

# 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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## 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

## I. BACKGROUND TO THE STUDY

The Human Immunodeficiency Virus (HIV) and the set of symptoms associated with opportunistic illnesses known as AIDS (Acquired Immune Deficiency Syndrome) are recognized as a major global health issue. In 2008 there were estimated to be around 2.7 million people newly infected with HIV, of these approximately 2.3 million were adults and 430,000 children under 15 years of age (UNAIDS, 2009).

In Thailand, there were more than 1 million people infected with HIV and around 430,000 adults were living with HIV (Punyacharoen and Viwatwongkasem, 2009). In Thailand E-San<sup>1</sup> society and local traditions emphasize and respect the concept of 'faithfulness' between husband and wife as the foundation of family life so it is not surprising that HIV infection is viewed as evidence of unacceptable behavior. People with HIV/AIDS not only have to deal with health problems but also suffer from social discrimination and stigmatization (Klunklin and Greenwood, 2005, Knodel and Center, 2006, Wisersith et al., 2004).

The impetus for this study began with my work experience in the "WHO AM I, WHY I AM HERE?" project which is a program for children affected by HIV infection and conducted in Khon Kaen, a large province in the northeast of Thailand which comprises 26 districts 198 subdistrict and 2,307 villages. Khon

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<sup>1</sup> E-San is the North-Eastern region of Thailand

Kaen is located at the Northeast. Its poor soil makes low agriculture productivity and many of its people are poor. While I was working with children who were infected with HIV/AIDS it occurred to me that something needed to be done to assist families whose lives have been affected by HIV and/or AIDS and this motivated my research.

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. In relation to this I found 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. It is not known how families incorporate new roles into their daily lives. Therefore my study seeks to address this gap in the literature.

This research enabled me to work alongside families who are living with HIV and/or AIDS. Its setting was a community in E-San which is the rural area of North-Eastern of Thailand. The significance of this study is that it will provide insight into participating families' relationships and roles. This research enabled me to work alongside families who are living with HIV and/or AIDS. Its setting was a community in E-San which is the rural area of North-Eastern of Thailand

## II. RESEARCH QUESTION

My study's research question is:

What can be done to assist families whose lives have been affected by HIV and/or AIDS?

## III. AIMS OF THE 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; and
- 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.

## IV. LITERATURE REVIEW

This section contains the literature reviewed for the study including; the search strategies, information on HIV/ AIDS and the impact of HIV/ AIDS infection, particularly in Thailand.

### A. *Information on HIV/ AIDS*

In this paper the terms HIV and AIDS are always linked, for two main reasons. First Thai villagers tend to associate one with the other, not understanding that they are different because in their experience people, who living with HIV inevitably develop AIDS, thus making it difficult for them to identify the difference between HIV and AIDS. Secondly, there are several articles or scholarly papers, written in relation to Thailand, which focus on and discuss HIV and AIDS together. (WHO, 2002).

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). Unless the person receives antiviral therapy, or is involved in a program for the prevention of opportunistic infections, illness progresses alongside the destruction of the immune system. When the destruction of immune competency takes hold, the person is likely to have 'full blown AIDS' and experience a host of opportunistic infections such as tuberculosis, pneumocystis carinii

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(PCP), toxoplasmosis and cryptococcus. Some infections can spread to a number of different organs, a situation known as ‘disseminated’ or ‘systemic’ disease (Pratt, 2003). Many of the opportunistic infections that occur at this late stage can be fatal (Ruyter, 1996, WHO, 2002).

### *B. HIV transmission*

There are three potential ways that HIV can be transmitted. The first of these is through blood or sexual fluids; the second is via transmission from mother to child during pregnancy, birth and/or via breast milk from an HIV infected mother; and the third via the contaminated needles used for injection.

Surasiengsunk et al (1998) asserted, that sexually promiscuous behavior is a driving force in the HIV epidemic (a moralistic assertion not taking into account the impact of prolonged marital separation necessitated by financial circumstances, however consistent with current Thai mores). Furthermore, Rongkavilit et al. (2007) emphasized that ‘risky’ health behavior amongst the HIV infected youth in Bangkok is a serious issue amongst both young men and women. They identified that 20 of the 45 (44.4%) young people who volunteered for HIV testing reported that they had sex in the previous 30 days without using condoms. This placed them at risk of either contracting or, if HIV positive, spreading HIV. Ford & Chamrathrithrong (2004) noted that of 3426 migrant workers in the southern coastal and northern areas of Thailand in 2004, 25% of the participants reported visiting sex workers and 6% reported having sex with other non-regular partners.

