEARCH ETHICS COMMITTEE



THE UNIVERSITY OF
NEWCASTLE
AUSTRALIA

Notification of Expedited Approval

To Chief Investigator or Project Supervisor:
Cc Co-investigators / Research Students:

Professor Diana Keatinge
A/Professor Kessarawan Nilvarangkul
Dr Margaret Harris
Professor Tina Koch
Miss Juraporn Tangpukdee

Re Protocol:

The impact of HIV/AIDS: a participatory action research study to explore what can be done to assist Thai families when children are orphaned.

Date:

09-Dec-2008

Reference No:

H-2008-0325

Thank you for your **Response to Conditional Approval** submission to the Human Research Ethics Committee (HREC) seeking approval in relation to the above protocol.

Your submission was considered under **Expedited** review by the Chair/Deputy Chair.

I am pleased to advise that the decision on your submission is **Approved** effective **09-Dec-2008**.

The full Committee will be asked to ratify this decision at its next scheduled meeting whereupon a formal *Certificate of Approval* will be issued. In the interim your approval number is **H-2008-0325**.

If the research requires the use of an Information Statement, ensure this number is inserted at the relevant point in the Complaints paragraph prior to distribution to potential participants

You may then proceed with the research. Best wishes for a successful project.

Professor Val Robertson
Chair, Human Research Ethics Committee

For communications and enquiries:
Human Research Ethics Administration

Research Services
Research Office
The University of Newcastle
Callaghan NSW 2308
T +61 2 492 18999
F +61 2 492 17164
Human-Ethics@newcastle.edu.au

Appendix B: The ethics approval from the Human Research Ethics Committee of Khon Kaen University



KHON KAEN UNIVERSITY

This is to certify that

The Project Entitled: The impact of HIV/AIDS: A Participatory Action Research study to explore what can be done to assist Thai families when children are orphaned

Principle Investigator: Miss Juraporn Tangpukdee et al.

Address: Department of Nursing, Faculty of Nursing,
Khon Kaen University, Thailand

Document Acceptance:

1. An application form for ethical review version 1.1 dated 4 March 2009
2. Full Proposal, Amended version 1.1 dated 4 March 2009
3. Information sheet and consent form Thai Amended version 1.1 dated 4 March 2009
4. Instrumentation Amended version 1.1 dated 4 March 2009

Has been reviewed and approved by the Ethics Committee of the Khon Kaen University, based on the Declaration of Helsinki and ICH-GCP.

Date of Approval: 27 March 2009

Date of Expire: 26 March 2010

Associate Professor Jiraporn Sithithaworn, M.D.

Vice chairman,

The Khon Kaen University Ethics Committee for Human Research

Record No. 4.3.18: 02/2009

Reference No. HE522028

Office: 17 floor room 1733 Somdetprasinakarindra...Building
Faculty of Medicine, Khon Kaen University, Khon Kaen, Thailand
Tel. & Fax: +66-0-433-66617

Institutional Review Board Number; IRB00001189
Federalwide Assurance; FWA00003418

Appendix C: The English information letter

The school of Nursing and Midwifery

The University of Newcastle

University Drive, Callaghan

NSW, 2308 Australia

Tel: +61 2 49216770 Fax: +61 2 49217069

Information Statement for the Research Project: The impact of HIV/AIDS: A participatory action research study to explore what can be done to assist Thai families when children are orphaned

You are invited to participate in the research project identified above which is being conducted Miss Juraporn Tangpukdee, a student undertaking her Doctor of Philosophy at the University of Newcastle, Australia under the supervision of Professor Diana Keatinge, Professor Tina Koch, and Dr. Margaret Harris from the same University.

Why is the research being done?

The purpose of the research is to (1) identify and understand how families deal with 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 interrupts people lives and traditional Thai family structures (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.

Who can participate in the research?

We are seeking members of families who are currently caring for orphaned children of relatives who have died from HIV/AIDS and who speak fluent Thai to participate in this research. Approval to conduct the study has been given by the University of Newcastle Human Ethics Committee and **the Human Ethics Committee, Khon Kaen University, Thailand.**

What choice do you have?

Participation in this study is entirely your choice. Only those who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you in any way and will not affect your relationship with staff of the primary health care setting. If you decide to participate, you may withdraw from this project at any time

without giving a reason and also withdraw any information you have provided. **At the end of the study the participants will be offered a summary of the research findings. If you are not literate, arrangements will be made for a third party to read the summary report to you.**

What would you be asked to do?

One to one interview and follow up conversations.

You will be asked to participate in an interview of approximately 1 hour duration. During the interview you will be asked to share your story about your experiences of caring for orphan/s in your family, including issues that have arisen and suggestions you have about how these issues could be addressed. With your permission the interview will be audio taped. You can ask for the audio tape to be turned off at any time during the interview and not restarted until you are ready. You can also stop the interview at any time. The student researcher will also take some notes during the interview. If for any reason, you feel you would like some additional support because of talking and thinking about your situation the student researcher will offer you the opportunity to talk to a community nurse. The student researcher will provide you with a summary of your interview so that you can discuss it with her and change or delete anything you wish. This may lead to further conversation and/or you may wish to talk to her some more about your story. She will request your permission to audiotape these conversations and check her summary of these with you.

