

# STIGMA: THAI FAMILIES LIVING UNDER THE SPECTRE OF HIV

Juraporn Tangpukdee<sup>1</sup>, Diana Keatinge<sup>2</sup>, Kessarawan Nilvarangkul<sup>3</sup>, Tina Koch<sup>4</sup>

<sup>1</sup>PhD, Nursing, Faculty of Nursing, Khon Kaen University, Thailand

<sup>2</sup>Professor Paediatric, Youth & Family Health Nursing, School of Nursing and Midwifery, the University of Newcastle, Australia and Hunter New England Local Health District, USA.

<sup>3</sup>Director of the research and training centre for enhancing quality of life of working aged people, Faculty of Nursing, Khon Kaen University, Thailand.

<sup>4</sup>Adjunct Professor, School of Nursing and Midwifery, Flinders University of South Australia, Adelaide, Australia.

\*Corresponding Author Email: c3064883@uon.edu.au, juraporn.tangpukdee@uon.edu.au

## ABSTRACT

This inquiry took place in one of the poorest region of North Eastern Thailand, Isan. The research question revolved around the actions to be taken to assist Thai families whose lives have been affected by HIV and/or AIDS. There were abundant literature around stigma, orphans and caregivers, but none had woven topics together to explore the condition of Thai families living under the spectre of HIV. In this inquiry, participants were asked to talk about their experiences, their accounts, their events and their stories. The research team consists of four members: a bilingual Thai Ph.D. candidate and her three supervisors and the inquiry took place in 2009-2010. Koch and Kralik's (2006) participatory action research (PAR) approach had been adopted as inquiry methodology in this work. This methodology consists of two distinct phases. Phase one was storytelling (one to one interviews with each participant) consisting of nine participants from five families. Caregivers were predominantly grandmothers. Stories for commonalities of experience were analyzed (referred to as construct). The families experienced stigma and discrimination as the most dominant construct. The second phase of the methodology was a PAR group discussion with the same nine participants and local community health nurses, holding four PAR groups, spaced at monthly intervals. Patient living with HIV not only suffer the dramatic disruptions in their lives but they also need to confront a community viewing them as less than a normal member. We suggest that our role as health care professionals could be focused on enabling people to confront their fears in tackling the social world.

**Keywords :** Isan, HIV, participatory action research (PAR), construct, community

## INTRODUCTION

Living under the spectre of HIV is not well understood. It was required to analyze what Thai families had to say about living with HIV. The research question was: What can be done to assist Thai families whose lives have been affected by HIV and/or AIDS?

It is important to assess current research work revolving around HIV-stricken families in Thailand and to identify how the inquiry has been positioned. The concept of the stigma is the major interest of this work, the impact of stigma of people living with HIV/AIDS and the influence of stigma in the everyday life of families. For the purposes of this inquiry, our definition is that a family is a social group sharing a

common ancestry and having a long-term commitment to one another. An orphan is a child who has lost one or both parents.

In the third decade of the HIV, epidemic stigmatization 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 minimize transmission of HIV (Bowtell, 2007). These Grim Reaper messages were

frightening, and defined characteristics of people who were identified as threatening agents of infection like the sex workers and drug users .

In the 1990s in Thailand HIV/AIDS was campaigned as an infection associated with certain groups e.g. Men who have sex with Men, Intravenous Drug Users and Commercial Sex Workers. 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 mother to child transmission programs (PMCHT) (Mawar *et al.*, 2005).

Most research on HIV/AIDS in Thailand is carried out at Chiang Mai Research Centre, Northern Thailand. The majority of research is biomedical with a keen interest in developing HIV vaccines. The social health research team at Chiang Mai has a strong youth research program but even this has a measurement arm e.g. it is quantitative research while qualitative research is non-existent at this centre. Some work on stigma and HIV has been reported by the Chiang Mai group (Maman *et al.*, 2009) although several countries took part in their study 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 the young people of Thailand (Renwick, He & Gu, 2011).

A study on grounded theory was done to study how primary caregivers managed problems when caring for children with HIV infection in Thailand (Thampanichawat, 2008). Grandparents had suffered as a result of the stigma of AIDS while providing care for children with HIV. Furthermore, the grandparents experienced increase 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.