Transmission of HIV in the intravenous drug using (IUD) population largely occurs through the users sharing needles with people infected with HIV. Beyre (2007) suggested that the risks of the spread of HIV infection among injecting drug users (IDUs) arise from needle sharing and equipment lending and borrowing. Strathdee et al (2006) identified efforts to increase education about the safe use and disposal of needles by all drug users, as well as initiatives such as those enabling needle exchange and methadone programs, have been increased in an attempt to address HIV infection in intravenous drug users.

### *C. Background to the development of the HIV & AIDS pandemic.*

HIV has emerged as a global health issue since 1981. Since then the global AIDS pandemic has become one of the greatest threats to human health. Originally HIV/ AIDS were promoted as a sexual transmitted disease associated with homosexual contact. Unfortunately, despite evidence to the contrary, the stigma associated with this has remained a dominant theme in popular culture, which is a significant obstacle to appropriate intervention policies, such as clean needle depots, condom use among sex workers and the PMCHT program mentioned above.

In the instance of HIV infection, there is often a long, silent period known as the “latency period”. 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 how quickly this occurs may depend on the 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 nutrition status and prevention from opportunistic infection (Ford and Chamrathrithrong, 2007). Because of the ‘silent period’, many people with HIV do not know that they are infected (Ford and Chamrathrithrong, 2007) therefore, they may pass their infection on to their partners and/or children. More recently married women have been identified as “at risk” groups for HIV/AIDS because they are frequently infected by their male partners (Sinprajakpol et al., 2004).

E-san the context of the proposed study is the most drought-affected area in Thailand. These harsh conditions mean that many men, because of their role as primary breadwinners must be relocate to other areas of Thailand in order to find work and earn a living. Stay away far from family causes men visit sex workers consequently they might get HIV infection from unprotected sexual.

Sinprajakpol, Plipat, & Rattanasuporn (2004) conducted research in Pattanee<sup>2</sup>. There were 282 AIDS cases (31% of all AIDS patients) among fishermen in Pattanee. These authors identified that the AIDS problem among fishermen in Pattanee is the most important priority for health care providers to act upon in terms of prevention in this extremely vulnerable population

#### *D. The impact of HIV/AIDS infection*

The HIV infection and the subsequent AIDS illnesses have physical and psychological consequences and these potentially negative consequences affect people living with HIV themselves as well as their family members, including their children, parents and other relatives (Rodsom and Tangjareansatean, 2005, Foster, 2007). There are four aspects that negatively affect people who are living with HIV/AIDS including: physical disabilities, psychological distress, prejudice and stigmatization by their community and financial distress.

#### *E. The impact of HIV/AIDS infection among People living with HIV/AIDS*

Mawar et al, (2005) state “Infected people are blamed for causing the condition through their risky behaviour” India for example, as in Thailand, people living with HIV/AIDS are stigmatized because their disease is related to behaviors that are not socially acceptable. HIV/AIDS is often related to behavior which goes against religious and traditional moral beliefs and therefore HIV/AIDS is thought to be the result of deviant behavior and consequently deserving punishment (Visser et al., 2006). These behaviors are considered deviant in Thai communities (Janjaroen and K, 2001, Knodel and Center, 1996, Knodel and Center, 2006) as in other communities, despite their widespread occurrence.

Community members may fear any person living among them who is HIV positive as a threat to their safety. They possibly associate HIV as an incurable disease with devastating consequences. Unfortunately, as a result of such attitudes people living with HIV/AIDS are therefore shunned and vilified by the other ‘upright citizens’ (Mawar et al., 2005, Moskowitz and Wrubel, 2005). People in the community often have little or no understanding about the disease (WHO, 2002, Apinundecha, 2007 ) or how it is contracted, which increases their level of fear (Knodel and IM-em, 2003, Donnell, 1996). Thai people will not openly discuss their sexual practices, and are therefore extremely uncomfortable in open discussions regarding HIV/AIDS (Plipat et al., 2004, Rojanapithayakorn and Hanenberg, 1996), which makes effective education difficult.

