

2013

Impact of HIV and AIDS on Elderly Caregivers in Chiang Mai, Thailand

Sarah-Kate Hawkins
Walden University

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Walden University

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Sarah-Kate Hawkins

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Walden University
2013

Abstract

Impact of HIV and AIDS on Rural Elderly Caregivers in Chiang Mai, Thailand

by

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MA, Lynchburg College, 1991

BS, Randolph Macon Woman's College, 1985

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Policy and Administration

Walden University

May 2013

Abstract

The UN General Special Assembly on HIV/AIDS reported that Thailand's elderly are living on the edge of poverty. Those who become caregivers for the children who have been orphaned by AIDS incur even greater challenges. The 2007 Survey of Older Persons of Thailand concluded that there is a range of financial and social safety nets provided by the government, nongovernmental (NGO), and faith-based organizations (FBOs) to help the elderly caregivers and their families. The research literature offered limited studies on Thailand's elderly caring for these children. The purpose of this phenomenological study was to explore the social, religious, and familial experiences of this population. The theoretical framework was Erikson's theory of the 8 ages of man. In-depth interviews were conducted with 14 elderly caregivers participating in the Grandma Cares Partnership Program. They were asked about their caregiving experiences, cultural and Buddhist beliefs, and programs that help them. Data were verified through member checking with a translator. The details of the caregivers' experiences and environments were transcribed and analyzed with Creswell's 6-step process to identify textural and structural themes and patterns. Results of this study indicated that caregivers gained comfort and strength from Buddha's teachings, as well as from their cultural beliefs, to continue to maintain a home for these children, but they would like more support. Implications for social change include informing policy makers and leaders of the Thai government, NGOs, and FBOs that more financial and educational support is still needed to help these caregivers. Plans are in place for the caregivers to share their insights with their representatives, in order to make their lives more manageable.

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Dedication

Without the love, care, values, and encouragement given to me by my late wonderful parents, Irene and Dan Hawkins, this dissertation would not have been possible. In my early twenties, I experienced some difficult challenges, which lead my parents to give me Patrick Overton's poem that I continue to hold dear to my heart:

When you walk to the edge of all the light you have and take that first step into the darkness of the unknown, you must believe that one of two things will happen. There will be something solid for you to stand upon or you will be taught to fly.

To my Love of my Life, Jeff Lynn, who helped me through my grief. Without his love, support, and hours of editing, I would never have had the courage to finish this journey.

To Hope and the GCPP's Thai caregivers for this study would not have been possible without their willingness to share their valuable experiences.

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The following names are in alphabetical order per the APA 6th Edition:

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Life is not about waiting for the storm to pass. It's about dancing in the rain.

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Chapter 1: Introduction to the Study

Background

Thailand's families and children already living in poverty have been affected the most by the HIV epidemic (Kaiser Family Foundation [KFF], 2010a, 2010b; Richter, Beyrer, Kippax, & Heidari, 2010; [UN], 2009a, 2010b; Development Programme [UNDP], 2009a). The consequences of HIV and AIDS touch them financially, physically, emotionally, and socially (HelpAge International [HAI], 2005, 2007a; Lee, Li, Jiraphongsa, & Rotheram-Borus, 2010; Nyamathi, Covington, & Mutere, 2007; Safman, 2004). Studies conducted by Knodel (2008), Knodel and Chayovan (2008a, 2008b, 2009a, 2009b, 2011), and Phengjard, Brown, Swansen, and Schepp (2002) reported that in Thailand's culture of filial obligation, the care of adult children living with HIV, as well as caring for any grandchildren, falls to the parents. Caregiving to either their adult children or grandchildren significantly affects them because of their age, health, and finances.

With the HIV epidemic turning into a chronic illness, Thailand's caregivers' burdens are increasing, while social programs appear to be decreasing or nonexistent, as most are targeted to Thais under 55 (HAI, 2008a; Phengjard et al., 2002; Population Fund & HelpAge International [UNFPA & HAI], 2011). The researchers have found that the elderly, many already living on the edge of poverty with health issues and without outside resources, fall into greater debt. This is because of the cost of medicines and other expenses related to caregiving to a PLHA, as well as caregiving to their grandchildren

(Ageway, 2008; HAI, 2010; General Special Assembly on HIV/AIDS [UNGASS], 2008, 2010).

In contrast, Knodel (2008) and Knodel and Chayovan (2008b, 2011) shared that there are a variety of social safety nets to help PLHA, their caregivers, and any grandchildren in need. This conclusion is based on the 2007 SOPT that found 96% of elderly Thais are healthy and can care for their PLHA (Knodel & Chayovan, 2011).

After 3 decades of HIV initiatives and programs, researchers have found that much of the early progressive work has fallen by the wayside as Thailand continues to have ongoing political and economic issues (Isaranurug & Chompikul, 2009; World Bank, 2009, 2011a). Thailand's early success in eradicating HIV, which is the sixth item listed in the Millennium Development Goals (MDG), seems to have lost momentum, and the epidemic may be on the rise again (Joint Program on HIV/AIDS [UNAIDS], 2011a; UN, 2009a, 2009b; Development Programme and the Population Fund [UNDP & UNFPA], 2006; UNGASS, 2010).

Much is still to be done in Thailand for this group of elderly who are rarely targeted for HIV education and prevention programs, let alone services for the family (HAI, 2008a, 2008c; Joint Learning Initiative on Children and HIV/AIDS [JLICA], 2009; Lee et al., 2010). The implications for positive social change include adding to the knowledge base about Thailand's elderly caregivers and sharing the findings with Thailand's government policy makers, and the leaders of the various NGOs, and FBOs. , They will be asked to invest in creating interventions that will improve the lives of Thailand's caregivers. A more detailed review is presented in Chapter 2.

Problem Statement

There is a problem with the lack of acknowledgement and services that Thailand's rural families receive from the government for caregiving to their adult children living with HIV and their grandchildren orphaned from or affected by AIDS (Lee et al., 2010; Nyamathi et al., 2007; Sorajjakool, 2006; UNAIDS, 2011b). Currently, the elderly caregivers' issues with finances and health are documented, while the emotional and social burdens are less acknowledged. Thailand's culture and religious beliefs dictate intergenerational family care (Cooper & Cooper, 1996). However, the lack of educational, economical, and social resources for the caregivers and families cause short and long term consequences for all (HAI, 2005; Phengjard et al., 2002; Wacharasin & Homchampa, 2008).

This problem affects the elderly caregivers because of their age, limited income, and health. It also affects them because of the financial and emotional needs of a chronically ill adult child and grandchildren (HAI, 2007a; Lee et al., 2010; Nyamathi et al., 2007; Safman, 2004). There are many possible factors contributing to this problem, among which are a lack of research focused on this population, a lack of social assistance programs, a lack of coordination of services available, and a lack of understanding of Thailand's cultural and religious beliefs. This study contributes to the body of knowledge needed to address this problem by seeking out caregivers for their opinions, thoughts, feelings, and insights, while determining what public policies need to be developed to help this population successfully raise their grandchildren, nephew, or nieces.

Nature of the Study

This phenomenological study described elderly caregivers' social, religious, and familial experiences associated raising their juvenile charges orphaned by AIDS. The study was conducted in Chiang Mai Province of Northern Thailand. The elderly caregivers are part of the GCPP. Before the literature review was completed, I decided to use Van Manen's (1984) methodological steps for human science research to analyze the transcribed interviews. This decision was amended to use Moustakas (1994) and Husserl's (Keller, 1999) psychological, phenomenological method after reading the studies already conducted with the Thai caregivers. Almost all of the studies reported in the literature review allowed the participants (caregivers) the freedom to share their stories without the researchers' interpretations or experiences attached. I decided on this style of methodology to provide the audience stories full of emotions and experiences, which help support an understanding of the daily tasks of the caregiver's life.

The data were collected through interviews using semi-structured questions. The interviews were audio recorded at the caregivers' homes and each took about an hour to complete. A translator helped in conducting the interviews. The data collected were analyzed using the Atlas.ti qualitative data analysis program and Creswell's (2007) six-step phenomenological analysis methods. The translator and I returned for a second visit, about 15 to 20 minutes, and presented an overview of the interview to validate the accuracy of it in the process of member checking (Denscombe, 2007). The research answered the following questions.

Research Questions

1. What are the experiences of the elderly grandparents in rural Thailand as the caregivers for their grandchildren who have been orphaned by AIDS?
2. How do Thailand's cultural beliefs relating to family duty, as well as their Buddhist religious beliefs, support or impede the caregiving by the elderly grandparents for their grandchildren who have lost their parents to AIDS?

Subquestion

3. What community programs do Thailand's elderly caregivers know about and use? Which are having the most significant impact to help them take care of their family members and themselves?

A more detailed review of these research questions will be presented in Chapter 3.

Purpose of the Study

The purpose of this phenomenological study was to explore and describe the lifestyles of the rural elderly caregivers who care for their grandchildren affected by AIDS. Part of this role is demanded by Thailand's cultural values of filial responsibilities. Another part is their Buddhist convictions of karma and merit making. The goal is to understand their experiences, frustrations, joys, needs, and wants in relationship with their cultural and religious beliefs. This information will help develop and deliver programs to aid all family members affected by HIV. With limited research of this population, the phenomenological study resulted in greater knowledge of their experiences. Collaborations have begun among the NGOs, FBOs, and the various Thai government agencies. Topics relating to creating more family-oriented programs and

public policies focusing on the needs of the caregivers and their families are being discussed.

Theoretical Framework for the Study

How do Thailand's rural elderly deal with their lived experiences giving care to a loved one with a chronic illness such as HIV? How do they cope with their grieving grandchild while they too are mourning the loss of their adult child from AIDS? These are life-changing stories, filled with a broad spectrum of thoughts and feelings. A majority of these stories are only shared among trusted family members, due to the Thai tradition of *naa*, saving face, which is connected to "one's personal dignity, reputation, and honor," (Kittikorn, Street, & Blackford, 2006, p. 1287) as well as the Thai belief of *krengjai*, a Buddhist concept which means "consideration of others and self" (Cooper & Cooper, 1996, p. 83).

The theoretical framework for the study on Thailand's culture and religious beliefs was Erikson's eight ages of man (1950) theory. This theory explains a person's lifetime moral, social, and spiritual development in stages of thinking and learning. Each stage has a positive and negative outcome, which determines a person's ego development. For example, the family is the first safe world a Thai child knows (Cooper & Cooper, 1996). This belief is mirrored in Erikson's first three stages—trust, autonomy, and initiative—which support the dependency and safety of the child to parents (Erikson, 1950; Hoare, 2005). As the child grows and explores new environments and people outside of the family, the stages of industry, identity, and intimacy are encouraged by the parents (Erikson, 1950; Hoare, 2005). Supported by the family and armed with values and

integrity, the expected outcome is success in school, sports, relationships, and work. The Buddhist belief of *dukkha*, that the mind creates all experiences of either suffering or happiness for which each Thai must take personal responsibility, is equivalent to Erikson's personality stages (Yeshe, 1998).

With the onset of the HIV epidemic and a lack of understanding of the disease, many Thai families experienced fear, confusion, discrimination, and loss. The happiness, harmony, and foundation of the family, *krengjai*, was shaken by this unknown illness (Nilmanat & Street, 2007; Phad, Siltragool, & Panthachai, 2010). Thais were required to look within themselves for physical, emotional, and spiritual strength to help the sick family member and to come to some understanding of what was happening. These behaviors correspond to Erikson's stages of psychosocial development, which are based on conflicts that help a person develop qualities to cope successfully with life's disappointments (Erikson, 1950; Glassman & Hadad, 2009).

To gain comprehension of the caregivers' reactions in response to their experiences, there needs to be first an understanding of the caregivers. This study's qualitative inquiry focused on the GCPP caregivers' multiple roles and behaviors within their everyday lives. This resulted in the understanding of the how of their circumstances, culture, and beliefs (Barbour, 2007). Moustakas's (1994) psychological phenomenology process was specifically used as it "focuses less on the interpretations of the researcher and more on a description of the experiences of participants" (as cited in Creswell, 2007, p. 59). Liamputtong and Ezzy (2005) stated this method "allows researchers to understand the issues under study from the experiences of those who have lived through

them” (as cited in Liamputtong, Haritavorn, & Kiatying-Angsulee, 2009, p. 3).

Many researchers used this method when conducting research with Thailand’s caregivers affected by the HIV epidemic (see studies presented in Chapter 2). Semi-structured interview questions were used when interviewing the caregivers (Appendix A). The next section clarifies the meaning of Thai words as well as the definition of uncommon words that will be used throughout the following chapters.

Definitions

Antiretroviral treatment: The drug treatment regime used in Thailand, which can slow the HIV virus and prolong a PLHA life. It is not a treatment to prevent or rid oneself of the infection (UNAIDS, 2011a).

Puñña (merit making): The positive and negative merit making relating to the Buddhist belief of karma, one moves up or down the social ladder with the accumulation of merit (*bun*) and demerit (*baab*) (Nilmanat & Street, 2004). Giving of *bun* and avoiding actions of *baab* are completely related to one or the other outcome (Sethabouppha & Kane, 2005).

Caregiver: A female or male Thai, over 60, Buddhist, and is part of the Grandma Cares Partnership Program who is caring for a child or young person.

Dukkha: The Buddhist belief that it is each Thai’s responsibility to create their suffering or happiness in life (Yeshe, 1998).

Faith-based organizations (FBOs): Groups that offer HIV and AIDS support with a religious focus.

Family centered services: Services that target all members living within the household (Richter, 2010).

Rok khong khon mee kam (karma): A Thai's choices that create the cause and effect in life (Yeshe, 1998).

Krengjai: The Buddhist concept that is the consideration of others and self, which establishes and maintains harmony within the family and within society (Cooper & Cooper, 1996).

Assumptions, Limitations, Scope, and Delimitations

Assumptions

The first assumption was that the caregivers have lived this phenomenon daily and as such have emotional and cognitive experiences that they would share in an open and honest manner. The second assumption was that the participants felt comfortable sharing their stories. The third assumption was that the process of translation was a smooth one between the caregiver, translator, and the researcher. The use of a semi-structured interview style allowed for the caregivers the freedom to share their experiences. This process also allowed them to return to a certain question or parts of a story to ensure clarity.

Limitations

One of the main limitations of this study was that the collected data came from only one province, Chiang Mai, Thailand. It is unclear from the research whether persons from other provinces might have a different perspective, perhaps because of their area's economic, ethnic, and social issues. The second limitation was that there may be other

caregivers in the Chiang Mai province, but only GCPP caregivers were interviewed. The actual number of caregivers interviewed was 14, which far exceeded the minimum number of eight. It was suggested that some of the caregivers would decline due to discrimination and shame, which Liamputtong et al. (2009) stated was still attached to this illness. This problem did not present itself.

Scope and Delimitations

Data was collected in the province of Chiang Mai, Thailand. The GCPP director identified elderly persons over 60 years, Buddhist, and the caregivers to children who have been orphaned by AIDS. The identified caregivers were audio recorded as they answered semi-structured questions of their experiences as well as programs they have used or would like to have available to them and their families.

Significance of the Study

In the last 3 decades, Thailand's Ministry of Public Health (MOPH) collaborating with other governmental organizations, NGOs, and FBOs have designed and delivered a variety of educational HIV and AIDS programs for people 55 years and younger (Drimie & Casale, 2008; HAI, 2008a; UNFPA & HAI, 2011). Despite the knowledge that Thailand's elderly are the main caregivers for their sick adult children, and many are raising their grandchildren, these caregivers continue to receive negligible financial and psychosocial support from Thailand's government (Ageway, 2008; HAI, 2008b; Nyamathi et al., 2007; UNDP, 2007).

According to the 2007 SOPT, of the 45% of the elderly who are also caregivers, 21%, almost double the national average, are living in poverty (as cited in HAI, 2008a,

Suwanrada, 2009). The caregivers are mostly employed within the informal sectors, which have no pension plans and have limited social safety nets. Before the arrival of HIV, Thailand's elderly depended on their grown children for financial and physical support. When help is requested, they generally ask family members, close friends, and the monks at their local wat. If they cannot help, they may refer them to an FBO or NGO that they know about (Knodel, Kespichayawattana, Saengtienchai, & Wiwatwanich, 2009; Nilmanat & Street, 2004; Wacharasin & Homchampa, 2008). Most of these organizations still target their services to the children affected by HIV or orphaned by AIDS, leaving out their main caregivers, the elderly (Desmond, 2008; Erb, 2011; Heymann & Kidman, 2009).

In Thailand's National Plan, there are no programs or strategies to help the rural caregivers (UNDP, 2007). Yet the hardships of this population are well documented (Desmond, 2008; Janjaroen & Khamman, 2002). To understand and inform other stakeholders of the depth of the Thai caregivers' plight, this study described the daily experiences of the rural caregivers. In view of the limited studies conducted about Thailand's rural elderly caregivers, the knowledge gained from this study facilitates increased collaborations among the various NGOs, FBOs, and the Thai government. Governor Supasaen of Chiang Mai will be asked to review and use the study's information as a guide to generate positive social change by updating public policies for family-oriented programs as well as financial programs that address the needs of the caregivers and their families.

Summary

The rationale for this phenomenological study was to investigate and describe the lifestyles of rural elderly caregivers who care for their grandchildren orphaned by AIDS. This methodology was used by the majority of the authors who conducted research on Thailand's caregivers affected by HIV, which is presented in Chapter 2. The limited studies located prove that there is a lack of educational, economic, and social resources for the caregivers. A qualitative inquiry was conducted to understand this group of caregivers' opinions, thoughts, feelings, and insights. Questions dealing with the whats and hows were successfully answered by this elderly group as they continue to fulfill their multiple responsibilities as parents, wives, husbands, daughters, sons, and workers.

Thailand's rural elderly are the main caregivers to their adult children living with HIV and their grandchildren orphaned from or affected by AIDS. It appears from the literature review that the majority of programs and financial support are directed to orphaned children or made vulnerable by HIV as well as people living with HIV, with little attention and support provided to the caregivers themselves. The studies compiled on Thailand's rural elderly caregivers have been limited, and the lack of social safety programs for the elderly causes many of them to live in poverty. What data there are have concentrated on the financial and physical side of caregiving, with little being asked about the emotional or social issues involved. Another missing question is what programs or social services are they receiving and which ones worked; for example, do they need or want more programs that are educational? Alternatively, do they need more financial help to meet the needs of their growing grandchild? With this study, a greater knowledge

was gained of this marginalized population.

The research investigated and described the current living conditions of Thailand's rural caregivers. Through this process, the Thai belief system of family, *krengjai*, *rok khong khon mee kam*, and *dukkha* were explored. Several questions were asked in reference to a family-based approach. With the completion of this research, the complex plight of Thai caregivers is being shared with health care professionals, policy makers, and other concerned stakeholders. It is hoped that social change will be achieved through the building of a unified front for Thailand's families affected by HIV. Working together with these common goals will lead to effective policy and programming interventions. Chapter 2 opens with a brief history of Thailand's HIV epidemic and status. Thailand's culture and Buddhism are introduced in relation to the caregivers for PLHA and their young wards affected by AIDS. Studies are offered for the reader to gain a deeper understanding of the predicament of these caregivers. The methodology of this phenomenological study is the subject for Chapter 3.

Chapter 2: Literature Review

Introduction

Each country's culture, economics, and government policies determine its response to the global HIV epidemic. Accordingly, Thailand's initial response had the government, health department, and NGOs collaborating to deal effectively with this new illness. In the ensuing years, the many various stakeholders and sectors, working together, have created educational and medical programs targeted for Thailand's citizens (Kittikorn et al., 2006). With research advancements in both understanding the virus and antiretroviral drug therapy, HIV is no longer a terminal illness; instead, it is a chronic illness requiring treatment for life. Despite these achievements that have resulted in Thailand having low HIV prevalence among 15 to 49 years old, the illness continues to affect many families (CIA, 2011b; UNAIDS, 2010c, 2011a). Instead of being at the receiving end of healthcare, adult children living with HIV and their grandchildren orphaned by AIDS are being cared for by elderly parents (HAI, 2007a; Kuo & Operario, 2009; WHO, 2008). In addition to caregiving for their loved ones, they live with discrimination, shame, and other financial, emotional, physical, and psychosocial consequences (Apinundecha, Laohasiriwong, Camerson, & Lim, 2007; Lee et al., 2010; Wacharasin & Homchampa, 2008).

The literature review began with searching Walden's databases: EBSCO Academic Search Complete/Premier, CINAHL, Cochrane, eBooks on EBSCOhost, ERIC Education Research Complete, Expanded Academic ASAP, MEDLINE, ProQuest

Central, PsycARTICLES, PsycBOOKS, PsycINFO, Psychology: A SAGE Full-Text Collection, PubMed, SAGE Online Journals, SAGE Premier, and SocINDEX.

Within the databases, tools used included the advanced search, Boolean search operators of *and*, *or*, *not*, the thesaurus, and limiters (i.e., peer reviewed, full text, publication date).

The search began using keywords such as *HIV*, *AIDS*, *acquired immunodeficiency syndrome*, *human immunodeficiency virus*, *Thailand*, *caregiver burden*, *caregiving outcomes*, *family caregiving*, *organizations*, *grandparents*, *grandchildren*, *orphan*, *vulnerable children*, and *people living with HIV*. The use of the thesaurus expanded the search to include the following words: *HIV infections*, *HIV seropositivity*, *sexually transmitted disease*, *sexually transmitted infection*, *health services*, *kinship care*, *adolescent*, *child*, *female*, *male*, *humans*, *financial management*, *nonprofit organizations*, *governmental organizations*, *faith based organizations*, *AIDS organizations*, *HIV organizations*, *ageing*, *economics*, *consequences*, *parents*, *households*, *funerals*, *impact*, *caregiving*, *youth*, *risk perception*, *education*, *living arrangements*, *poverty*, *discrimination*, *development*, *environment*, *culture*, *ethnicity*, *gender*, *communities*, *families*, *dignity*, *happiness*, *diversity*, *values*, *morals*, *political*, *Buddhism*, *temples*, *ceremonies*, *rituals*, *social conditions*, and *economics*. Alerts for the keywords within the databases were established, allowing for any updates of research to be forwarded to email.

Extensive research was found, especially from sub-Saharan Africa, on the concerns and issues surrounding caregivers for PLHA. In the majority of the articles, the care of grandchildren orphaned or made vulnerable by AIDS was also addressed. Fewer

peer-reviewed articles were found that focused specifically on Thailand's HIV epidemic in relationship to the elderly caregiving for their grandchildren. If the article was relevant, two actions were performed: One, the citation and several keywords were added to a spreadsheet, and, two, the article was downloaded to a folder according to its theme. The following are examples of a few of the folders: Buddhism, caregivers_Thailand, caregivers_Africa, NGO reports, Phenomenology, and other studies. A spreadsheet was used as a tool to quickly scan and review an author's main points and citation for the article.

Reports and studies from published gray literature were included in this review by NGOs such as the General Special Assembly on HIV/AIDS (UNGASS), the International Children's Emergency Fund (UNICEF), the World Health Organization (WHO), the Joint Program on HIV/AIDS (UNAIDS), HelpAge International (HAI), and the Joint Learning Initiative on Children and HIV/AIDS (JLICA). Although not peer-reviewed, the research compiled was conducted by experts in the fields of health, science, statistical analysis, and policymaking. The findings and conclusions from this gray literature added to the body of knowledge.

An analysis of Thailand's history with HIV and the AIDS epidemic opens this chapter and the literature review. The analysis establishes Thailand's leadership abilities to confront this new illness. To understand this successful endeavor, Thailand's culture and Buddhism are addressed in connection to the care given by the elderly grandparents for their adult children living with HIV as well as their grandchildren affected by AIDS. For example, Knodel and Chayovan (2011), Kittikorn et al. (2006), Nilmanat and Street

(2004), Phengjard et al. (2002), and Wacharasin and Homchampa (2008) explained Thailand's culture of filial obligation, which dictates that the care of PLHA, as well as caring for any grandchildren, falls to the parents. Generally, the grandmother becomes the caregiver, but if there is no female relation to give care, then the grandfather may provide care (Knodel & Saengtienchai, 2005). If even this is not possible, girls will be sent to an orphanage and boys to the local wat to be cared for by the monks.

UNAIDS, USAID, AND UNICEF projected that by 2010, Thailand will have 374,000 children orphaned by AIDS (UNGASS, 2010, p. 130). Furthermore, Thailand's 2007–2011 National Plan for Strategic and Integrated HIV and AIDS Prevention and Alleviation reported from 2005 data that there are 500,000 children living with one or both parents who had tested positive for HIV. The number of children who have lost one of their parents to AIDS is 380,000 while there are 30,000 children orphaned because both their parents died from AIDS (UNDP, 2007, p. 8). These statistics indicate that a vast number of Thais are in need of care and assistance. Parents' caregiving to either their adult child living with HIV or their grandchildren significantly affects them because of their age, health, and finances. The negative images surrounding HIV can also lead to social and emotional burdens.

These problems and their impact on Thailand's elderly caregivers and their cultural beliefs were the focus of the research questions describing their caregiving experiences. They also helped gain an awareness of their predicament and circumstances. The literature review provided data documenting the rural elderly Thai caregivers' roles in relationship to the HIV epidemic as well as the specific burdens for them. There is a

lack of resources and support for those not living in a city (Lee et al., 2010; Nyamathi et al., 2007; Sorajjakool, 2006). The principles and responsibilities stated in the Millennium Declaration and the Madrid International Plan of Action on Ageing (MIPAA) helped Thailand develop its National Plan to address this issue (Albone, 2011a; Beales, 2011; UN, 2002, 2009b; Zelenev, 2008). Burdens, such as the onerous emotional and social ones, are borne within their cultural traditions and their Buddhist beliefs of suffering, karma, and merit making (Cooper & Cooper, 1996; Nilmanat & Street, 2004, 2007; Sethabouppha & Kane, 2005).

Previous researchers have supported the knowledge of the physical, emotional, social, and economic toil on the caregivers. What was not covered in detail was how the Thai elderly caregivers are faring in the face of ongoing consequences of living with the current HIV epidemic. Most researchers agreed that further research is needed to identify what interventions, resources, and programs are needed to attend successfully to the caregivers' burdens. Missing from the existing literature is the answer to the question, "What is needed to significantly impact Thailand's elderly caregivers' lives and the family members who are depending on them?" This research question is answered in this study.

A Brief History of Thailand's HIV Epidemic

In 1984, Thailand had its first reported case of HIV (AVERT, 2011b; Chitwarakorn, 2003; Nilmanat & Street, 2004). More cases soon followed, prompting the Thai Royal Government to search for collaborations with Thai businesses, academic institutions, social agencies, hospitals, and many nonprofit organizations to address the

novel disease. Knowing that the lack of information and knowledge about this new illness could lead to mass fear and gossip, Thailand's King Bhumibol and the PM, working with several government agencies, sought help from UNICEF, WHO, and UNAIDS. These NGOs answered the call to help Thailand fight what soon became an epidemic (Ainsworth, Beyrer, & Soucat, 2003; Janjaroen & Khamman, 2002). The request for assistance from the stakeholders who already had experience with and knowledge of HIV and AIDS, along with the financial commitment, allowed goals and solutions to emerge from all partners (Ford et al., 2009; Punpanich, Ungchusak, & Detels, 2004).

This collaboration of stakeholders resulted in Thailand's National Plan for Strategic and Integrated HIV and AIDS Prevention and Alleviation as well as many life-changing policies (Chitwarakorn, 2003; Maneesriwongul et al., 2004). The actions of these leaders positioned Thailand as a successful example for other developing countries to model as they began to address their HIV and AIDS epidemics. Thailand's success came after many failed programs and policies. Initially, Thailand's MOPH and government communicated to the public that this illness only affected gay men, as the first patient had been homosexual (Chitwarakorn, 2003; Phongpaichit & Baker, 1998, p. 293). This advisory was then updated to include high-risk populations, such as "gay men, then injecting drug users (IDU), and then male sex workers (MSW)" (Phongpaichit & Baker, 1998, p. 294). In fact, Ross-Larson, Saadah, McCrocklin, and Wiley (2004) explained that Thailand's first response to the public was "muted" (p. 3) because these persons are part of Thailand's *invisible population*. Over the next 4 years, the MOPH discovered cases involving MSW, IDUs, and then in sex workers and their clients

(Chitwarakorn, 2003; Im-em & Suwannarat, 2002; Phongpaichit & Baker, 1998, p. 294; Punpanich et al., 2004; Ross-Larson et al., 2004).

This discovery, along with the increased knowledge of HIV epidemiology, forced the MOPH and government to include HIV testing of all its high-risk populations. By 1990, these groups in various provinces of Thailand had been tested, including recruits of the Royal Thai Army, the thought being that these young men frequented brothels for sex (Ainsworth et al., 2003; Punpanich et al., 2004). The results shocked all of the stakeholders, as results showed that 44% of Chiang Mai (Northern Thailand) sex workers (Ainsworth et al., 2003, p. 15; AVERT, 2011b, para. 3) and 30% to 50% of Thailand's injecting drug users (IDUs) tested positive for HIV (United States Agency for International Development [USAID], 2010, para. 2).

Chitwarakorn (2003), Ainsworth et al. (2003) and Punpanich et al. (2004) noted that these figures finally got the attention of Thailand's leaders, who had been in denial of this epidemic. At the same time, the public had taken notice that a new illness was invading their country. This awareness was supported by reports received from hospitals throughout the provinces that pregnant women were testing HIV positive. Along with these reports came those of the first mother-to-child transmissions, as infected babies were identified and attention was given to them (Chitwarakorn 2003; Janjaroen & Khamman, 2002).

