Buddhism and Transition: Thai Families Moving on When HIV/AIDS Interrupts Their Lives

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Abstract—This paper is a research study to answer: What can be done to assist Thai families whose lives have been affected by HIV/AIDS? This article will argue that Buddhist philosophy including the practice of meditation has not been acknowledged in English literatures previously in assisting families in difficult situations to ‘move on’. Methodology the first author, a Thai speaking nurse academic, was in Khon Kaen in North Eastern Thailand for one year and recruited five families to the study. We used Koch and Kralik (2006) participatory action research (PAR) methodology to answer the research question. The methodology comprised storytelling (one to one interviews) followed by PAR group sessions. Nine people were interviewed: five grandmothers, one grandfather, two aunts and one mother who is living with HIV. Together they care for six orphans. Results 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. We 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. In this paper we theorize about families’ experiences we will draw on concepts of Thai philosophy and transition theories. Conclusion we argue that this PAR approach of participants’ response to incorporating the consequences of living with HIV in their lives was that they talked about their experiences as a family. We 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. In this paper we theorize about families’ experiences we will draw on concepts of Thai philosophy and transition theories. Conclusion we argue that this PAR approach was the most suitable for this inquiry. When researching alongside families, we worked toward building sustainable relationships that continued when we had left the field. Health care professionals can assist families impacted by HIV/AIDS through prevention of the situation reaching a crisis and they need to be aware of the shock impact when people are told they have HIV. While the five grandmothers are resilient and managing quite well at the moment; their socio-economic situation is precarious. Grandmothers need to be acknowledged for the key role they play in keeping these Thai families together.

Keywords—Buddhism, transition, HIV.

1. INTRODUCTION

This inquiry took place in North Eastern Thailand. A HIV/AIDS clinic a ‘one stop shop’ or Comprehensive Continuum of Care Centre is housed in one of the main hospitals in Khon Kaen. Family members infected by HIV are provided a comprehensive service at this hospital. Just outside Khon Kaen is Pralab Primary Health Care Unit (PCU) which provides a community health service to nine villages in its surroundings. It is from these villages that recruitment of five families took place.

The 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 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. In this paper an orphan is a child/adolescent who has lost one or both parents to HIV/AIDS.

Using Koch and Kralik (2006) participatory action research (PAR) methodology the first author researched alongside five Thai families. The methodology comprised storytelling with nine participants followed by PAR group sessions. The first author, a Thai speaking nurse academic and PhD candidate, was in the field for one year. Ethical approval was granted by the University of Newcastle, Australia, and Khon Kaen University, Thailand.

Buddhism in Thailand

The population of Thailand is almost entirely Buddhist, except a small Muslim minority in the south. Theravada Buddhism is the main religion and has become ‘Thai peoples’ way of life and the basis for a moral philosophy. 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 Buddhist beliefs. This influence is less evident in big city life in Thailand for a number of reasons including globalization. Nevertheless, the majority of Thai peoples’ lives are underpinned by Buddhist philosophy. This philosophy values simplicity in living, tolerance and peace.

A Buddhist Temple or Wat is the focal point of a Thai village. Buddhist monks are highly revered and have more status and prestige than the village head person. A monk may be consulted first if a villager needs support or counselling. Furthermore the Buddhist monks offer a ‘free’ school education program for children.

It is important to understand the principles of the Buddhist religion/philosophy as these relate to 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. 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 and to display courteous behaviour. Good behaviour includes good manners, tactfulness, diligence, honesty, frugality, helpfulness and selfless.
Five families

Participants who volunteered to this inquiry were from five families (names are fictional). 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 consist of Grandmother Sue, her daughter Norris and Ron who is Norris sister’s son.

Grandparents were the main caregivers. Three families shared the characteristics typical of a Thai village population in terms of their low education and difficult socio-economic circumstances. Their main occupation was as a farmer, each worked rice paddy, either as owner of the land or as labourer. In the rainy season participants 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. This sometimes provided work for grandparent. 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 have their own land and a small grocery shop. Whereas, Sue’s family breeds frogs and this gives them a reasonable income. ‘Orphans’ cared for by these families were five boys and one girl. All these children except one, Kenyan attend school. Kenyan had recently started work as a labourer. Only one of the six children was infected with HIV through maternal child transmission.

Storytelling

The entire research process was conducted in the Thai language. One to one interview data were digitally recorded with the consent of each participant, and verbatim transcripts of those interviews were made. The first author transcribed all Thai interview recordings and analysed them concurrently using Koch and Kralik’s protocol (2006) described elsewhere. The story was returned to the participant and they were invited to take ownership.

Nine people were interviewed: five grandmothers, one grandfather, two aunts and one mother (Lee) who is living with HIV. The interview, analysis process and the participants’ short stories were repeated for each transcript in both languages. We then compiled a list of all significant statements from each of the participants’ short stories. We wrote up the commonalities based on these. There were fourteen common constructs. In this paper we will explore what can be done to assist Thai families whose lives have been affected by HIV and/or AIDS. Fourteen constructs resulting from one to one interviews with nine adult participants described the experiences as participants dealt with the impact HIV/AIDS in their families.