Group Discussions

If participants from different families raise similar issues the student researcher will ask each of these participants (separately) whether they wish to discuss these issues, and think about how they could be addressed together as a group. This group meeting/s would take approximately 2 hours according to the group's wishes. The student researcher would facilitate the group.

What are the risks and benefits of participating?

Risks

The student researcher will keep all information that you share with her confidential. However, although she will request participants who wish to meet as a group to keep these discussions confidential she cannot guarantee that this will occur.

If for any reason, you feel you would like some additional support because of talking and thinking about your situation the student researcher will offer you the opportunity to talk to a community nurse.

Benefits

You will have the opportunity to tell your story and share your experiences with another person (the student researcher) and this may be helpful to you. This process may also help you to identify good things that have occurred in this experiences, examine those that have been difficult and ways these could be addressed. The process may help with taking action to address some issue you raise.

How will your privacy be protected?

No real names of participants will be used in the study or on any documentation relating to it. You will be asked not to use real names during the interview and, if this occurs, **they** will be deleted and replaced by pseudonyms during transcription of the audio tapes. Pseudonyms will be used in any presentation or publications that may occur as a result of the study.

How will the information collected be used?

The information collected will be reported in the research student's PhD thesis, and in related papers in scientific journals and presentations at professional conferences. Information reported will be in summary form.

During the study all documents and CDs will be locked in filings cabinets to which only the student has the key. All data will be removed from the computer at closure of the study and downloaded on to a USB. This USB and CDS will be stored securely in the School of Nursing and Midwifery, the University of Newcastle for five years and then destroyed. **All paper documentation will be shredded; CDs will be destroyed in the appropriate way (eg. cut up) and the information from the USB will be wiped.**

What do you need to do to participate?

Please read this Information Statement and be sure you understand its contents before you consent to participate in the research. If there is anything you do not understand, or you have any questions, please don't hesitate to contact the researcher. If you would like to participate, please complete the attached consent form and return it to Miss Juraporn Tangpukdee using the stamped address enveloped provided or in person at the faculty of Nursing, Khon Kaen University. You will then be contacted by Miss Juraporn Tangpukdee and given further information.

Further information

Professor Diana Keatinge

Miss Juraporn Tangpukdee

School of Nursing and Midwifery

Research student

The University of Newcastle

University Drive Callaghan

NSW 2308, Australia

Tel: +61 2 492 6010

Fax: +61 2 492 6301

Email: Diana.Keatinge@newcastle.edu.au

Email: juraporn.tangpukdee@studentmailnewcastle.edu.au

Thank you for considering this invitation.

School of Nursing and Midwifery

The University of Newcastle

University Drive Callaghan

NSW 2308, Australia

Tel: +66 43 202 407 (Phone Number in Thai)

Professor Diana Keatinge

Project supervisor

Miss Juraporn Tangpukdee

Research student

Thai Contact detail

Associated Professor Dr. Kessarawan Nilvarangkul

Associated Dean Faculty of Nursing

Khon Kean University

Khon Kaen ,Thailand

40002

Tel 043 202 407

Complaints about this research

Should you have concerns about your right as a participant in this research, or you have a complaint about manner in which research is conducted, it may be given to the researcher(s), or the Dean of Faculty of Nursing, Khon Kaen University 043 202 407. Should you wish to do so you may also contact the Human Research Ethics Officer, Research Office, the Chancellery, The University of Newcastle, University Drive Callaghan 2308, Australia, telephone 0249216333,

Email: Human-Ethics@Newcastle.edu.au

Appendix D: The Thai translation information letter

แบบชี้แจงอาสาสมัครสำหรับโครงการวิจัยทางสังคมศาสตร์ ที่ใช้แบบสัมภาษณ์ และสนทนากลุ่ม

ดิฉันนางสาวจุฬารัตน์ ตั้งภักดี นักศึกษาระดับปริญญาเอก จากคณะพยาบาลศาสตร์ มหาวิทยาลัยนิวคาสเซิล ประเทศออสเตรเลีย ดิฉันใคร่ขอเรียนเชิญท่านเข้าร่วมในการศึกษา เรื่อง ผลกระทบจากโรคติดเชื้อเอชไอวี/เอดส์: การวิจัยอย่างมีส่วนร่วมกับครอบครัวเพื่อค้นหาวิธีการส่งเสริมครอบครัวในการดูแลเด็กกำพร้าจากโรคติดเชื้อเอชไอวี หรือโรคเอดส์ โดยมีวัตถุประสงค์คือ 1) เพื่อศึกษาถึงการปรับตัวของครอบครัวในการดูแลลูกหลานที่สูญเสียบิดา

มารดาจากการติดเชื้อเอชไอวี หรือ โรคเอดส์ 2)

เพื่อศึกษาผลกระทบทางสังคมต่อการดำเนินชีวิตและโครงสร้างของครอบครัว

เมื่อมีสมาชิกในครอบครัวติดเชื้อและเสียชีวิต จากโรคติดเชื้อเอชไอวี หรือ โรคเอดส์ และ 3)