In 1989, this heightened awareness by all concerned stakeholders led to the creation of the National HIV Serosurveillance Program. This program monitored Thailand's HIV and AIDS numbers and evaluated how hospitals and staff, along with the

Thai Red Cross, handled patients (Punpanich et al., 2004). Due to the fear surrounding this new illness, the government created the AIDS Bill (Ainsworth et al., 2003, p. 15; Ford et al., 2009, p. 260), which required all patients receiving any medical treatment to consent to HIV testing. Names of those infected were then sent to the government. This “fear promotion” (Lyttleton, Beesey, & Sitthikriengkrai, 2007, p. S44) helped bring people in for testing, yet it also led to discrimination and stigma that is still associated with HIV and AIDS in many provinces today (Apinundecha et al., 2007; Chan & Reidpath, 2007; Liangputtong et al., 2009; UNAIDS, 2011b).

Many NGOs already involved in the medical issues of the HIV epidemic then turned their attention to this bill. Their questioning of the possible violations of human rights forced the government to drop it. These empowerments to be heard and listened to helped people become more organized. By the 1990s, coalitions resulted in the emergence of dozens of new NGOs with missions to create strong collaborations with the government and medical sector to rid Thailand of HIV. They began working directly with UNICEF, WHO, UNAIDS, and the Thai Red Cross to help the government arrive at wise policy decisions (Chitwarakorn, 2003; Ross-Larson et al., 2004; UNGASS, 2008; UNDP, 2008).

In 1991, the National AIDS Control Program moved from the MOPH to the Office of the PM (Ainsworth et al., 2003; Chitwarakorn, 2003; Janjaroen & Khamman, 2002). With this change of offices and personnel came changes in Thailand’s HIV/AIDS programs, which placed Thailand at the top of a list of countries successfully dealing with the epidemic. King Bhumibol wisely decided to maintain the partnerships among the

government agencies, national and private health care systems, and international nongovernment organizations (INGOs), while expanding these relationships to include many local NGOs performing grassroots programs in the rural provinces. Out of these partnerships came Thailand's policies on HIV and AIDS (Chitwarakorn, 2003; Maneesriwongul et al., 2004; UNGASS, 2008).

In 1997, 13 years after the first HIV positive patient was identified, Thailand introduced the National AIDS Prevention and Alleviation Committee (UNGASS, 2008). Under the direction of PM Anand Panyarachun, this committee, made up of stakeholders from private and public sectors, was charged with the formation and delivery of Thailand's educational, medical, and prevention programs and projects (Janjaroen & Khamman, 2002; Ross-Larson et al., 2004; UNGASS, 2008). PM Panyarachun became the leader who transformed Thailand's approach to the HIV campaign (AVERT, 2011a; Ainsworth et al., 2003; Ford et al., 2009; Lyttleton et al., 2007). Supporting the collaboration created by King Bhumibol among all the sectors, PM Panyarachun then allocated a national budget to help get the word out. Listening to the various civil societies' knowledge of HIV and AIDS, the government supported public awareness programs through radio, television, and flyer campaigns. In addition, AIDS educational and awareness programs for Thailand's youth were introduced into the public school curriculum.

Even before Thailand's stakeholders understood the wide-ranging effects of HIV and AIDS, they created collaborations. The health, government, private, and public sectors collaborations grew out of the necessity to learn what this new illness was and

how to treat it. Individuals formed groups to gain knowledge and share information with other sectors. The Thai Network of People with HIV/AIDS (TNP+) is one such group (Ainsworth et al., 2003; Chitwarakorn, 2003; Ford et al., 2009; Lyttleton et al., 2007). Marginalized due to a general lack of understanding about the new illness, TNP+ formed to seek and gain support from each other. TNP+ collaborations with the MOPH and many other stakeholders resulted in a national policy that requires antiretroviral treatment be provided to any Thai who tests positive with HIV. TNP+ is now the forerunner pushing for the advancement of medical research, drug treatment, and prevention programs (Family Health International [FHI], 2008; Knodel et al., 2009; Thai Network of People Living with HIV/AIDS, [TNP+], n.d.; UNGASS, 2010).

TNP+ continued to work closely with such organizations as the National Access to Antiretroviral Program for People living with HIV/AIDS (ACCESS), Doctors without Borders/Médecins Sans Frontières (MSF), and the Thai Foundation for Consumers (TFC). Together they created policies regarding human rights and HIV/AIDS as well as defining the requirements for medical confidentiality (Ainsworth et al., 2003; Chitwarakorn, 2003; Ford et al., 2009; Lyttleton et al., 2007). The willingness to be open to these and other organizations' views by the Thai MOPH staff created the foundation for a greater understanding of HIV and AIDS. Ainsworth et al. (2003), Ford et al. (2009), Lyttleton et al. (2007), and UNGASS (2008) pointed out in their research that the inclusion of these various stakeholders placed Thailand as a forerunner in successful treatment interventions of the epidemic.

The interventions were successful; yet, equally important was Thailand's 100% Condom Program (Chamrathirong et al., 1999; Phongpaichit & Baker, 1998; UNAIDS, 2000). Surveys and observations conducted by health workers reported that the radio, television, and flyer campaigns were not reaching the sex workers. This population had rising infections of 60 to 70% testing positive for HIV while persons with sexually transmitted infections (STI) were testing around 50%. A majority of those infected reported low condom use and frequented sex workers (Chamrathirong et al., 1999). The director of the MOPH followed up with this information by requesting and receiving permission to start the 100% Condom Program. It started small in Ratchaburi province early in the outbreak in 1991, against much negative outcry and disbelief that it would work. However, it quickly became a national program (Chitwarakorn, 2003; UNAIDS, 2000). Supported by the PMPM along with the National AIDS Committee members and enforced by the MOPH, the following resolution was issued to the country:

The governor, the provincial chief of police and the provincial health officer of each province will work together to enforce a condom-use-only policy that requires all sex workers to use condoms with every customer. All concerned ministries will issue directives that comply with this policy. (UNAIDS, 2000, p. 3)

Meanwhile, the HIV epidemic was creating shock waves throughout the world, especially in sub-Saharan Africa. Consequently, after the 2001 closing of the General Assembly Special Session on HIV/AIDS (UNGASS), world leaders of 189 countries gathered and signed into effect the MDG, which was the first program of its kind

(Chhotray & Hulme, 2007; Fay, Leipziger, Wodon, & Yepes, 2005; UNGASS, 2008).

The signatory countries agreed to collaborate to achieve worldwide by 2015 the established goals and objectives to free the world of extreme poverty, hunger, illiteracy, and disease. They also established targets for achieving gender equality and the empowerment of women, environmental sustainability, and a global partnership for development (Asian Development Bank [ADB], 2009; King, 2009; UNDP, 2009b). The MDG report figures established that much progress towards these goals and objectives has been achieved in the past 11 years in Thailand, as well as the rest of the world (UN, 2009c).

Thailand continued to build on its achievements with the completion of the third National Plan for HIV and AIDS Prevention and Alleviation. Stakeholders from all the sectors, government, NGOs, civic organizations, FBOs, and other concerned organizations, collaborated to create the current National Plan for Strategic and Integrated HIV and AIDS Prevention and Alleviation for 2007 – 2011 (Ford et al., 2009; UNDP, 2007). The development of meaningful goals and objectives and the implementation of effective strategies were possible because the stakeholders of these different sectors understood the needs of PLHA as well as those at risk of HIV exposure and created programs to address the community issues related to the disease (Janjaroen & Khamman, 2002; UNDP, 2007; UNGASS, 2008). One goal of the National HIV/AIDS Prevention and Alleviation plan was to “strengthen a community’s education about AIDS that leads to the understanding of community and social members, which will allow HIV and AIDS patients to access services and live happily in the society” (UNGASS, 2008, p. 13).

In addition, developing a system of medical, public health, social, and consultation services to improve the quality of life of PLHA and developing medical biotechnology, medicine, and AIDS vaccination research are components of ridding Thailand of this epidemic (Research Institute for Health Sciences [RIHES], 2011). Jongsthapongpanth (2007), Apinundecha et al. (2007), and the Children's Fund (UNICEF, 2008) reported these sectors had the capability to emotionally, physically, and financially support each other in the campaign to prevent HIV and AIDS transmission and improve the lives of Thai citizens.

These qualities have supported and given strength to Thailand's successful and effective responses to the HIV epidemic. Hailed as one of the world's leaders in confronting this lethal illness, Thailand took another bold step in confronting the HIV epidemic when its government agreed to begin to break patents on AIDS drugs (AVERT, 2011b; Chitwarakorn, 2003; Ford et al., 2009). King Bhumibol gave his full support to the initiative after reviewing the Doha Declaration, which supports developing countries in creating health programs as well as medicines, to save lives. Discussed and agreed on by the members of the World Trade Organization (WTO), the Trade-Related Aspects of Intellectual Property Rights (TRIPS) was passed in 2001 (WHO, 2011). This decision, welcomed by all stakeholders, especially PLHA groups (GIPA), has saved lives and money for Thailand (UNAIDS, 2010b; UNGASS, 2008). The other strength that helps place Thailand as a leader in the fight against AIDS is the government's financial commitment. Thailand is one of the few countries that requests limited funding from international sources to pay for its HIV and AIDS treatment and prevention programs.

Ainsworth et al. (2003), Chitwarakorn (2003), Lyttleton et al. (2007), and Ross-Larson et al. (2004) ended their articles with praise for Thailand's "visionary responses" (Punpanich et al., 2004, p. 132), yet caution against becoming complacent. There are still many goals to reach, especially in the prevention realm (Ford et al., 2009; UNGASS, 2008). There are also many key populations at higher risk in Thailand, such as the elderly and women, that still do not receive HIV or AIDS medical, educational, or prevention services. All sectors and stakeholders must be willing to seek new solutions that address HIV and AIDS in the milieu of Thais' changing culture and lifestyles, particularly that of the elderly, women, and Thai youth, to be able to achieve these goals (Chamrathirong et al., 2009; Haque & Soonthorndhada, 2009; UNDP, 2007).

The Status of HIV and AIDS in Thailand

With these directives in mind, multi-sector collaborative projects continue to address HIV and AIDS issues and concerns throughout Thailand. These ongoing and new programs must take into consideration the economic and social changes that are affecting the lives of the Thai people (FHI, 2008; Prasartkul & Vapattanawong, 2011; Richter, 2009). Thailand's wise economic investments enabled the World Bank to upgrade them to a middle-income country (Knodel, 2008). With Thailand having more material wealth comes better public education, increased enrollment in universities, expanded job opportunities in developing technologies, and migration from the rural areas to the urban centers. The relocation of Thailand's youth from their families' rural farms to seek employment in cities such as Bangkok and Chiang Mai as well as tourist locations like Phuket (Podhsita & Xenos, 2009; Prasartkul & Vapattanawong, 2011) caused a shift in

their material needs and wants. New necessities and extra money have resulted in new behaviors, including unprotected sex, multiple sex partners, drinking, and drug use (Haque & Soonthorndhada, 2009).

This trend of “casual partners,” “one night stands,” or “Khong/Gig,” (Kittisuksathit & Guest, 2009, pp. 101, 103) the Thai slang words for girls/boys looking for sex, is supported by the new styles of entertainment that come with expendable money. Karaoke bars, pubs, massage parlors, guesthouses, and restaurants serving liquor are common throughout Thailand (FHI, 2008; Haque & Soonthorndhada, 2009). These “indirect establishments” (UNAIDS, 2000, p. 37) are not on the government radar, whereas brothels are considered direct sex businesses and have been since the 100% Condom Program was created. For this program to continue to be successful, it will need to engage these other businesses for support.

Engagement in casual relationships has been supported by the increased availability of cell phones, Internet, social networks, cable television, and foreign films. Many young people base their wants, needs, desires, feelings, and relationships on the unrealistic expectations of these types of connections (Haque & Soonthorndhada, 2009; Kittisuksathit & Guest, 2009). The continued weak curriculum on sex and AIDS education in Thailand’s public schools has not helped (WHO’s Epidemiological Report, 2008); Chamrathirong & Phuengsamran, 2009). Secondary school and college age youth participated in discussion focus groups as well as answered a questionnaire. The results proved that they lack the understanding of how they might become infected with HIV as well as how they can transmit it to another. Currently, sex education is delivered

in the public schools by health teachers who are comfortable in sharing their knowledge of this information (Chamrathirong, 2009; UNAIDS, 2000; UNDP, 2007). The Education Minister has rejected all proposed national sex education curriculums on the basis that one is still not needed (UNGASS, 2010). The consensus among Thais is that this type of information should be communicated within the family (Chamrathirong et al., 2010; Chamrathirong & Phuengsamran, 2009).

In addition to youth's status with respect to the HIV epidemic, the tracking of other groups continues to be important. More data on pregnant women, military recruits, sex workers, men who have sex with men (MSM), and intravenous drug users (IDU) is needed. These survey needs have been added to the National Plan for Strategic and Integrated HIV and AIDS Prevention and Alleviation 2007-2011 (UNDP, 2007). Thailand's government officials have been challenged to create a better "strategic plan and design a model of evaluation" (p. 21) that will ensure that all provinces' management will follow through with them.

Lack of data collection is also the case for the elderly. They are the last group mentioned in the National Plan for Strategic and Integrated HIV and AIDS Prevention and Alleviation 2007- 2011 (UNDP, 2007). As defined by the Thai government, elderly is a person 60 years and older (Knodel & Chayovan, 2011). Suwanrada (2009) shared that two identified factors, poverty and financial security, are the foremost concerns among the 7.02 million elderly persons answering the 2007 SOPT. Thailand's culture supports the concept of filial duty, where grown children will help their parents as they age. This may not be the case for some of the elderly who have lost their adult children to

AIDS. Many of them work in Thailand's informal sectors (e.g., farming or fishing) where there is no pension plan (HAI, 2007, 2008; Suwanrada, 2009). Having an income was rated as one of two items needed to enter successfully into old age (Nanthamongkolchai, Tuntichaivanit, Munsawaengsub, & Charupoonphol, 2011). . These issues were not taken into account when the stakeholders wrote the National Plan. Ensuring a livelihood for the elderly is not listed in the objectives for this group; listed instead is the need to develop "care systems" (UNDP, 2007, p. 43). It is unclear what these goals are or how they will be met.

Without knowledge on these key populations at higher risk, Thailand's stakeholders will not be able to create educational and prevention programs to serve all persons who have the potential to become infected or affected by AIDS (KFF, 2010a). This information has the potential to help the Thai government's stakeholders create better public policies and help other concerned stakeholders understand what is working and what is not (UNDP, 2007; UNGASS, 2010; WHO, 2010; WHO, UNAIDS, & UNICEF, 2009). In the 2 years from 2008 to 2010, the statistics for these individual groups have shown both an increase and decrease of reported HIV and AIDS cases. The discrepancies in the figures depend on which province the data is being collected from (Kittikorn et al., 2006). Thailand's AIDS epidemic has slowly but steadily declined if these individual groups are viewed separately. However, when taken together:

The number of new HIV infections in Thailand has not decreased. A trend of increasing spread of HIV is noted in the population of adolescents, and HIV

prevalence remains high in the traditionally higher-risk populations and shows no indications of declining any time soon. (UNGASS, 2010, p. 3)

This situation persists in a country that now offers a free antiretroviral treatment program for all its citizens, called the National Access to ARV for People with HIV/AIDS (NAPHA; UNGASS, 2010, p. 124). Research centers such as the Research Institute for Health Sciences (RIHES) located in Chiang Mai and connected with Chiang Mai University (CMU) have made major advances with their HIV and AIDS studies. RIHES began performing “biomedical, clinical, epidemiological, and behavioral research in 1991” (RIHES, 2011, pp. 1, 2), which has led to major breakthroughs of new AIDS drugs, vaccines trials, and prevention programs. The WHO’s (2010) report shared the success, where “61% [50%–78%] of infected Thais were receiving these treatments in 2009” (p. 55). The unconstructive part of this program is that it leaves out many of the key populations at higher risk (e.g., older people and children) in need of treatment and education (UNDP, 2007). Ignorance of this program also affects many in the rural villages of Thailand (FHI, 2008; Ford et al., 2009; UNGASS, 2010).

Almost 3 decades have passed since Thailand discovered its first case of HIV. The stakeholders in all the sectors, working together, have made considerable progress towards ridding Thailand of HIV. When the PM chaired the National AIDS Committee, these partnerships created and provided successful HIV and AIDS programs. Recent PMs have chosen to delegate this responsibility to junior ministers, creating a perception that HIV and AIDS education and prevention is not the national priority. Isaranurug and Chompikul (2009) found that Thailand’s decentralization process has given the funding

and responsibility for HIV and AIDS programs directly to the local (provincial and sub district) administrations. Many of these local administrations do not understand the principles of HIV or AIDS prevention and have, therefore, ended or limited programming (Chan & Reidpath, 2007; FHI, 2008; UNGASS, 2010).

These changes in policy have resulted in the lack of HIV and AIDS programs being delivered to many of Thailand's vulnerable populations. One such group is the caregivers, primarily grandparents, of orphans and vulnerable children (OVC), who have lost one or both parents to AIDS (Heymann, Earle, Rajaraman, Miller, & Bogen, 2007; JLICA, 2009; KFF, 2010a). According to the research, Thailand's success towards Goal 6 of the MDG, which is to combat HIV and AIDS, has lost momentum, and the epidemic may be on the rise again (DeGennaro & Zeitz, 2009, p. 12; UN, 2009a, 2009b; UNDP & UNFPA, 2006). Much is still to be done in Thailand for this group of elderly who are rarely targeted for HIV/AIDS education and prevention programs (HAI, 2008c; Lee et al., 2010; Phengjard et al., 2002). Meanwhile, they are the main caregivers for their sick adult children as well as helping raise and educate their grandchildren (HAI, 2005, 2007a; Manesriwongul et al., 2004; Nyamathi et al., 2007; Safman, 2004).

In the early years of the initial outbreak of this illness, Thailand, like many of the INGOs and other concerned stakeholders, focused on the health issues, which was sensible. Because health problems can be connected with ageing, the NGO HelpAge International (HAI) began investigating how HIV and AIDS were affecting Thailand's elderly population, defined as persons 60 years of age and older (HAI, 2007a, 2008a; Population Fund, [UNPF], 2006; Williams, Knodel, & Lam, 2010). They discovered Thai

elderly, like most of the world's elderly, are a vulnerable population receiving minimal attention and service (Ageway, 2008; Beales, 2011; HelpAge International & International HIV/AIDS Alliance [HAI & Alliance], 2003). According to the 2007 SOPT, compiled by the Bureau of Socio-Economic and Opinion, Thailand's elderly population has slowly grown from 10.7% in 1994 to 16.0% in 2007 (Nanthamongkolchai et al., 2011; Pimolvitayakit & Aruntippaitune, 2007; Suwanrada, 2009).

The marginalizing of elderly affected by the AIDS epidemic has continued despite the 2000 UN Millennium Declaration, the 2001 Declaration of Commitment on HIV/AIDS, the 2002 MIPAA, and the 2006 Political Declaration (Albone, 2011a; Jitapunkul & Wivatvanit, 2009; UN, 2009b, 2010a, 2010b). These declarations officially acknowledged the elderly population ongoing commitment to ensure their families' members who are affected and infected by HIV and AIDS are cared for and supported (Albone, 2011b; Beales, 2011; Pimolvitayakit & Aruntippaitune, 2007). These declarations have three common objectives for elderly caregivers: (a) the physical, economical, and emotional care, (b) their anticipated age related health issues, and (c) their long term needs (Aging and Development, 2008; HAI, 2008b; UN, 2002; Zelenev, 2008). Unfortunately, the UN General Assembly ratification and implementation of the declarations in these documents to help the world's elderly affected and infected by HIV and AIDS is voluntary by the signatory countries. Consequently, years after their approval by hundreds of governments, public policies have been slow to be created or changed. A better understanding of HIV and how it affected all aspects of the PLHA,

their family, and friends, guided HAI (2008b) to include the elderly in research and policymaking.

With data on their citizens' aging, as well as the information on the marginalizing of their elderly, Thailand's stakeholders gathered to review the MIPAA. With the knowledge that Thais are living longer, many without adult children to care for them in their senior years because of the AIDS epidemic, the actors sought to effect political, financial, and social changes in Thailand's policies. The National Plan on Older Persons emerged out of the conversations on social protection for the elderly. This plan and its policies took into account Thailand's economic, social, and political arenas along with the fact that HIV is now a chronic health issue (Jones, 2011; Vejjajiva, 2011). PLHA are living longer with the aid of antiretroviral therapy (Knodel & Chayovan, 2011; Knodel, Kespichayawattana, Wiwatwanich, & Saengtienchai, 2007). They are growing older as are their caregivers (Knodel, Chayovan, & Prachuabmoh, 2011). As both populations age, both will have the possibility of serious health issues (FHI, 2008; Knodel et al., 2011; Williams et al., 2010).

The call to action has been supported in part by Thailand's stakeholders signing into practice the MIPAA. Policy changes helped form the Asian Epidemic Model (AEM), the National Economic and Social Development Plan, and the National Plan for Strategic and Integrated HIV and AIDS Prevention and Alleviation, which mandates preventive and educational programs for all Thai citizens, especially the elderly. Numerous INGOs, FBOs, various government agencies, local civic organizations, and the TNP worked together to create the new goals, objectives, and strategies to prevent and alleviate

problems associated with HIV and AIDS in Thailand (FHI, 2008; UNDP, 2007; UNFPA & HAI, 2011). One such goal is that 80% of HIV and AIDS infected people and people affected by AIDS have availability to social services (FHI, 2008). These plans are the beginning of a process to ensure that all PLHA, their caregivers, and their affected family members will have their physical, financial, emotional, and social needs met (Knodel et al., 2009; UNGASS, 2010; UNFPA & HAI, 2011).

To achieve these goals, the stakeholders will need to guarantee the increased collection of data on Thailand's elderly caregivers. The need to collaborate and share information will further this process. Although there is much literature available on the orphans and vulnerable children affected by AIDS, there is little literature on how the elderly caregivers are faring. Meanwhile, the caregivers' unselfish acts helped Thailand's government and other NGOs focus on campaigns to educate the public while creating policies to address the epidemic. This unquestioning caregiving is due to Thailand's Buddhist belief of *rok khong khon mee kam* and supported by the acts of "*hai* (giving) and *siasala* (sacrificing)" (Sethabouppha & Kane, 2005, p. 48).

Thai Culture, HIV, and AIDS

"Culture is deeply embedded" and yet, "dynamic, not static," wrote Lewis (2007, pp. 234, 261). Hofstede (2003) shared that each culture has its own value system, gender differences, ethos of working as a group versus as an individual, and communications. Thailand's culture and values are tied to the practice of Buddhism (Nilmanat & Street, 2007). As with any religion or philosophy, Buddhism can be taught and practiced through many methods. Buddhism is practiced by 94-95% of Thais and is the foundation of its

social structure (Kittikorn et al., 2006; Kusalasaya, 2005; Nilmanat & Street, 2007; Sethabouppha & Kane, 2005). Kusalasaya (2005) shared that Thailand's "culture and philosophy, its art and literature, its ethics and morality and many of its folkways and festivals" (p. 23) are interwoven with the practice of Theravada, also known as Hinayana Buddhism (Chamrathirong et al., 2010).

This form of Buddhism supports the belief of *rok khong khon mee kam*, where a person's actions (positive or negative) will influence their current and future lives. This, then, brings to the fore the belief in reincarnation, which results from a person's life choices. Reincarnation is affected by positive *bun* and negative *baab* merit making, among other actions. *Baab* are connected to bad karma and bad consequences in life (Nilmanat & Street, 2007; Sethabouppha & Kane, 2005). The giving of various financial and other types of gifts to the wat (temple) and monks gains *bun* merits. Merit making is required on a daily basis because a person is sure to break one or several of Buddha's commandments each day. The five commandments ordained by Buddha are (a) no killing, (b) no stealing, (c) no adultery, (d) no lying, and (e) no alcohol or drugs (Cooper & Cooper, 1996). The National Statistical Office (as cited in Chamrathirong et al., 2010) shared for the majority of Thais who practice Buddhism that there is still freedom of choice. The cycle of life is complete when a person achieves enlightenment (Chamrathirong et al., 2010; Kusalasaya, 2005; Nilmanat & Street, 2007).

Each Thai has a responsibility to interpret Buddha's commandments and then act accordingly. The concept *dukkha* means, "all life is suffering" (Cooper & Cooper, 1996, p. 78), and deals with each individual's "own mental attitudes, concepts, perceptions and

consciousness” (Yeshe, 1998, p. 20). Each family teaches their members the right and wrong behaviors of society depending on the values, political views, environment, and culture of the family. For instance, Sethabouppha and Kane (2005) reported this lifetime of suffering is viewed as “a natural and incurable illness” (p. 54). The caregivers were able to deliver kind and patient care because of their belief that life is about suffering, karma, and merit making.

Krengjai, another concept of Buddhism, supports the values held by a Thai family (Bechtel & Apakupakul, 1999; Nyamathi et al., 2007). Cooper and Cooper (1996) noted that *krengjai* means “consideration of others and self” (p. 83). Social order, rules, and protocols are governed by this concept, which establishes and maintains harmony within the family and within society. Creating and keeping harmony, along with the sense of duty for family, supports and ensures the welfare and happiness of all members of the Thai family (Bechtel & Apakupakul, 1999; Kittikorn et al., 2006; Phengjard et al., 2002). Noteworthy to this concept is the past and current research on Thailand’s family structure, which is based on filial obligation (Knodel & Chayovan, 2009a, 2009b; Knodel et al., 2011, Knodel et al., 2007). For example, Phengjard et al. (2002), Nilmanat and Street (2004, 2007), and Wacharasin and Homchampa (2008) reported identical themes while interviewing Thai families. In Thailand, filial obligation means that adult Thai children have a duty to take care of their parents in their golden years. Conflicts are both unacceptable and avoided, ensuring *krengjai* within each family as well as in work and social relationships.

Many of these beliefs, as well as the social-economic structure of the family, have been affected by the HIV epidemic and the industrialization of Thailand. Thais adopt elements from other cultures and mix them into their own. They see and feel their own power and realize that anything they want can be found in their own country. Individualism has taken root, especially when it comes to technology and communication, though these behaviors are more common in the urban areas of Thailand than in the rural areas (Chamrathirong et al., 2010; Haque & Soonthorndhada, 2009; UNGASS, 2008). Rural provinces continue the tradition of family over individualism (Phongpaichit & Baker, 1998).

Overall, Thais have been shaken but not completely changed by the economic growth of their country. Nisbett (2003) wrote, “The peg that stands out is pounded down” (p.48). This Asian proverb sums up the collective behaviors that continue to be part of Thailand’s culture. The tradition of saving face, *naa* along with showing consideration and respect (*krengjai*), is instilled at an early age. Respect for the elderly, family or not, continues to be important in Thailand. A majority of Thai youth still live with their parents or close by in the village because of this connection and respect for family (Knodel et al., 2007). Although a recent survey found that due to the increased numbers of youth migrating to the cities for employment, AIDS deaths, and decreased family size, this figure has dropped to around 56% (Knodel & Chayovan, 2011, p. 24). Despite the change of living arrangements, *krengjai* has helped families and Thai society in general in many ways, as HIV and AIDS have forced many Thais to adjust their way of life economically, emotionally, physically, and socially (HAI, 2005, 2007a, 2008a; Nilmanat

& Street, 2004; Nyamathi et al., 2007; Phengjard et al., 2002; Sorajjakool, 2006; Wacharasin & Homchampa, 2008).

Thai's Krengjai and Erikson's Psychosocial Development Stages

Erikson's (1950) psychosocial development theory was the theoretical framework within which the Thai Buddhist concept and practice of *krengjai*, *dukkha*, and *rok khong khon mee kam* were examined in order to understand the experiences of the elderly rural grandparents caring for their young wards. The Erikson described both the positive and negative outcomes of a child's psychosocial growth in connection to such relationships.

Beginning at birth, the attachment between the mother or caregiver and child establishes the foundation of a child's life. Along with this attachment of love, meeting the basic needs of food, shelter, and clothing provides for the child's well being and development of trust. This process depends on the caregiver and child building a relationship based on trust, care, age appropriate boundaries. Erikson's theory asserts the need for children and their caregivers to learn in stages the life lessons that teach independence, self-control, initiative, and productiveness. A child who fails to achieve these life stages can become mistrustful, doubtful, dependent on others, and exhibit unconstructive behaviors (Nevid, 2007; Rosenthal, Gurney, & Moore, 1981; Wittig, 2002). The findings of Janjaroen and Khamman (2002) supported Erikson's early research that found that these behaviors resulted from "emotional deprivation" (pp. 12, 248).

Accordingly, the Thai family is the first safe world that a child knows (Cooper & Cooper, 1996). *Krengjai* is taught from birth within a Thai family. Children learn at a

young age that being considerate and humble results in a calm way of life. The display of *krengjai* is between fathers, mothers, siblings, and others, thus maintaining calmness and peace within the family. Erikson saw this behavioral education as the developing of the person's ego. Through establishing various kinds and levels of relationships within the immediate and extended family, this sense of self expands and matures (Nevid, 2007).

The importance of *krengjai* in a Thai child's development supports Erikson's concept of the early childhood growth of trust, autonomy, and abilities. Each of the stages involves social interactions with self, family, and extended family. Feeling safe with family members creates a foundation of trust. This trust and respect provides the framework for new experiences and information, which brings about independence to enter successfully later in life into other communities, such as school, sports, college, and business. Moving from the family to the community allows for independence but can also bring conflict. According to Erikson, conflict is good; it forces the person to grow emotionally and cognitively (Hoare, 2005; Nevid, 2007). The growth achieved from life's positive and negative experiences can benefit a young person when parents become ill, and other caregivers, such as their grandparents, must care for them (Miller, 2001).