Families are a dynamic unit

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. We 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. In theorizing about families experiences we will draw on concepts of Thai philosophy and transition theories.

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 we observed that constructs 1-7 were about the dramatic events that happened a decade ago. Yet the experiences recalled were as if they 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’.

Major re-structuring 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

It became evident that all participants had made major changes in their lives. We make a distinction between change and transition: change is what happens to people whereas transition is what people actually experiences (Bridges, Pratt, Corp, & OverDrive, 2008). We were interested in the way families were able to ‘move on’ with their lives in the shadow of HIV. We use the term ‘moving on’ for transitions families made in their lives and will further explicate these meaning in the section to follow.

Once the dramatic events had been recounted, the conversations in the one to one interviews then 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 we 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.

Families moving on

Despite difficult circumstances families managed to ‘move on’ in their own way. We demonstrate 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. Grandparents battled with serious illness of their offspring, they lost children they loved, and their grandchildren were at risk. Eventually participants were able to confront adversity and appeared to find hope and meaning in life. We were able to observe the movement each family made over the last few years. When talking about: ‘moving on’ we 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 moved on over time.

One of the most salient characteristics about these five families in that they worked as a team. Although they came together out of necessity, they pulled together. Even ten year old Pete helped his mother on days she was feeling fatigued. The fifteen old Kenya wanted to protect his family from further discrimination by challenging his neighbour to stop his jeering. Grandfather Noi gave up drinking alcohol so that his new family could thrive economically.

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 in their paddies.

We explored what participants said about their motivations. 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, the most favourite topics of discussion was about the orphans they were concerned about their grandchildren’s welfare, they said about the future. Concern about orphans and creating a future for them was a major observation. 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. Most grandparents are already in their 60s, and while this is not ‘old’, diabetes had taken its toll. It was not surprising that grandparents want to a secure future for their grandchildren.

Theorizing about families and transition

We were interested in the theories of transition as it was obvious that families in this study have ‘moved on’. We wanted to explore the way these families were able to incorporate the consequences of HIV in their lives and we sought clarification from the literature. We turned our 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, 1986:239, 240).

A definition of transition that speaks to our 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.

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. We paid attention to Kralik and Van Loon’s (2006:152) definition of transitions as:

The transition theory exposes a process of learning to adapt to life’s adverse disruptions such as chronic illness, by utilizing processes inherent in participatory action research (PAR) that may strengthen a person’s capacity to move through the disruption towards a sense of living well.

We agree with Bridges (2003) that transition is not the same as change. When talking about: ‘moving on’ we 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 us as we can apply it in this inquiry.

Buddhism and transition

Perceptions and meanings held by participants influence the conditions under which transitions occur. In this study we 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 (Ariyabuddhiphongs, 2009). Although participants did not talk

about suffering as part of life, we suspect that many Buddhist practices are internalised. We 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.

Participants often referred to their Buddhist practices and this referred to their spiritual beliefs, meditation, herbal medications and massage (Kitsripisarn, Fongkaew, Chanprasit, & Rankin, 2010). Spirituality and the practice of meditation helped them to make sense about their situation. Often participants changed and corrected their life style through meditation. Researchers McCabe and 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 experienced by their participants. These conditions 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).

Grandmother Nancy visits the temple every day and talks with her son who is a Buddhist Monk. She does not only believe in the teachings, but she is encouraged to explore them, understand them, and test them against her own experience. Grandmother Sue admitted that she is supported by her beliefs in Buddhism, she frequents to temple with offerings regularly.

We suggest that one of the reasons these families have been able to move on is precisely because they practice Buddhism. This means understanding that the circle is a part of life, therefore it is an approach to leaving the past behind, tolerating the present and moving on to the future (Loue, Lane, Lloyd, & Loh, 2010). As discussed above our participants held Buddhist beliefs. Meditation and believing in Buddha gave them the spiritual strength to ‘move on’. In other words, Buddhism was central in their lives, and we suggest, facilitates transitions. Believing in the Buddhist Five Precepts (Silas) was reassuring, Nancy said; ‘Because my Buddhism is so much who I am’.

In a PhD study completed by Baltihip (2010), our contention that Buddhism provided an important spiritual guide to living with HIV/AIDS is supported. Baltihip’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 an 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: surviving to struggle and living life. Categories are further divided into ‘encountering distress’ ore 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 ‘oneself’ – that enabled them to obtain peace and harmony of mind (kwarmsa-ngobjai) (Baltihip, 2010 p.2).

Grandparents in this study often talked about tamjai which is similar to kwarmsa-ngobjai or in English, it means letting go. Bridges (2003) in a quote given earlier was about being able to let go as part of transition. Being able to let go may be one way that our participants were able to move on. Moreover, Chalerm San 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).

We note that internal processes have taken place and mostly participants have been able to let go of their previous way of living prior HIV infection and focus on the tasks awaiting them. We 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 may be able to facilitate movement toward better outcomes for families.