เพื่อร่วมจัดลำดับความสำคัญของปัญหาที่ค้นพบ และปฏิบัติการให้การสนับสนุนช่วยเหลือ ครอบครัว เพื่อให้การดูแลช่วยเหลือเด็กกำพร้า จากโรคติดเชื้อเอชไอวี หรือ โรคเอดส์

หากท่านมีความสนใจเข้าร่วมศึกษา ท่านจะได้ร่วมใน 2 กิจกรรม คือกิจกรรมที่ 1 การสัมภาษณ์เชิงลึก และเข้าร่วมการสนทนากลุ่ม โดยการสัมภาษณ์เชิงลึก

ผู้วิจัยจะดำเนินการในระหว่างเวลาไม่เกินครึ่งละหนึ่งชั่วโมง

ตามระยะของรูปแบบการศึกษาซึ่งประกอบด้วย 1) ช่วงของการวิเคราะห์สถานการณ์ 2)

ระยะการร่วมวางแผนการดูแลเด็กกำพร้า 3) ระยะการดำเนินงาน และ 4)

ระยะการประเมินผลการดำเนินงาน โดยในแต่ละระยะจะมีการสัมภาษณ์ประมาณ 2-3 ครั้ง

กิจกรรมที่ 2 การสนทนากลุ่ม การสนทนากลุ่ม ทั้งนี้ ขึ้นอยู่กับความสมัครใจจากผู้ร่วมการวิจัย

ระยะเวลาในการดำเนินกิจกรรมสนทนากลุ่มจะจัดอยู่ไม่เกินสองชั่วโมง

ตามความเหมาะสมของเวลาในการร่วมแสดงข้อคิดเห็นของสมาชิกกลุ่ม

โดยผู้วิจัยจะทำหน้าที่เป็นผู้ประสานงานให้เกิดการสนทนากลุ่มเมื่อผู้ร่วมวิจัยมีความสนใจที่จะพูดคุย แลกเปลี่ยนแนวทางในการดูแลเด็กกำพร้าร่วมกับสมาชิกผู้ร่วมวิจัยจากครอบครัวอื่นๆในรูปแบบของการสนทนากลุ่ม ทั้งนี้

จะไม่มีผลกดดันผู้ร่วมวิจัยให้เกิดการกิจกรรมสนทนากลุ่มหากไม่ได้เป็นความประสงค์ของผู้เข้าร่วมวิจัย เพราะผู้วิจัยตระหนักถึงการรักษาสถานภาพความลับของการติดเชื้อเอชไอวีหรือ

โรคเอดส์ของสมาชิกในครอบครัวของผู้เข้าร่วมวิจัยโดยระหว่างการสัมภาษณ์

ผู้วิจัยจะซักถามถึงประสบการณ์ในการให้การดูแลเด็กกำพร้าในครอบครัวท่าน

ตลอดจนการให้ท่านได้ร่วมเสนอแนะข้อแนะนำที่ท่านได้เรียนรู้มา ในทุกครั้งที่การสัมภาษณ์

ผู้วิจัยจะต้องได้รับคำอนุญาตจากท่านในการบันทึกเทปคำสัมภาษณ์

ท่านสามารถหยุดการบันทึกเทปได้ทุกเวลา ตลอดการให้สัมภาษณ์

รวมทั้งท่านสามารถยุติการให้สัมภาษณ์ได้ทุกเวลา ในระหว่างการสัมภาษณ์

ผู้วิจัยจะจดบันทึกย่อการให้สัมภาษณ์ร่วมด้วย

ทั้งนี้ผู้วิจัยขออนุญาตบันทึกเสียง เพื่อความถูกต้องของเนื้อหา

ผู้วิจัยจะใช้รหัสแทนชื่อและนามสกุลจริงของท่านลงในแบบบันทึกข้อมูลเทปการสัมภาษณ์

และจะทำลายเมื่อการศึกษาครั้งนี้สิ้นสุด

ผู้วิจัยขอรับรองว่าข้อมูลที่ได้รับจากท่านจะถูกเก็บเป็นความลับและจะนำเสนอผลการวิจัยในภาพรวมเท่านั้น ซึ่งจะไม่ก่อให้เกิดความเสียหายแก่ท่านแต่ประการใด

จะไม่มีภาระระบุชื่อ/ข้อมูลส่วนตัวของท่าน ในการเข้าร่วมเป็นอาสาสมัครของโครงการวิจัยครั้งนี้

ท่านเข้าร่วมด้วยความสมัครใจและสามารถถอนตัวเมื่อใดก็ได้โดยไม่เสียสิทธิใดๆ ทั้งสิ้น

ไม่ว่าท่านจะเข้าร่วมการวิจัยครั้งนี้หรือไม่ ท่านจะไม่เสียสิทธิใด

และจะไม่ระบุชื่อ/ข้อมูลส่วนตัวของท่าน

จึงไม่เกิดผลกระทบต่อการปฏิบัติงานของท่านแต่ประการใด/

ไม่มีผลต่อการรักษาพยาบาลอันพึงได้รับในปัจจุบันและอนาคต

หากท่านมีปัญหาสงสัยหรือต้องการทราบข้อมูลเกี่ยวกับการดำเนินการวิจัยสามารถติดต่อสอบถามผู้วิจัยได้ที่