Thai children practicing Buddhism may have a strong foundation to cope with the loss of a parent from AIDS. As other people pass away due to complications of AIDS, the child's family becomes smaller. The deaths of parents, a favorite uncle, a schoolteacher, or the noodle shop person change the landscape of the child's family and social environment. Due to sensitive issues, shame and stigma still surrounding HIV and AIDS, each of these conflicts brings about an emotional and cognitive shifting of experiences,

information, and interactions with others and self. Of course, these changes affect the entire family, yet they can depend on each other through the strength of *krengjai*, self-control, and trust to struggle successfully through the crisis of HIV (Kittikorn et al., 2006; Phengjard et al., 2002). The issues faced by rural elderly caregivers are what Erikson defined as the opportunity to grow psychologically. To confront the gossip and discrimination is not done or condoned in Thai culture. Rather, people seek inner peace through the “Buddhist belief of karma to create meaning and purpose” (Nilmanat & Street, 2007, p. 94).

The value to the psychosocial development of a child gained through the Thai tendency to focus on the family is also supported by research conducted by Bhana, McKay, Mellins, Petersen, and Bell (2010), DeGennaro and Zeitz (2009), Richter (2010), and Richter, Beyrer, Kippax, and Heidari (2010). Each of the authors stated that HIV is a “family-based disease” (Bhana et. al., 2010, p. 1) and should be treated as such (JLICA, 2009; KFF, 2010b; Richter et al., 2009). Long after the adult living with HIV has passed away, the other family members continue to be affected by the loss (Wacharasin & Homchampa, 2008). The family members might be going through one or several of Erikson’s stages of shame and doubt, guilt, confusion, and isolation. These negative feelings depend on the individual’s ego development. Maybe the family did not understand the nature of the illness. Maybe they did not trust the doctors or did not reach out for help from any of several sources of assistance, resulting in the death of the person living with HIV. Maybe the family did not have a strong enough ego to share with the community, keeping the person living with HIV hidden until it was too late to get help.

On the other hand, adults receiving antiretroviral treatment gain strength and improved health, yet there are lasting consequences for the family members affected by the illness (Kittikorn et al., 2006; Lee et al., 2010; Nilmanat & Street, 2007; Wacharasin & Homchampa, 2008). Relationships may have been damaged beyond repair between the community and family. Rebuilding trust and intimacy will take time. Some of the family members may still have some fear or confusion about HIV and not want to continue the relationship. Each of these reactions represents a behavior that Erikson's psychosocial development stages address.

Three decades after the first AIDS case was identified in Thailand in 1982, HIV and AIDS continue to play a major role in the future of Thai families (Liamputtong et al., 2009; Warachit, 2011). In their literature review, Leeper, Montague, Friedman, and Flanigan (2010) stated caregivers continue to struggle with limited resources, yet little of this data has been translated into action (viz., financial, psychosocial, and other support). Thai caregivers move back and forth between Erikson's stages of development. Giving of themselves assures *krengjai* and good *rok khong khon mee kam*, but at the same time, there is a cost. For example, Erikson's identity versus confusion stage may be experienced by Thai caregivers and the grandchildren. Without the son/father, what will happen? Who will help in the rice fields? The Buddhist belief of sacrificing of financially, physically, emotionally, and socially for the family brings about conflicts that mirror Erikson's stages of ego development.

Buddhism and AIDS

In the early days of AIDS, Thais turned to their community wat, seeking out the abbot (head of each wat) and monks for help. Since the earliest days of Buddhism in Thailand, monks have supported the people with their moral and spiritual guidance (Chamratrithirong et al., 2010; Nilmanat & Street, 2004; Phad et al., 2010). The monks, living in myriad monasteries and temples, have offered guidance on various topics, allowing people to find peace and success (Kusalasaya, 2005). Monks are “friends, philosophers, and guides” (Kusalasaya, 2005, p. 19) to all. The wat is the center of community life in the rural environment. Besides being a place of worship, wats are also a place where children can go for their primary education and where boys can stay and receive room and board in exchange for helping the monks in their daily chores. It is a community center, a recreation center, and a hospice for the elderly, needy, and sick. Besides their Dhamma learning, the monks’ education includes knowledge on legal, social, and medical matters. The changing demands of the world have affected people living in the urban parts of Thailand, but families living in the rural areas continue to seek consultation with the monks at the wat (Im-em & Suwannarat, 2002; Sangha Metta Project, 2011a, 2011b).

The leadership skills of the abbots and monks are taught through the many lessons of Buddha, such as the “Four Noble Truths--suffering (*Dukkha*), the cause of suffering (*Samudaya*), the cessation of suffering (*Nirodha*) and the path leading to the cessation of suffering (*Magga*)” (Maund, 2011, para. 6). Bechtel and Apakupakul (1999), Chamratrithirong et al. (2010), and Kusalasaya (2005) also wrote on this topic with

additional commentary on the monks' vows of deprivation and humbleness. Another part of the novice's lifetime vow is "Kusala Kamma, meaning to do good" (Kusalasaya, 2005, p. 22). They must understand and be prepared to be, as the world renowned Zen teacher, Thich Nhat Hanh, shared, "socially engaged Buddhists" (Swearer, 2010, p. 314). Following Buddha's example, novices begin a lifetime of learning and caring for the betterment of others (Chamrathirong et al., 2010; Cooper & Cooper, 1996).

This learning and taking care of others by monks, as well as the services of other counselors throughout the world, has been tested by the HIV epidemic. With the first case of HIV in Thailand in 1984 (AVERT, 2011b; Chitwarakorn, 2003; Nilmanat & Street, 2004), the monks not only continued providing guidance on personal, financial, and social matters, but also began dealing with the failing of *krengjai*. Due to a lack of understanding about this unfamiliar illness, many family members, friends, colleagues, and community members treated those with HIV and AIDS as if they had leprosy (Bechtel & Apakupakul, 1999; Kittikorn et al., 2006).

Part of this stigma resulted from fear and myths surrounding the illness, such as being able to catch it from another by a handshake. Another part is the belief that Thais who have this illness are engaging in illegal and immoral behaviors (Ainsworth et al., 2003; Chan & Reidpath, 2007; Songwathana & Manderson, 2001). JLICA (2009) and Knodel et al. (2009) documented that this mentality changed slowly as information and education spread to the Thai population. The reinstatement of *krengjai* in families and communities was helped by the successful collaborations of NGOs working with and

educating Thailand's monks (Bechtel & Apakupakul, 1999; HAI, 2005, 2007a; UNICEF, 2009b).

These collaborations were possible in the early stages of the HIV and AIDS epidemic because the monks and wats kept their hearts and doors open to treat those in physical, emotional, and financial need (Bechtel & Apakupakul, 1999; HAI, 2005, 2007a; UNICEF, 2003, 2009a). The Thai monks were able to help this group of people because of their belief in the Buddha's Four Noble Truths, especially the belief that life is suffering. Using their educational and leadership skills, the monks began to reach out to their communities to address the people's fears. This outreach was especially directed to people infected with HIV and their family members (Maund, 2011; UNICEF, n.d.). One of the first wats to be used as a hospice was Phra Baht Nam Phu, outside of Bangkok, in the early 1990s. The education and support given to this program opened the door to many other organizations willing to work with the monks. These collaborations began to help eliminate the stigma and discrimination towards people with HIV and AIDS. Over the years, specialized health training has enhanced their ability to counsel and educate (UNICEF, 2003, 2009a).

This unconditional caring of Thailand's abbots and monks continues today with programs such as UNICEF's project, The Sangha Metta, meaning "compassionate monks" (UNICEF, n.d., para. 15). It was started in 1998 by a novice in Chiang Mai who was concerned about the stigma connected with AIDS, as well as the lack of education and services for PLHA and their family members (Sangha Metta Project, 2011a, 2011b). Abbot Dhannawat shared, "The problem was on both sides, people who had HIV-AIDS

were secretive, while the community would not accept them. Everything was negative, threatening the community's ability to survive peacefully” (Williams, 2011, para.7). The Four Noble Truths are used as the foundation of this project, along with other educational tools. Monks and nuns are trained to use various methods to educate the general population about the truth and myths of HIV and AIDS. Prevention programs, spiritual guidance, and financial support are offered throughout Thailand by these monks and nuns (Borthwick, 2002; Maund, 2011; Thongsa-aad, 2011).

The success of the Sangha Metta Project is undocumented in the sense of qualitative or quantitative inquiry. This is the case for a majority of the local NFOs, NGOs, and FBOS offering HIV and AIDS interventions and programs. Information from these organizations is generally collected from their websites, people connected to said program, and from the gray literature. Even in the peer-reviewed literature, the data might be conflicting or questionable. For example, the quantitative and qualitative studies of Knodel (2008) and Knodel and Chayovan (2008b) contended that the elderly in Thailand have many social safety nets to alleviate the burdens of caregiving. This premise was further established by their recent findings (Knodel & Chayovan2011). In contrast, Lee et al. (2010) used multiple regression models that concluded that the Thai elderly caregivers are under tremendous burdens due to the lack of social safety nets. Two other studies by Chan and Reidpath (2007) and Kittikorn et al. (2006) supported the conclusions of Lee et al (2010). They contended that shame and stigma continued to be attached to PLHA as well as those that are caring for them. This shame prevented many from seeking outside help, which caused them further hardships.

Caregiving in Thailand

The Orphans and the Vulnerable Children

As defined by UNAIDS, UNICEF, & USAID's (2002) joint report and updated with the 2004 report, an orphan is a "child whose mother, father, or both have died from AIDS" (pp. 6, 8). The 2004 report changed the age limit from 15 to 18 years. Children under the age of 18 become vulnerable when their "survival, well-being, or development is threatened by HIV/AIDS" (USAID, 2006, p. 6). UNICEF supported this assessment in their 2006 report, with the following statement: "HIV/AIDS is wreaking havoc with children's lives in the worst-affected countries" (p. 16). From these in-depth reports came the acronym, OVC, orphans and vulnerable children, to distinguish them from other children who have lost their parents from natural disasters, war, poverty, and deaths from other causes (FHI, 2005, KFF, 2010b; UNAIDS, UNICEF, & USAID, 2004). Peer reviewed journals and books along with the supplementary gray literature (e.g., research and reports compiled by UNAIDS or UNICEF) use this definition.

The *Children on the Brink* series began in 1997, when three of the top INGOs, UNAIDS, UNICEF, and USAID, collaborated to write the first report. The fourth installment of these groundbreaking reports continues to disclose the impact of how the HIV epidemic is affecting families and children throughout the world. The conclusion from this research stated that the number of children left behind would increase as the illness spread and more parents' lives were lost. Many of the orphans will be taken care of by extended family, such as grandparents or older siblings. Older siblings, who may only be a year or two older, will find themselves in the role of the adult protector of their

brothers or sisters. As parents pass away from the epidemic, so do teachers, health workers, uncles, aunts, and siblings. This leaves children in the care of their elderly grandparents or fending for themselves. For many of these children, this is the beginning of learning how to survive. Besides the emotional loss of loved ones, these children now must protect themselves from violence, sexual abuse, prostitution, and HIV (Hawkins, 2008).

Thailand's Orphans and Vulnerable Children

In Thailand, as in sub-Saharan Africa, extended families take care of the children orphaned by AIDS. In that region of Africa, 90% of orphans (Ice, Yogo, Heh, & Juma, 2010) are taken in by members of the family and the majority of these households are run by females (HAI, 2005; Knodel & Saengtienchai, 2005; Mall, 2005; Williams et al., 2010). As is the case in sub-Saharan Africa, Thailand's culture is based on an intergenerational system. Knodel and Chayovan (2009a) reported that it is estimated that more than 70% of adult children live with or close to their parents. This arrangement allows for a flow of financial, physical, and emotional help between younger and older family members. This figure rose slightly with the return of PLHA adult Thai children who were sick and in need of care (Knodel & Chayovan, 2008b, 2009a; Knodel et al., 2007; Suwanrada, 2009). Prior to the availability of antiretroviral treatment, many of these adult children passed away, leaving behind grieving elderly parents with some debt and possibly grandchildren (HAI, 2005, 2007a; HAI & Alliance, 2003; Janjaroen & Khamman, 2002).

It is unclear how many children orphaned by AIDS and vulnerable children exist. The statistical information available is limited and at times contradictory. In the early years of the epidemic, Thailand's MOPH and UNAIDS (2002) estimated that 300,000 children 15 years old and younger had lost a parent to AIDS (as cited in Safman, 2004), whereas the current UNAIDS Global Report (2010b) lists no figures for the number of orphans in Thailand. This lack of data is also found in UNICEF's (2011) report, where the number of children orphaned in Thailand because of AIDS is "unknown" (p. 102). Thailand's most recent national report where figures are from a survey completed in 2006, list 854,215 orphans (UNGASS, 2010). It is unclear if this figure was for children whose parents passed away due to AIDS or if it was for children orphaned by all causes of parental deaths.

In connection with the numbers is the equally important reduction in the number of children in a Thai family due to the increased family planning component of Thailand's health education (Jones, 2011; Knodel et al., 2011; Vejjajiva, 2011). Wachter, Knodel, and Vanlandingham (2002) first reported this trend in their research on the effects of the AIDS epidemic on the Thai household. Knodel and Saengtienchai shared in their 2002 research that with this type of planning, over half of the deceased AIDS parents left no children. Therefore, many parents of these adult children are not raising any grandchildren. This information is supported by further research conducted by Knodel and Saengtienchai (2005) as well as HAI (2007a), which also found that about half of the deceased adults had no children at the time of their deaths.

On the contrary, Knodel and Chayovan (2011) reviewed the 2007 SOPT, which confirmed that of the 66% of people living in rural Thailand, 44.5% are elderly grandparents, 60 years and older, who have grandchildren under the age of 16 living with them (p. 21). Of that 44.5%, a little more than 20% of grandparents have both an adult child and grandchild living with them, although Knodel and Chayovan (2011) do not clarify if this parent is HIV positive, nor whether they work. Another 27% of the 44.5% of elderly households have no parent present, but a young person of 16 and older. This is the first survey to introduce the concept of the “skipped generation” household (Samuels & Wells, 2009, para. 3), where a family has lost both parents to AIDS and grandparents are raising grandchildren. This description fits 38% of the surveyed households. Without any middle generation, Thailand’s elderly grandparents are raising their grandchildren, no matter how young or old they are.

The Caregivers

The word caregiving explains itself, giving care. WHO (2004b) shared that caregivers are those that tend to babies and children. For the majority of the world’s children, this is the nurturing love and care of a mother or mother substitute (Drimie & Casale, 2008; Wakhweya, Dirks, & Yeboah, 2008). Berman (2002) asked,

Who cares for the carers, and why is it taken for granted that women provide, and will continue to provide, care and support to family members and loved ones, with no sense of the cost and value of this work to society and the economy in general (as cited in Ogden, Esim, & Grown, 2004)?

Researchers support that most caregivers are females and this holds true for Thailand (Ageway, 2008; Mathambo & Gibbs, 2008; UN, 2010b; UNAIDS, 2010b). This first maternal attachment of newborns begins the cycle of life (Parkes, Hinde, & Marris, 1991). John Bowlby's theory of a child and mother attachment is the foundation of the WHO's (2004b) report. Besides providing for food, shelter, and various other physical needs and wants, caregivers must be able to give of themselves. They need to be able to connect with the child in an intimate and long-term relationship, which brings happiness to both (Bowlby, 1951, 1958; Bretherton, 1992). In Thailand's culture, this caring relationship begins the moment the child is born into the family (Cooper & Cooper, 1996). As discussed previously, with the practice of Buddhism comes the belief of *krengjai*, *merit making*, and *rok khong khon mee kam*. Each person within the family is responsible for upholding the concepts to build and maintain the family's foundation. Each person is important, yet more important is the entire family working together to achieve happiness and harmony (Bechtel & Apakupakul, 1999; Nilmanat & Street, 2007; Phad et al., 2010).

With cases of HIV and AIDS, family responsibilities are multiplied by the many roles that each family member must play to help the PLHA. This is especially true for the mother of the sick adult. She becomes the caregiver for both the adult child and any grandchildren. The slow process of the PLHA immune system breaking down results in distress for everyone involved. The grandparents and grandchildren bond as the illness runs its inevitable course, leading to the eventual death of their loved one. Caregiving for children who have lost one or both parents to AIDS results in ramifications, which

compound their care (Cook et al., 2003; Kuo & Operario, 2009; Lee et al., 2010; Safman, 2004).

One of the first indicators of this serious situation was in UNICEF's 2006 report. Besides creating policies and programs to protect and provide services for orphans and vulnerable children, this report also called for economic, psychosocial, and other types of funding to ensure the success of families. Throughout the world, the family is identified as the first line of defense in caregiving of those with HIV or AIDS (KFF, 2010b; DeGennaro & Zeitz, 2009). Cook et al. (2003) found that family members working together to keep the children after the loss of a parent due to AIDS were troubled by financial, physical, and psychosocial issues.

Of noteworthy relevance to this research was the facts compiled by JLICA (2009). JLICA is a group of independent stakeholders concerned about the world's HIV situation. They gathered in 2006 to discuss what was working and what was not. In 2009, after countless studies conducted and several dozen papers written, their concluding report was released. In this report, the stakeholders arrived at the consensus that an "integrated approach" (JLICA (2009, p. 5) must be created. Instead of targeting the PLHA, or the vulnerable child, or orphan, the key is to strengthen the entire family. Their conclusion supported many other authors' assertion that families must be placed at the center of all interventions (Betancourt et al., 2010; Bhana et al., 2010; Leeper et al., 2010; Richter et al., 2010; UNICEF, 2006). In years past, INGOs working with health organizations offered services only to the PLHA. When children were involved, services were offered to them. The caretakers' needs and concerns for both these populations continue to be

lost in the shuffle of care. This is especially true in the caregivers' lack of understanding on the matter of the epidemiology of HIV. Not understanding how HIV is spread places the caregivers at risk for infection, as well as other members of the family. Providing piecemeal services dealing with the PLHA or the OVC, instead of working with the whole household, has had some limited success, but more often it "has led to confusion and misdirection of the global, national and local response" (Richter, 2010, p. 1). Until specific interventions are created that address all the family members, infected and affected, this limited success will continue. Although home based services have been successful in the mental and physical health field, the family model to address the AIDS household continues to lack the backing of stakeholders and policy makers (DeGennaro & Zeitz, 2009; Richter et al., 2010; WHO, 2004a). Until they find value with this approach, Richter et al. (2009) shared, "We will not be in a position to interrupt the cycle of infection, provide treatment to all who need it, and enable affected individuals to be cared for by those who love and feel responsible for them" (p. 3).

Thailand's Caregivers

Despite the common knowledge that Thailand's elderly, primarily grandmothers, are the main caregivers of their sick adult children and many are raising their grandchildren, they receive minimal financial and psychosocial support from the government (Ageway, 2008; HAI, 2007a, 2010; Lee et al., 2010; UNDP, 2007; Wacharasin & Homchampa, 2008). When support is available, the majority of it comes from other family members, close friends, FBOs, or NGOs such as GCPP (Desmond, 2008; Erb, 2011; Heymann & Kidman, 2009; Knodel et al., 2009). The bulk of this

support is financial and generally targeted for the grandchildren's educational fees, clothing, and meals (HAI & Alliance, 2003; KFF, 2010b; Knodel & Saengtienchai, 2005).

This is to some extent true of GCPP, which was created in 1992. Conducting HIV research with the Thai Red Cross in Chiang Mai and surrounding rural villages of Thailand, several individuals became concerned with what they saw. Through this work, they met many orphaned children who lived with their grandparents. Most of these families were living below the poverty level. Most used what little money they had to try to find a cure for their adult child dying of AIDS. Out of their concern for these grandmothers, these individuals created GCPP with the theme of helping one AIDS affected family at a time. This organization has grown from helping one family to 76 families by ensuring they receive emotional, financial, and physical help (Suprasert, 2004; HAI, 2007a).

As GCPP has grown and changed, so has the HIV epidemic. With the creation of antiretroviral drugs, HIV is now a chronic illness rather than a terminal one. With research centers such as Chiang Mai University Research Institute for Health Sciences (RIHES) that are developing and testing new drug regimens to help PLHAs live longer and healthier, Thailand is experiencing a low prevalence of HIV (1.3%) (CIA, 2011b; UNAIDS, 2010c, 2011a).

Thai Parents and Their HIV Positive Adult Children

HAI (2007a), Knodel and Chayovan (2008), Wacharasin and Homchampa (2008), and Kuo and Operario (2009) pointed out that it is the Thai mothers of PLHA that take on

the main role of caregiving. The fathers share in caregiving by seeking extra income through work outside of the home, providing transportation to doctor appointments, clinic visits, and other such important, but supporting roles (HAI, 2007b, 2008c; Ogden et al., 2004; Phengjard et al., 2002). The caretaking by Thailand's females is interlocked with both cultural traditions and the religious beliefs of Buddhism. These traditions and beliefs were the focus of the research conducted by Chan and Reidpath (2007), HAI (2007a), Kittikorn et al. (2006), Lee et al. (2010), Maneesriwongul et al. (2004), Phengjard et al. (2002), and Songwathana and Manderson (2001). . The researchers' noted that the concepts of *krengjai*, *rok khong khon mee kam*, and *dukkha* were intertwined in the lives of Thai females.

Maneesriwongul et al. (2004) reported stories of "moral duty" (p. 28) where the Thai caregivers upheld their religious and cultural beliefs while they tried to maintain a normal home environment. Kittikorn et al. (2006) interviewed eight families, who shared similar stories of shame, disgrace, and isolation. Consequently, the family members interviewed by Chan and Reidpath (2007), Kittikorn et al. (2006), Maneesriwongul et al. (2004), and Phengjard et al. (2002) did not share their situation with others for fear of being ostracized. Thais' cultural belief of *rok khong khon mee kam* prevented them from seeking outside help. This is because majority of the rural population still believed this contagious illness was the result of promiscuous and immoral behaviors. The type of hardship (suffering) also depended on the age of the person; for instance, physically lifting a grown adult as an elderly caregiver.

Similarly, HAI (2007a) surveyed the rural elderly caregivers in Cambodia, Thailand and Vietnam. Cultural norms of these countries dictated that the women were the main caregivers. Finances and the physical responsibilities of running a home, along with caring for their sick adult children, as well as their grandchildren, were the main issues shared by the elderly women. Many of them were widowed and had the added responsibility to find work. This was often difficult due to their age, and since many are also living in poverty, chronic health issues were a problem. As with the elderly in many low-income countries, the elderly of Cambodia, Thailand, and Vietnam are working well past 60 years, which is considered retirement age (Ministry of Affairs, 2011).

HAI (2007a) found that each caregiver had a different experience, as well as a variety of feelings connected to taking care of a PLHA. These differences depended on such things as their beliefs, their age, their income, and whether they received help from other family members or the community. These same issues were documented years earlier by Songwathana and Manderson (2001). In 2008, 48 families were interviewed by Wacharasin and Homchampa (2008). They shared how *dukkha* influenced their life experiences caring for a PLHA. Through their trials and errors, these lessons helped them learn better methods to care for them. The Thai women caring for PLHA expressed feelings of “fear, stigma, hopelessness, sorrow and empathy, and hope” (Wacharasin and Homchampa, 2008, p. 31).

. The Thai stakeholders who wrote the 2007-2011 National Plan for Strategic and Integrated HIV and AIDS Prevention and Alleviation added the population of elderly caregivers to its agenda. The suggested measure is to support and develop programs for

the older people affected by HIV/AIDS (UNDP, 2007). The plan of action for these interventions is not clearly defined nor do they appear they have financial backing (HAI, 2007a; UN, 2009a, 2009b, 2010a, 2010b). Thailand's policymakers continue to make decisions on the belief that female caregivers, with possible support from other family members, will bear most of the responsibility to care for their sick. Lee et al. (2010) agreed with the lack of follow through when they interviewed 408 Thai caregivers using several measurable scales. .Of this number, 66% of them fell in the "moderate to severe or severe burden" category (pp. 3, 4). The day-to-day issues of living and maintaining relationships became complex when the caregiver took on the long-term care that accompanies a PLHA.

Lee et al. (2010) confirmed what was discovered 10 years prior in the first qualitative study that addressed Thailand's aging caregivers in relationship to HIV and AIDS. Compiled in the early part of 1999 by Knodel et al. (2001) with Thailand's MOPH, the authors interviewed 963 adults living in Bangkok or one of eight rural and urban regions. More than half of the PLHA lived with or close to their parents and that, the majority of their parents, aged 50 and older, cared for them. Knodel et al. (2001) noted the following concerns: (a) the physical demands of caring for a terminally ill person, (b) financial expenses for medical treatment and other related costs, (c) care of grandchildren, (d) emotional stress, and (e) the loss of adult children's earnings.

In 2002, Phengjard et al. completed an interpretive phenomenology study with 13 families in Bangkok, Thailand. Each family had someone being cared for due to the complications of HIV or AIDS. Similar to the research of Knodel et al.(2001), Phengjard

et al. (2002) found that the families, especially the women, were the main caregivers to their PLHA. Receiving little to no financial or other aid from the Thai government, a majority of these families were living in poverty. The researchers' revealed four themes: (a) shunning, (b) keeping silent, (c) shielding, and (d) suffering (Phengjard et al., 2002).

Emotionally, parents typically grieve in silence throughout their adult child's illness and after their death (Cadell, 2007; Waldrop, 2007). They grieve for the adult child's pain and the possibility that the illness will kill them. They may not understand what HIV or AIDS is, be fearful that they or others in the family might become ill, and wonder, what will happen if they become sick. This lack of understanding about AIDS can affect the entire community. Discrimination within the community can cause financial and emotional fallout (HAI, 2005, 2007a; Lee et al., 2010; Phengjard et al., 2002). For instance, customers may quit frequenting the noodle shop because they believe they may catch AIDS, or share gossip or unkind stories about the adult child's behavior and karma, causing sadness, hurt, and shame among the family members. These negative behaviors by family and community members can lead to further suffering and lack of resources when help is needed (HAI, 2005, 2007a, 2007b, 2008c; Kittikorn et al., 2006; Lee et al., 2010). Depending on the caregivers' age, health, and other support, all these negative strains can build up and cause them to succumb to their own sickness (Ageway, 2008; Knodel, 2008; Knodel & Chayovan, 2008a, 2008b, Ogden et al., 2004).

A great amount of knowledge and data have been collected about grief and loss. Meuser and Marwit (2001) explained specifically about "caregiver grief, which includes the intellectual, affective, and existential elements of changing care demands and

expectations” (as cited in Waldrop, 2007, p. 197). This definition supports the collected evidence, which found Thailand’s families experience a wide range of hardships (e.g., emotional, financial, physical, and social) during their adult child’s illness and possible or eventual death (Knodel, 2008; Knodel & Saengtienchai, 2002; Nilmanat & Street, 2007). Dealing with the daily maintenance of the household along with the adult child’s health needs, a woman can become physically exhausted, leading to her own health problems. This is also true for the men who may be forced to take on several physically demanding jobs to earn extra money to pay for their adult child’s medicine and other needs (HAI, 2007b; KFF, 2010b). The family expends all their money and may end up having to sell their land and possessions to pay for their adult child’s medical treatments (Knodel & Imem, 2004). Mothers who would normally be cooking in a noodle shop or working in the fields, no longer are because they are home caring for their sick adult child. Fathers may have to work at night so that they can transport their adult child to the clinic or hospital during the day. While caring for others in the family is emotionally draining, the expectation of *krengjai* must be honored (Nyamathi et al., 2007; Phengjard et al., 2002; Sorajjakool, 2006).

Further evidence of the hardships encountered by Thai caregivers was found in studies conducted by Nilmanat and Street (2004, 2007) and Wacharasin and Homchampa (2008). The authors’ focused on the caregivers’ narrative reports on caring for a child or PLHA and the issues surrounding this chronic illness. Caregiving for a chronically ill family member is hard enough without the additional stigma that is connected with HIV and AIDS (Chan & Reidpath, 2007; Kittikorn et al., 2006; Wacharasin & Homchampa,

2008; UNAIDS, 2011b). The caregivers shared their feelings of sadness, frustration, fear, and joy in caring for their loved ones. They also shared their financial, social, and physical concerns that caused them stress on a daily basis. These issues, coping with them, and the stress associated with the issues, were confirmed by Cadell (2007). In his study, the 15 participants shared their reliance on spirituality, humor, outside resources, and other supports to caregive for and eventually bury their loved one.

Although given freely in the Buddhist belief of *rok khong khon mee kam*, commitments of time, money, and care place burdens on families. The researchers' conclusions supported the literature review that a variety of interventions was urgently needed to address the caregivers' burdens (Lee et al., 2010). One such intervention was the introduction of the antiretroviral treatment for HIV. Supported by various international stakeholders, RIHES has conducted long-term clinical trials and other research on the drugs' effectiveness. One of the outcomes is that antiretroviral treatment is slowly becoming available throughout the country (Knodel et al., 2009; RIHES, 2011; USAID, 2010; WHO, 2010). This action is being supported by the National AIDS Plan, which calls for (a) cutting new infections by half, (b) providing antiretroviral treatment to all persons needing this treatment, and (c) social support to PLHA and all others affected by AIDS (UNGASS, 2010).

For those who have not lost an adult child to AIDS because they have gained access to antiretroviral treatment, research completed by Knodel et al. (2009) and WHO (2010) concluded that the intervention of this drug therapy has been beneficial for them and their families. WHO (2010) estimated that 50%–78% of Thais received antiretroviral

treatment in 2009 (p. 55). This is supported by data collected by FHI (2008), Knodel et al. (2009), UNGASS (2010), and UNAIDS (2010a). Despite the scale-up of medical treatment and educational programs throughout the country, there are many who are not receiving these services. They may not because they are (a) unaware of their HIV positive status, (b) in denial due to stigma and discrimination issues, (c) asymptomatic, (d) symptomatic but too ill to travel, or have no one to help them, or there is no money for transportation, and (e) not close to a clinic that provides antiretroviral treatment (FHI, 2008; HAI, 2005, 2007a; Wacharasin & Homchampa, 2008).