It is apparent; in Thailand that families in which one or more family members suffer from HIV/AIDS usually experience economic difficulties (Janjaroen and K, 2001, Knodel and IM-em, 2003, Knodel and Center, 2006, Wijngaarden and Sheldon, 2005). Wijngaarden & Sheldon (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).

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 recognized that the average annual Thai family income stands at US\$ 876<sup>3</sup> (Steinbrook, 2007).

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<sup>2</sup> Pattanee is a province in southern coastal of Thailand

<sup>3</sup> The original article speaks of Thai Bath, but I have converted it into US\$, as a universally recognised currency.

#### *F. The role of elderly parents in Thailand*

In Thailand the traditional extended families are still the norm. Older generations contribute to the care of the family and in the circumstances discussed in this paper, 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. 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 (Knodel.J et al., 2001). This study 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 situation.

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.J et al., 2001). 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 the infected disease for example tuberculosis (TB). Additionally the health of older people may suffer through physical strains associated with care, for example exhaustions from caring for HIV/AIDS adult children.

Stigmatization 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 stigmatization regarding HIV/AIDS in a South African community. The study demonstrated that 17% of respondents had a high stigmatizing attitude follow by 42% who perceived a high level of stigmatization by others in community. These results demonstrate that **more than one half** of people living with HIV/AIDS and their families are affected by the stigmatization from their community.

#### *G. Orphans who experienced loss of their parents through HIV/AIDS.*

Internationally, the orphan crisis caused by the human HIV/AIDS pandemic remains a serious issue with long-term social consequences (Safman, 2004, Crampin et al., 2003, Birdthistle, 2004). Children are directly affected by HIV/AIDS when they are orphaned as a result of their parents' AIDS related deaths. There are three major aspects, which are discussed in the literature: physical health issues; psychological issues and social issues. Orphans may also be HIV positive, as a result of mother to child transmission, or other ways of transmission, such as open wounds. Many HIV infected children come from poor families, and do not have access to adequate health services and they may not be able to afford ARV therapy, which is important to improve their physical health (Janjaroen and Khamman, 2002). Consequently these infected children are more likely to become sick more often.

Pancharoen & Thisyakorn (2003) revealed that children who were infected with HIV often had impaired development, multiple and prolonged hospitalization and early death. Moreover, family financial stress forces children to be at risk for malnutrition and the lack of basic items like clothes, medicines and accommodations. Similarly, the report of "Children on the Brink 2004" by UNAIDS (2004) claimed when children become orphaned, they may also experience increased vulnerability. This report found that without the care of parents or an appointed caregiver, children may face malnutrition, poor health, inadequate schooling, migration, homelessness, abuse and may be in the position of having to bring up younger siblings. Orphans who experience the loss of their close relatives and /or parents as a result of HIV/AIDS are at the additional risk of their relatives abandoning them at state orphanages and do not receive HIV treatment (Tulloch et al., 2004). It is hard to imagine a child seeing, his or her parent becoming, little by little, sicker and sicker and dying. One further issue that has been noted to impact orphans is changing family structures (Knodel, 2006). 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 labors in order to survive because they live with caregivers who are either too old or too young to adequately provide for their needs. The Thai literature does not reveal such hardships, however this study will explore these issues in the context of Thai families' experiences.

## V. SUMMARY OF LITERATURE REVIEW

I have provided a critical review of the literature relating to the topic of my study. 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. Little is known about 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 and yet this is an increasingly common situation in Thailand. My study seeks to address this gap in the literature and is likely, depending on what participating family members tell me in the course of my data generation, to also provide some insight into positive, as well as negative factors associated with this experience.

## VI. METHODOLOGY

Participatory Action Research (PAR) was selected because it enables the researcher to work alongside, listen to, capture and address the experience of families living with HIV/AIDS in this Thai village. Although the literature around the topic of HIV and AIDS is prolific, it appears that researchers have not listened to the voices of families who are currently caring for children of relatives who have died from HIV/AIDS. This study seeks to address this gap and will enable me to explore, using a participatory action research methodology, participants' experiences of providing this care, the issues this raises for them and the care-giving strengths they might reveal. It also enabled me to work alongside families as 'we' prioritise identified issues and celebrate the strengths. It is hoped that actions decided upon by participants will be sustained after the researcher leaves the field.