- จุฬารักษ์ ตั้งภักดี มือถือ: 08 0317 1906

คณะพยาบาลศาสตร์ มหาวิทยาลัยขอนแก่น

- Prof Diana Keatinge เบอร์โทรศัพท์ระหว่างประเทศ: (61) 2492 6010

จากคณะพยาบาลศาสตร์ มหาวิทยาลัยนิวคาสเซิล ประเทศออสเตรเลีย

หากท่านมีปัญหาสงสัยเกี่ยวกับสิทธิของท่านจะเข้าร่วมการวิจัยนี้

โปรดสอบถามได้ที่ประธานคณะกรรมการจริยธรรมการวิจัยในมนุษย์มหาวิทยาลัยขอนแก่น

สำนักงานคณะกรรมการจริยธรรมการวิจัยในมนุษย์ฯ

อาคารสมเด็จพระศรีนครินทราบรมราชชนนีคณะแพทยศาสตร์ ชั้น 17 มหาวิทยาลัยขอนแก่น

จังหวัดขอนแก่น 40002 หรือทางโทรศัพท์หมายเลข (043) 366616-7 ต่อ 66616, 66617

Appendix E: The English formal consent letter

Professor Diana Keating

Professor Tina Koch

Dr. Margaret Harris

Assoc.Prof Dr Kessarawan Nilvarangkul

Miss Juraporn Tangpukdee

School of Nursing and Midwifery

The University of Newcastle

University Drive, Callaghan

NSW, 2308 Australia

Tel: +61 2 49216770 Fax: +61 2 49217069

Consent Form of the Project: The impact of HIV/AIDS: A participatory action research study to explore what can be done to assist Thai families when children are orphaned

I agree to participate in the above research project and give my consent freely. I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained. I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing.

I consent to

- Participation in an initial interview and then some ongoing conversations relating to the topic and having these recorded.
- Participation in a focus group, if you, other participants and the researcher feel it helpful to meet as a group.

I understand that my personal information will remain confidential to the researchers. I have had the opportunity to have questions answered to my satisfaction. **I understand that I have the right to review and edit any recording of my interview.**

Print Name: _____ Date: _____

Signature: _____

Due to I am illiteracy, the researcher read this consent form for me. I am clearly understood consequently I will stamp my thumb in this form with pleasure.

Researcher

(.....)

Witness.....(Who is not the researcher)

(.....)

Appendix F: The Thai formal consent letter

แบบยินยอมอาสาสมัคร

สำหรับโครงการวิจัยทางสังคมศาสตร์ที่มีบันทึกเทปสนทนา

ข้าพเจ้า (นาย, นาง, นางสาว).....นามสกุล.....อายุ.....ปี

อยู่บ้านเลขที่.....หมู่ที่.....ตำบล.....อำเภอ.....

จังหวัด.....

ข้าพเจ้าได้รับฟังคำอธิบายจาก

นางสาวจุฬารัตน์

ตั้งภักดี

เกี่ยวกับการเป็นอาสาสมัครในโครงการวิจัยเรื่อง“ผลกระทบจากการติดเชื้อเอชไอวี/เอดส์:

การวิจัยอย่างมีส่วนร่วมกับครอบครัวเพื่อค้นหาวิธีการช่วยเหลือครอบครัวเพื่อให้การดูแลเด็กกำพร้า
จากการติดเชื้อเอชไอวีหรือโรคเอดส์” โดย ข้อความที่อธิบายประกอบด้วย

วัตถุประสงค์ของการศึกษา ประโยชน์ที่คาดว่าจะได้รับ และวิธีการดำเนินการวิจัย
โดยการเข้าร่วมโครงการวิจัยเป็นไปโดยความสมัครใจ การรักษาความลับของการวิจัย

และค่าตอบแทนการเดินทางในการมาร่วมโครงการตามการจ่ายจริงไม่เกิน 100 บาท
รวมทั้งสิทธิในการถอนตัวออกจากการเข้าร่วมโครงการวิจัย

ข้าพเจ้าได้อ่านและเข้าใจตามคำอธิบายข้างต้นแล้ว

จึงได้ลงนามยินยอมเข้าร่วมโครงการวิจัยนี้

ลงชื่อ.....อาสาสมัคร

(.....)

พยาน.....

(.....)

ในกรณีที่อาสาสมัครไม่สามารถ อ่านหนังสือ/ลงลายมือชื่อ ได้ ให้ใช้การประทับลายมือแทนดังนี้:

ข้าพเจ้าไม่สามารถอ่านหนังสือได้ แต่ผู้วิจัยได้อ่านข้อความในแบบยินยอมนี้ให้แก่ข้าพเจ้าฟังจนเข้าใจดี

ข้าพเจ้าจึงประทับตราลายนิ้วมือขวาของข้าพเจ้าในแบบยินยอมนี้ด้วยความเต็มใจ

ลายมือชื่อผู้อธิบาย.....

(.....)