Persons who receive the antiretroviral therapy must subscribe to a daily drug therapy schedule for the rest of their lives and must maintain good health for the drugs to work (Knodel et al., 2009; UNAIDS, 2010b; WHO, 2010). This daily drug regimen must go hand-in-hand with attention, care, and support from the medical sector as well as from the family (FHI, 2008; Knodel et al., 2009; UNAIDS, 2010a). The inevitability of burying an adult child may be ending in Thailand, but the cycle of long-term care, as well as dealing with day-to-day stressors, will continue with this chronic illness (KFF, 2010b).

For the families of adult children who did not receive or take the antiretroviral treatment and died, they must bury them and deal with their grief. According to HAI (2005), between 2001 and 2004, 240,000 elderly parents buried adult children who died from AIDS (p. 2) Losing a grown child is overwhelming for any parent, but because of Thailand's intergenerational relations, this loss is profound (Knodel & Chayovan, 2009a). Sharing a home or living within walking distance, helping each other in the fields, the noodle shop, or with the household chores and raising younger children, this loss is

overwhelming on many levels (HAI, 2005, 2007a; Knodel & Saengtienchai, 2005; Worden, 2009). Nilmanat and Street (2007) reported how four families and their dying adult children found peace through Buddha's teachings. Under the constant burden and stress of caregiving and experiencing discrimination within their community, these families found strength and understanding in their suffering (Nilmanat & Street, 2007, p. 97). This sense of peace and understanding of life's purpose in relationship to the afflictions of AIDS were also identified by the caregivers in Cadell's (2007) research.

If it was a parent's only adult child, who had yet to marry or have children, the emotional loss was compounded with the knowledge that there would be no grandchildren. Other significant consequences after their adult child's death could be debt and isolation after spending everything (viz., time and money) in hopes of saving their child (Cook et al., 2003; HAI, 2005, 2007a). For many, mourning of the death of an adult child is also the start of providing for their grandchildren's daily care, which includes helping them handle their grief over losing a parent(s).

Dealing with their grandchildren's grief is only the beginning of the physical, financial, emotional, and social consequences surrounding the loss of their adult child from AIDS. Physically they are worn out from the around the clock care their sick adult child required. Many rural Thai families were already financially struggling when their sick adult child returned home (Jitsuchon & Richter, 2007; Household Socio-Economic Survey, 2007; UNDP, 2004). Savings are depleted from buying medicine and paying for the funeral. Their emotions are raw, and socially they may not know where they stand in their community because of the lingering stigma associated with this illness. If they

qualify for a pension, it may not cover all the monthly needs. The Thai government does provide a small financial safety net, but they would need to know how to apply (HAI, 2008a, 2008b; Suwanrada, 2009; Wacharasin & Homchampa, 2008). HAI (2007a) identified that the consequences of this life changing process are “severe, interconnected, and enduring” (p. 6). In the early days of Thailand’s research on AIDS, Knodel, VanLandingham, Saengtienchai, and Im-em (2001), Phengjard et al. (2002), and Songwathana and Manderson (2001) shared that these particular consequences were known. Minimal attention was focused on this population in relationship to the what next of their lives, which were forever changed by the HIV epidemic.

The Predicament of Thailand’s Caregivers

Economic Considerations

By the late 1980’s, Thailand was moving from an agricultural labor force to an industrial one (ADB, 2011; Phongpaichit & Baker, 1998). As has been the case for many developing countries, a small percentage of Thai youth slowly migrated to the cities for better employment (Zimmer & Knodel, 2010). In spite of this, more than 70% of Thai families still had at least one adult child living with or near them (Knodel et al., 2011; Zimmer & Knodel, 2010). A majority of migrating adult children send part of their income home to help their parents have a better life (Knodel, Kespichayawattana, Saengtienchai, & Wiwatwanich, 2010; Suwanrada, 2009; Zimmer & Knodel, 2010). This financial arrangement conforms to the Buddhist concept of *krengjai*, whereby adult children deem they have a moral obligation to their parents for having raised them; it also further supports the paradigm of Thai families and Erikson’s stages of personality.

Knodel and Chayovan (2009a, 2009b), Knodel et al. (2007), and Knodel et al. (2010) admitted that though Thailand's culture is changing with the assimilation of many attitudes of more developed countries, the majority of working Thai youth still believe in *krengjai* and financially help their parents. The loss of an adult child eliminates this extra income, placing a possible financial burden on the parents (HAI, 2007a, 2010)).

Suwanrada (2009) pointed out that a little over 31% of the elderly had no savings or assets of worth (p. 51). If there are grandchildren, depending on their age, raising them can be difficult due to the elderly grandparents' age. In addition, to take into account is the financial, physical, and emotional issues involved with raising a child (HAI, 2005; 2007a; KFF, 2010a, 2010b; Safman, 2004)

The quality of life of many elderly Thais improved with material goods purchased with their adult children's earnings before they became too ill to work and passed away (Knodel et al., 2009; Knodel & Saengtienchai, 2005; UNFPA, 2006). As they aged, the elderly parents depended on their adult children living at or near home to do more of the physical work (HAI, 2005, 2007a). With the onset of HIV, sick adult children who had migrated to the city came home in need of their parents' care and support (Knodel, 2008; Knodel & Saengtienchai, 2002). Instead of receiving financial help from their grown children to help in their senior years, these elderly parents used most or all of their savings, many sold their land, to buy traditional medicines, herbals, and various other questionable treatments (Knodel & Im-em, 2004). This was before the development and free access to antiretroviral therapy. The hope was to stop the illness that was making

their adult children sick (Chamrathirong & Phuengsamran, 2009; Punpanich et al., 2004; Ross-Larson et al., 2004; UNGASS, 2010).

The loss of a young, physically healthy person can cost the family in many ways. In several studies (Knodel & Im-em, 2004; Knodel et al., 2010, 2011; Suwanrada, 2009), it was pointed out that without the extra income from an adult child who passed away due to AIDS, or other causes, not all, but many caregivers and their extended families live in destitution. They have only what they earn daily to provide for themselves and their grandchildren, if they are raising them. Many elderly are not raising any grandchildren, leaving them lonely and perhaps in poverty from using all their money to help their sick adult child, who is now gone (HAI, 2007a; Zimmer & Knodel, 2010).

Nanthamongkolchai et al. (2011) interviewed 400 elderly (60 to 80 years), who shared that having a monthly income allowed for their happiness. The Household Socio-Economic Survey (2007) found that the national wage earning for a Thai household to be around 18,660 baht per month (p. xi). Broken down, earnings within the formal sectors are the highest, 42,863 baht while, within the informal sectors, earnings are the lowest, around 9,185 baht (p. xii). Thailand's 2007 SOPT reported 20.7% of the elderly, almost double the national average, earn 1,443 baht or less a month (about \$48), which means they are living in poverty (HAI, 2008a; Suwanrada, 2009; UNDP, 2009a).

Chandoevwit and Chawla (2011) asserted that 60% of Thais work in the informal sectors, farming and service. The earnings from this work are unreliable (Jitsuchon & Richter, 2007; UNDP, 2009a). This income is also dependent on all adult members of the family working. Many intergenerational families who once tilled land together for rice

planting and harvesting, now work alone. Many work their former land, which was sold to pay for medical expenses for their sick adult child. To do the same amount of work without any healthy adult children is a struggle.

Many do not have access to their former land and cannot find new employment (UNDP, 2009a). As the body ages, so does the ability to perform long and physically tiring work, such as digging, bending, lifting loads, climbing, and standing on one's feet for hours. Working fewer hours yields lower earnings for the elderly. For example, HAI (2005, 2007b, 2008a), Ageway (2008), and Mathambo and Gibbs (2008) reported that retired grandfathers seek farming work to earn extra money to cover the additional expenses of caring for their PLHA or for the raising their grandchild. Without formal education or marketable skills, they are not able to seek other types of employment (UNDP, 2009a). This is also the case for many of the grandmothers (KFF, 2010b; UNFPA, 2006; UNFPA & HAI, 2011). Depending on their knowledge and ability, some may work for a cottage textile industry. Others may run their own shop or work for someone who owns a shop. They may join their husbands in the rice fields during planting and harvest time (Jones, 2011; Knodel et al., 2011; Vejjajiva, 2011). This depends on the age of the grandchild, if any are being raised. Grandchildren not in school must be attended to either in the home or at work. Sometimes an extended family member or close friend helps (Chandoevrit & Chawla, 2011).

Extra money might come from a family member's pension. The Thai government has several retirement programs for those employed by the formal sector (e.g., government workers, school personnel and certain private businesses) (Suwanrada, 2009;

Wacharasin & Homchampa, 2008; Vejjajiva, 2011). Those who work in the informal sectors may qualify for the Old-Age Allowance System, as well as the semi-free outpatient services program, “Green Channel or Fast Lane,” (UNFPA & HAI, 2011 p. 43). To be eligible for the old-age allowance, persons 60 years and older must have an income that does not meet minimal daily living expenses or they have no income because they cannot work due to poor health. After filing with their local government agency and being accepted, they received 200 baht (about \$6) a month. This changed to 500 baht (\$16) after the 2007 SOPT found data supporting the need for an increase (HAI, 2007, 2008a; Suwanrada, 2009; Vejjajiva, 2011). Thailand’s semi-free health care program along with the old age pension money has lightened some of the poor elderly caregivers’ load. HAI (2008a), Jitsuchon and Richter (2007), Suwanrada (2009), and UNDP (2009a), concluded that by and far, the majority of the elderly living in Thailand’s rural provinces are not receiving other social safety nets. Caregivers who have used their life savings trying to save their sick adult child and now raising their grandchild may find the old age allowance insufficient to make ends meet. Mall (2005) supported this assessment by adding to the literature that a grandmother financially raising her grandchildren is an “immense project” (para. 6).

Despite these struggles, elderly caregivers continue to support their grandchildren after the loss of their adult child. Safman (2004) focused on Thailand’s aging caregivers in his qualitative study. His attention was on the relationships between the caregivers and the orphans and vulnerable children. The survey was conducted in Chiang Mai, Thailand, where prevalence rates for HIV and AIDS continued to be one of the highest in the

country. This region in northern Thailand also has one of the largest elderly populations, a majority living in poverty (HAI, 2005; Safman, 2004). At the time this article was published, Safman (2004) shared that no data had been collected on the number of children orphaned by AIDS or other causes, their living arrangements and care, or the economics of raising them. He found that the greater part of these children had been taken in and were being cared for by their grandparents or aunts. Besides the financial aspects of raising these children, several other issues arose during the interviews: (a) the caregivers' advanced ages (b) the logistical considerations of caring for a young child while continuing to maintain a home and outside employment, and (c) the communities' discrimination towards the grandchildren (Safman, 2004).

Another difficult aspect for grandparents, who may or may not be raising their grandchildren, is the past and ongoing political upheaval within Thailand's government that was affected by the 2008 world economic crisis (Richter, 2009). Fallout resulted in a loss of jobs in the exporting and tourism industries, both major revenue producing sectors (Green, King, & Miller-Dawkins, 2010; Jitsuchon & Patanarangsun, 2009). This affected many elderly Thais, who worked in the informal sector making jewelry, wood, bamboo, textile, and ceramic products. With the loss of overseas contracts, many of the elderly could not repay loans taken out to cover their sick child's medical treatment and daily expenses (Green, et al., 2010; Jitsuchon & Patanarangsun, 2009; World Bank, 2009, 2011a). Equally important and affected by Thailand's continuing instability, political chaos is decreasing rice prices (Forssell, 2008; World Bank, 2009). Added to this problem are increasing food prices connected with the drought throughout Thailand

(ADB, 2011). All these factors exacerbate a caregiver's financial struggle to buy food and basic supplies for everyday living. These factors contribute to an elderly caregiver's stress while caring for a PLHA or raising the grandchildren (Albone, 2011b; Jitapunkul & Wivatvanit, 2009; UNPF & HAI, 2011).

HAI (2005) conducted a qualitative study in three districts of Northern Thailand. As with Safman's (2004) research, the authors chose this region for its significant elderly population, the majority of who live in poverty. In addition, this area also continues to have a high HIV and AIDS occurrence rate. Interviewed were 380 elderly affected by HIV or AIDS and various community stakeholders. They found that 51% of the households' elderly, the average age was 66, with 91 being the oldest, were raising grandchildren who had lost one parent. Of the rest, 21% of the households' elderly were raising grandchildren with both parents deceased while 37% of the households' elderly were made up of the elderly parents, the infected parents, and the children (HAI, 2005). Out of the 380 elderly interviewed, 192 had lost their adult children to AIDS and half of these households (96) have grandchildren. These elderly caregivers are doing everything they can to support their extended families. They wish for their adult children to get better and for their grandchildren to have a better life. As noted above, their concerns mirrored those shared by Safman (2004) and Knodel et al. (2001), especially the lack of outside help. HAI (2005) reported this failure to help is due to a lack of awareness of the caregivers' contributions by the government and other sectors.

This dearth of help from outside sources was also expressed in the findings of several years of research and investigation by the JLICA. The JLICA (2009) and Richter

et al. (2009) reported that families, not health professionals, are the main caregivers for PLHA as well as other affected family members. The family, not outside sources, is responsible for its financial earnings. The HIV epidemic compounded many issues already faced by families, such as poverty and poor health (Chandan & Richter, 2009). The lack of wrap around services to address financial, physical, emotional, and social needs for the entire family, not just the PLHA or OVC, continues to ignore what the struggling families share in surveys and interviews.

The daily struggles do not prevent the grandparents from sending their grandchildren to school. Grandparents know their grandchildren must complete their education to ensure they have better opportunities for a good job and future. Since 2009, the Thai Constitution has guaranteed fifteen years of free public education to all Thai children (Foreign Office [FO], 2009, 2010; Schlenker, 2011; Vejjajiva, 2011). Besides the tuition, this educational policy is to include the yearly cost of one uniform, one pair of shoes and socks, milk and lunch for the elementary students, books, and any educational field trips (FO, 2009).

As with all good intentions and rhetoric, in principle the Ministry of Education agreed to cover all educational costs. In reality, about 26% of rural children do not attend school because their families cannot afford to pay for an extra uniform, shoes and socks when the ones from the government wear out, and other required educational fees (Ministry of Education, 2007). Another reason is the children are needed to work. Local government officials need to ensure that the educational policies are being enforced to ensure all children attend school. Attending school enables children, especially girls, the

knowledge and skills for better lives and jobs. This in turn, may help prevent their vulnerability to HIV and other less desiring job choices, such as sex work.

Many children attend school with tuition and fees paid by various sponsors, FBOs and the previously mentioned GCPP. Sponsors help pay for uniforms, educational supplies, sports uniforms, and afterschool or weekend activities (HAI, 2005, 2007a). The cost for these items was roughly 3,000 baht a year (\$67) according to Safman's (2004) research. Taking into account inflation and current costs, this figure is now around 6,000 baht a year (\$180) (Hawkins, 2011). Added to the costs of sending children to school are the continually increasing expenses of feeding and clothing them. These costs escalate as the child grows and matures. Thailand's Country Progress Report (UNGASS, 2010) listed that there had been no government support for the care of orphaned or vulnerable children in skipped generation households since 2006.

Another economic factor to consider as a child develops is the ever-changing information technology and material culture of Thailand. As Thailand moves from one world income status to another, its citizens' desires and cares change. The joint report, UNAIDS, WHO, and UNICEF (2010), listed Thailand as a lower-middle income country. This was refuted by UNAIDS (2010a) and the World Bank (2010b) as they listed Thailand as a middle-income country. Either status indicates that the Thai people are earning better wages than the last generation. Like other young people around the world, the youth of Thailand are not different in their wants and needs for expensive items, such as cell phones, computers, designer clothes, and accessories. All are

discretionary expenses, yet their grandparents are working longer hours to buy them (HAI, 2010; World Bank, 2010).

Physical Consequences

The number one complaint from the interviews of rural elderly women was being tired (HAI, 2005). This same feeling was voiced by the caregivers interviewed by Safman (2004) and Knodel and Saengtienchai (2002). Currently about 66-69% (PRB, 2010; CIA, 2011a) of Thais live in the rural areas, 44.5% are elderly (Knodel & Chayovan, 2011), where life is harder and poverty greater than in Thailand's cities (Jones, 2011; PRB, 2007; United States Department of State [US Department of State], 2011). In addition, 45% of the women are widows and earn less than the elderly men (HAI, 2008a; Knodel & Chayovan, 2008a; Nyamathi et al., 2007). The arrival of the HIV epidemic pushed both genders further into the cycle of hardship and debt (HAI, 2010; UNDP, 2010). This chronic illness has forced many, especially the women, already struggling to work the long and exhausting hours of a farmer or tradesperson to buy the basic items to survive, to take on the role of caregiver, adding to their onerous obligations (HAI, 2008a; Maneesriwongul et al., 2004; Wacharasin & Homchampa, 2008). As noted previously, many elderly had retired and were depending on their adult children's earnings to help pay for some of their daily needs (Lee et al., 2010). Many stopped working due to age-related illnesses because their adult children were helping physically and financially (HAI, 2005, 2007a). The return and eventual death of their adult children forced them back to work (Knodel & Chayovan, 2008a; Knodel & Im-em, 2004; Knodel & Saengtienchai, 2002, 2005).

In the case of women, working from before sunrise to well past sunset, the physical demands of maintaining a household and caring for grandchildren are both full time exhausting jobs. Still recovering from the death of her adult child, she is now the mother to her grandchildren. She may have further troubles as her grandchildren may be HIV positive themselves and have health and cognitive issues (Burns, Hernandez-Reif, & Jessee, 2008; Puthanakit et al., 2010; Willen, 2006). She may have no grandchildren but she may be the caregiver to her sick husband. She may be a widow. She may or may not have help from other females, namely sisters, aunts or close friends, living near. She may have her son's widow living within the household. She may need to help her daughter-in-law raise her children because she is HIV positive and is too sick and weak to work. Both may be struggling, as they have lost their steady income with the death of their husband or son (Nyamathi et al., 2007; Sorajjakool, 2006). With or without grandchildren, her tasks of cooking meals and cleaning up afterwards, washing and hanging clothes, dusting and sweeping, and other household tasks, are only a fraction of a female's responsibilities within the Thai culture where she follows the teachings of Buddha (Nilmanat & Street, 2007; Nyamathi et al., 2007; Phengjard et al., 2002).

Keeping social order, maintaining harmony, and doing one's duty are all aspects of *krengjai* for which each Thai family member is responsible (Bechtel & Apakupakul, 1999; Cooper & Cooper, 1996; Safman, 2004). This is especially true for the females, who are the families' linchpins. Unlike a matriarch, where the female is the head of the family, the Thai female is just one, but an essential element of the Thai family unit (Knodel & Chayovan, 2008a, 2011). Raising her children and supporting her husband

through good and bad times, she now must honor her deceased adult child by caring for her grandchildren. This task will become physically more difficult as she and her husband ages (Drimie & Casale, 2008; HAI & Alliance, 2003; Lee et al., 2010).

If her grandchild is HIV positive, she is responsible for giving medicine, ensuring a proper diet, and arranging for transportation to and from the clinic or hospital (HAI, 2005, 2007a, 2008b; KFF, 2010b; Wakhweya et al., 2008). Generally, the grandfathers are in charge of securing the funds for these activities and items (HAI, 2005; Knodel & Chayovan, 2011). On the other hand, depending on the young person's health, maturity and common sense, assistance can be given to help their elderly grandparents. Thailand's intergenerational connections are supported by the ongoing belief of filial duties as noted by Phengjard et al. (2002), Knodel (2008), and Knodel and Chayovan (2011). Teenagers can take on or help with physical chores that could tire their grandparents. They can run errands, allowing their grandparents to rest. Attending school is necessary, yet some of their weekends can be used to help in the fields or in the family's noodle shop. This additional physical assistance, as well as the extra income, helps the family meet basic living expenses, while giving the elderly grandparents some respite (Knodel & Chayovan, 2009a; UNICEF, 2009b, 2011).

Emotional and Social Consequences

While the majority of the literature researched considered the economic and physical costs for the Thai elderly caregivers, consideration of the emotional and social impacts were limited. The research highlighted such pain as the emotional rollercoaster of watching your adult child leave home to find employment only to return physically

sick (HAI, 2007a, 2008a; Knodel, 2008). In the early days of not knowing how the virus attacked the immune system, a PLHA could have healthy days and then be gravely ill and in bed for weeks (Knodel et al., 2001). Without much information or understanding, elderly parents were caring for their adult child while coming to realize that they were slowly dying (Maneesriwongul et al., 2004; Nilmanat & Street, 2007; Phengjard et al., 2002; Wacharasin & Homchampa, 2008). Before the development and availability of antiretroviral treatment, adult children returned home to be cared for and eventually buried by family (KFF, 2010b; Knodel et al., 2001, 2009; Knodel & Im-em, 2004). In embracing the concepts of *krengjai* and *dukkha*, the majority of Thai families suffered their loss in silence (Phengjard et al., 2002; Nilmanat & Street, 2007; Wacharasin & Homchampa, 2008).

This silence may also be due to the family's lack of understanding as to what AIDS is. Most HIV and AIDS educational programs are targeted to Thais under 55 (HAI, 2008a, 2008c; UNFPA & HAI, 2011). Another reason for this silence is the reported incidences of continued stigma and discrimination by people who believe that infected people are bad due to their engagement in negative behaviors (Chan & Reidpath, 2007; Nilmanat & Street, 2004; Phengjard et al., 2002; UNAIDS, 2011b). This shame and disgrace is perpetuated by the wives of husbands who become HIV positive by visiting sex brothels and not using a condom. The husbands' misbehaviors label them as "promiscuous (*samson*)" (Kittikorn et al., 2006, p. 1288). There are no individual good or bad actions within the Thai culture of family. As discussed earlier, the Thai family has several generations living under one roof, working, eating, and playing together. Each

person brings or takes away the family's honor with positive or negative behaviors. It is this belief along with the Buddhist faith that ensures the women of these families to keep silent by any means to ensure the honor of husband and family (Kittikorn et al., 2006). These authors' findings and conclusions were rejected by Knodel et al. (2009). They insisted that these negative attitudes and actions have almost disappeared due to the creation and availability of antiretroviral drug treatment. The silence is broken when the family member passes away. A death in a rural Thai community is known by all. Gossip and speculation can generate fear, anger, and stereotyping. Feelings of shame and guilt, along with depression and sadness, can lead to isolation for the elderly parents as well as the grandchildren within their community (HAI, 2005, 2007a; HAI & Alliance, 2003; Maneesriwongul et al., 2004; Wacharasin & Homchampa, 2008).

In his book on grief, Worden (2009) points out that a death from complications of AIDS is a "special type of loss" (p. 179). For instance, a family living and caring for a PLHA will experience death from this chronic incurable illness differently than death from a sudden or more common illness or accident. Each person and family must go through a mourning process to accept and move on from the loss of a loved one. This process is different for each person due to many factors, such as personality, life experiences, and culture.

For those able to obtain the antiretroviral treatment and maintain the regimen required, the illness is now regarded as a chronic health condition rather than a necessarily fatal one. Before, families and their PLHA lived day to day, not knowing if today would be the last for their PLHA (HAI, 2005; Phengjard et al., 2002; Nilmanat and

Street, 2007). However, remission creates other emotional and social issues. The emotional rollercoaster of living and dying is replaced by the emotions of excitement and fear. The parents and grandparents are joyful yet fearful because of the nature of this illness. Returning to work or school is part of the process of rejoining life. Along with it goes the possibility of rejection by others because of their fear or ignorance (HAI, 2005; UNAIDS, 2011b, Worden, 2009). As discussed earlier, in contrast, Knodel et al. (2009) concluded that with Thailand's antiretroviral treatment available to all PLHA, these negative attitudes and actions have almost disappeared. They reasoned that the unselfish acts of caregiving by the elderly parents might have led to the limited programs being offered to them. Although the financial and emotional aspects of caregiving are mentioned, Knodel et al (2009) contended that these concerns have also lessened again due to the antiretroviral treatment availability. They offered no data to confirm this statement.

The claims made by Knodel et al. (2009) disagree with the immense research presented in this chapter, as well as Thailand's PM Vejjajiva's UNAIDS speech, where he introduced new HIV policies (UNAIDS, 2011b). These policies were designed to address the issues of stigma and discrimination. He explained they were two of the main reasons for people failing to access medical services as well as not seeking comfort and support from extended family members and community members. His words supported what much of the literature review revealed, that fear and shame continue to be associated with the HIV epidemic and that the Buddhism belief of suffering and keeping the silence to maintain the family's honor is supporting these negative beliefs and

attitudes. The new HIV and AIDS policies are intended to address these issues through community driven educational programs (FHI, 2008).

In addition to the above mentioned authors, Kittikorn et al. (2006), Lee et al. (2010), and Wacharasin and Homchampa (2008) contended that negative beliefs and biases about HIV are still around partly due to lack of knowledge which leads to discrimination. Additionally, the lack of social safety nets for caregivers and families underlines their fear and shame, which then adds to the community's mistrust and discrimination (Apinundecha et al., 2007; Liamputtong et al., 2009).

Families reported in HAI's (2005) survey, that they moved their grandchildren to another school due to cruel teasing by some students. In Chan and Reidpath's (2007) mixed method research, interviews were conducted with 20 nurses. The data collected showed a clear correlation between the nurses' values and their behaviors towards those that were in the hospital for HIV treatment. For instance, a person who had a blood transfusion cannot be held accountable, thus treated differently than a person who had sex with a sex worker. The hope is that with ongoing education about HIV and AIDS, the displays of stigmatizing and discrimination will be eliminated. As previously noted, this vision was voiced by PM Vejjajiva in his speech with UNAIDS Executive Director, Sidibe (UNAIDS, 2011b).

The feelings of anxiety, sadness, loneliness, and fear were shared by the 13 Thai family members in Phengjard et al.'s (2002) study. Knowledge of discrimination, through direct and indirect experiences and knowledge, led them not to seek help from their community. This early study found that most people did not have an understanding of

HIV or AIDS and connected it to the PLHA promiscuous behaviors. Although the Thai cultural belief of *krengjai* and *metta* (“universal love”) (Sethabouppha & Kane, 2005, p. 48) demands that family help family, this was not the case for many in the early years of the AIDS epidemic. The emotional stigma attached to this illness, along with the lack of educational programs, caused many families to refuse to care for their loved ones living with HIV (Apinundecha et al., 2007; Cadell, 2004). These emotional stigmas, fear of infection, shame, and disgrace were also found in the early research conducted in rural villages of Southern Thailand by Songwathana and Manderson (2001).

Besides the emotional stigmas in the early years, feelings of depression, guilt, despair, and hopelessness, were the emotional consequences felt by the PLHA as well as the affected family members (Cadell, 2007; HAI, 2005, 2007a; Knodel et al., 2001). As previously noted, the concept of *dukkha* is determined by each Thai according to their state of mind, belief system, and sense of self worth. In data compiled by Cadell (2007) and Nilmanat and Street (2004), both the negative and positive feelings were examined in relation to caregiving for PLHA. The shift from negative to positive feelings was closely connected with the PLHA and the affected person’s ability to grow from the experience. In Waldrop’s (2007) mixed methods study, this growth and connection was accounted for by the number and kinds of relationships among family members and friends. This theme of family relations and social associations was found to be true when Nanthamongkolchai et al. (2009, 2011) interviewed 400 older persons, ages from 60 to 80 years. This was also found to be true in Maneesriwongul et al.’s (2004) qualitative inquiry of 18 family

caregivers and 18 nurses. The relationships between these two groups slowly grew from fear to hope.

The consideration of others and self in the Thai's belief of *krengjai* within the family may already be disturbed due to the loss of parents (adult child) or the cycle of illness. Fear, confusion, shame, helplessness, and denial are emotions felt when life seems out of control (Cadell, 2007; Lee et al., 2010; Nilmanat & Street, 2004, 2007; Waldrop, 2007). Living with a chronically sick person can harm the natural flow of order within a household, as well as with other family members (Apinundecha et al., 2007; Kittikorn et al., 2006; Wacharasin & Homchampa, 2008). Emotions can run high, and *krengjai* may be affected because of the care a PLHA requires. These feelings are compounded with the daily struggle of making a living, buying food, and paying the bills. Control of self may not be achieved due to the constant worrying about their sick adult child. Will he live another day? Where will the money come from for his treatment or transportation to the clinic? How will they take care of their two young grandchildren? What will the abbot at the local wat think? All of these are silent worries that arise for the elderly every morning as they start their day of caregiving (Maund, 2011).

In the last 3 decades, Thailand has produced and delivered many educational and prevention HIV and AIDS programs for its citizens. These have led to a greater understanding of this epidemic, now chronic, illness. Findings from previously mentioned researchers support the study by Lee et al. (2010). They interviewed 409 caregivers and a significant number, over 66%, reported "moderate to severe or severe burden" (Lee et al., 2010, p. 4) as related to their caregiving duties. The following

questionnaires were filled out by the participants: (a) the WHO quality of life (Thai edition), (b) the Thai depression test, (c) the medical outcomes study social support scale, and (d) the caregiver burden scale. Lee et al. (2010) discovered from these surveys and assessments, that the more responsibilities the caregiver undertook, the higher the level of depression. The more tasks needing to be done, the less time the caregiver had for family and social commitments. This “social isolation” (Lee et al., 2010, p. 4) was identified as one of the stressors that affect the caregivers’ quality of life, which was restricted due to all of the demands placed on them.

Once an HIV diagnosis is made, a person’s quality of life is forever changed. Researchers have agreed that HIV and AIDS is a family illness that has a number of consequences for both the infected and the affected (KFF, 2010a, 2010b; Madhavan & DeRose, 2008; UNGASS, 2010). As previously shared, the research supports developing “family-oriented HIV interventions” (Richter, 2010, p.3). The authors shared that this style of community-based services would eventually lead to the management of the hardships for those PLHA as well as those affected.