PAR enables people to contribute to overcoming their own oppression so that they can build on empowerment process (Koch & Kralik, 2006:p14). This methodology is suitable for my research for three main reasons:

- People living with HIV/AIDS and their families are a vulnerable population because of stigmatization and isolation, and they have little opportunity to speak up for themselves. PAR is an emancipator approach that seeks to empower people and build their confidence in expressing their experiences and difficulties
- PAR provides a way of exploring participant experiences and working with them to address the issues that they prioritize
- PAR enables a planning process to address issues related to the topic in a sustainable way.

## VII. THEORETICAL FRAMEWORK FOR THE STUDY

In 1937 Critical Social Theory (CST) was defined by Max Horkheimer of the Frankfurt School of Social Science (Lindsey et al., 1999). Lindsey and colleagues (1999) also declared that the main point of CST is that knowledge does not exist separate from the knower. Furthermore Streubert & Carpenter (1999) defined "critical theory as a philosophy of science based on a belief that revealing the unrecognized forces that control human behavior will liberate and empower individuals". The focus of critical theory is on consciousness raising which arises throughout the process of critically questioning the taken for granted during reflective participatory discussion, and action to address the authority imbalances and thereby end oppression (Freire, 2000). The aims and process integral to PAR, reflect these theoretical concepts in that they enable researcher and researched to work alongside each other in a process that encourages critical questioning of taken for grants in a supportive environment and, through this process enables consciousness raising, of both the researcher and participants. This research process enables sustained change that can continue after the researcher has left the field.

## VIII. PARTICIPANTS IN THE STUDY

Five families were recruited in the study. The definition of family applied in this study is the unit of people who are living together and are biological family members caring for children who have lost one or both parents due to HIV/AIDS.

### A. *Setting*

Data collection for the study was conducted in a rural community in Khon Kaen, which is in North – Eastern, Thailand.

### B. *Recruitment Process*

The issue of HIV infection is a sensitive topic in my country. Therefore It was essential not only to ensure their participation in the study was voluntary, but also that I maintained confidentiality of my participants and their families as a whole.

I asked the community nurse who works in the primary health setting, which is located in the study field, to mention the study to people visiting the village health care clinic and invite them to take a copy of the study information statement, consent form and stamped addressed return envelope if they were interested in learning more about it or in participating in it. The information statement provided my contact details for families who wanted further information about the study, and a request to them to sign and return the consent form if they wished to participate in this study.

## IX. METHODS OF STUDY

### A. *One to one interviews*

One to one semi-structured in-depth interviews were conducted with participants in the study. This ensured that participants who were willing to tell me their story but who might have been uncomfortable about talking in a group, unable to attend a group or wishing to maintain the confidentiality of the information in their story (Koch and Kralik, 2006) had the opportunity to do this.

With the permission of the participants I audiotaped the interviews, advising that the tape could be switched off at any time they wished. The one-to-one ‘interviews’ were designed to provide participating family members with an opportunity to tell their story about caring for a child or children in their family who had been orphaned as a result of their parents dying from HIV/AIDS. The story telling was facilitated by the use of prompts, which were phrased around the terms Look, Listen, Act used in Koch and Kralik’s (2006) model of PAR. I informed participants that I would provide them with a summary of their story captured during interview, invite them to edit this without providing any reason for the removal or alteration of any part of it, and return, if they permitted, to again talk to them, review and discuss the summary of their story and clarify issue arising from it.

Immediately after each interview, I transcribed the audio recording and created a Microsoft word document. This resulted in a short summary of what appeared to be, to the researcher, the key aspects of their story. I met with each participant to provide and discuss their summary story. This enabled validation of the summary story prior to further story clarification and development discussions if and when participants agreed to these.

### B. *Observation conducted during interviews, use of Field Notes and a Reflective Journal*

During the interview, I noted all of the participant’s non-verbal expressions in the field notes. These include, for instance, body language, and emotional expressions. This proved extremely important because the topic of the study was a very emotional one for participants as well as an emotional experienced for me in the researcher role. I found I was unable to do more than a single interview on any one day because of the extent of emotional fatigue I experienced listening to these participants’ stories. Nevertheless, through

this story telling process and the stories themselves participants enabled me to gain a deeper understanding or their situation and all the complexities they experienced in their lives resulting from it. Documentation in a reflective diary also enabled me to capture my thoughts and feelings about these families, their situation and my interaction with them. These were all part of this research.