พยาน.....(ไม่ใช่ผู้อธิบาย)

(.....)

วันที่.....เดือน.....พ.ศ.....

Appendix G: The reflective journal prompt list

The reflective journal prompt list

- Note your immediate impressions about the interview.
- Reflect on what you have learned about the participant.
- Identify what has surprised you about the interview.
- Reflect on what you have learned as a researcher.
- Isolate your questions and determine whether they are direct or indirect.
- Did you ask the participant to tell her story in which ever way she would like?
- Did the participant take the lead?
- Did you ask what really matters?
- What are the gaps in the story?
- Which areas of the story could you attempt to explore next time?
- What are the person's strengths?
- Can you validate her actions?
- Can you identify readings, preparation or literature search that you may have to complete before the next interview or session in order to help you understand more about what might be happening?
- Does your analysis bring you closer to answering your research question? Developing the storyline

Appendix H: The analysis document 1 - 6

The following section is a complete example of my audit trail relating to the analysis process of Lee's story.

Document 1: Lee's Translated Story

The daughter's story: Lee

Two years ago I became sick and I was admitted to hospital. I then found out that I had the HIV infection. My dreams were shattered; I had hoped for a perfect family life. But I was very ill, and my husband thought I would die. He sought the support of his family. We moved from ... to live in his hometown in Chum Pae district¹ with his family. Then we both became very ill at the same time but while I survived my husband died. When it became known that I had the HIV infection it made many people show their prejudice. I felt they discriminated against me. I was very upset. I sat alone and cried. I asked why life is so difficult. I was often sad. But I survived that severe illness episode. The reason I wanted to continue to live is for my son. The last time I was ill I thought I would die. I asked my mother to look after my son if I should die. The doctor told me that I now have full blown AIDS so I have to take the ARV.

My main concern when I was first diagnosed was about my son. Some people did not allow their children to play with my son. The worst experience was when his school friends taunted him by saying "Like mother like son, your mother has HIV so you are bad boy too". My son was victimised. He found that he was blamed for instigating fights when playing with other children. He has since made a choice not to play with those friends. He avoided their company.

We now live in Khon Kaen with my mother. My son is doing well at school. His school performance is excellent: he came first in his class and won a scholarship to pay his school books for next year. He is good boy. And he will be in grade five in the next school year. He tells me he loves me.

¹ Chum Pae district* is a district in Khon Kaen province approximately 70 Km far from Khon Kaen.

We worry about each other. I have told him about his father's death from AIDS so that he knows should something happen to me. Pete is worried about me and reminds me to take my medications. I sometimes tell him "I don't know when will I die, I could die soon but I want to be alive until you grow up". I am disappointed that I cannot provide for all his needs. I do prepare his school uniforms. And I cook food for him except breakfast because that is rush time. We don't have a meal together because I worry that he might be infected eating with me. I earn only 30-60 Baht a day how can I save some for our future?

I work at home. Initially I was employed in the laundry shop downtown but because I was ill so often I had to quit the job. I work when I am not too tired. Fortunately I have financial support from my mother and the government.

Document 2: Significant statements

Becoming ill

Two years ago I became sick and I was admitted to hospital. I then found out that I had the HIV infection.

My dreams were shattered when I was diagnosed with HIV

*My dreams were shattered; I had **hoped** for a perfect family life. But I was very ill, and my husband thought I would die. He sought the support of his family.*

Returning back home to family

We moved from ... to live in his hometown in Chum Pae district with his family. Then we both became very ill at the same time but while ...

Dealing with death

I survived my husband died. When it became known that I had the HIV infection it made many people show their prejudice.

Being discriminated against

*I felt they discriminated against me. I was very **upset**. I sat alone and cried. I asked why life is so difficult. I was often **sad**. But I survived that severe illness episode.*

Motivation to continue living for her son

The reason I wanted to continue to live is for my son. The last time I was ill I thought I would die.

Future? Making plans for the future should I die

I asked my mother to look after my son if I should die. The doctor told me that I now have full blown AIDS so I have to take the ARV.

Discrimination: Pete was discriminated against

*My main **concern** when I was first diagnosed was about my son. Some people did not allow their children to play with my son. The worst experience was when his school friends taunted him by saying “Like mother like son, your mother has HIV so you are bad boy too”. My son was victimised. He found that he was blamed for instigating fights when playing with other children. He has since made a choice not to play with those friends. He avoided their company.*

Upheaval: Shifting house again

We now live in Khon Kaen with my mother.

About: Concerned but proud of son

*My son is doing well at school. His school performance is excellent: he came first in his class and won a scholarship to pay his school books for next year. He is good boy. And he will be in grade five in the next school year. He tells me he **loves** me.*

Disclosure of father’s HIV/AIDS

*We **worry** about each other. I have told him about his father’s death from AIDS so that he knows should something happen to me.*

Relationships: Mother and son relationship is strong

*Pete is **worried** about me and reminds me to take my medications. I sometimes tell him “I don’t know when will I die, I could die soon but I want to be alive until you grow up”.*

Worried about finance: Disappointed that there are financial constraints

*I am **disappointed** that I cannot provide for all his needs. I do prepare his school uniforms. And I cook food for him except breakfast because that is rush time.*

Interrupted routine in everyday life

*We don't have a meal together because I **worry** that he might be infected eating with me. I earn only 30-60 Baht a day how can I save some for our future?*

Finance: Finding suitable work that provides an income

I work at home. Initially I was employed in the laundry shop downtown but because I was ill so often I had to quit the job. I work when I am not too tired. Fortunately I have financial support from my mother and the government.