The hardships of this population are well documented and strengthening Thailand’s families, using the family approach, would clearly address many of the ongoing issues that prevent them from successfully living, while caring for their grandchildren. Thai families support the notion of filial duty as they care for their PLHA as well the children orphaned or affected by AIDS. It is in a family setting that this population is cared for, loved, and protected. To develop and deliver educational programs and other social safety nets for and within the family setting would be the most

effective method of helping Thailand's caregivers and families. Maneesriwongul et al. (2004) suggested that the "most powerful weapons against the hopelessness of an AIDS diagnosis are effective treatment and education" (p. 34).

Thailand's prevention and education programs appear to be slowly moving forward. In particular, the AEM Projections for HIV/AIDS in Thailand (2008) listed unclear strategies for programs that targeted PLHA but did not address the caregivers or family's needs. It was also unclear who would organize the financial resources and follow through with the local officials on the determined programs.

Summary and Conclusions

Chapter 2 offered a brief synopsis of the HIV epidemic in Thailand and then moved on to explore and describe the impact of the HIV epidemic on Thailand's people. This extensive review of the literature would not have been complete without the recognition of how Thailand's culture and the elements of Buddhism supported the family through the good and bad times of this, at one time, terminal and now chronic illness for families. Studies were presented to underline the knowledge that HIV and AIDS have affected the Thai elderly, especially the women, in terms of caring for their PLHA and their relatives orphaned by AIDS. This unquestioning caregiving is part of Thailand's belief of *rok khong khon mee kam* and supported by the acts of "*hai* and *siasala*" (Nyamathi et al., 2007, p. 350). Caregiving is also seen as being Thai and a woman; women care for, while men provide for (HAI, 2005, 2007a; Nilmanat & Street, 2007; Phengjard et al., 2002). Both enable a balance of *krengjai* within the family.

Knowing one's responsibilities supports the principles of Buddhism, which establish future happiness through the belief of reincarnation.

These principles, *krengjai* and *naa*, are taught from birth and reinforced throughout a Thai's life (Kamnuansilpa & Wongthanavas, 2005; Kusalasaya, 2005; Sorajjakool, 2006). The method of indirect communication is the acceptable and respectful one between colleagues, friends, and even family members (Ishikawa, Pridmore, Carr-Hill, Chaimuangdee, 2010; Kittikorn et al., 2006). One simply smiles and shares, "*mai pen rai*," meaning it is okay or it does not matter (Ishikawa et al., 2010; Kittikorn et al., 2006). The introduction of the HIV epidemic forced many Thais to reexamine these principles as family members fell sick to the HIV illness. The Thai government and the Ministry of Health helped create today's ongoing discrimination and stigma by their initial fear that was displayed by their negative actions. The public was informed that this illness was restricted to high-risk populations: gay men, IDUs, and MSW, populations from which the majority of Thais look the other way. At the same time, many male Thais frequent sex workers. It became clear that the information being shared was not correct when rural pregnant women, who had not left their villages, began testing HIV positive, as well as their newly born babies (AVERT, 2011b).

Combine these societal attitudes and feelings with the Thai belief of family and the moral principles of Buddhism, having a PLHA was, an embarrassment and shame that impacted the entire family (Maneesriwongul et al., 2004; Phengjard et al., 2002; Songwathana & Manderson, 2001; Wacharasin & Homchampa, 2008). Following an initial diagnosis, depending on the family's tolerance and knowledge of the disease, as

well as the method of transmission, a spectrum of reactions were expressed by the family members. Social contact ended or became limited by either the family or the community. This action was taken because many rural Thais did not completely understand the nature of this illness, due to the lack of educational programs (Lee et al., 2010; Maneesriwongul et al., 2004; UNDP, 2009a). Out of fear many PLHA and their family members did not reach out when outside support was greatly needed (Phengjard, et al., 2002; Songwathana & Manderson, 2001). This fear based reaction was also true for the community (Liamputtong et al., 2009; Nilmanat & Street, 2004; UNAIDS, 2011b; Wacharasin & Homchampa, 2008). Rural communities are close knit and little that happens goes unnoticed. As previously explained, the wat is the village community center, and when a family quits going to religious ceremonies and other gatherings, others pay attention. Shame and fear continues to be linked with PLHA as well as towards the family members who have buried a loved one with AIDS. These feelings can be expressed in nonverbal and verbal discrimination and stigma.

On the other hand, Knodel et al. (2009) reported that discrimination displayed in the early years towards those who were infected, as well as the extended family (“secondary stigma”) (p. 51) has almost disappeared because of the availability of antiretroviral therapy. They supported the contention that Thai families are faring well due to the creation of antiretroviral drugs. Because the PLHA is able to enjoy a healthy life, the caregivers and other family members can find stability and joy once again. This conclusion did not take into account that 1 in 10 persons living in rural Thailand are living in poverty (UNDP, 2009a). Although it is unclear how many of these persons are

HIV positive or are caregivers to a PLHA, it is well documented that poverty is one factor that increases the families' risk and vulnerability to HIV (KFF, 2010a, 2010b; Richter, 2010; Richter et al., 2010; UN, 2009a, 2010b). Even with antiretroviral treatment, there are other factors, such as the possibility that due to discrimination, the PLHA may not be able to find work or they may not be physically able to work. Knodel et al. (2009) did not inquire into the burdens associated with families caring for a person with a chronic health issue. These themes were the subject of a study by Lee et al. (2010). They concluded that caring for a PLHA under the treatment of antiretroviral drugs created ongoing burdens. To demonstrate, the PLHA may be physically healthy but displaying severe signs of depression, even considering suicide, which means the caregiver, must be on alert at all times, canceling any social or work responsibilities.

The lack of prevention programs, as well as the discrimination problems, was addressed by Thailand's PM Vejjajiva, who introduced new HIV policies specifically to concentrate on these issues (UNAIDS, 2011b). No mention was made of Thailand's rural elderly caregivers or the organizations such as TNP+, HAI, Rak Thai Foundation, GCPP, the Metta Project, and many more that have provided social assistance programs and services to rural communities. In spite of the commitment from these organizations' people, there appears to be a lack of alliance between them. There is also a lack of adequate empirical data for their results. This can also be said about Thailand's government and health department's data collection methods (FHI, 2008). In the early years of the HIV epidemic, data collections were the driving force for the creation of programs such as the 100% Condom Program. Without proper data, the task of

Thailand's stakeholders to assess what is needed for its elderly caregivers and families remains confusing.

The JLICA (2009) team presented data that also identified the many burdens of caregivers for PLHA. The final report recommended the creation of "family-centered services" (Richter, 2010, p. 1). This model of intervention would address the entire family's needs. Most current interventions are exclusively targeted for the PLHA or the child affected by AIDS, leaving the Thai caregivers completely out of the picture. Considering the Thai's commitment to the family structure, a family centered approach might be successful. The need for programs and other interventions for the elderly caregivers are addressed in Thailand's National Plan for HIV and AIDS Prevention and Alleviation, the AEM, and MIPAA. The proposed services are addressed in the abstract rather than in any measurable manner and no evidence were found that they have been developed and delivered.

These three documents are part of the literature review that helped establish how the HIV epidemic has affected and continues to shape Thai families in many ways. This is especially true for the rural elderly caregivers. The presented research established that there is a gap of knowledge in what community programs and interventions they want and needs. Data analysis from this phenomenological study may be used to guide Thailand's government and the various NGOs to collaborate to create and deliver the requested programs. After review of the emotional and social issues connected with the HIV epidemic and the caregivers, the following research question was added to address the gap presented in the literature: How do Thailand's cultural beliefs (family duty) as

well as their religious beliefs (Buddhism) support or impede their caregiving? The following chapter explains the qualitative study that answered this question along with the other two research questions.

Chapter 3: Methodology

Introduction

The rationale of this qualitative study was to gain an understanding of Thailand's rural elderly caregivers who have been affected by the HIV epidemic. The role of caregivers was taken on because of filial responsibilities that are closely connected with the cultural beliefs of Thais. The following chapter describes the specifics of the research design, the researcher's role, and the measures that were used to collect the data. The explanation of how the data was analyzed, which ensured the credibility of the research findings, is presented. The practicability details, along with the ethical considerations that arose from the study, conclude the chapter.

Research Design

Unlike the world of formulas and equations, the actions and reactions of humans can be unpredictable. A person's response to a situation, another person, or place, can depend on education, gender, culture, language, religion, and experiences (Cerbone, 2006; Keller, 1999; Macann, 1993). It can also be related to a memory known or lost. The ability to have many perceptions of the same experience was what Husserl believed to be the essence of being human. Consciousness and unconsciousness, when explored, could help one achieve a deeper connection with another human being, an event or situation (Denscombe, 2007; Moran, 2002; Keller, 1999). This school of thought is now known as Husserl's "transcendental phenomenology," (Cerbone, 2006, p. 12) which is the "lived experience of human beings within the life-world" (Denscombe, 2007, p. 77).

Narrative research studies one person, while grounded theory research studies

people to create a theory behind the experience. Phenomenology, by contrast, requires the researcher to remain attentive to the experiences of those being interviewed. This style of qualitative research gave me the opportunity to interview 14 elderly rural Thai caregivers to capture in depth their daily experiences. Semi-structured interviews supported the rural elderly caregivers' storytelling. It was an effective methodology for this research because the Thai caregivers loved to tell their stories about their Buddhist faith and about their family traditions. What makes the story? Is it the characters? The places? The events? Or is it the entire telling of the story that creates the picture for those listening? This is what phenomenology seeks to answer. By explaining the whole and then the parts and then putting it all back together again, the essence of the experience is explained (van Manen, 1984).

A quantitative study was rejected for this research project due to its limited ability to collect data that would develop a full description to describe the essence of the phenomenon. Unlike other research methods, the reason why the participants are caregivers was not important to this study. Rather the focus was on the people, their emotions and experiences that set them apart in their daily lives as elderly caregivers. The consideration of walking in another person's shoes by way of listening to their life stories was created using "phenomenological reduction" or "bracketing," which ensured that the my interpretation of meanings, attitudes, beliefs, and feelings were placed aside (Denscombe, 2007). Bracketing prevented prejudgments that might have clouded the picture of the caregiver's life. I achieved this by acknowledging two of my own experiences related to caregiving, which then allowed me to conduct the interviews with

an open mind. The goal of this methodology was to provide stories rich in the emotions and experiences of the caregivers' lives so that the reader will be able to envision what it means to experience life in this phenomenological way. This was achieved with the Thai elderly caregivers' stories that were full of ample information to add to the knowledge base on the phenomenon of caring for their young wards affected by AIDS.

The Researcher's Role

Living in Chiang Mai, Thailand, where I have been working with children affected by AIDS, as well as their aged grandparents, inspired this study. I have lived and worked in Southeast Asian for 8 years and have gained some insight into the values, behaviors, and attitudes that are important to this culture. From insight comes understanding. When a person begins to understand him or herself, they also slowly begin to understand those around them. This greater awareness of other cultural values and behaviors supports relationship building and trust. Creswell (2007) shared that the validation process is the assurance that what has been recorded and written is accurate. The validation of the study was aided with my development of a professional relationship with the caregivers.

The use of Husserl's (Creswell, 2007) technique of bracketing allowed me to interview 14 caregivers without any defined definitions or preconceived notions as to the nature of their experiences. Some unanticipated feelings surfaced during two interviews and I employed a therapeutic technique, which is to be with what you resist. In this process, I made note of my feelings in my field book and then asked the interviewee for clarification. This ensured that my feelings did not color the data; rather the caregiver's

words and feelings were understood and recorded.

As a Licensed Professional Counselor (LPC), I used my 15 plus years of clinical experience to conduct myself in a professional and ethical manner. The interviews were successful because I treated each caregiver with respect. Cultural differences of language and custom were also respected. The use of silences and reflective questioning gave each elderly caregiver time to think and reflect over the research questions. The interviews were audio recorded and conducted in both English and Thai. The use of semi-structured research questions set the stage for the elderly rural caregivers to open up, which led them to share many stories in relationship to their caregiving experiences. Ultimately, I kept all the information secure, as the data was organized, analyzed, and synthesized. The findings, implications, and conclusions are presented in Chapters 4 and 5.

Data Collection Procedures

Study Setting

The study was conducted in the GCPP caregivers' homes. Located in Chiang Mai, Thailand, GCPP provides a variety of services to families affected by HIV in the districts of Lamphun, Hang Dong, Sanpatong, San Sai, and Mae Rim. Families in these districts of Chiang Mai Province consist of rural elderly grandparents, single mothers, aunts, and older sisters, raising one or more children who have lost their mom or dad, or both, to AIDS. Their living conditions also influenced this decision. Currently 1 in 10 Thais living in the countryside are living in poverty (UNDP, 2009a). The majority of the elderly caregivers interviewed fit in this category. Two live in one-room shacks, without electricity or running water, and little furniture. I showed no feelings of discomfort or

embarrassment of the caregivers' living situations. This encouraged a trusting relationship that produced the successful interviews.

Ethical Protection for Participants

Approval to conduct this research was given by the Institutional Review Board (IRB) at Walden University (Appendix E), and the director of GCPP, located in Chiang Mai, Thailand (Appendix D). Walden University's consent for participants over 18 was explained and signed by all caregivers who agreed to be interviewed and audio recorded for this study (Appendix E). In addition, it was explained that, at any time, the caregivers had the right to withdraw from the study with no explanation required. It was also explained that they had the right to stop the interview if the subject matter they were sharing became too difficult, they became too emotional to continue, or for any other reason that they need not explain. I was responsible for the monitoring of the caregivers' behaviors. As a LPC, I have many years of employment history working with clients who have had stressful or traumatic experiences, which allowed me to use a therapeutic and supportive manner. I ensured that each of the caregivers' welfare was the first priority. I did not have to stop or reschedule any of the interviews, as all the elderly caregivers appeared to enjoy their time in the spotlight.

At no time was formal counseling offered to any of the caregivers from me. Instead, each caregiver received information listed on the consent form that included the name of a Thai psychiatrist, his phone number, and email. It also listed several community resources (e.g., the Thai Red Cross, HAI, and Sri Phat Hospital) that agreed to be referral avenues if the need arose. Each caregiver was told that all participants of

the study received this same information. To my knowledge, none of the caregivers used any of these suggested services.

It is common practice to ensure the anonymity of participants of qualitative studies by using pseudonyms. I am aware that there are still issues of discrimination in Thailand towards PLHA as well as towards their family members. For this reason, I double-checked all data to ensure the confidentiality of the interviewed caregiver. This was explained in detail to the caregivers before receiving their written consent to participate. The overall reason behind this research, which is to help gain an understanding of the phenomenon for possible changes in Thailand's public policies, was also clearly explained. All this spoken information was presented in writing of both English and Thai. The caregivers were given plenty of time to read and ask questions. They were allowed to change their minds and not be part of the study, but none did. Signing the required forms was the signal that they understood and agreed to the interview, video recording of it, writing up of the collected data, and the published findings.

All paper forms are in my office, in a locked file cabinet, with a key available only to me. The audio recordings are on an external drive, which is password protected. When not in use, it is locked up with the paper forms. All identifying data will be destroyed, as will be the electronic and paper records and taped recording of the interviews. Both the Thai and English transcripts will be held for 5 years for possible academic purposes at which point, they will be destroyed (Walden University, 2010).

Sample and Eligibility Criteria

In this study, participants came from GCPP. Because of the HIV epidemic, they became caregivers to their sick adult child and now the main caregivers to their grandchildren. The criteria for selecting the caregivers were the following:

1. The caregiver is part of the Grandma Cares Partnership Program.
2. The caregiver is the person responsible for the care of child/children.
3. The caregiver is 60 years of age or older.
4. The caregiver speaks Thai and/or English.
5. The caregiver agreed by written permission to be interviewed and audiotaped for sharing their experiences.

When conducting qualitative research, purposeful sampling is utilized. This meant that I sought out persons and places that have experienced the phenomenon. Their understanding allowed them to answer the research questions with authority, giving credibility and validity to the study (Creswell, 2007; Denscombe, 2007). There are over a dozen types of purposeful sampling. Because the goal of this research was to document the “authentic experiences” (Denscombe, 2007, p. 80) of the GCPP caregivers, a combination of intensive, convenience, and criterion sampling was used. Intensity sampling is precisely what it is called; the participants were chosen because of their powerful experiences related to the phenomenon. The approaches of convenience and criterion sampling related to the easy contact with the caregivers and the straightforwardness of data collection from them.

Denscombe (2007) shared that conducting surveys use a statistical calculation for sample size, whereas researchers performing interviews, depend more on the wealth of data collected from the participants than the sample size. He further stated that “there is a general tendency to choose the minimum sample size that is feasible in light of the level of accuracy demanded of the findings” (Denscombe, 2007, p. 28). Initially, due to the language barrier and their advanced age, the plan was to interview a minimum of eight GCPP Thai caregivers to acquire a complete picture of the phenomenon from those who have experienced it. Out of the 17 caregivers that volunteered, 14 were interviewed. The other three declined due to health issues related to their age. For the 14 elderly rural caregivers interviewed, neither the language nor the age barrier, were an issue. The majority of the caregivers understood and spoke some English; consequently, the interviews were lengthy from the many stories shared versus the need for translation.

Participant Recruitment

Approval to conduct this research was received from the Institutional Review Board (IRB) at Walden University. I met with the director of GCPP, to explain the study and answer any questions. At this meeting, the purpose of the study, the number of participants needed and how to select them, the research questions, the interview structure, and how the data would be analyzed was discussed. The consent form for adults and the confidentiality agreement was also explained to the director. Approval was given and the letter of cooperation was signed (Appendix D).

The director of GCPP and I made home visits to discuss the study with the caregivers who speak Thai and/or English. I explained the study and purpose and

answered all their questions. I assured them if they do not want to participate, no one would know. If the caregiver agreed to participate, an appointment was made. To gain an encompassing perspective, the director of GCPP and I first visited households that were headed by either widowed grandfathers or grandmothers. The next households were of aunts and then married couples. After conducting 14 interviews, I concluded that I had reached the saturation point of the study as no new data presented itself (Creswell, 2007).

Data Collection

I conducted all the interviews with the caregivers at their homes. With the aid of the GCPP's translator, the study's purpose and interview procedures, including a clarification of the need for audiotaping the interviews, was explained. The confidentiality issue of storing all data collected in a secure place was also reviewed. I assured that neither the caregivers' names nor demographic information would be shared in the written report or shared verbally.

The last item that was explained before the interview started was the consent to participate in the survey form. As this is an important piece of documentation, with the aid of the translator, I asked if the caregivers understood the entire form. It was also made clear to the caregivers that at any time, for any reason, they could withdraw from the study. At the end of each presented piece of information, time was given for the caregivers to ask any questions or concerns. This show of patience built trust and positive feelings between the caregivers and me. After all necessary explanations were given; there were no questions. To begin each interview, the recorder was turned on as I asked, "*sa-bai-dee-mai* (□□□□□□□□) /how are you doing?" in Thai, showing respect and

care for the caregivers. The data was gathered through face-to-face, lengthy interviews, using a semi-structured format that allowed the GCPP caregivers ample time to reflect and describe their personal experiences of this phenomenon (Appendix A). As a LPC, I used reflective listening, momentarily silences, and empathic responses to show respect and support for the caregivers and their shared experiences.

The order of research questions asked was determined by the caregiver's sharing. At several of the interviews, I requested clarification on a word used or an experience shared to ensure the understanding of the caregivers' inference. In qualitative research, this is called member checking (Carlson, 2010). With this technique, the caregivers' were given unspoken permission to clarify and sometimes elaborate on what they just shared. This process of double-checking what the caregiver shared was completed at the end of the interview to ensure that they had nothing more to add and that all was understood. .

I made notes during the interviews. Noted were such items as the caregivers' nonverbal actions, displayed emotions, lack of emotions, and facial expressions. Also included were my personal insights or comments related to the caregiver's behavior or storytelling. This procedure allowed me to listen to the caregiver's stories for inflection while reading the translation for understanding.

Immediately after the interviews, the audiotape and field notes were reviewed by the translator and me. The Thai parts were transcribed verbatim and then translated to English. This process ensured accuracy and trustworthiness to the original storytelling of the caregiver. I double-checked all translations to ensure the accuracy of the collected data. All information is stored in Walden University's dashboard (internet) and in

Atlas.ti, which is on my external drive. Both are protected by passwords and can only be accessed with these codes.

The caregivers were visited approximately a month after their initial interview for member checking. This was done to make certain I had captured the accuracy of the caregivers' words, feelings, and views. Many researchers present the entire transcription for review but due to the issues surrounding the Thai's cultural respect for the elderly, this was not done. The majority of the rural elderly caregivers interviewed cannot read or write. It did not make sense to read the entire interview's transcript to them, which might have caused them embarrassment due to their improper use of language and colloquial expressions. Instead, at this short meeting I presented for their review the significant statements identified from their interview transcripts. Little if any changes were made.

The Translator's Role

The director of GCPP as well as the office manager translated and transcribed all documents needing these services. After agreeing to help, both were methodically introduced to the procedures of the study (e.g., collection of data, interview structure, and method of translation). I also reviewed the ethics of interviewing the caregivers with them. Having worked at GCPP for the past 10 years, both have vast knowledge about HIV and AIDS as well as the caregivers of this NGO. In addition, they were assets to the study by their ability to speak Thai and understand the cultural issues of respect given to the rural elderly.

All information connected with the study was handed over to me at the end of each interview and any meetings. The interview data that needed translating was

completed after each interview with me present. The translators agreed and signed confidentiality consent forms (Appendix F and G). The backtranslation was completed by another person, whose employment was just that (Appendix C).

Data Analysis

All required consent forms and paperwork were written in English and translated into Thai. Walden's IRB required that the accuracy of the translations be confirmed by another translator, so the process of backtranslation was completed by another translator. The data was transcribed, and if needed, translated then backtranslated, and analyzed immediately after each interview. This included the listening of the taped interviews, reading over the transcripts and the field notes, which were used to take note of the caregivers' nonverbal behaviors. Creswell's (2007) six-step phenomenological analysis methods were used for this study.

Step 1 in this process was the writing out of all thoughts and feelings of my own experiences related to the study's phenomenon. The goal of the study was to describe the emotions and experiences of the caregivers' lives. This was achieved, by setting aside my attitudes, beliefs, and feelings, which helped maintain my focus on the caregiver's experiences. The interviews' text and audio recordings were downloaded to Atlas.ti to complete Step 2. Also added were my field notes of possible themes, memos, and insights in connection with the caregivers' nonverbal behaviors, facial expressions, displayed emotions, and the lack of emotions as related to their storytelling. In Step 3, I created code markers that guided Atlas.ti to perform a methodical analysis of all the downloaded data and created coding schemes for the data.

I began Step 4 by reviewing the significant statements (themes) within the caregivers' stories, which were established by Atlas.ti. From these themes, I wrote the detailed recounting of the "textural description" (the what) of their experiences (Creswell, 2007, p. 159). The same process was used to write the "structural description" (the where) in Step 5 (Creswell, 2007, p. 159). This explained how the caregivers' environments factored into their experiences. The last step was writing a vivid and comprehensive portrait of the phenomenon using both the textural and structural stories of the caregivers. This portrayal created the "essence" of their experiences (Creswell, 2007, p. 159).

Evaluation Criteria

The study's validity was determined using Polkinghorne's validation standards (Creswell, 2007). The essential question I asked and answered with an affirmative was "Did the data collection provide a complete picture of the 'what and how' of the caregivers' experiences of the phenomenon being studied?" That being so, all five of the following questions were asked and each was answered with "yes," which supported the credibility of the study:

- Did the researcher express understanding of the concepts associated with the study of phenomenology?
- Did the researcher state the phenomenon to be studied?
- Did the researcher use proven data analysis procedures?
- Did the researcher accurately describe the essence of the participants' experiences of the stated phenomenon?

- Did the researcher remain open during the study? (Creswell, 2007, pp. 215, 216)

Besides the validity of the study, I worked to achieve trustworthiness, which is the test of reliability in qualitative inquiry. This criterion was achieved using “thick description” (Carlson, 2010, p. 1103). This description included the vivid details of the caregivers and their environment. Audio recording along with field notes assured this process, where their storytelling of feelings, experiences, and thoughts were acutely captured on paper. Chapters 4 and 5 allow the reader to imagine living the experience being described and explained.

Summary

To understand fully the opinions, thoughts, feelings, and insights of the Thai rural caregivers’ lived experiences, a qualitative inquiry was conducted. The decision to conduct phenomenology research, along with an explanation of this type of inquiry, opened the chapter. The framework for the study, selection of participants, and ethical issues were defined. The core of phenomenology research is the researcher’s presentation of the textural and structural descriptions, the “what and how,” of the experience being studied (Creswell, 2007, p. 159). The steps to the data collection and analysis of said data was also explained. The chapter closed with the criteria used for the evaluation of this qualitative study. The descriptions of these experiences of being an elderly rural caregiver in Northern Thailand are the topics of Chapters 4 and 5.

Chapter 4: Results

Introduction

The purpose of this phenomenological study was to explore and describe the lifestyles of the rural elderly who care for their grandchildren whose lives have been affected by their parents contracting HIV and dying from AIDS. The goal was to understand their experiences, frustrations, joys, needs, and wants in relationship to their cultural and religious beliefs. The research answered the following questions.

1. What are the experiences of the elderly grandparents in rural Thailand as the caregivers for their grandchildren who have been orphaned by AIDS?
2. How do Thailand's cultural beliefs relating to family duty, as well as their Buddhist religious beliefs, support or impede the caregiving by elderly grandparents for their grandchildren who have lost their parents to AIDS?
3. What community programs do Thailand's elderly caregivers know about and use? Which are having the most significant impact to help them take care of their family members and themselves?

This chapter addresses the settings, the caregivers' characteristics, data collection plus analysis, trustworthiness strategies, and results. Through the revealing and informative caregivers' stories, themes are introduced. A selection of quotations is offered to support the four themes. The chapter concludes with a synopsis of the themes generated from the research questions asked at the interviews. Chapter 5 will address in depth the specific themes mentioned in this chapter along with my interpretations and conclusions.

Setting

The caregivers were recruited from GCPP. During the study and data collection, there were no changes within the infrastructure of the organization. The interpretation of the study's results were not influenced by any changes of personnel.

Demographics

Of the 17 caregivers that agreed to be interviewed, 14 actually were. Two of the grandfathers had to decline due to health reasons, while one of the grandmothers passed away. As shown in Table 1, out of the 14 caregivers interviewed, five were male and nine female. In this group, there was one widower, 2 widows, and the rest (11) married. Six caregivers are raising a grandson, five a granddaughter, one is raising both a granddaughter and a grandson, one a nephew, and one her nieces. The ages of the caregivers ranged from the required age of 60 to 81, with the average age being 72. According to Thailand's government standards, all of the caregivers were of retirement age (60 and older) and received a small pension (600 to 825 Thai baht per month, about \$20 to 27). This small pension did not pay for many of their caregiving expenses. All of the caregivers shared that they continued to be self-employed. Five of the caregivers reported that they have excellent health; while five others shared, they are healthy. This meant that they continued to work but not for as long each day. The three that reported taking medication to control their diabetes also reported they were doing okay. The one caregiver who is living with HIV shared she is doing better now that she, too, is on medication. All 14 caregivers reported that they felt good enough to handle the physical work required to till, plant, and harvest their rice fields, tend to their orchards, run their

noodle shops, or make crafts, which then would allow them to meet their financial obligations to care for their young ward.

Table 1

Summary of Caregivers' Demographic Characteristics

* Name	Gender	Age	Marital Status	Children	Health Status
Tem	Male	81	Married	Grandson	Diabetes
Supaporn	Female	78	Married	Grandson	Fair
Boom	Male	79	Married	Granddaughter	Excellent
Siam	Female	77	Married	Granddaughter	Diabetes
Ploy	Female	73	Widowed	Grandson	Excellent
Somchai	Male	81	Widowed	Granddaughter	Excellent
Jing	Female	60	Married	Nephew	Excellent
Nam	Male	72	Married	Grandson	Fair
Wand	Female	67	Married	Grandson	Diabetes
Somoh	Female	63	Married	Grandson	Excellent
Pong	Female	70	Married	Granddaughter	Fair
			Widowed	& Grandson	
Waewdao	Female	60	Married	Nieces	HIV+
Nong	Male	70	Married	Granddaughter	Fair
Thai	Female	80		Granddaughter	Fair

Note. * For confidentiality purposes, pseudonyms are listed instead of the caregivers' actual names.

Data Collection

In this study, the 14 caregivers came from the GCPP. Each of the participants met the following inclusion criteria:

6. The caregiver is part of the Grandma Cares Partnership Program.
7. The caregiver is the person responsible for the care of child/children.
8. The caregiver is Buddhist.
9. The caregiver is 60 years of age or older.

10. The caregiver spoke Thai and/or English.
11. The caregiver gave written permission to be interviewed and audiotaped for sharing their experiences.

All of the participants were interviewed at their homes, which are located in Chiang Mai province, Thailand, within the districts of Lampung, Hang Dong, Sanpatong, San Sai, and Mae Rim. Walden University's consent for participants was explained and signed by all caregivers. In addition, it was explained that, at any time, the caregivers had the right to withdraw from the study with no explanation required. I also made clear that they had the right to stop the interview if the subject matter they were sharing became too emotionally difficult for the participant to continue, or for any other reason, which they did not need to explain. None of these situations occurred.

Interviews were conducted during the months of July, August, September, and October 2012. All interviews were audio recorded. The data was gathered through face-to-face interviews, using semi-structured questions that allowed the GCPP caregivers ample time to reflect and describe their personal experiences of the phenomena.