### C. PAR Group discussions

At the start of the research it was unclear whether or not participants would want to engage in addressing and acting on issues they raised individually or whether they would want to do this within a PAR Group discussion. I gave families the opportunity to take up either or both of these options. After several individual discussions, all participants chose to be part of a PAR group. This afforded them the advantage of accessing possibly greater motivation towards action and the opportunity to learn from others who had similar experiences, thereby reducing their sense of isolation and stigmatization (Koch and Kralik, 2006).

## X. ROLES OF RESEARCHER

The major strengths as a researcher in using PAR is that it enabled me to. I “walk alongside” those who participated in this research. I also listened to the participants making every effort not to judge them. Of particular importance in this situation was that I made every effort during this data generation phase to ensure participants’ confidentiality.

A process of reflection on the information that the participants divulged is also an important role in the research process. This process of personal reflection, coupled with reflecting to the participants what I understood them to have said, lead to my facilitation of discussions of ways in which the participants felt they were able to enhance their lives and reduce their distress levels.

## XI. PARTICIPATORY ACTION RESEARCH

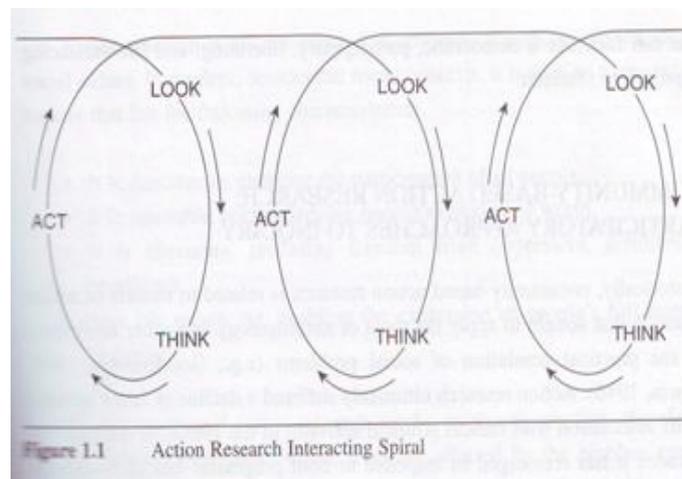


Figure 1. Action Research interacting Spiral Source (Stringer, 2007).

Data generation followed the cyclical PAR process of looking, acting and thinking outlined in Figure 1. Throughout the data generation phase of the study I was concerned with its evaluation component, an essential process in PAR. Chenail, George, & Wulff (2007) declared an evaluation process must be included in action research in order that the quality and outcome of the process be assessed and recorded. There are two main types of evaluation; formative evaluation and summative evaluation. Formative evaluation occurs throughout the implementation of the PAR data generation process and summative evaluation occurs at its conclusion (Streubert and Carpenter, 1999). In the PAR process, continual validation by participants of feedback data works in the same way as process evaluation.

## XII. DATA ANALYSIS

Data in this study comprised verbatim transcripts of audio tape-recorded interviews, field notes and my reflective journal. All of these data were analysed using a ‘look, think and act’ process which enabled identification of themes and resulted in the development of individual families’ summary stories, and a summary ‘story’ of issues common to all participants. This summary story of issues emerging in the data was presented at the PAR group and participants discussed and addressed each of these issues during the PAR group discussion. All data in the study was captured in Thai language, which required translation into English.

In order to ensure participant confidentiality I transcribed all of the interview recordings myself. However for the translation process I worked with my field supervisor in order to move from “spoken” Thai, to “spoken” English: moving backwards and forwards together to obtain the closest possible accurate and meaningful translation.

## XIII. ETHICAL CONSIDERATIONS

Ethical considerations in this research are avoidance of physical and psychological harm, identifying (relating) the benefits from research, and respect for human dignity, and justice (Polit and Hungler, 2004). I ensured that my participants would not face any moral or ethical dilemma as a result of my study (Polit and Beck, 2006). I was mindful of four major issues; research merit and integrity; justice; beneficence and respect (The University of Newcastle, 2007).