Document 3: Clusters

Shock being diagnosed

My dreams were shattered when I was diagnosed with HIV

*My dreams were shattered; I had **hoped** for a perfect family life. But I was very ill, and my husband thought I would die. He sought the support of his family.*

Upheaval

Upheaval: Shifting house again

We now live in Khon Kaen with my mother.

Returning back home to family

We moved from ... to live in his hometown in Chum Pae district with his family. Then we both became very ill at the same time but while ...

Illness and care

Becoming ill

Two years ago I became sick and I was admitted to hospital. I then found out that I had the HIV infection.

Death

Dealing with death

I survived my husband died. When it became known that I had the HIV infection it made many people show their prejudice.

Relationships & role of extended families & restructuring

Relationships: Mother and son relationship is strong

*Pete is **worried** about me and reminds me to take my medications. I sometimes tell him “I don’t know when will I die, I could die soon but I want to be alive until you grow up”.*

Changes & Interruption to everyday life

Interrupted routine in everyday life

*We don’t have a meal together because I **worry** that he might be infected eating with me. I earn only 30-60 Baht a day how can I save some for our future?*

Finance

Worried about finance: Disappointed that there are financial constraints

*I am **disappointed** that I cannot provide for all his needs. I do prepare his school uniforms. And I cook food for him except breakfast because that is rush time.*

Finance: Finding suitable work that provides an income

I work at home. Initially I was employed in the laundry shop downtown but because I was ill so often I had to quit the job. I work when I am not too tired. Fortunately I have financial support from my mother and the government.

Discrimination

Being discriminated against

*I felt they discriminated against me. I was very **upset**. I sat alone and cried. I asked why life is so difficult. I was often **sad**. But I survived that severe illness episode.*

Discrimination: Pete was discriminated against

*My main **concern** when I was first diagnosed was about my son. Some people did not allow their children to play with my son. The worst experience was when his school friends taunted him by saying “Like mother like son, your mother has HIV so you are bad boy too”. My son was victimised. He found that he was blamed for instigating fights when playing with other children. He has since made a choice not to play with those friends. He avoided their company.*

Disclosure

Disclosure of father's HIV/AIDS

*We **worry** about each other. I have told him about his father's death from AIDS so that he knows should something happen to me.*

About grandchildren

Lee About: Concerned but proud of son

*My son is doing well at school. His school performance is excellent: he came first in his class and won a scholarship to pay for his school books for next year. He is good boy. And he will be in grade five in the next school year. He tells me he **loves** me.*

Moving on

Motivation to continue living for her son

The reason I wanted to continue to live is for my son. The last time I was ill I thought I would die.

Making plans for the future should I die

I asked my mother to look after my son if I should die. The doctor told me that I now have full blown AIDS so I have to take the ARV.

Document 4: Constructs

Discussion

Nine people were interviewed. Lee gave a first person account being diagnosed with HIV/AIDS and the financial, physical and emotional impact this is having on her life. She has made a transit across Thailand and returned to a small abode in her birth village, a shelter which she now shares with her mother and her son, Pete. The five grandmothers and one grandfather talked about major upheavals in their lives when family members were diagnosed with HIV/AIDS and its subsequent consequences. Two siblings of people who had contacted HIV/AIDS, Mary and Norris, described the way in which they support their mothers and, with other extended family members, manage to hold the family together financial and emotionally. Five boys, Pete, Kenya, Golf, Feat and Ron and one girl, Lula, are the offspring of women who

have HIV/AIDS. Lula's mother is still alive but living elsewhere and I interviewed Pete's mother, Lee. Three mothers have died. I did not have ethical permission to talk with the grandchildren, but the nine people interviewed talked about these six children/adolescents.

The interview, analysis process and storyline writing was repeated for each transcript in both languages. I then compiled a list of all significant statements from each of the stories. I wrote up the commonalities as constructs based on these. In other research clustered text, commonalities or constructs might be called 'findings'. In this discussion section I will give details of the main constructs. There were commonalities in the nine stories, these were:

Shock at being diagnosed

My dreams were shattered when I was diagnosed with HIV

*My dreams were shattered; I had **hoped** for a perfect family life. But I was very ill, and my husband thought I would die. He sought the support of his family.*

Upheaval

Upheaval: Shifting house again

We now live in Khon Kaen with my mother.

Returning back home to family

We moved from ... to live in his hometown in Chum Pae district with his family. Then we both became very ill at the same time but while ...

Illness and care

Becoming ill

Two years ago I became sick and I was admitted to hospital. I then found out that I had the HIV infection.

Death

Dealing with death

I survived, my husband died. When it became known that I had the HIV infection it made many people show their prejudice.