Yet another study (Kittikorn, Street & Blackford, 2006) conducted a longitudinal ethnographic case study in Thailand 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 choose to disclose their infection status or still conceal it as a secret. Furthermore, Thai women who participated in the study often reported that they were afraid of experiencing aversion from others in their social network because they were HIV positive.

The United Nations General Assembly Special Session on HIV/AIDS (UNGASS) acknowledged that stigma associated with HIV/AIDS is still a major concern, and the eradication of stigma and aversion toward people living with HIV/AIDS is the foundation for effective solutions. This paper attempts to assess the effect of stigma in the everyday life of Thai villagers who live with HIV/AIDS and ask them for ways in which they might address their concerns collaboratively.

Goffman's classic work *Stigma: Notes on the Management of Spoiled Identity* defined three types of stigma. The abomination of the body is the first characteristic. AIDS fits this category in the terminal stages of AIDS when marked on the body by its wasting syndrome and sometimes by the lesion of Kaposi's syndrome. Such images stir up fear in the community at large. Clinically whether a person has AIDS is a matter not only of seropositivity (being infected with HIV, the human immunodeficiency virus) but also having an immune system so weakened that one is subjected to a number of opportunistic infections such as pneumocystis pneumonia. Until Antiretrovira treatments became available being diagnosed with AIDS was tantamount to a death sentence. The idea is that a person infected with HIV/AIDS is automatically sentenced to death and are marginalized as the carriers or hosts of a deadly transmissible disease. But a diagnosis of HIV will no longer be a condemnation to death in the near future.

The second of Goffman's characteristic is the blemish of individual character: often those infected with HIV are seen as lacking control, as immoral or promiscuous. Often the first question in people's minds

when hearing about someone diagnosed with HIV is how he or she contacted the virus and to determine the degree of responsibility or culpability of the person infected. If the trait is identified is sexual orientation or promiscuity the effect is to treat the seropositive person as somehow deserving HIV because of its roots in their behaviour. This illness flushed out an identity that might have remained hidden from employers, neighbours, family and friends. Hence Goffman's term spoiled identity.

Third and probably relevant in the Thai context are what Goffman calls tribal stigmas of race, nation or religion. This is when strong traditional ways of conducting one's life are promulgated. Here we turn to the Buddhist philosophy in conducting one's life in Thailand. 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. The foundation of Buddhism is based on the Four Noble Truths: (1) suffering (Dukkha) (2) cause of suffering (Samudāya) (3) the end of suffering (Nirodha) 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. Understanding the wheel 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 *et al.*, 2010). Certain groups e.g. men who have sex with men, intravenous drug users and commercial sex workers carry a weighty stigma because they cut through each of Goffman's categories: an undesired difference. Goffman's (1963) explains stigma as "... the situation of the individual who is disqualified from full social acceptance". People living with AIDS suffer the biological consequences of a terrifying, fatal disease as well as deep social stigma. But that was in the 1990s. Yet some of these characteristics of stigma are evident today, particularly in traditional Thai society.

Deacon, (2006) and others have identified stigma as a major barrier to health care. HIV-related stigmatization remains a potent stressor for HIV-positive people (Natale, *et al.*, 2010). Deacon argues that a theory of stigma would help researchers to move from theory into practice and develop a comprehensive measurement tool for stigma and advance the

evaluation of anti-stigma interventions. According to Hamra, *et al.*, (2006) it can be stated that we need programs focused on stigma reduction. He argues that evaluating the impact of these programs depends on having a good set of measures that effectively capture and distinguish the complexities of HIV stigma. It is interesting that Genberg *et al.*, (2008) have recently developed scales to measure stigma. Their HIV/AIDS-related stigma scale has strong psychometric properties. Our interest is not so much on the scale but the main factors related to stigma. The authors have identified as (1) shame, blame and social isolation (2) perceived discrimination (3) equity. In conclusion, the definition of the stigma that we will adopt for this inquiry is that stigma is an attribute that is deeply discrediting.

## METHODOLOGY

Koch and Kralik's (2006) participatory action research (PAR) approach had been adopted as inquiry methodology in this work. This methodology consists of two distinct phases. Phase one is storytelling (one to one interviews with each participant), collaborative construction of their story, then an analysis of all stories in the effort to find commonalities of experience. Nine participants from five families were interviewed, many several times. Fourteen constructs were developed to describe their commonalities. The families experienced stigma and discrimination as one of the most dominant constructs. Another construct that we have named financial impact was experienced as the most crippling.