This research study received ethical clearance from

- The University of Newcastle Human Research Ethics Committee H-2008-0325 and
- The Human Research Ethics Committee of Khon Kaen University HE522028

## XIV. PRELIMINARY FINDING

This paper reports the preliminary findings of the first phase of this research. In this phase there were ten participants from five families, and two community nurses who worked in the Primary Health Unit. The study’s one to one interviews were conducted from April 2009 to August 2009, and its PAR group discussions were accomplished between September 2009 and January 2010

Most families’ participants were grandparents and aunts who were motivated by their familial relationship to care for the orphans. The participants were aged between 37 and 69 years old. They reflected features typical of a Thai village population in terms of their education, socioeconomic status and employment. All participants graduated from primary school. They are farmers and complement their family income by selling food that they collect from farms or ponds, for example fishes and vegetables. Some participants work in the construction fields as construction labor.

The most general concern expressed by participants was who would look after their orphans in their absence because most of them were elderly. The participants worried who would continue to look after their orphaned children after their deaths. The participants had raised this concern with their other family members. It raises the possibility of a lack of caregivers for these orphans in the near future.

Another concern was financial distress in these families because they had lost the family breadwinners and they were not able to access social welfare. Furthermore the range of income for these families extended from 3,600 Baht (Aus \$ 120) to 9,000 Baht (Aus \$ 300) per month. The elderly participants could not earn sufficient income to provide a comfortable life for their family members. However, the Thai government provides the following aid to people who are living with HIV/AIDS and affected families of people who are living with HIV/AIDS. This aid is as follow

- Local government subsidizes funding for people who are living with HIV/AIDS for 500 Baht (Aus \$ 17) per month

- Social Development and Human Security office provides aid for affected family also for 2,000 Baht (Aus \$ 66) for each family per year.

One family in my study had not yet received this funding, even though they meet the funding criteria. Lack of access to information that would enable them to access this funding was found to be the main reason that prevented this family securing it.

In addition, the orphans themselves experienced community stigmatization resulting in their rejection by school personnel, thus excluding them from education and isolation, which meant they had few or no friends. The experience of and extent of stigmatization varied across participants, however one participating family was being verbally insulted by a neighbor and this had continued for seven years. It was a painful experience for them particularly the orphans concerned who in that time had grown to be teenagers who could not longer tolerate this situation.

These results were summarized and presented within the PAR group members in the second phases of the study, which is not including in this presentation. They plan for action had been released.

## XV. DISCUSSION AND CONCLUSION

In this paper I have sought to outline my study, its process and its preliminary findings. I am currently conducting in depth analysis of the data and this will enable me to engage in more detailed, critical discussion of the findings in the light of what is already known in the literature.

I was humbled by the opportunity this study provided me for working alongside this vulnerable group of participants. Participants shared with me that their experience of being involved in research studies in the past had not been in any way similar to their participation in this study. Being listened to by the researcher appeared to be much appreciated by the participants. This, they said was because previously the researcher have taken information from them but they had not felt really involved in these studies, nor had they had the opportunity to gain personally from them. These participants were grateful to participate in a study where they were really listened to, heard and empowered to take action.

My involvement in the role of researcher in this PAR enabled me to develop my active listening skill. In addition, one to one interview were a very useful strategy to gain more understanding about each participant's and to hear their story about his or her circumstance and experience of the topic. Nevertheless, it took a long time to establish trust between researcher and participants. The PAR approach allowed me to work alongside this vulnerable group of participants and enabled us to build a trusting relationship which enabled us to share information that might not have been so readily forthcoming without this relationship and trust.

The ongoing process of Looking, Thinking and Acting in a cyclical way in this PAR process in which researchers and participants, *systemically work together in cycles* to explore concerns, claim or issues impacting upon or disrupting people's lives" (Koch and Kralik, 2006) provided participants with a model that they found useful and would be able to use in a sustainable way to address issues in the future.

Finally, this presentation has focused on preliminary finding from my study. My intention is to conduct an in depth analysis of my data and the critically review it in light of the literature. The methodology used in my study and the opportunity it gave me to work alongside participants in a mutually trusting way is likely to enable me to identify new knowledge on this topic.

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