Relationships & role of extended families & restructuring

Relationships: Mother and son relationship is strong

*Pete is **worried** about me and reminds me to take my medications. I sometimes tell him “I don’t know when I will die, I could die soon but I want to be alive until you grow up”.*

Changes and interruption to everyday life

Interrupted routine in everyday life

*We don’t have a meal together because I **worry** that he might be infected eating with me. I earn only 30-60 Baht a day how can I save some for our future?*

Finance

Worried about finance: Disappointed that there are financial constraints

*I am **disappointed** that I cannot provide for all his needs. I do prepare his school uniforms. And I cook food for him except breakfast because that is rush time.*

Finance: Finding suitable work that provides an income

I work at home. Initially I was employed in the laundry shop downtown but because I was ill so often I had to quit the job. I work when I am not too tired. Fortunately I have financial support from my mother and the government.

Discrimination

Being discriminated against

*I felt they discriminated against me. I was very **upset**. I sat alone and cried. I asked why life is so difficult. I was often **sad** but I survived that severe illness episode.*

Discrimination: Pete was discriminated against

*My main **concern** when I was first diagnosed was about my son. Some people did not allow their children to play with my son. The worst experience was when his school friends taunted him by saying “Like mother like son, your mother has HIV so you are a bad boy too”. My son was victimised. He found that he was blamed for instigating fights when playing with other children. He has since made a choice not to play with those friends. He avoided their company.*

Disclosure

Disclosure of father's HIV/AIDS

*We **worry** about each other. I have told him about his father's death from AIDS so that he knows should something happen to me.*

About grandchildren

Lee About: Concerned but proud of son

*My son is doing well at school. His school performance is excellent: he came first in his class and won a scholarship to pay for his school books for next year. He is a good boy. And he will be in grade five in the next school year. He tells me he **loves** me.*

Moving on

Motivation to continue living for her son

The reason I wanted to continue to live is for my son. The last time I was ill I thought I would die.

Future?

Future? Making plans for the future should I die

I asked my mother to look after my son if I should die. The doctor told me that I now have full blown AIDS so I have to take the ARV.

Document 5: Discussion

Discussion

Nine people were interviewed. Lee gave a first person account being diagnosed with HIV/AIDS and the financial, physical and emotional impact this is having on her life. She has made a transit across Thailand and returned to a small abode in her birth village, a shelter which she now shares with her mother and her son, Pete. Five grandmothers and one grandfather talked about major upheavals in their lives when family members were diagnosed with HIV/AIDS and its subsequent consequences. Two siblings of people who had contracted HIV/AIDS, Mary and Norris, described the way in which they support their mothers and with other extended family members manage to hold the family together financial and emotionally. Five boys, Pete,

Kenya, Golf, Feat and Ron and one girl, Lula, are the offspring of women who have HIV/AIDS. Lula's mother is still alive but living elsewhere and I interviewed Pete's mother, Lee. Three mothers have died. I did not have ethical permission to talk with the grandchildren, but the nine people interviewed talked about these six children/adolescents.

The interview, analysis process and storyline writing was repeated for each transcript in both languages. I then compiled a list of all significant statements from each of the stories. I wrote up the commonalities as constructs based on these. In other research clustered text, commonalities or constructs might be called 'findings'.

Seventeen (17) main constructs were identified in the close analysis of nine stories. (1) Being diagnosed with HIV/AIDS was a shock for all concerned. (2) There were major upheavals associated with changed living arrangements. (3) The person with HIV/AIDS was often sick and requiring ongoing support and care. (4) Most interviewees talked about death in the family and a few people were still grieving. (5) Grandmothers in particular 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. (6) Restructuring of families occurred, relationships changed, and there was often reliance on extended families for housing, financial and emotional support. (7) The impact on families as they were forced to adjusting to new ways of living and how they managed interruption to daily routines. (8) Financial difficulties were experienced by three families but five families made comments to changes they had to make to secure income. (9) Living in a close village community meant one's status was at risk if HIV positive status was revealed; there were rumours that disturbed families, judgments were made about 'bad' behaviours associated with sexual mores. (10) Discrimination was brought to my attention in all stories. (11) Disclosure, whether a child should be told about their parents or their own health status, was a problem for a few people. (12) All families used the services of Khon Kaen Regional Hospital. (13) Although I was not able to interview the children, all participants talked about their offspring. (14) I was interested in the way families were able to move on with their **lives**, so that constituted another construct. (15) I would like to contribute to transition theory so I made some preliminary notes on how people had made major transformations in their life. (16) One way to monitor the way in which people **have moved on was** to pay attention to what they said about the future. (17) One of the actions coming from these participants was their desire to initiate and support prevention of HIV/ AIDS programs in their community.

Being diagnosed with HIV/AIDS was a shock for all concerned.

Lee was devastated when both she and her husband were diagnosed with HIV. Her dreams of having a good family life were crushed. She became even more alarmed when she succumbed to an opportunistic infection, and had to seek help from her husband's family. When her husband died and she returned to her village, she did not convey this diagnosis to her mother. Sandy and Nancy found out from the physician in Khon Kaen Regional Hospital only because their daughters were critically ill. Lee had no choice except to confide in her mother that she was HIV positive.