The second phase of the methodology was a PAR group discussion. Although our participants were willing to join the PAR group most said that they did not want to discuss their own story that they had shared with us during interview or talk about the problems they had raised in their story; individuals did not want to share their private stories in public. Nine adult participants agreed to meet with the facilitators and community nurses. Prior to meeting participants set the agenda for discussion. This included rumour and discrimination as items for discussion. We held four PAR groups, spaced at monthly intervals.

Ethical approval was granted by the University of Newcastle, Australia, and Khon Kaen University, Thailand. Principles guiding this inquiry were:

democratic principles - social justice, social equity, freedom of speech and human rights. PAR demanded a systematic and rigorous data generation/ analysis process, responsive reflection and a documented account of the PAR process whilst researching. The protocols of PAR analysis frameworks are published elsewhere: lack of word space prevents further explication here.

**RESULT AND DISCUSSION**

**Storytelling**

In Thailand, the story of AIDS has not even begun to be witnessed in personal narratives. In this inquiry, participants were asked to talk about their experiences, their accounts, their events and their stories. Looking, thinking and acting invited active reconstruction of the story line. As we listened, it was noted that the PAR process actually pushed people to focus on previously invisible aspects of their lives. Freire's (1970) concept of praxis flows from the position that action and reflection are the same side of the coin: action and reflection go together. The shaping of the story, analysis and editing were done in collaboration with participants in the Thai language. Nine stories were generated with participants and Koch and Kralik's analysis protocol was used to gather words into a storyline that was acceptable to participants. Participants were in receipt of their own stories. Later stories were translated into English in collaboration with three Ph. D. supervisors. Participants from five families (names are fictional) are:

1. Family One: Sandy is a grandmother. Lee is her daughter living with HIV/AIDS and her nine year old orphan son is called Pete.
2. Family two consists of Nancy who is the maternal grandmother of two orphans, Kenya and Golf.
3. Family three is made up of husband and wife, Tracy and Noi, who are grandparents to orphan Lula.
4. Family four comprises Grandmother Grace, her daughter Mary and orphan Feat.
5. Family five consists of Grandmother Sue, her daughter Norris and orphan Ron.

Grandparents were the main carers of orphans.

This work has selected short excerpts of stories that were generated in one to one interviews to show what

was said about stigma. These were private accounts (Table 1).

**Table 1: One to one private encounter sessions**

| Name of the participants | Information about the participant   | Report about own experience of HIV stigma  |
|--------------------------|---|--|
| Sandy                    | Lee lived with HIV/AIDS and is on antiretroviral (ARV) treatment. She lives with her mother Sandy and has a son, ten-year-old Pete Sandy, who is living with diabetes, was employed in several jobs and this had made her financially independent. She had lived alone for a decade. Then Lee became ill and Sandy was shocked to hear about her daughter's HIV/AIDS diagnosis. Sandy became the responsible person for the family, both financially and emotionally. She had to share her small living space which was just one room. She had to earn enough money to feed and support three people. However, this family totally relied on Sandy to hold things together. Sandy said in her own words 'I am old', and her ability to continue working as hard as she does to secure the income this family needs is uncertain. Once she accepted that being the main salary earner 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. | <p><i>"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 it is one of the reasons why some people do not disclose their infection status."</i></p> <p>Sandy was worried about the stigma attached to HIV/AIDS should her neighbours find out about Lee and Pete. It is often said that secrets cannot be kept in small communities. In these small villages, everyone usually knows everyone else's business.</p> |
| Grace                    | Grandmother of Feat (an Orphan with HIV)  | Villagers gossiped about her daughter-in-law dying from AIDS and when Feat (an orphan with HIV) was a little older "we became the subject of a village rumour". Sue was angry because her daughter had become infected with HIV through 'bad' behaviour and at the same time she was sad because she believed that her daughter would die soon.  |
| Nancy                    | Grandmother of her daughter's orphan kid while her daughter and son in law had died of AIDs.  | Nancy said that her daughter being unmarried caused great shame and marriage was hastily organized before Kenya was born. Saving face in public was very important in the village hence the marriage. Loss of face was perceived to be a disaster for grandparents. She confessed that she had no respect for her daughter's partner and her suspicions were later realized as she blamed him for infecting her daughter. Both daughter and son in law have since died.  |