Establishing authentic rapport was the first objective of the interview. Because the order of questions is not important when conducting semi-structured interviews, I was able to create a connection with the elderly caregivers' interests. This development allowed the flow of conversation to move easily into the questions about their lifestyle as rural caregivers for their young children affected by AIDS. This method allowed the caregivers to set the tone and depth of sharing of the interview. By giving control of the interview to the caregivers, I was able to move beyond the essential questions to query

about areas connected to their caregiving role that became known from their sharing.

Atlas.ti and Creswell's (2007) phenomenological analysis method were used to exam the data. The goal of the study was to describe the emotions and experiences of the caregivers' lives. This was achieved by having the interviews transcribed, translated, and backtranslated immediately after each interview. Each transcript was then downloaded into Atlas.ti, where a hermeneutic unit (HU) was created, named PhD Research. The HU: PhD research holds all the documents, including transcripts of the interviews and field notes, for analysis. My external drive is password-protected and when not in use, is locked up with the paper forms.

These documents were read and reviewed by me so I could become familiar with the rhythm of the interviews. Highlighting selections from the documents created quotations, which received an identifier by Atlas.ti. For example, the following quote from my field notes has the identifier 6.20 because it is the sixth document in the HU and the 20th quote within the document.

The other room has three medium-size mattresses lying directly on the floor, with piles of clothes on one of them. Looking around, I realize there is no electricity to turn on. There are no windows; the only light is coming from an open space above my head, which is about 2 inches wide.

This quote also has a code, lifestyle, attached to it by me, which was later changed to environment. The change was made because I realized that this quotation described the caregiver's surroundings rather than the daily life. Constant reviewing of the documents allowed me to discover and make new and improved codes and quotes. The

differentiation between the codes lifestyle and environment created the opportunity for me to see clearer how and where the caregivers live.

This code was assigned to the quote because I felt it might be of significance to the lived experience of caregiving. Besides marking the passage, coding also allowed me to compare each of the caregiver's words, meanings, and contexts with those of the other interviews. This technique was also applied to my field notes. This was achieved by using Atlas.ti query tool, text search, auto-coding, coding analyzer, and the four code managers. Each of these tools helped me retrieve significant words and statements that were then given codes.

There is a great deal of information found within the four object managers. I began with the downloading of all data, which can be found in the primary documents manager. Each document is labeled as P 1: name of caregiver.docx {32}, P 2: name of caregiver.docx {24}. The last item listed in { } is the number of quotes found within the document. I determined what was to be highlighted for quotes, which were then given a one-word code. ATLAS.ti then filtered the quotes to the quotation manager and the codes to the codes manager.

This process was repeated continuously for possibly identifying new knowledge and insights. Initially, I had 14 codes. Through the continuing review process, I began to see the overlapping of words and meanings, which resulted in some of the codes merging. For example, the code AIDS was deleted and all quotations under this former code were absorbed under the code AIDS stories.

To achieve an overview of the collected data, I placed each of the codes into

families. The three families are background, resources, and Thai rural lifestyle. The family background has three codes: aids stories, death, and family history. The resources family includes the education, finances, medical, and GCPP help codes, while the Thai rural lifestyle family includes compassion, faith, environment, lifestyle, and the Thai way. Assigning codes to families permitted me to see the overall patterns among the data. This was accomplished by applying the sorting and filtering applications in the HU editor's menu. Using the identified families through the code manager, I was able to locate quotes that supported the emerging themes. Each code has a frequency count of how many quotations connect to the code; these are labeled groundedness. The list of codes, the groundedness of codes, and the families are shown in Table 2.

Table 2

Code Manager Loadings for Theme Analysis

Code	Frequency Count	Families
AIDS stories	{18-0}	Background
Compassion	{21-0}	Thai Rural Lifestyle
Death	{9-0}	Background
Education	{21-0}	Resources
Environment	{22-0}	Thai Rural Lifestyle
Faith	{22-0}	Thai Rural Lifestyle
Family history	{23-0}	Background
Finances	{47-0}	Resources
GCPP help	{22-0}	Resources
Lifestyle	{25-0}	Thai Rural Lifestyle
Medical	{27-0}	Resources
The Thai Way	{43-0}	Thai Rural Lifestyle

Hawkins, S. (2012). Atlas.ti Qualitative Data Analysis Program (7) [Software].

From this process, I established that four themes emerged from the descriptions of the experiences of the interviewed caregivers. The three research questions are answered from these findings. The themes uncovered were: (a) the Thai family and Buddhism, (b) life as an elderly caregiver, (c) the consequences of being a caregiver, and (d) outside the family. As per agreement of the consent form to keep data confidential, pseudonyms were used instead of the names of the elderly rural caregivers.

Results

Theme 1: The Thai Family and Buddhism

This theme answers the first research question, which was, “How do Thailand’s cultural beliefs relating to family duty, as well as their Buddhist religious beliefs, support or impede the caregiving by the elderly grandparents for their grandchildren who have lost their parents to AIDS?”

Thailand’s culture and values are coupled to the practice of Buddhism, which is practiced by 95% of Thais (Nilmanat & Street, 2007, p. 95). An 81 year-old, widowed grandfather, Somchai, the head of a “skipped generation” household (Knodel & Chayovan, 2011, pp. 20, 21), where both parents had died from AIDS and he cares for his granddaughter explained,

Faith is about stepping up to take care of my children and grandchildren. My daughter-in-law had no way to support her daughter after her husband, my son, died. I have no hard feelings that she moved to find a job and remarried; that is part of life. She must have a husband to have a good life. I have had a good life by working for the Thai government, so I could provide for my family, and now my

granddaughter.

Like many of the caregivers interviewed, Somchai and his granddaughter live within a stone walled compound that comprises the main house and two smaller houses, as well as several various sized wooden sheds. Several generations coexist within the compound, where they pool their resources to help each other raise children, work the fields or run a noodle shop, share meals, and pay the bills. Living in a compound helps in that everyone is within walking distance. When problems arise, they look to each other for help. Although most are very connected to their Wat and community, they seek help only when it is beyond the resources of the family.

On this matter, none of the elderly caregivers shared that they had actually asked for help; rather, help found them. For example, none of the caregivers sought help from GCPP; instead, their names were given to this NGO and volunteers visited with the families to find out what was needed. The elderly grandparents accepted help because it benefited their grandchildren, which is their number one reason for continuing to get up in the morning and fulfilling their duties as caregivers, according to their cultural and Buddhist upbringing.

In the case of Pong (70) and Vichai (79), who look their ages as elderly and frail grandparents, Vichai is one of the grandfathers who due to feeling exhausted, excused himself from the interview. They are farmers and continue to work in their little orchard. The fruit and vegetables grown and harvested are sold to the neighbors. Early mornings, Pong can be found outside of her gate, selling her produce. She relates, “They buy from

me because it is organic.” The money made goes towards helping raise their 16-year-old grandson and 13-year-old granddaughter.

The family continues to live in the home that their son started building prior to his wife’s disappearance after she had been diagnosis with AIDS. The house would have been a beautiful addition to the neighborhood. Built on the corner overlooking acres of rice paddies, the view from upstairs is excellent. There is no glass in the windows and several monsoons have given the house an old, moldy smell and look. The building supplies are in the downstairs area and are still there. The house has been repossessed by the bank but the family will continue to live in it until it is sold. Another GCPP family lives in a similar situation. Due to the belief in karma, bankers are not willing to throw people out of their homes. These families have been told they can stay in the house until it is sold.

Both grandchildren were under the age of five when their mother left. Their father got inebriated one day and had a motorcycle accident. His injuries have prevented him from finishing the house he designed as well as from being hired for any construction jobs within the community. Presently, he and his son work on a chicken farm.

As senior citizens, each of the grandparents receives 600 baht per month from the Thai government. Like all GCPP families, they have and use the Gold Card for their medical needs, which allows them to pay 30 baht per visit to cover all costs for the treatment of a wide range of illnesses, conditions or injuries. Like her brother, the granddaughter helps her grandparents in the orchard on the weekends, while during the weekdays; she is busy completing her homework. Pong shared they are “doing okay.”

All the elderly caregivers shared similar feelings of compassion, family duty, and that their caregiving is supported by their Buddhist beliefs and practices. Practices such as the acts of *hai* and *siasala* are part of the Buddhist concept, *krengjai*. Harmony, social order, and conduct within the family and society are governed by this concept. “Hurt not others in ways that you yourself would find hurtful” (Teaching Values, 2009, para. 3) is one of the moral teachings of Buddha.

Caregiving is entrenched in the Buddhist philosophy of *krengjai*, as is evident in the loving actions of these caregivers. One set of grandparents, Tem (81) and Supaporn (78), looking relaxed and younger than their years, opened up to me by sharing that their grandson is not their blood relative. They explained,

Our son, our grandson’s father, was a neighbor's child that we took in when his parents passed away. We were not sure if they had AIDS back then (because) no one knew what the illness was. The boy grew up as our son and met a young lady and they married. We were happy when we heard they were to have a baby. Our daughter-in-law was sick off and on before, during, and after having our grandson. She died when he was around 2 maybe 3 years old. This caused his father, our son, much pain and his grief drove him away from his son and family. After many years, our son showed back up with his new wife and newborn baby. We embraced them immediately. They live in the neighborhood.

As a Buddhist, each of the Thai caregivers shared that family is the most important thing to them. Besides providing for shelter, food, and various other physical needs, the caregivers explained how in Thailand’s culture with the practice of Buddhism

come the beliefs of *krengjai*, merit making, and *rok khong khon mee kam*. With the death of their grandchild's parents, they became responsible for upholding and teaching these concepts to their grandchildren. The happiness and harmony of their grandchildren is dependent upon being within the family.

The majority of the caregivers reported finding peace through Buddha's teachings. Waewdao (60), an aunt raising her three nieces, explained: "Our time of meditation and nightly prayers gives us our sense of peace." Prayers through meditation were given as an example to help them calm their minds and find inner peace. This gave them strength and understanding when suffering the loss of their adult son or daughter. This sense of peace and understanding of life's purpose in relationship to the consequences of AIDS helped the elderly caregivers move successfully into their role as providers and parents to their grandchild.

A widow, grandmother Ploy, is very hard working and fit at 73. Her grandson came to live with her at the age of two. He is nine now. Her son died in a car accident. She shared the following story in the common stoic manner of the other elderly Thais interviewed,

He had become so thin and was exhausted all the time. He left behind his wife, my daughter-in-law, pregnant. She and the baby moved in with me so I could help. She met a man, who is now her husband and they moved to Lampung. My grandson came back to me because he became sick. His mother's new husband did not want him in their home. The thought was that my dead son might have what we now know as AIDS. He might give something to their new son.

Ploy went on to say that in the beginning, her grandson's mother stayed with her to help care for him, but as time went on and he did not get better, she went home to her new family. Now, she visits once a month and brings rice and a little money.

Her grandson was diagnosed with leukemia at the age of four. He was doing well until several months ago when he came out of remission. Still, she expressed her joy that her life became better when he came to live with her. As she folded the laundry, she shared that she had been lonely, but now she has something to live for. "Caring for my grandson has been a very positive change for me." Ploy accepts her fate and responsibility of taking care of her grandson, just as she accepts the fate of her son dying at the young age of 21. She smiled at me as she ended the interview with, "It is our way; the way of Buddha."

The interview with grandmother Siam (77) and grandfather Boom (79) took place at their stone table while several dogs and chickens ran about. The television was left on and background noise of one of Thailand's popular soap operas came through the window of their two room wooden house. The large, mostly dirt, yard is clean, with several bikes various farm tools placed against the wall of a bamboo shed.

They are raising their granddaughter, who is 11 and in the 5th grade. Besides being her caregivers, they also take care of her mom, who is living with HIV and was working until recently, when upper respiratory issues stopped her from continuing. Their granddaughter had not been born when her father passed away from AIDS. This is the only home and family she knows. Boom explained their decision for taking in their daughter-in-law and her child,

It is our Buddhist beliefs that create the foundation for family values and compassion. When my granddaughter's mom was diagnosed with HIV and became quite sick, I moved them into my home. We have lived together ever since. AIDS doesn't think or feel about such things, I must think for us for today to care for my family. Positive thinking; the past is the past.

Siam supported these thoughts with, "We do not waste time on negative thoughts instead focus on the positive ones. Our acceptance of life is part of the elderly rural way."

It is clear that cultural beliefs related to family responsibility, as well as the teachings of Buddha, support them in their roles as the primary caregivers. The rural elderly caregivers gave little attention to their losses from AIDS; instead, their focus is on their living and caring of their juvenile charges. Each of the stories shared by the caregivers interviewed was filled with love and pride for their grandchildren. Each caregiver was actively doing something to help guarantee their grandchild's positive future.

Theme 2: Life as a Rural Elderly Caregiver

What are the experiences of the elderly grandparents in rural Thailand as the caregivers for their grandchildren who have been orphaned by AIDS? For the majority of the caregivers interviewed, daily life starts early so they are ready to get their grandchildren up, dressed, and fed for school. Besides ensuring their children have food, shelter, and clothing, the caregiver role models personal hygiene, integrity, and spirituality.

Boom, who has raised his granddaughter since her birth, shared his story that due to his wife having diabetes; he has taken on the majority of the work in and outside of the home. Although there is no show of emotions, his love for his granddaughter and wife are apparent as he shares his story:

My daily life is up early to fix breakfast and help get my granddaughter out to school on time. I then go to the market for lunch and dinner shopping. Then to my fields and back in late afternoon for snack with family and then I may do some small jobs around the home or in the community. Then I fix dinner and make sure my granddaughter does her homework and is ready for bed.

For Ploy, 73, widowed and caregiver to her grandson, daily life begins before dawn. She rises early to get him up and ready for school, then she goes to work as a maid. He helps her on the weekends. They eat dinner together and usually watch one or two shows on the Thai channel. "We like the funny ones" she says.

For Somchai, daily life is about taking care of his granddaughter and the rest of his family. As mentioned previously, they live in a small compound that consists of her relatives, uncles and aunts and all their children. Somchai's granddaughter is looked after not only by him, but also by all the adults living within the compound. They eat their meals as a large family; this way his granddaughter "can spend time with her aunties, who as women can help guide her to make good choices." Evenings are spent completing homework and watching television. On the weekends, she takes dance lessons and hangs out with her friends. He speaks softly but with love in his voice as he shares about his granddaughter,

It's different now. When she was small, she was always next to me, but now that she is in her teenage years, she wants to learn to dance and join her friends at the mall. The boys can wait...I want her to study so she can have a bright future. I would like to see her go to Maejo University and be a teacher.

“Raising my nephew is simply part of my life, like breathing,” shared Jing (60). Her nephew's dad died of AIDS before he was born and his mom disappeared when he was 8 months old. At the time, they (nephew and his parents) were living with his grandmother. Jing helped her mom raise him until she passed away at the age of 80. He then came to live with her and her husband.

She shared this family history as she sat on the living room floor. At one time, this was the accepted method of sitting for everyone. Now with Thailand's development, homes are built to accommodate furniture such as chairs and sofas. As in the majority of the rural caregivers' homes, Jing's has minimal furnishings. The beds are in the common room so that they can be used for sofas while watching television or entertaining guests. The small house is clean and all the pictures are of family members. It is located on the backside of the town so the house is surrounded by trees and rice fields.

Her routine is similar to the other caregivers, which entails getting up early and ensuring that her nephew is ready for school. “I used to have a stall at our local market but I decided to give it up with my nephew growing older and needing more supervision.” She now stays at home and makes jewelry, which she then sells to a wholesaler. This work allows her to make a living while supervising her nephew to complete his homework as well as any chores.

When their grandson came to live with them almost 10 years ago, Wand (67) and Nan's (72) schedule was almost identical to the other caregivers' interviewed. He is now 17 and ready to graduate from high school. Their daily schedule as caregivers slowly changed, as he grew older. Their circumstances changed in other ways, too. As health issues related to their farming lifestyle arose, they had to slow down. The grandmother has problems walking due to diabetes while the grandfather has back issues. Their niece, Prapasri, who also lives within the small compound, has started helping.

The daily schedule has also changed over the years for Waewdao as her nieces have grown. They now get up and ready for school by themselves as well as sharing the household chores. The oldest niece completed high school and now "she works as an accountant for a women's group" a smiling and proud aunt elaborates. Helping with the daily chores and earning some extra money is also the case for the teenagers being raised by Wand, Nan, Nong, and Thai. Nong's granddaughter washes the weekly laundry, as does Wand's grandson.

For four caregivers, medical care must be ensured, as their grandchildren are living with HIV. Part of their daily lives includes medication management as their grandchildren are undergoing antiretroviral treatment. Besides making sure all the pills are taken at the right time, the caregivers provide a healthy diet for their grandchildren. Understanding what HIV and AIDS are has helped these caregivers realize they need to keep their grandchildren's immune systems healthy. This will allow them to develop physically and cognitively. Having this knowledge helps them monitor for symptoms that might point to a change of health.

This is also true for caregivers, Siam and her husband, Boom, who for the past several years have cared for their daughter and granddaughter, both of whom are HIV positive. Their daughter was working until recently. A nighttime cough had them take her to the AIDS hospital, where it was determined she has upper respiratory issues. “She will return to work once it clears up,” explained Siam. Boom related further,

Our daughter and granddaughter are doing well with their treatment. We must go to the AIDS hospital every two months to have their CD4 count checked to ensure they are staying healthy. It takes three taxis to get to the correct hospital.

All the caregivers caring for persons living with HIV shared similar stories of medical activities and travel. Besides the regular appointments to make certain that their antiretroviral treatment is going well, the caregivers shared that other doctor visits are required for them, due to their age. Depending on where the hospital or clinic is, how many people are waiting to be seen by the doctor, and type of transportation taken, it can be an all day event.

As stated previously, three of the caregivers have diabetes. Although, all are being regulated by medicine, this still means regular trips to the hospital for checkups and such. In the case of Jing’s grandson, they must go to the hospital every Saturday for chemotherapy since he recently came out of remission with leukemia. While interviewing Somoh (63), she disclosed her husband would not be joining the interview because he was not feeling well. They had just returned from the hospital where he was diagnosed with colon cancer. She shared the news of this life threatening illness in the stoic manner typical of the other elderly caregivers interviewed. She went on to explain that her son is

living with HIV (he lives at a church) while her son-in-law is currently in the hospital for a flare up of his diabetes. Her face and voice gave no signs of emotion until she started talking about her six-year-old grandson. “He is naughty and stubborn, but I am happy with him. He is a clever boy so taking care of him is not a problem.”

Considering all the caregivers’ numerous life challenges along with their advanced ages, they appear to be handling their grandchildren’s’ daily schedules and weekend activities quite well. They all spoke with love and pride as they shared their various daily events with me. For the majority of the caregivers, watching one of the popular Thai sitcoms was, a time of relaxation and relationship building with their grandchildren.

Theme 3: The Consequences of Caregiving

With the advancements from research that developed antiretroviral drug therapy, HIV is no longer a terminal illness; instead, it is a chronic illness requiring treatment for life. For the majority of caregivers of grandchildren interviewed, these medical breakthroughs came too late to save their adult children. Theme 3 continues to answer the question, “What are the experiences of the elderly grandparents in rural Thailand as the caregivers for their grandchildren who have been orphaned by AIDS?” Each of the caregivers discussed hardships, with financial problems being the foremost issue. Yet, over all, they shared positive experiences. In the sharing of their stories, it became clear that the elderly rural Thais did not question the notion or the responsibility of filial duty for their dead adult child’s child. They took on the task of raising their grandchildren with profound love, care, and protection.

With love and pride, grandfather Tem showed off his grandson's computer. His grandson is a slow learner, which may be related to his HIV, despite antiretroviral therapy. His slow processing and understanding of spoken and written words was worrying his grandfather. Hiring a tutor would have been a burdensome ongoing expense; so instead, he saved money and recently bought his grandson a used computer. Tem can now check his grandson's homework to ensure he understands the words and sentences. He relates:

It is the Thai way, our values as rural families, face value, a little religion, but a lot more about family. Not about merit making, about family. About looking after each other, no matter if they are blood related or not.

Like Tem and Supaporn's situation, Somoh is not her grandson's biological grandmother. Just as Tem and Supaporn took in their adult son who at the time was living on the street after his parents died, Somoh and her husband took in their neighbor's baby when he was four. His biological mother would leave him with them when she needed to work. Then one day she did not return. Although Somoh is the boy's main caregiver, like the majority of the caregivers interviewed, they live in a small corner compound with plenty of extended family members to keep an eye on him. "My daughter's two sons (7th and 10th graders) and this grandson enjoy spending time together working on the computer." Their younger daughter (36) continues to live with them, which is natural, given Thailand's culture that supports the concept of filial duty. Since the house only has two bedrooms, the grandparents had another bed fitted into their bedroom so half of the room is one huge bed covered with countless pillows of various sizes. The grandson

sleeps with his grandparents. It is a common practice for Thai children to sleep in the same bedroom with their parents for the first six to 10 years. “This way he is near us if he has bad dreams and becomes uncomfortable from them,” Somoh explained. The bedroom seemed a comfortable and warm nest.

The worse has already happened to these caregivers, having lost one or both of their grandchildren’s parents, and they have moved on. Little emotional discussion, if any, was engaged with me; instead, their stories were full of what is happening today and hopes for the successful futures of their grandchildren. Siam, who is raising her granddaughter, explained,

Acceptance of life is part of the elderly rural way; it is not the way of today’s children. My only concern is that we are together and well today. Every day lived is only of concern; not yesterday or tomorrow. We cannot do anything different; we can only live for our family.

In addition to the positive aspects of raising their grandchildren, several less positive issues arose during the interviews. Raising a child can place an inordinate financial burden on an elderly rural caregiver. As stated previously, all of the caregivers reported that taking on the caregiving of their grandchildren greatly affected their finances. Most of them either depleted their savings or sold their rice fields. However, not all of the caregivers had to sell their land. With pride, Boom, shared,

I own two rai (about 0.80 acres) of rice fields and still work them myself. I hire a tractor when it is time to harvest the rice. I plant because I can. I also cut firewood to sell to my neighbors. I do not depend on the government to take care of my

family or me. I look for little jobs around the community, such as cutting firewood to sell to my neighbors, to make extra money for my family because what I get from the government is not enough.

As senior citizens, each of the caregivers interviewed receive a monthly pension from the Thai government. The amount varies from 600 baht (\$19.50) to 825 baht (\$26.79) depending on their age. They also benefit from the Gold Card, which provides free outpatient services. This is Thailand's medical plan for those citizens who do not have private insurance. It allows a person to pay 30 baht (about a \$1) per visit for any medical services needed. The hidden cost is the money that will be needed to make the round trip. This will depend on the distance that the hospital or clinic is from the family's home. An extra 500 baht (\$16) is given to the caregivers who have grandchildren that are living with HIV. Thais earning 1,443 baht a month (about \$47) are living in poverty (UNDP, 2009a). The caregivers are living just slightly above this income level. Unlike foster care in America, the Thai government does not give money to the caregivers that are raising their grandchildren, nieces, nephews, or children helped off the street. Other sources of income come from NGOs like GCPP. Each caregiver supplemented their pension by earning extra money by finding odd jobs within their communities. Several of the older grandchildren helped by selling homegrown food at the local market or helping make baskets, which they sold.

Other costs such as transportation, snacks, school supplies, and weekend activities add up quickly and increase as the child grows. This was especially true for the caregivers raising boys. Nan shared that she did not know where her 17-year-old

grandson put all the food he ate. Having adolescent friends comes with additional financial costs, too. Meeting up and hanging out with friends becomes an important weekend activity for teenagers, as Pong, Waewdao, Jing, and Somchai testified. From Somchai,

When she was small not much but now that she is in her teenage years, the cost of transportation and extra snacks has increased. She wants to learn to dance and join her friends at the mall. All these things cost money. Then there is the extra money needed for snacks when she is out.

Waewdao's niece, as does Wand and Nan's grandson, plays the drums for the school's band. Each caregiver shared their pride for this accomplishment but in the same breath, each shared the ongoing worry about the extra cost for instruction. There was also concern expressed about the rising cost of fuel, which directly increased the cost of transportation. Most of the families had at least one motorbike to get around town to shop and transport their grandchildren to school. The school provides transportation for Supaporn and Tem's grandson. This is not a typical service provided by Thailand's public schools. All the rest of the caregivers interviewed shared that they have had to make travel arrangements for their grandchildren.

Somoh explained that her husband was taking their grandson to school on his motorbike, but now with his health issue, they have arranged for a *songtaew*, a pick-up truck with two parallel benches along the sides of the roofed bed, to take him to school and bring him home. She has had to pay a 1,000 baht a month for this help. Nan and Wand bear this cost for their grandson, too. His school is quite far from the family's

compound and for him to get there he must take a songtaew. Nong and Pong's expense is the fuel needed for their granddaughters to ride their motorbikes to school. Na's granddaughter also does the daily shopping at their local market before coming home. Although far cheaper than taking a songtaew to and from school and using it for errands, at 40 to 45 baht per liter (\$4.75 a gallon), the cost of gas for a motorbike adds up. When asked about providing care to a growing child, which might mean physical activities that an elderly caregiver may find taxing, all shared that their grandchildren understood their age limitations. From this question, I asked about their current health. Out of 14 caregivers, three take medicine for diabetes; each of these acknowledged their condition was under control. All the other caregivers interviewed shared that they were in good health despite their advanced ages. One 79 year-old grandfather went so far as to proudly claim, "My body is strong; I can face challenges and difficulties for my family."

Another caregiver, Waewdao, shared that she is living with HIV, which she contracted from her late husband, who died from AIDS. After their parents passed away from AIDS, her three nieces came to live with her. She decided to support them and herself by operating a frog and cow farm, as well as taking in mending. The physical tasks were wearing her out. She shared:

I found myself getting weaker and weaker with every day's physical work. My exhausting schedule of caring for my granddaughters and farms caused my immune system to weaken, which then led to ongoing health issues related to my HIV. I am now receiving antiretroviral treatment, which has allowed me to regain my strength. I had to give up the farms, which helped improve my health and now

I focus all my energy on my sewing and raising my granddaughters.

It is clear from the interviews; the greatest worry of the caregivers is the financial demand associated with raising their grandchildren. Nong and Thai along with the rest of the caregivers interviewed voiced their hope and dream that the child would attend college. However, this will cost more than any of them can afford. Although this concern has placed additional burdens on them, each of them has responded positively and creatively to the challenge presented. One grandfather cuts firewood, another picks up bottles and cardboard for recycling, while a grandmother makes jewelry to sell at the nearby market. Regardless of their welfare, each of the caregivers has taken seriously the role as caregiver for their grandchildren.

Theme 4: Outside the Family

“What community programs do Thailand's elderly caregivers know about and use? Which are having the most significant impact to help them take care of their family members and themselves?” To answer these questions the caregivers shared a story to explain how GCPP helped them. Tem shared that Grandma Cares saved his family and grandson. He went on to explain how hard everything had been in the early days of AIDS:

I was worrying, my wife was worrying, and then two of GCPP volunteers, Chatwand and Temduan, came to see us. We did not know who they were when they came to visit that first time. They said they were from Grandma Cares and our family's name had been given to them by the Thai Red Cross or from the monks at our Wat. Many families needed help. I remember them saying there

were many people from many countries wanting to help us.

A history similar to Tem's was also voiced by Nong and Thai, about their granddaughter who will soon graduate from high school. She came to live with them in their small one-story house, which sits in the center of a dirt yard surrounded by tall trees. At four, she and her dad came to live with them when her mom died of a heart attack. She became an orphan when her dad passed away several years later. They have received educational funding from GCPP. Without it, they realize that their granddaughter might have ended up dropping out of school and working as a maid, market seller, or getting pregnant with or without a husband to support them.

Both appear sad and malnourished, and though tall, both are bent over from years of farming. When asked a question, they would slowly smile and then one or at the same time, they would simply say, "*mai pen rai*." Almost all the elderly caregivers uttered this when questioned about AIDS and other past life events. Grandfather Thai finally shared, "We are only worried about our granddaughter getting into the university. We ask her everyday if she has done everything she needs to do to be accepted." Nong added, "We know she is smart but many other students are also smart." Clearly, her grandparents are quite proud of her achievements and know that if she can secure the money, she will be successful in earning a degree in teaching. With the help of GCPP, she was able to secure a four-year scholarship to attend Chiang Mai University's (CMU) College of Education.

This is also true in the case of Nan and Wand's grandson, with emotions barely checked, they quietly share the following story,

Without GCPP financial support, our grandson would not have been able to

continue to attend high school. He would have had to drop out to find a job to help his family. We are glad you (GCPP) came in, because during that time, nobody helped us support the boy. Even now, there is no support. We have put our names on the town's needy list but take it off when we go and see those who are worse off than us. Our concern is that the government says he (grandson) is an orphan, which means (according to the Thai government officials) he is a street kid. He will need to apply for a loan to go to the Teacher's College. We are afraid that they will not give it to him because they will think he is an orphan because he has no parents. But we are his parents! We have been here for him these ten years. He is a good boy and must go to this college.

The past 10 years of their lives connected with their grandson was shared as I sat on Nan and Wand's stone porch overlooking their large compound consisting of three houses and several sheds. As was the custom of the other Thai caregivers, this story was shared as if they were reading about someone else's life. Wand started,

His father (our son) disappeared before the boy was born. He may have known that he had AIDS because our daughter-in-law (his wife) slowly became sick and had to quit her job. She passed away from AIDS when our grandson, was seven. She was 35 years old.

Ten years ago the current regimen of drug treatment had not been developed. Meaning she may have passed the virus to her son during birth. His grandparents said he has experienced only good health since his birth. Nan continued with their story,

At seven, we took over raising him. As we have gotten older and our health has

slowed us down, our niece, Prapasri, (at this point of the story, Nan points across the dirt yard to another smaller wood house) started helping out. I have problems walking due to my diabetes. Her husband works a day job while she helps us and takes in laundry from the neighbors to earn some money. Our grandson also helps with the laundry duty as well as selling snacks.