Five grandmothers vividly recall receiving the HIV/AIDS diagnosis. It was a great shock and accompanied by feelings of anger and sadness. Anger because they usually found someone to blame; the women's partners, sad because they feared losing their child or grandchild. They may have been suspicious when their daughter or grandchild was unwell, or rumours may have reached them, but when they heard the actual words HIV/AIDS they were alarmed. Grace remembered looking at Feat, and thinking that '*he was so small*'. Grace collapsed when she heard. Sandy felt her heart break. Sue found her daughter to be desperately ill, emaciated and weak and four months pregnant. Sue daughter's diagnosis of HIV/AIDS was confirmed at Khon Kaen Regional Hospital. Receiving this diagnosis threw their lives into chaos.

Realising that shock often accompanies this diagnosis means that there is a potential role for health care professionals to provide support. Open, genuine communication with the willingness of the health care professionals to listen would be affirming to those in receiving this diagnosis. In addition those hearing for the first time that they have HIV/AIDS will be dealing with raw emotions, and there is so much information that has to be absorbed alongside their anger and disbelief. And then there are questions about life and death that may need to be answered.

There were major upheavals associated with changed living arrangements.

Upheaval

Upheaval: Shifting house again

We now live in Khon Kaen with my mother.

Returning back home to family

We moved from ... to live in his hometown in Chum Pae district with his family. Then we both became very ill at the same time but while...

Illness and care

Becoming ill

Two years ago I became sick and I was admitted to hospital. I then found out that I had the HIV infection.

Death

Dealing with death

I survived my husband died. When it became known that I had the HIV infection it made many people show their prejudice.

Relationships and role of extended families and restructuring

Relationships: Mother and son relationship is strong

*Pete is **worried** about me and reminds me to take my medications. I sometimes tell him “I don’t know when will I die, I could die soon but I want to be alive until you grow up”.*

Changes and interruption to everyday life

Interrupted routine in everyday life

*We don’t have a meal together because I **worry** that he might be infected eating with me. I earn only 30-60 Baht a day how can I save some for our future?*

Finance

Worried about finance: Disappointed that there are financial constraints

*I am **disappointed** that I cannot provide for all his needs. I do prepare his school uniforms. And I cook food for him except breakfast because that is rush time.*

Finance: Finding suitable work that provides an income

I work at home. Initially I was employed in the laundry shop downtown but because I was ill so often I had to quit the job. I work when I am not too tired. Fortunately I have financial support from my mother and the government.

Discrimination

Being discriminated against

*I felt they discriminated against me. I was very **upset**. I sat alone and cried. I asked why life is so difficult. I was often **sad**. But I survived that severe illness episode.*

Discrimination: Pete was discriminated against

*My main **concern** when I was first diagnosed was about my son. Some people did not allow their children to play with my son. The worst experience was when his school friends taunted him by saying “Like mother like son, your mother has HIV so you are bad boy too”. My son was victimised. He found that he was blamed for instigating fights when playing with other children. He has since made a choice not to play with those friends. He avoided their company.*

Disclosure

Disclosure of father’s HIV/AIDS

*We **worry** about each other. I have told him about his father’s death from AIDS so that he knows should something happen to me.*

About grandchildren

Lee About: Concerned but proud of son

*My son is doing well at school. His school performance is excellent: he came first in his class and won a scholarship to pay his school books for next year. He is good boy. And he will be in grade five in the next school year. He tells me he **loves** me.*

Moving on

Motivation to continue living for her son

The reason I wanted to continue to live is for my son. The last time I was ill I thought I would die.

Future?

Making plans for the future should I die

I asked my mother to look after my son if I should die. The doctor told me that I now have full blown AIDS so I have to take the ARV.

Document 6: Fourteen main constructs

There are final fourteen main constructs were identified in the close analysis of nine stories.

- (1) Being diagnosed with HIV/AIDS was a shock for all concerned.
- (2) There were major upheavals associated with changed living arrangements.
- (3) The person with HIV/AIDS was often sick and requiring ongoing support and care.
- (4) Most interviewees talked about death in the family and a few people were still grieving.
- (5) Grandmothers in particular 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.
- (6) Restructuring of families occurred, relationships changed, and there was often reliance on extended families for housing, financial and emotional support.
- (7) The impact on families as they were forced to adjusting to new ways of living and how they managed interruption to daily routines.
- (8) Financial difficulties were experienced by three families but five families made comments about changes they had to make to secure income.
- (9) Living in a close village community meant one's status was at risk if HIV positive status was revealed; there were rumours that disturbed families, judgments were made about 'bad' behaviours associated with sexual mores.
- (10) Discrimination was brought to my attention in all stories.
- (11) Disclosure, whether a child should be told about their parents or their own health status, was a problem for a few people.
- (12) All families used the services of Khon Kaen Regional Hospital.
- (13) Although I was not able to interview the children, all participants talked about their offspring.
- (14) One of the actions coming from these participants was their desire to initiate and support prevention of HIV/ AIDS programs in their community. All constructs show transition in people's lives.

Omitted construct, (14) 'move on'. (15) 'Transition' and (16) what participants say about the future.