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 we will discuss the obstacles which may have prevented families to move forward. If we can understand these obstacles we may be able to assist, thus answering the 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). The impact of HIV/AIDS has a major socio economic impact Mhalu (2006), and we 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 stigmatization remains a core feature of the person’s experience living with this disease (Fair & Ginsburg, 2010). 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 (De Moor, 2010). Prostitutes and drug users were portrayed (Rovin, Young, & Hardee, 2008). Sandy recalled this propaganda and said that HIV/AIDS was the ‘Sum Het’ disease. She still believed that HIV was spread through unprotected sex. 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, Pridmore, Carr-Hill, & Chaimuangdee, 2011; Jongsthapongpanth & Bagchi-Sen, 2009; Walsh, 2011).

Shock

We suggest that participants were not able to leave their troubles behind them because the peak crisis situation identified earlier in this paper 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 that something was very wrong. In these situations there were few options for daughters 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. Vithayachokkitikun (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 nursing 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 their critical ill. When it emerged that HIV was the reason for their daughter’s 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 very upset. Grace was deeply shocked because she was unprepared to care for Fear, he was a sick baby. Sue’s fear about July having HIV/AIDS was realized.

Physical limits experienced by grandmothers

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. So it is not surprising that the six orphans in this study are being cared for in a newly reconstructed family with a grandparent at the helm. No doubt that managing diabetes alongside all the other new activities associated with the organizing a new family would be stressful. Grandmothers: Sandy, Nancy, Tracy, Grace and Sue felt increased responsibility when the orphan joined the ‘new’ family.

Financial difficulties

Financial security is not something Thai families can take for granted; there are few 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 experienced physical, psychosocial and financial hardships in caring for their daughters, and their orphaned grandchildren.

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 THB 100 (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 could move on, given their dire circumstances, but they did.

Stigma

Grandparents were troubled by the social isolation and rejection experienced by their grandchildren at school and at play. Grace felt sad that Fear had few friends. “Villagers refuse to let their children play with him and 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 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.

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. Saving face was very important in the village and its loss was perceived as a disaster for grandparent’s. Tracy was angry with her daughter, Lily, for bringing public disgrace on the family. ‘We have to “Tam Jai” her poor behaviour. I am ashamed if Lily’s HIV/AIDS status was known in public’. It was not surprising that families were keen to save face.

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. 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’. Lee disclosed her HIV status to everyone. Restrictive disclosure was chosen by Fear’s family as they told school teachers. The third disclosure strategy was to tell to 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 grandchildren were unsure about the best way to tell Lula about her mother’s HIV status but they did not want her to know yet. Fear 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.

Participatory action research group

Collaborative research, being given a voice and setting the group agenda was a new experience for participants. 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. We expected that it would take time understand this democratic process, but participants lost their reserve and almost immediately wanted to exchange ideas, experiences and opinions. They took over the PAR sessions and provided peer support. The actual research process sped up their transition. Being involved in a PAR group enhanced transition and resulted in actions being taken. ‘Moving on’ was obvious the most rapid movement being in the year of the research process finding a voice, and collaboratively sharing the action.

II. CONCLUSION

Koch and Králik’s (2006) participatory action research approach has been used and the actual protocol for analysis and PAR groups has been described elsewhere. In this paper we have shown the way families can make transitions through this event and create a sense of continuity in their lives. We have shown that poverty and HIV is likely to be synonymous, and we have drawn attention relentless and tiring role of grandparents in taking care of orphans. Although there are two role choices, grandparents take on the care of orphans with pride.

Participants were able to move on. Underpinning their transition, a Western concept, is possibly a philosophy of Buddhism or ‘letting go’, an Eastern philosophy. Buddhism was central in their lives, and we propose believing and meditating facilitates transitions. Believing in the Buddhist Five Precepts (Silà) was reassuring. Meditating was part of life. We repeat, Nancy said. ‘Because my Buddhism is so much who I am’. We made a distinction between change and transition: change is what happens to people whereas transition is what people actually experience.

Our 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 had occurred.

There were considerable strengths within families as shown by their resilience and ability to move. Transition was possible despite emotional upheaval, financial hardships and social injustices experienced living a culture where HIV is stigmatized. As facilitators we were 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 into their lives. We helped five families to work together to improve their lives (reform).

Implications for practice

We strongly believe that family support groups should continue, and we have heard that the group is continuing to meet. It was clear that many actions resulted when participants were part of a group and their transition was accelerated. Health care professionals can assist families impacted by HIV/AIDS through prevention of the situation reaching a crisis. We know that a peak crisis 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 crisis occurs. 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 Thai health policy (and budget required to bring expert counsellors on board). While the five grandmothers are resilient and managing quite well at the moment; their socio-economic situation is precarious. Contingency plans need to be in place. Some families may need help with planning, and others may need economic support, realizing that the grandmother is usually the main bread winner. While on the subject of grandmothers, we propose we need to acknowledge the key role they play in keeping the family together and functioning.

We argue that this PAR approach was the most suitable for this inquiry. When researching alongside families, we worked toward building sustainable relationships. It was clear that being part of this research process further enhanced participants’ ability to ‘move on’ as evidenced by actions undertaken.

REFERENCES