They use the Thai Gold Card for their health issues. As mentioned previously, this card allows the elderly caregivers and the children in their care to receive medical treatment and medicine. Nan and Wand receive 600 baht each for being senior citizens from the Thai government. They and their niece receive nothing for raising their grandson/nephew. If he were living with HIV, they would receive 500 baht for his health needs. The question to inform him of this medical issue is a sensitive one. As a healthy youth, his immune system may be controlling the virus or he may not have it. As he becomes older, his immune may be compromised causing health issues. If he does have the virus, he could fall ill.

Meanwhile, he has maintained good grades and has decided to apply to Chiang Mai's Teacher College. He wants to receive a teaching degree in music so that he can return to his hometown school and teach. It is clear from the grandparents' nonverbal reactions that they are proud of their grandson. "We only want the best for him; he is a good boy and has worked hard."

In the respectful manner of all interviewed caregivers, they nodded their heads when asked if they are doing okay. When asked what more can GCPP do to help them, most of them laughed aloud as they answered, "We're doing okay." When I asked this

question to the rest of the interviewed caregivers, they all gave me a small smile while looking around them, and then shared, “*mai pen rai*,” meaning in this situation, all is okay.

Jing who makes jewelry and sells it to a wholesaler also had the attitude of *mai pen rai*. “I used to have a stall at our local market but I decided to give it up, with my nephew growing older and needing more supervision.” Everyone in the community knew of her situation so it was not surprising when one of her neighbors approached her. He asked if she might want to be productive at home. Making bracelets, necklaces, and earrings allows her to make a living while staying at home to ensure he completes his homework, as well as any chores. Auntie Jing shared,

This is especially true on the weekends, when he wants to be running around with his friends and maybe not making good choices. He is a good boy but he likes to spend too much time with his friends. I worry that he will start to make not so good choices. I am not at home all the time and I worry.

Currently the family receives financial sponsorship from one of GCPP’s American friends. Her commitment to GCPP’s mission is seen by her support for him for the past seven years. Her allegiance has greatly helped the aunt and uncle, as they do not receive any financial support from the Thai government to raise their nephew. They have the Gold Card for health purposes but the extras of raising a growing boy must be covered by them. Transportation, school PE and Boy Scout uniforms, snacks, and weekend activities, all quickly add up.

As is the case with all the GCPP caregivers interviewed for the study, the ongoing

commitment of the sponsors allows them to manage to live just above the poverty level. The unselfish act of caregiving to their grandchildren, nephew, or nieces, along with the GCPP sponsorships, optimistically will ensure their successful futures.

Support also comes from other family members, as is the case for four of the interviewed caregivers. These four raise their grandchildren with the financial, emotional, and physical assistance of extended family members. They live in compounds, which are made up of one to three houses as well as several smaller buildings, where they co-exist with other people, who may or may not be extended family members. In the case of Somchai and his family, everyone appeared to be happy and content with their belongings, which is not much when seen from my viewpoint. Sitting in semi-darkness because they have no electricity, Somchai explained that he and his wife had seven children but lost two to the skinny disease. In the early years, Thais called the unknown illness this because people with AIDS lost a large amount of weight. Somchai supported what others had shared through their life stories, “When problems arise, we look towards each other for help. Although we are very connected to our Wat and community, we seek help only when it is beyond the resources of the family.”

Asking for outside help was done only when all other resources within the family had been exhausted. This is the case with a majority of the caregivers in the study. Without much explanation about their child’s wasting disease, they sought spiritual and emotional help from their Abbot and the monks within their community Wat. Prayer and meditation, along with hard work were seen as two powerful mechanisms for self-help for the caregivers interviewed, but Somoh admitted that the family is better with GCPP’s

help,. “Knowing there will be baht to care for my grandson has been a relief for us.”

Waewdao shared similar feelings for her nieces and herself. Although only one niece has a GCPP sponsor, the extra money goes a long way in helping meet their monthly expenses.

This was also voiced by Pong who shared they are “doing okay.” She said “*mai pen rai*” as she told how the family’s motorbike was recently stolen. While at a red light, her grandson was hit over the head. When he woke up, he found the bike gone.

Meanwhile, during his last visit, a GCPP sponsor from America bought the granddaughter a camera and a cell phone. Both are gone now. She loaned her phone to friends and did not get it back. Some relatives borrowed her camera and broke it. Still, she uttered “*mai pen rai*” to me with a smile.

For all the caregivers, their main concern was about their grandchildren’s future, especially in relationship to their attending college. Each caregiver interviewed shared this dream of higher education. Each understood education is the way to a better life. The caregivers’ unspoken question was how to pay for this dream? Like Thai and the other caregivers, Somchai shared that “the financial worry was weighting me down.” Standing taller and sounding stronger, he shared with us that his granddaughter’s sponsor from Spain had visited them recently.

It was good to sit down and discuss this matter. His assurance that his sponsorship would see her through college allows me and my family to focus on other important matters relating to my granddaughter. Many other things are important for her to understand and know as she completes her high school education. She

will have many exams to take to be ready for the challenges of college.

This financial concern is foremost for Jing, who is raising her nephew with little help from her husband, who due to his age (78) and health, is on the sidelines. “We love him and we will miss him, but for his future...” shared his aunt. Jing’s love for her nephew is clearly heard as I interviewed her. The monsoon rains had stopped and the warmth of the sun shone through the front door. Sitting on the floor of the living room, Jing discussed how her nephew is doing at school and at home. On the hilltop straight behind her home, sits the famous Doi Saket Wat. Looking towards it, Jing explained,

We are thinking about his future and we believe the best path will be for him to continue his education up in Doi Saket. We put him there several months ago and he did well. Moving him there to live and attend school will give him the chance to complete high school. Along with an education, he will receive discipline and structure that is connected with living the life of a monk. If he does well and proves he has the ability and thirst for learning, there are grants to attend college.

This was the sole conversation held with Nong and Thai. Their only worry was about their granddaughter getting into college; nothing else mattered. This was also the case with Tem and Supaporn. There was little conversation about AIDS. That time has passed and now the main key for them and their grandson was to live for the day.

Medication management and healthy eating were seen as forces to ensure that their grandson, who is living with HIV, grows up strong and ready to attend college. They voiced no concern for themselves, only for him. This was true for all the caregivers interviewed.

Not a single caregiver discussed any stigma or discrimination towards themselves or the children they are raising. In fact, all reported having good relationships within their communities. For example, grandparents, Boom and Siam, shared with pride that their granddaughter is treated well at school, where she has good relationships with her teachers, as well as with many friends. These Thais have strived to maintain good relationships within their family and community; it is part of their cultural and Buddhist beliefs. This has not always been possible, especially during the first years when HIV and AIDS was an unknown disease. As quoted earlier in the chapter, Tem, step-grandfather to a boy who is not his biological grandson, explained, “It is the Thai way, our values as rural families ... about looking after each other, no matter if they are blood related or not.”

Summary

This chapter introduced the four themes discerned in the face-to-face interviews with 14 GCPP caregivers living in Chiang Mai, Thailand. The interviews focused on the rural elderly caregivers’ lifestyles as they relate to taking care of their grandchildren, nephew, and nieces orphaned by AIDS. The process of how the data were analyzed, as well as how the four themes were recognized, has been explained. The goal of understanding the caregivers’ experiences in relationship to their cultural and religious beliefs has been achieved. The following research questions were answered.

Question 1: What are the experiences of the elderly grandparents in rural Thailand as the caregivers for their grandchildren who have been orphaned by AIDS?

Not a single caregiver interviewed expressed negative feelings about their role as

provider for their grandchildren. Joy, pride, and love were the primary emotions expressed by the caregivers when they shared their stories, which contained limited information about the loss of their adult child to AIDS. Instead, their stories were full of the happiness gained by having their grandchildren live with them. Daily life for the caregivers is full, including duties involved in rising early to get their grandchildren up and ready for school. While their grandchildren attend school, the caregivers are busy maintaining a home, shopping for and cooking meals, as well as farming or working at various jobs to earn money. Once the grandchildren return from school, the caregivers ensure that homework is done and that they are available to talk, listen, and relax with the children, which several of them cited is an important responsibility.

Because several of the grandchildren require medication for HIV, healthy lifestyle management and healthful eating is overseen by the caregivers to ensure that the well-being of everyone in the household is maintained. The healthy development of the grandchildren and opportunities for higher education in the future is the top priorities for the caregivers.

Question 2: How do Thailand's cultural beliefs relating to family duty, as well as their Buddhist religious beliefs, support or impede the caregiving by the elderly grandparents for their grandchildren who have lost their parents to AIDS?

None of the caregivers interviewed reported being impeded by their Buddhist beliefs or cultural beliefs related to filial obligation. In fact, when I asked about *rok khong khon mee kam*, the majority of the caregivers explained it was not about *rok khong khon mee kam*; rather it was about doing right by your family. When the Buddhist

concept of *krengjai* was addressed with the caregivers, again the answer was about family. The elderly caregivers saw their role as parents to their grandchildren supporting the concept of *krengjai*.

Question 3: What community programs do Thailand's elderly caregivers know about and use? Which are having the most significant impact to help them take care of their family members and themselves?

GCPP along with family and friends within the community were the main sources of help for the interviewed caregivers. Most had developed a relationship with the school's principals and teachers to ensure a smooth path for the grandchildren's educational needs. After GCPP, the government's Gold Card medical assistance for those who do not have private insurance and the Old-Age Allowance System are the two programs having the most significant impact for the elderly caregivers. With the Gold Card for 30 baht a visit, the elderly caregivers and their grandchildren can receive medical treatment and medicine, regardless of the total cost of the examination, tests, or treatment regimen. The old-age allowance system is Thailand's pension for those 60 years and older, who worked in the informal services, where no pension plan or retirement pay is provided.

In Chapter 5, the four themes derived from the semi-structured interviews with Chiang Mai, Thailand's rural elderly caregivers will be explained in relationship to the research literature through a vivid and comprehensive portrait of the phenomenon using both the textural and structural stories of the caregivers. The implications and limitations

of the study will follow. Chapter 5 will close with my plan of action for creating positive social changes, recommendations for practice, and a summary of my conclusions.

Chapter 5: Discussion

Introduction

In the fight against AIDS, medical research has developed an extensive battery of antiretroviral drug treatments whose effectiveness have in turn led to HIV no longer considered a terminal illness. Instead, it is regarded as a chronic illness requiring treatment for life. In 2009, it was estimated that 50%–78% of Thais living with HIV received antiretroviral treatment (UNAIDS, 2010a). Despite this medical achievement, research found that HIV and AIDS continued to affect numerous Thai families (CIA, 2011b; UNAIDS, 2010c, 2011a). Many of these families are headed by elderly grandparents raising grandchildren, nieces, nephews, and street children orphaned by AIDS (HAI, 2007a; Kuo & Operario, 2009; WHO, 2008). In addition to caregiving for their loved ones, they may live with financial, emotional, physical, psychosocial, and discriminatory consequences (Lee et al., 2010; Wacharasin & Homchampa, 2008).

The 2007 SOPT found that 44.5% of elderly grandparents, 60 years and older, living in rural Thailand, have a child under the age of 16 living with them as a result of their parents having died from AIDS (Knodel & Chayovan, 2011). The survey also recorded that of the 44.5% elderly, 21%, almost double the national average, are living in poverty (HAI, 2008a, Suwanrada, 2009). There are no strategies in Thailand's National Plan (UNDP, 2007) to help these elderly, rural caregivers. Having made their living working as farmers, crafts makers, small shop owners, and such, they receive no company pension. Before the arrival of HIV, Thailand's culture of filial obligation allowed the elderly to depend on their grown children for financial and physical support.

With the loss of their adult children's support, if help is needed, it is sought from other family members, close friends, or the monks at their local wat. Other sources are the many NGOs and FBOs that came to Thailand to help in the HIV and AIDS struggle (Knodel et al., 2009; Wacharasin & Homchampa, 2008). The children affected by HIV or orphaned by AIDS are generally the recipients of these organizations, which leave out the primary and main caregivers, the elderly grandparents (Desmond, 2008; Erb, 2011; Heymann & Kidman, 2009).

From the limited research focusing on this population, it was unclear what consequences the elderly caregivers of Northern Thailand were experiencing as they raised their grandchildren affected by AIDS. Furthermore, the studies that exist in the literature focused more on the child or the PLHA rather than the caregiver. For that reason, the incentive for this phenomenological study was to fill the gap in the literature by exploring and describing the lifestyles of this population of rural, elderly caregivers living in Northern Thailand. Because Thailand's culture is based on the Buddhist philosophy of living a compassionate life, the study set out to understand their experiences, feelings, needs, and wants in relationship to their cultural and religious beliefs. Another purpose of this study is to present the data to the stakeholders within the Thai government, the Red Cross, the health department, NGOs, and FBOs for their investment in creating programs and policies that might improve the lives of the caregivers and their families.

I postulated three questions, which were then explored through semi-structured interviews with the elderly caregivers of the GCPP. Creswell's (2007) phenomenological

analysis methods and the Atlas.ti program were used to exam the data. The interviews were transcribed, translated, and back translated immediately after each interview. After this, they were downloaded into Atlas.ti. Constant reviewing of the documents allowed me to label interview quotes that resulted in codes. I kept notes of my insights as the data were analyzed and coded. The codes were then listed into themes. The research questions and themes are presented in Table 3. This process is described in detail in Chapter 4. Each theme interlocks with the other to give the audience a complete picture of Thailand's elderly, rural caregivers' experiences.

Summary of Findings

The data from this study found it is true that Thailand's rural elderly are the main caregivers to their adult children living with HIV and their grandchildren orphaned from or affected by AIDS. The data also revealed that these caregivers do not need acknowledgement for performing their filial duty, which as a Thai and a Buddhist is ingrained in them from birth. The cultural and religious belief of *krengjai* and *dukkha* prevented them from feeling that their caregiving is a burden. While Lee et al. (2010), HAI (2008a), and Wacharasin and Homchampa (2008) shared that the lack of educational, economic, and social resources for caregivers and families causes both short and long term consequences for all involved, this study found that the elderly had adjusted to and accepted their roles as caregivers.

Burden generally implies feelings of stress or strain, worry, inconvenience, discontentment perhaps even resentment or anger. These feelings are called *jai rohn* in Thai, which means being of hot heart (literally – heart hot), and alludes to being quick to

react in anger. When confronted with questions about AIDS and the changes that this illness brought to them, the caregivers showed *jai yen*, a cool heart. Their upbringing as a Thai and as a Buddhist required them to see the illness and its consequences as part of their life suffering, which then allowed them to let go and move on (Nilmanat & Street, 2007). This process of detachment is part of Buddha's teaching and cannot be achieved by brooding over one's life. For these reasons, throughout the interviews, all the caregivers showed their *jai yen*. Instead of feeling overwhelmed with what life and fate dealt them as indicated by prior research, I found that they used their energy to create the best living environment so their grandchildren might have better futures. The recent changes made in Thailand's National Plan for Strategic and Integrated HIV and AIDS Prevention and Alleviation have helped the elderly caregivers. The elderly population now receives a pension from the government, which is determined by their age and health (UNDP, 2007). The caregivers and their families also now receive free health care; this includes antiretroviral drug treatments if needed, plus the opportunity to attend educational programs on HIV and AIDS, as well as other health related issues. Similar to the findings of Knodel and Chayovan (2011), my analysis of this study's data revealed that the caregivers have grown more secure economically, emotionally, physically, and socially.

Table 3

Research Questions and Themes

Research Questions	Themes
1. What are the experiences of elderly grandparents in rural Thailand as the caregivers for their grandchildren who have been orphaned by AIDS?	Life as a Rural Elderly Caregiver. The Consequences of Caregiving.
2. How do Thailand's cultural beliefs relating to family duty, as well as their Buddhist religious beliefs, support or impede the caregiving by elderly grandparents for their grandchildren who have lost their parents to AIDS?	The Thai Family and Buddhism.
3. What community programs do Thailand's elderly caregivers know about and use? Which are having the most significant impact to help them take care of their family members and themselves?	Outside the Family.

Interpretation of the Findings

Research question 1 (See Table 3)

The lifestyle and consequences as a Thai rural elderly caregiver.

The information collected from the interviewed elderly caregivers did not support the literature, which stated that it is Thailand's grandmothers who are the main caregivers raising their grandchildren (Ageway, 2008; HAI, 2010; Lee et al., 2010; UNDP, 2007; Wacharasin & Homchampa, 2008). Found in this study was that the duties of being a caregiver were shared among elderly couples, widowed grandfathers, widowed

grandmothers, aunts, and other family members living within a shared compound. The interviewed caregivers painted their daily lives as being no different from that of anyone else that are raising children. As the primary caregivers, they were up before the rest of the household to ready themselves for the day. Their duties depended on the age of the child being raised. For example, five of the children are now teenagers and need attention in the afternoons to ensure homework and chores were completed. On the weekends, they were able to help with a variety of chores, such as delivery of laundry because they can drive the family motorbike. The younger ones, ages from seven to 11, still need attention in the mornings to get dressed and ensure they have everything with them for a successful school day. This attention was given again when the child returned from school. Besides providing for their physical needs and wants, the caregivers spend time and extend patience teaching the children in their care various life lessons related to making choices, integrity, and spirituality. With this approach, the caregivers are protecting their way of life, and ensuring their juvenile charges understand what is required of them as a good Thai and Buddhist.

While their child was at school, caregivers completed household chores. Once these were completed, all the caregivers, save two, continued to work their land and sell what they have grown at their local market or in front of their homes. Many of the female caregivers shared how they earn extra money by making jewelry and taking in mending and laundry. Several of the men explained they earned extra money by collecting wood to sell as firewood. This need for the elderly caregivers to continue to work to earn extra money was noted by Ageway (2008), HAI (2008a), Jones (2011), Knodel et al. (2011),

and Vejjajiva (2011). KFF (2010b), UNFPA (2006) and UNFPA and HAI (2011) observed that many of Thailand's elderly continued to work past the Thai retirement age of 60 in order to be able to meet their financial responsibilities as caregivers.

Afternoons were busy times for the caregivers and their juvenile wards. Time was spent completing homework and practicing playing musical instruments. Many of the children are involved in sports training and competition. After ensuring homework was completed, time was spent watching television or playing a favorite Thai board game, *mak yaek*, which is somewhat like chess. Weekends were busy times, too, with fun activities such as riding bikes, playing volleyball, soccer or badminton with friends. The caregivers and their charges were also involved in activities that are not so much fun but necessary for the well being of the family, such as helping out with household tasks and preparing meals, managing a stall or booth at the local market, working in the fields, or washing, drying, and ironing laundry. Each of the caregivers added that these are just tasks among life's many demands nothing unusual for anyone raising children.

economic and physical consequences.

No matter what age, all the caregivers expressed pride in their ability to work to bring in the extra baht (Thai currency) to help raise the children in their care. As mentioned above, a variety of odd jobs allowed the caregivers to earn extra money to supplement their old age allowance from the government (UNFPA, 2006; UNFPA & HAI, 2011). The amount each caregiver received monthly, ranging from 600 baht (\$19.50) to 825 baht (\$26.79), depended on their age and health status. This program was initiated after the 2007 SOPT gathered data supporting the need to increase the financial

support from the government (HAI, 2007, 2008a; Suwanrada, 2009; Vejajiva, 2011). All of the caregivers were in agreement that the increase of their retirement allowance, along with the creation of the Gold Card health care program, has helped them better meet their monthly finances. This validates the research of Lee et al. (2010), Nyamathi et al. (2007), Sorajjakool (2006), and UNAIDS (2011b) that identified financial concerns as the supreme one for elderly caregivers of children.

This concern for finances was rated as the highest priority shared among the 7.02 million elderly persons answering the 2007 SOPT. Suwanrada (2009) and more recently Nanthamongkolchai et al. (2011) identified two factors, poverty and financial security, as the top concern for Thailand's elderly. According to their research, having a dependable, steady income was rated as one of two items needed successfully to negotiate with old age. This sentiment held true for all the caregivers interviewed in this study. Each interviewee expressed anxiety about not having enough money to buy basic daily supplies, as well needing to save for college for the children in their care. Having sufficient food and suitable clothing for the child was far more important than providing for themselves. Although all the caregivers looked healthy, many appeared quite thin, causing me to think that the children received a good-sized portion at meals and whatever was left, the caregivers ate. This was also apparent when looking at the caregivers' worn and old, but clean, clothing. It was not their future needs, but rather their child's higher education and the better life that education will bring, that concerned them.

This was also seen in the upkeep of their homes. Almost all of the elderly caregivers lived within a compound of several houses and amongst many other family

members. The homes were built of wood or concrete, usually with one, large common room minimally furnished, but invariably holding the family's small but functional television set. The other rooms of the home were sleeping quarters, along with a common toilet. If there were not enough bedrooms for everyone to sleep separately, the caregiver slept in the common room, allowing the children to have more privacy. Thai kitchens are generally found in the rear and outside of the house under a *sala* (an open covered patio area) or wide overhanging eave. This prevents the house from smelling of whatever is being cooked and helps keep the house cool since, for most of the year, it is hot in Thailand. Most kitchens did not have a refrigerator; the few that did had small ones. Washing machines were another appliance missing in these households. Hand washing was common for these caregivers, even those who took in laundry.

As with their clothing and appearance, the caregivers' pride in their surroundings was evident. Regular upkeep of their yards and cleanliness within their homes was a priority. The caregivers shared that these chores are part of being a family and, so everyone was expected to help. This family care of property was evident even with several of the caregivers' homes being repossessed by the bank. They were able to continue living in their homes because of the Thai's belief of *rok khong khon mee kam*. Also involved was not wanting to cause anyone to lose face, which is primary among the reasons that influence the bank's decision not to evict the tenants, who were the former owners of the homes. None of the houses was dilapidated, but maintenance depended on the availability of extra money or having family members who are competent to perform the required work. Although the homes were clean and organized throughout, the

majority of money and care was expended on the bedrooms of the children. Within these rooms were curtains and carpets, along with a nice bed and cover. In all of the teenagers' rooms, there was a desk, lamp, and for some, a computer.

Interestingly, I found a television in every home, no matter what the housing situation or financial circumstances of the caregiver and family. Several caregivers answered my question relating to this matter. Not having extra money for transportation, entrance fees, and snacks to take their child to activities in the community such as going to the movie theater, making an excursion to the zoo, or going bowling or swimming, the television was their source of free entertainment. Unlike other developed countries, Thailand broadcasts several free channels that provide a variety of shows, including soap operas, sit-coms, sports, and news. It was also explained that due to the caregivers' advanced age, it was easier and better for them to sit at home to enjoy a television show with their extended family than to do an activity that will tax them both physically and financially.

These physical and financial issues for the aging caregivers were uncovered by the earliest qualitative study in Chiang Mai, Thailand (Safman, 2004). The decision to study Thailand's elderly was made because there had been no data collected in Northern Thailand, where at the time, prevalence rates for HIV and AIDS were one of the highest in the country. The other reason was that it had one of the largest elderly populations living in poverty (HAI, 2005). The researchers focused on the relationships between the caregivers and the orphans and vulnerable children they were raising. Although this information is nine years old, the conclusions made then are still true. The majority of

children orphaned by AIDS are being cared for by one or both grandparents or an aunt who are dealing with financial and physical problems. This is further validated by the findings of Lee et al. (2010), Nyamathi et al. (2007), Sorajjakool (2006), and UNAIDS (2011b). These authors identified that the second most significant consequence for elderly caregivers was their deteriorating health or health concerns related to their advanced ages. This matter is compounded by the fact that 44.5% of elderly Thai people live in the rural areas, where life is harder and poverty greater than in Thailand's cities (Jones, 2011; Knodel & Chayovan, 2011; PRB, 2007; US Department of State, 2011).

HAI (2010), Jitsuchon and Richter (2007), and UNDP (2010) compiled research that supported their hypothesis that the HIV epidemic pushed the elderly population further into a cycle of hardship and debt. They further asserted that this illness, now a chronic one, affected the uninfected elderly, particularly the women, who became caregivers of their ailing PLHA and their orphaned or nearly orphaned by AIDS grandchildren or other juvenile relatives. Their findings reflected the cultural demands on a Thai woman. These cultural responsibilities included household tasks such shopping for and cooking meals, cleaning up afterwards, dusting and sweeping, and washing and hanging clothes (Nilmanat & Street, 2007; Nyamathi et al., 2007; Wacharasin & Homchampa, 2008). HAI (2007a), Knodel and Chayovan (2008a), Knodel and Saengtienchai (2005) reported that the elderly retired from working their rice fields or noodle shops to allow their grown children to take over. The arrival of HIV caused the majority of them to return to work as their adult children became sick and died (Knodel & Chayovan, 2008a; Knodel & Im-em, 2004; Knodel & Saengtienchai, 2002, 2005).

Unlike previous findings which shared that stereotypical gender roles continued throughout the HIV crises (HAI, 2008b; KFF, 2010b; Wakhweya et al., 2008), this was not the case for those interviewed. The authors of these studies also found that the financial burdens of the family were not the sole responsibility of the grandfathers, as claimed by Knodel and Chayovan (2011). In the case of this study, the caring for the family, while maintaining a household, was shared with everyone within the home and compound.

The ages of the 14 caregivers in this study spread from 60 to 81 years old. Each shared that their juvenile charge understood that their caregiver's age prevented them from engaging in certain activities. When the activity was connected with school, a younger family member, generally an aunt, was asked to help, supporting the findings of Chandoevrit and Chawla (2011) and Lee et al. (2010). Help from extended family members was part of the Thai culture tradition relating to family duty. To say "No" would mean to lose face, and Thais will do almost anything to prevent this action. The dignity and honor maintained within the elderly caregivers' families was evident through the stories told about how the daily activities were divided among the family members according to who had the physical ability to perform whatever task was required. The caregivers in this study realized that for their families to be successful, they had to adjust their thinking in connection with their upbringing regarding traditional Thai gender roles. For example, the widowed grandfathers of their young girls undertook the duty of washing, hanging, and folding the laundry. Another illustration is that many of the caregivers took their young child to the market with them, while older youths went on

their own. The research of Knodel (2008) and Knodel and Chayovan (2011) on Thailand's intergenerational filial duties were supported by the families of this study. All of the interviewed caregivers shared that their teenagers helped with the physical chores that tired their elders. Because they can drive the family's motorbike, the adolescents were able to run errands, go to the market, and pick up or deliver laundry. On the weekends and holidays, they helped sell vegetables and fruit, grown in the family's small orchard or field. Several of the caregivers run noodle shops where the teenagers help. Those who are able help to cook, clean, and run the home. As stated by Knodel and Chayovan (2009a) and UNICEF (2009b, 2011), sharing household tasks and earning extra moneys helped each of these families. In addition, it gave the elderly caregivers respite for their well-being.

The well-being of all members within a Thai family was important to their collective continuing harmony. Doing one's duty contributed to the overall well being of the family. This way of life stemmed from the cultural concept of *krengjai* and was the responsibility of each Thai family member (Bechtel & Apakupakul, 1999; Cooper & Cooper, 1996; Safman, 2004). *Krengjai* was taught to the children by their caregiver from birth (Cooper & Cooper, 1996). I found a pervading calmness and peace, in each of the caregivers' homes, which was not disturbed by the interview questions. By displaying *krengjai* to everyone, including me, the caregivers and their extended family members maintained kindness and tranquility within their homes and compounds.

social and emotional consequences.

Almost all of the research presented in the literature review dealt with caregivers caring for both their PLHA and grandchildren or other children in their care. For example, HAI (2005), Knodel et al. (2001), Maneesriwongul et al. (2004), Nilmanat and Street (2004), Phengjard et al. (2002), Safman (2004), Sethabouppha and Kane (2005), and Songwathana and Manderson (2001) reported that caregivers and their families shared feelings of dread, anxiety, isolation, and sadness. These feelings were due to or prompted by their lack of knowledge of what the illness actually was. Also linked to the propagation and harboring of these negative feelings was the belief that immoral behaviors had resulted in the person becoming infected with HIV. Such biases have led to emotional stigmas, fear of infection, shame, and disgrace. Direct and indirect experiences of discrimination have caused some caregivers not to seek outside help from their extended family or from their community and wat. Within the Thai culture at this time, though still widely held in many areas, especially among the more uneducated rural poor, these biased and judgmental opinions or beliefs are no longer acceptable and do not support the custom of *krengjai*.

As awareness of the illness grew so did multi-sector collaborative projects throughout Thailand (FHI, 2008; Prasartkul & Vapattanawong, 2011; Richter, 2009). These programs educated Thai citizens. Slowly the emotional effects of depression, guilt, despair, hopelessness, and shame that were felt by the caregivers, the PLHA, family members, and community in the early years of the epidemic transformed into

understanding and support (Cadell, 2007; HAI, 2007a; Nilmanat & Street, 2007; Waldrop, 2007; Nanthamongkolchai et al., 2009, 2011).

The negative attitudes and emotions mentioned above were described by the caregivers interviewed for this study. The majority of caregivers lived in compounds where several generations lived together, working, sharing meals, and playing with one another. Their Buddhist faith plus their cultural belief of *krengjai* bonded them together. Each person's positive or negative actions uphold and enhance or detract from and diminish the family's honor (Cooper & Cooper, 1996; Kittikorn et al., 2006; Klausner, 1998). In embracing the concept of *krengjai*, along with the Buddhist tenet that "all life is suffering" (Cooper & Cooper, 1996, p. 78), these caregivers along with the majority of Thai families suffered their loss in silence (Phengjard et al., 2002; Nilmanat & Street, 2007; Wacharasin & Homchampa, 2008).

Suffering in silence was the rule among the caregivers interviewed for this study. Picking their words carefully, and devoid of any emotion, each of the caregivers discussed the financial hardships of raising children. The worst has already happened, having lost one or both of their grandchildren's parents, and they have moved on. The past is in the past and they engaged in little, if any, emotional discussion with me; instead, their stories were full of current endeavors and future hopes of college, jobs, and a better life for their grandchildren, nephew, or nieces.