|               |                                      |   |
|---------------|--------------------------------------|---|
| Noi and Tracy | Parents of an AIDs affected daughter | Saving face was on Noi's agenda too, but not to the same extent as his wife. The judgements village people held preoccupied Tracy to the extent that she avoided caring for her daughter. Although unusual for Thai men to provide personal care, her husband took care of their daughter when she was sick at home. Tracy was angry with Lily for bringing public disgrace on the family. She said 'they moved to live in Bangkok. We have to "Tam Jai" which reflects her poor behaviour. I know I would be ashamed if Lily's HIV/AIDS status was known in public'. Both Tracy and Noi had trusted and respected positions in their community and they said they could not handle gossip and its consequences. They feared to lose their status and recognition as respected health volunteers. |
| Sue           | Mother of an AIDs-stricken daughter  | 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' 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 scared of us because we cared for July when she was sick and they are afraid they might catch HIV".  |
| Mary          | Aunt of an AIDs-stricken kid Feat.   | Aunt Mary was able to ignore the bigotry; she was not concerned about neighbour's opinions. She had access to good information about HIV/AIDS; she said "The villagers tell me that my sons would be at risk or contact HIV from Feat. I don't worry because I know how HIV/AIDS is transmitted". Those participants armed with good information were less likely to be concerned about stigma.   |

Rural grandparents and other family members were concerned about basic needs: housing, food, and education. In these Thai rural areas caring for orphans is confounded by poverty. 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 condition

was revealed. Interviewees talked about rumours that disturbed their families, and those judgments were made about 'bad' behaviours associated with sexual activities.

Goffman's characteristics of stigma take hold of the above accounts. Family members have internalized the stigma and at the same time, they suffer the consequences of stigma as it is bestowed on them by villagers.

### PAR groups

All adult participants had agreed to join the group, although not all could attend every session. It was astonishing that they agreed to attend the group meetings, given the stigma attached to living with HIV/AIDS. Participants asked if two of the community nurses from the Pralab PCU could join the group, so they were often a group of twelve to fourteen people. Conversations were conducted in the Thai language. The public accounts participants were comfortable in sharing in the group.

### Setting the agenda

The research consists of items they might like to place on the agenda for discussion. 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 are ill or die (6) Services provided by the Primary Care Unit (PCU) (7) Health promotion. Participants planned for action and, where feasible, acted on issues raised and prioritized by families, caring for orphaned children of family members to assist them in this changed situation. This work focuses on agenda items two and four although many were underpinned by financial problems, as explained poverty and AIDS are somewhat synonymous. The group used collaborative problem solving which resulted in participants improving their financial status.

### Discrimination and verbal abuse

Private accounts that had been discussed in the one to one interviews were not raised in the more public PAR group. Lee had disclosed her HIV status to the PAR group and raised her concern in this public forum.

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 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. Nancy's problem was voiced in this group and its resolution was a collaborative effort. 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 saying 'your parents died of AIDS'. Not only was Nancy exasperated by this continual abuse, but the whole family had to change the way they entered and left their house to avoid 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. Nancy raised this concern in the PAR group and she asked for other people's opinions. This is what the group suggested. Lee offered support and said that it was an infringement of human rights that someone talked about her in this way. Having lived with HIV/AIDS for a while and attending the HIV/AIDS clinic at Khon Kaen Regional hospital had made Lee more aware of her rights and she was keen to share these with the PAR group. Noi and Tracy empathized with Nancy and advised her to seek help from the village Head Person. Grace and Mary encouraged Nancy to report the neighbour's abusive behaviour to police. Sue and Norris said they shared the pain with Nancy. They told that villagers refused to buy food from Norris's shop believing that food products would be HIV-contaminated. 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.

Nancy took all 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 about 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, the village Head Person. Nancy gently talked to him; she told him about her suffering. The neighbour said that he felt guilty. The village Head Person suggested that Nancy and the abusive neighbour sign 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.

It was clear that being part of this research process enhanced participants' ability to 'move on' as evidenced by actions undertaken. It was obvious that participants raised each other's awareness about living with HIV in the family, and this process was viewed as empowering.

Sandy recalled this propaganda and said that HIV/AIDS was the 'Sum Het' disease. She believed that HIV was spread through unprotected sex. In addition, in the 1990s when people returned 'home' such behaviour was suspected. 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 as 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 those judgments were made about 'bad' behaviours associated with sexual mores. The legacies of 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). As discussed, it is a strong interest of this work is to explore the way stigma associated with HIV/AIDS continues to batter families and this work desires to push toward the eradication of stigma and aversion toward people living with HIV/AIDS is one of our driving motives.

### Stigma

Being discriminated, often experienced by orphans, was hard to tolerate for grandparents. Grace felt sad that her grandson Feat had few friends. "Villagers refuse to let their children play with him and he is continually rejected". Sue confided that grandson 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 were 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. When daughters found out they had contracted HIV (from their husbands), they returned 'home' and sought help from their biological mothers. Although still married at the time, Lee, Katie, Lily and July returned home alone 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 the good nursing care they received from their parents. Lee and Lily 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. 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. Lee could not find

work, Lily has started a new life in the big city leaving her daughter with her parents.

In these small villages living with HIV-associated stigma was a common experience. Interviewees talked about rumours that disturbed their families, and those judgments were made about 'bad' behaviours associated with sexual mores. The 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 small community members discover the HIV status it is likely to have negative social responses in families ((Gonzalez *et al.*, 2009).

### Disclosure

Disclosure, whether a child should be told about their parents or their own health status, was a problem for grandparents. In the village context, where there was limited knowledge about HIV/AIDS, disclosure to villagers and neighbours was not an option as they believed 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 knew 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 has almost been excommunicated. Noi said, "I am aware that I don't want Lula to know much about Lily's health problem so it is best she stays away". The work agrees with Genberg *et al.* (2008) that shame, blame and social isolation are key components to stigma. Stigma, as experienced by participants, was deeply discrediting.

Participants experienced 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 be considered 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) have written 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 didn't have much to lose'. Rodkjaer *et al.* (2011) 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 we observe Feat's family to be adherent to this decision as they told school teachers. The third disclosure strategy was to tell to no one (being closed) and this strategy is applicable 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.*, 2009). 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 such news would have negative psychological consequences. The 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. 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.

## CONCLUSION

Therefore the present concern is the way that stigma associated with HIV/AIDS continues to batter families. In this study stigma was a major concern for

the participants. In listening to participants' accounts a better understanding of small-village family life is achieved. 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 peoples' minds: the 1990s Thai AIDS epidemic had not been forgotten. Living in a close village community it was reported that rumours disturbed families, judgments were made about 'bad' behaviours associated with sexual mores. Being discriminated against was brought to our attention in all stories. The legacy of the Grim Reaper still holds true for rural Thai people and continues to impact on families. It was interesting to note that most one to one interview accounts of stigma and discrimination were kept private and only general accounts reached the group.

Health care professionals need to deal with the problem of spoiled identity. The death of a child for a parent is a very powerful event, particularly when the illness and method of infection reflect their behaviour or values, which being inconsistent with their upbringing and challenges the family's integrity. Those living with HIV not only suffer the dramatic shattering of life stories they also need to confront a community which views them as less than a normal member. Goffman (1963) noted that the stigmatized person is one who has lost her wholeness in society's eyes. The person is reduced from a whole to a tainted discounted one. The role as health care professionals means enabling people to confront their fears in tackling the social world with a spoiled identity. It also means reversing Grim Reaper media messages and sending out positive stories about HIV/AIDS and current treatment ARV which is now free to all Thai Nationals.

Stigma plays a huge role in retarding family's access to health care. Efforts to de-stigmatize, education at both national and local levels needs to be kick started. The Grim Reaper messages need to be supplanted with current information. Access to HIV/AIDS services was 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 that prevention has always been the catch cry of Alma-Ata, we call for 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. Presently three Thai 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. The new campaign should contain clear understandings about HIV/AIDS

transmission rather than create terrifying images of the disease and pointing blame. The eradication of stigma and aversion toward people living with HIV/AIDS is the foundation for effective solutions. As an early step in this process, the PAR group participants are continuing to meet with each other and have started a local HIV/AIDS health promotion education program in collaboration with Pralab Community Nurses.

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