Over all, they shared positive experiences. In the sharing of their stories, it became clear that these elderly rural Thais do not question the obligations imposed by the responsibility inherent with filial duty for their dead adult child's child. They took on the

task of raising their grandchildren with profound love, care, pride, and protectiveness. Their unquestioning, culturally instinctive actions were consistent with the findings of Nyamathi et al. (2007) and Sethabouppha & Kane (2005). The researchers emphasized the Buddhist belief of *rok khong khon mee kam* as well as the Thai cultural concepts of “*hai* and *siasala*” (pp. 48, 350).

The interviewed elderly caregivers neither mentioned nor discussed their giving and sacrificing. Rather these unspoken themes were heard as they shared stories full of the pride and love in raising and caring for their grandchildren, nephew, or nieces. The thoughtful recounting of stories of evening and weekends activities, musical and athletic abilities, educational achievements, and other memories brought authentic smiles of joy to their faces. Thailand is known as the “Land of Smiles” (Cooper & Cooper, 1996, p. 18), but many types of smiles, while appearing beautiful and sincere may mask feelings other than joy, happiness, or pride. Smiling in the case of the caregivers interviewed showed their delight. Thais also use smiles to excuse, thank, avoid conflict, and cover up their embarrassment or another’s. The Thais’ smiling “masks” (Klausner, 1998, p. 144) allows them to take the middle ground, which maintains surface contentment while avoiding conflict.

These masks were seen when questions related to the past and AIDS were asked of interviewed caregivers. The common and correct social response to these questions had them smile and share with no show of emotions, “*mai pen rai*,” meaning that everything is okay now. This belief allowed the caregivers to wake up every day and

perform the duties of raising the children in their care with no resentment but with joy. This was the pervading sentiment that they evinced as they shared their stories with me.

The feeling that yesterday does not matter as today is a new day was reported by Knodel et al. (2009) in their research. They concluded that the fading away of discrimination and waning stigma previously associated with HIV and AIDS was because of Thailand's health program, which has provided free antiretroviral treatment since 2001 (AVERT, 2011b; Knodel et al., 2009). In the early days of HIV, before the development of these drugs, there was a plethora of physical symptoms of the disease, including fatigue or general enervation, persistent coughing, lesions and subcutaneous bruises on different parts of the body (Kaposi's syndrome), and rapid, unexpected weight loss, all of which were apparent to people in the community. These could not be kept hidden and a majority of PLWA were subjected to their families,' friends,' and others' fear, judgment, and discrimination (AVERT, 2011b; FHI, 2008; Knodel et al., 2009; TNP+, n.d.; UNGASS, 2010). With the advancement of medical treatment, the majority of these symptoms do not present themselves to PLHA. The feelings and behaviors of the recent past are not felt or seen by the grandchildren living with HIV. Although not spoken, I sensed a feeling of relief as the caregivers shared how their grandchild, nephew, or niece is loved by their teachers, friends, and community. To maintain the HIV-positive child's health and forestall the onset of AIDS, with the consequent appearance of the visible symptoms of the disease, they must strictly adhere to the antiretroviral treatment. This included rigorously adhering to a healthy lifestyle with a nutritious diet, which was already part of their lives as Buddhists (Knodel et al., 2009) Knowing that their juvenile

charges are being treated fairly and living a healthy life was of paramount importance to them and ensured their emotional well-being.

In summary, considering all the elderly caregivers' numerous life challenges, along with their advanced ages, they appeared to be handling their youngster's daily schedules and weekend activities quite well. I heard their pride as they spoke about their relationships with their children. It was clear they loved them. These caregivers are working hard as they strive to provide every benefit possible to ensure their future success. Part of this behavior is prompted by the cultural belief that demands intergenerational family care (Cooper & Cooper, 1996; Knodel & Chayovan, 2009a; 2011). The rules of respect within Thai families impose recognized and accepted standards of social order and behaviors. Parents raise the child. The child grows into adulthood, gains employment, and remains connected emotionally, physically, and financially with their parents. In this study, all but one of the caregivers had lost their grown children to AIDS. The responsibility of raising their grandchild, nephew, or nieces was placed on them. Not one of the interviewed elderly caregivers voiced a negative thought or feeling about this continuing role. Knowing that Thais smile in the face of adversity, I felt their desire to subscribe to the cultural norm of saving face significantly influenced how they answered many questions posed during the interview.

Another influential Buddhist belief, *dukkha* also factored into how the caregivers responded to interview questions. This belief guided their life choices for themselves and their family (Yeshe, 1998). For the caregivers interviewed in this study, their experiences with poverty, AIDS, and loss of life were in the past. Smiling, they shared about the

current day's events connected to the child they are bringing up to be a good Thai citizen and Buddhist. I discovered that family relations are the most important factor enabling these caregivers to move on with their lives after the experience of caregiving for a loved one dying from AIDS. My assertion is supported by Nanthamongkolchai et al. (2009, 2011), Richter (2010), Richter, Beyrer, et al. (2010), Richter, Sherr, et al. (2009), and Waldrop (2007).

The caregivers expressed in various ways that yesterday's life suffering was gone and discussing the past would not help them with the family's current situation. "Don't bother worrying; there is nothing to fear" (Borg & Riegert, 1999, p. 73). This quote reflects the caregivers' use of *mai pen rai*. Tomorrow has yet to arrive, and as Thais, they understand they do not need to worry until that day arrives. When it does, they still do not need to worry for the social protocols demanded by *krengjai* and *naa* will enable them to move through whatever life asks of them.

The study results did not support the research that the rural elderly caregivers are living with discrimination, stigma, or poverty with little to no resources available (UNAIDS, 2011b; Vejjajiva, 2011). It was not found that fear, shame, or the Buddhist belief that life is suffering kept them from seeking medical and other family and community help, as asserted by FHI (2008), Kittikorn et al. (2006), Lee et al. (2010), Liamputtong et al. (2009), and Wacharasin and Homchampa (2008). Instead, the HIV epidemic has allowed each of the caregivers to find hidden strength to carry on with their filial responsibilities while finding or creating new ways to support their families. For example, several of the caregivers who are still growing rice developed a system that

allowed them to harvest a full crop with little to no outside, hired help. Using a staggered method, they plant one small section of a rice paddy and just as it is ready to be cut, they plant another section. Their ability to learn and grow through this experience supports their Buddhist belief of dealing with and then letting go of life's suffering. With each added story from the elderly caregivers, I gained a better understanding and respect for the Thai tradition of *naa*. This concept allowed them to care for their young wards in peace.

Research question 2 (See Table 3)

buddhism in thailand.

Buddhism is alive and well in Thailand, with 95% of Thais living their lives adhering to the teachings and the interpretations of the doctrines set forth by the Buddha more than 2500 years ago (Kittikorn et al., 2006; Nilmanat & Street, 2007). The 95% follow the Theravada or Southern School of Buddhism. Thailand is the only country that has it written in the Constitution that the king must be a practicing Buddhist (Kusalasaya, 2005). Buddhism can be found at the center of Thailand's culture and social structure; from its king and royal hierarchy, to its philosophy, traditions, customs, guiding ethical and moral principles, language, legal system, art, music, dance, clothing, holidays, and festivals (Kittikorn et al., 2006; Kusalasaya, 2005; Nilmanat & Street, 2007; Sethabouppha & Kane, 2005).

Besides being known as "The Land of Smiles" (Cooper & Cooper, 1996, p. 18), Thailand is also known as "The Land of Yellow Robes" (Kusalasaya, 2005, p. 2). Saffron, which is actually more orange than yellow, is the color of the full-length robes

worn by all monks and novices. They live together in a wat. Each of the 21,000 wats throughout Thailand is run by a Chao Avas (abbot) (Kusalasaya, 2005). To achieve this discerning position, the monk must have completed higher education that included the understanding of (a) the Dhamma, which is the Buddhist Doctrine, (b) the ability to read and speak the Theravada writings, which are in Pali (an archaic language from the Indian subcontinent), and (c) secular subjects that help him guide his community members. The abbot of each wat ensures that all religious rituals and services are appropriately executed according to the Vinaya rules (Kusalasaya, 2005).

Equally important, is the abbot's choice of sect of the Buddhist Order. The tone and structure of the monks and novices' endeavors in and out of the wat depends on the abbot's sect. There are two found in Thailand. The oldest and more common sect is the Mahanikaya. The second and younger one is called the Dhammayuttika. Both require the following of the 227 Vinaya rules that Buddha wrote in the Basket of the Discipline (Kusalasaya, 2005). The difference between the sects is the level of discipline and due regard practiced by the monks with respect to Buddha's teachings. The Dhammayuttika sect requires the monks to live a more regimented and academic existence, while the Mahanikaya exacts fewer demands. Consequently, many Mahanikaya abbots now allow their monks to indulge in or avail themselves of the accoutrements of modern life, including owning cell phones and other personal digital or electronic devices, using public transportation, buying and eating food in restaurants, and smoking cigarettes. Despite their differing behaviors, each sect continues to find favor with the Thai people. I noted this when several caregivers shared that they had accepted these changes,

comparing them to the social and economic changes within their family and village. The abbots are also guided by the Holy Order, also known as the Bhikkhu Sangha and the Laity (Kusalasaya, 2005). The Sangha is made up of the Council of the Elders who work closely with Thailand's Department of Religious Affairs. The Laity is the relationship that the monks have with their community. Monks cannot find employment outside of the wat so their food, clothing, housing, and health needs are met by the members of their community. In return, they serve the community "for the gain of the many, for the welfare of the many" (Kusalasaya, 2005, p. 18).

Each abbot receives a yearly budget from the government for operating costs and maintenance of the wat, as well stipends for monks higher in the hierarchy. The majority of funding for upkeep of the facilities, amenities for the Sangha, and the salaries of lesser order monks are donated by each local community. The Thais, especially the rural Buddhists, give freely as they still consider the wat and its monks an essential part of their lives (Kusalasaya, 2005). The use and support of their wat and monks was evident in the rural caregivers' stories. Whether to attend a funeral or wedding, or sitting down with the abbot or a respected monk to engage in various levels of discourse on diverse topics kept them mindful of Buddha's teachings. They also shared that their wat provided nonreligious programs and resources, such as a library, clinic, community center, and a hospice. I was informed by one of the caregivers that his wat used loudspeakers to share news, ceremonies, and other information of interest to the community. This helped the people who could not travel to the wat so they would not miss some items that might be of interest to them. Two interviewees reported that their grandchildren attended their

wat's primary school. This is common, as about a half of Thailand's primary schools are located in wats with the monks being the teachers (Kusalasaya, 2005).

the thai family and buddhism.

Ensuring that the education of the children in their care was as good as it can be is part of being a good Thai, as well as following the dictates required of being a good Buddhist. Believing in the welfare of others is "to do good" (*kusala kamma*), which is vital to being a good Buddhist (Kusalasaya, 2005, p. 22). This is done by making merit (*puñña*). Thais donate financial gifts and offer food, cleaning services, kitchen and tableware, personal hygiene supplies, and medicine to the abbot and monks of their wat (Nyamathi, Covington, & Mutere, 2007). During the year, there are scheduled, organized processions, often spanning several evenings. They are associated with a religious holiday or an important event for the wat itself, such as the dedication of a new stupa or renovation or the investiture of novices. Any of these occasions will bring the subdivisions' (*muu baans*) community members out to proceed to the wat with their gifts. Sometimes the event calls for a festive parade where the people walk and sometimes dance as they are accompanied by young men playing traditional rhythms on horns, cymbals, and drums. Often, depending on the importance of the occasion, the procession includes *crystal boys*, young boys dressed in fanciful, brilliantly colored costumes and wearing sunglasses, who ride to the wat astride a prancing pony.

Being a good Buddhist, the caregivers began their day making *bun* by feeding the monks who walked through their community in the early hours. This is important for the monks, who must eat their one meal of the day before noon (Nilmanat & Street, 2007;

Sethabouppha & Kane, 2005). Blessings are given as they collect rice, vegetables, and fruit (they do not eat meat) for themselves and their fellow monks. *Puñña* was done by the rural elderly on a daily basis to ward off or counter life's *baab*, such as lying, cheating, gambling, or drinking, which can bring about negative *rok khong khon mee kam* (Nilmanat & Street, 2007; Sethabouppha & Kane, 2005).

The Buddhist doctrine that states that for every positive or negative deed performed an equivalent result influences a person's current and future lives is called the "Law of Karma" (Kusalasaya, 2005, p. 22). This law connects the Thai's belief of *naa* and *jai yen* to ensure good *rok khong khon mee kam*. For instance, during one of the interviews, a neighbor appeared at one of the elderly grandfather's door asking to come in. Somchai explained that it was not a good time for a visit. His neighbor, clearly curious about my presence, did not take the hint and took a step to come in. Although still speaking in a polite but tight tone, Somchai promised he would come around later with his special drink. This appeased the neighbor and he left. Returning to his mat on the floor, I could see Somchai's mouth in a tight line and his brow knitted. As he lowered himself, he looked down for a second and then when he looked up at me, his face held a smile and his brow was smooth. With his "*mai pen rai*," he returned to what he had been sharing before the interruption.

Each of these concepts supports the foundation of Thailand's social structure, which has been established and maintained for hundreds of generations to achieve harmony within the family, community, and throughout Thailand. It is achieved through the exercise of compassion, discipline, and dedicated effort in the search for and

attainment of enlightenment. Harmony is achieved and compassion expressed by embracing *dukkha*. Each Thai determines what *dukkha* means according to their family's "mental attitudes, concepts, perceptions and consciousness" (Yeshe, 1998, p. 20). The first step on the path to *dukkha* is being aware. This awareness is achieved when a Thai discovers that, in reality, they themselves are the source for their own suffering. Their suffering stems from their covert feelings of anger, frustration, disappointment, greed, envy, and revulsion. Negative behaviors and thoughts are acknowledged. The Thai is ready to proceed to the second step of Buddha's teaching, where one takes action. This action is a letting go of life's suffering, the negative thoughts, feelings, and behaviors that form in connection to an event, person, or situation.

This letting go of the past, along with letting go of the pain and grief associated with losing their loved ones from AIDS, was described in the caregivers' stories in relation to raising the children in their care. Letting go made it possible for them to greet every day with love, patience, and joy. I observed their actions and heard their words and feelings and they are not ones that are connected with the daily struggles of raising a child. Their positive view on life was because of their belief that life is about living each moment with cheer and delight. They are their own source of suffering or thriving. These caregivers, as demonstrated in this research, have chosen to thrive.

This might not have been true in the first years of the HIV epidemic. The research compiled in those early years found that the caregivers and their family members were experiencing financial, emotional, social, and physical hardships (Desmond, 2008; Janjaroen & Khamman, 2002; Knodel, 2008; Knodel & Saengtienchai, 2002; Nilmanat &

Street, 2007; Safman, 2004; UNDP, 2007). Their data are consistent with the findings of Apinundecha et al. (2007), Kittikorn et al. (2006), and Wacharasin and Homchampa (2008). These researchers concluded that the family unit was negatively affected by caregiving for a chronically sick family member. The more recent data of Lee et al. (2010), KFF (2010a, 2010b), and UNGASS (2010) confirmed what these earlier researchers asserted; that the Thai caregivers remain burdened by their duties.

Each of the interviewed caregivers agreed that their lives changed with the caregiving and eventual death of their adult child. HAI (2005) found that from 2001 to 2004, 240,000 elderly parents buried adult children who died from AIDS (p. 2). The loss of these adult children made a major impact as a majority of the deceased adult children lived with their parents or close by (Knodel & Chayovan, 2008b, 2009a; Nilmanat & Street, 2007). Forever gone were the extra sets of hands to help in the rice fields, in the noodle shop, in the house, and to care for their children (HAI, 2005, 2007a; Knodel & Saengtienchai, 2005).

What the caregivers in this study did not share were their thoughts or feelings about the early days of AIDS or their adult child's illness and eventual death. What was shared, in an emotionless, stoic tone, was that their son or daughter died from AIDS--period. Also not spoken, were their thoughts and feelings about their physical, emotional, or financial difficulties during and subsequent to those years.

The early research established that Thailand's rural, elderly poor believed the contagious AIDS sickness, the skinny disease, was the result of immoral or depraved behaviors (Chan & Reidpath, 2007; Kittikorn et al., 2006; UNAIDS, 2011b). The Thais'

religious belief in *rok khong khon mee kam* helps make this belief believable. This is consistent with the early research of Phengjard et al. (2002) and Kittikorn et al. (2006). The families in these two studies reported they did not share their situation with others for fear of being ostracized. On the other hand, like the caregivers of this study, as Buddhists, their unquestionable duty was to stand by, stay with, and care for their sick adult child.

As in every culture, funerals, weddings, and birthdays are significant life celebrations for Thais. The most important ceremony for Thais is the *ngarn sop* (cremation ritual), where the deceased begins the process of rebirth (Cooper & Cooper, 1996). The concept of rebirth or reincarnation is integral and central in the Thais' religious belief system. Creating good *rok khong khon mee kam* through religious *puñña* is thought to help the deceased find their way back to a better rebirth. Nilmanata and Street (2004, 2007) and Waldrop (2007) noted that the caregivers they interviewed believed they needed to make double and triple *puñña* to ensure a better reincarnation for their adult children dying from AIDS. In Thailand's early years of AIDS discrimination, the need to perform such *puñña* rituals connected them to the moral principles of Buddhism. With little understanding of the origins or cause of the illness, Thailand's MOPH indicated to the public that injecting drugs or having premarital, homosexual, or otherwise illicit sex led to AIDS (Chitwarakorn, 2003; Ford et al., 2009; Phongpaichit & Baker, 1998). A good Buddhist would not indulge in these culturally and socially unacceptable, deviant behaviors.

The caregivers' inability to share about this period in their lives was revealing about how Thais approach life. With an understanding of *krengjai*, *naa*, and *jai yen*, conflicts are to be avoided at any cost. The momentary injury to a Thai's self-esteem, dignity, or standing in the community is well worth the cost to sidestep controversy. From the time of a Thai's birth, the family's welfare depends on the successful self-control of all members. Therefore, these caregivers consciously choose to avoid all distasteful or hurtful memories.

Instead, their stories were about the joys of their daily lives, full of caregiving for the children in their care. Throughout these stories, each of them expressed their hopes and dreams for a better future for their young charges. This allowed them the peace to know they have done right by Buddha's teachings of *rok khong khon mee kam* and their belief in the primacy of the family and *krengjai*. To a degree, the beliefs in being good and doing good ensured that Thailand's children orphaned from AIDS found a family and community to raise them in love and care.

In fact, two of the caregivers interviewed shared that the children they are raising are not related biologically. One explained they found their now grown son wandering the neighborhood after losing both his parents to AIDS. No other family members came forward to claim him, so this couple took him in as their own. After losing their informally adopted son and his wife, the father disappeared after she died from complications of AIDS, they are now raising the boy. Without hesitation, they call him, our grandson, who is being treated successfully for HIV himself.

The other case is similar in that the child was taken in by an elderly couple who then passed away. Their adult married daughter had been helping them for several years, so she took the boy home with her when her parents died, where she and her husband are now raising him. She refers to him as my nephew. The stories told by these couples of raising a non-relative child had the same tone and depth of feeling that was heard from the caregivers raising their biologically related family members.

The caregivers also spoke of strength and peace, which they found through following Buddha's teachings. This is consistent with the findings of Nilmanat and Street (2004, 2007) and Cadell (2007), where they interviewed Thai caregivers tending to their dying adult children. Like the caregivers of this research, they came to understand and accepted the suffering engendered by and entailed with the caregiving of one for whom they had assumed responsibility. Through their selfless acts of caregiving, not asking for or expecting any rewards or recognition in this life, they gained peace, which passed all understanding through an accepting understanding of the heart of Buddha's teachings (Bechtel & Apakupakul, 1999; Kusalasaya, 2005; Nilmanat & Street, 2007; Nyamathi et al., 2007; Yeshe, 1998). *Rok khong khon mee kam, krengjai, puñña, dukkha, and naa* were used rarely throughout the interviews. Instead, almost all the caregivers used the phrase, the Thai way, to explain how their cultural beliefs relating to family duty and their Buddhist beliefs overlapped, permitting them to raise the children in their care successfully and joyfully. The Thai caregivers interviewed followed Buddha's path of emotional and spiritual values that support them in their ability to move forward no matter what life dealt them. These findings are consistent with the conclusions of

Kittikorn et al. (2006), Nilmanat and Street (2007), and Sethabouppha and Kane (2005). These researchers found that their participants could move on with their lives after the loss of their adult child because of their cultural and religious beliefs.

To conclude, as in most moral and spiritual matters, Thais, under the distress and fear associated with living with AIDS in their families, sought help from their community's wat's leader, the abbot, and the monks (Chamrathirong et al., 2010; Nilmanat & Street, 2004; Phad et al., 2010). As delineated in this research, the caregivers also sought out help and support from their wat's abbot and monks in the early days of caregiving for their PLHA. As discussed earlier, the wat is the rural community's base for a host of events and programs. It is a safe haven, a sanctuary, for those who have no other place to go (Im-em & Suwannarat, 2002; Sangha Metta Project, 2011a, 2011b). The interviewed caregivers still seek out their abbot and monks for guidance on legal, social, and medical matters.

Bechtel and Apakupakul (1999) and Kittikorn et al. (2006) revealed that Thailand's monks found themselves in unfamiliar territory with as little understanding of the new illnesses of HIV and AIDS as their community members. Seeking to help their community, the monks sought knowledge from INGOs such as UNICEF, WHO, and UNAIDS. Combining their newly discovered information with Buddha's Four Noble Truths--suffering (*Dukkha*), the cause of suffering (*Samudaya*), the cessation of suffering (*Nirodha*) and the path leading to the cessation of suffering (*Magga*)--they started programs to educate their community (Maund, 2011). These programs also addressed the panic and fear felt by PLHA and their families.

Through the inculcation, understanding, and belief in the teaching of Buddha's doctrines and abiding by the cultural norms of Thailand, *hai* and *siasala* for family members was not only expected but was required. The caregivers interviewed exuded strength and calmness throughout their storytelling. Their purpose in life was to be good Buddhists and good Thais. To do so, they lived into their beliefs with acknowledgement and acceptance that letting go and moving on from life's setbacks and through life's difficulties ensured reincarnation into a better life. As the data of Nyamathi et al. (2007) revealed, and this study's caregivers confirmed in their storytelling, caring for their deceased adult child's children created good *rok khong khon mee kam* for themselves.

The caregivers spoke in respectful tones when discussing their Buddhist and Thai beliefs. These religious and cultural anchors hold them securely to everything they hold dear in their hearts and provide the solid foundation upon which they have built their lives. This base of values supports them to be loving caregivers through thick and thin while raising children in uncertain economic conditions. These are often from unstable political situations, and the constant presses of ever-changing times, as progress proceeds, making the known and knowable ways of their traditional ways of living seem obsolete or archaic. Perplexing and confounding new communication technology has affected their lives, especially as the children in their care learn about and use this technology as they live in a modern world beyond the knowledge of their grandparents and other elderly caregivers.

The insights gained from this study's caregivers do not support Lee et al's (2010), Chan and Reidpath's (2007), and Kittikorn et al.'s (2006) prior research conclusions.

They concluded that Thailand's elderly caregivers were under enormous financial and emotional burdens, as well as having to bear the social stigma inflicted by ignorant, fearful, or simply insensitive members of their community. Furthermore, their conclusions conflicted with the data collected by Knodel et al. (2009). The authors emphasized that the negative attitudes and behaviors, once prevalent within most rural Thai communities, have almost vanished. They suggested this change was due to Thailand's free antiretroviral treatment plus the HIV and AIDS educational programs offered by the wats, health departments, NGOs, and FBOS. This assertion was supported by the information collected from the Thai elderly rural caregivers of this study.

Research question 3 (See Table 3)

outside the family.

The caregivers in the research of Knodel et al. (2009), Desmond (2008), Erb (2011), and Heymann and Kidman (2009), like those of this study, sought out help when it was needed from their extended family members, religious leaders, close friends, FBOs, or NGOs such as GCPP. With unusual shows of emotion, each of the caregivers shared how they came to meet the volunteers from GCPP. In the early years, GCPP worked closely with the Thai Red Cross. In turn, the Thai Red Cross worked closely with the elders of the rural villages as well as the wats' abbots. After the development and establishment of a sound basis of trust among the groups' leaders, the GCPP volunteers shared information about families that might be in need. While the Thai Red Cross, WHO, UNAIDS, and UNICEF created and led programs to educate the rural Thais about HIV and AIDS, GCPP volunteers took the list and began to make house calls. As Thai

culture and the practice of Buddhism demanded, all the caregivers welcomed these volunteers in their homes. Not sure what to expect, they politely seated their guests and offered water and snacks. Initially, the volunteers simply listened while the elderly caregivers shared whatever was on their minds. As a relationship developed between them, the caregivers opened up and shared the truth of their situation.

This is the extent of the interviewed caregivers' sharing of those days; almost 11 years have gone by. It is clear from the stories told by the caregivers that each of them enjoyed the visits of the GCPP volunteers. According to GCPP archives, the caregivers who opened their homes and were willing to accept help from people or organizations outside of their own families or communities, requested and received financial, psychosocial, life skills training, and physical support. With the passing of time that has seen many HIV medical breakthroughs, HIV clinics and educational programs developed, and changes made by Thailand's government, all the interviewed caregivers' current concerns revolved around finances. No one was fearful or shameful when they shared their concern about finances in relationship to their current and future educational costs of the children in their care. Although it is true that under the Thai Constitution all children are guaranteed fifteen years of free public education, there are many other costs associated with attending school and college (FO, 2010; Schlenker, 2011; Vejjajiva, 2011). These financial concerns of the caregivers about educational fees, PE uniforms, meals, fieldtrips, and weekend activities were also pointed out in the research of HAI and Alliance (2003), KFF (2010b), and Knodel and Saengtienchai (2005).

Results from this study failed to support the findings of Ageway (2008), HAI (2008c), Kittikorn et al. (2006), Knodel, (2008), and Knodel and Chayovan (2008a, 2008b). The authors wrote that families affected by AIDS were living in fear and isolation from their community, which prevented them from seeking help. They went on to further state that due to the caregivers' advanced age and possible health issues related to their ages, they could fall ill and not be able to carry out their caregiving roles. The caregivers in this study were frank about their health issues. They also shared how they adjusted their life choices to accommodate for them. These choices were known to the children in their care and as Thai children, due respect and appropriate consideration was given to their parents and the elderly of their families and in their communities. It was a given that they will help with the household chores as well as any outside activities. The caregivers were also frank about their attachment with their wat and monks. They spoke of seeking out their religious leaders for guidance on many topics.

In their qualitative studies, Kittikorn et al. (2006), Nilmanat and Street (2007), and Nyamathi et al. (2007) found that the belief of *naa* forced the caregivers to remain silent in their suffering. Those findings are not consistent with the findings of this study. In fact, the rural Thai caregivers interviewed were quite vocal about the rising costs of transportation, food, clothing, and higher education. As mentioned previously, they quickly opened up and shared with me about the early days of receiving help from the Thai Red Cross and GCPP. I heard no shame in their sharing of these times.

Similar to prior investigations into the financial and other social safety nets for caregivers affected by AIDS is the research of HAI (2008a), Jitsuchon and Richter

(2007), Suwanrada (2009), and UNDP (2009a). They concluded that the majority of Thailand's rural elderly were receiving minimal help from the government. Help came in the form of the old age allowance, which still left the elderly struggling to meet their family's basic living expenses. These feelings were also voiced by the caregivers of this study. They shared that Thailand's pension plan had been revised from 200 baht (\$6.68) per month per elderly person to 600 to 825 baht (\$20 to \$27) depending on the age and health of each elderly person. They also pointed out that a new source of financial help came from Thailand's Department of Health, which provided them and their family members with a Gold Card. After paying the 30-baht (\$1) per visit, this card covered all of their medical needs and costs. Another bonus of this program was the educational classes on various medical issues that are free for them. Even with these increased and new government programs, however, all the caregivers shared that they still needed to work to afford the current, ever-increasing educational and household expenses, as well as saving for the future costs of college for the children in their care.

RIHES and the Thai Red Cross provide free antiretroviral treatment clinics and hospitals throughout the Chiang Mai province (Knodel et al., 2009; RIHES, 2011; USAID, 2010; WHO, 2010). Each of the caregivers who have children or other family members needing this intervention shared that this drug treatment has changed their lives. The stories of PLHA rang with joy that the skin rashes, headaches, coughing, and lack of energy no longer prevented them from attending school or work. Their sharing was consistent with prior research by Knodel et al. (2009), UNGASS (2010), UNAIDS (2010a), and WHO (2010). The authors confirmed that the drug treatment to treat HIV

was changing the lives of PLHA as well as their family members and bringing them back into their communities.

In this study, when asked what else could be done for them, the caregivers gave shy smiles and answered “*mai pen rai*.” So common is this saying that they did not even stop to think about the question. This Thai cultural reply, quickly delivered in a calm yet assertive tone, paralleled the research of Knodel et al. (2009). They emphasized that the rural elderly caregivers’ attitude of *mai pen rai* allowed them to provide unselfish and stoic acts of caregiving. To the various NGOs and FBOs, not understanding this attitude, it might appear that they do not need or require assistance. Meanwhile, knowing what *mai pen rai* means, the Thai government and health department are providing some HIV and AIDS prevention and educational programs (UNFPA & HAI, 2011). In contrast, HAI’s (2008a) and UNFPA and HAI’s (2011) researchers argued that Thailand’s social programs for its rural elderly caregivers were disappearing, while their family responsibilities were increasing now that HIV is considered a chronic illness.

In the final analysis, the caregivers shared stories of unconditional giving and sacrificing so that the children in their care will have a better future. Only when they had exhausted all other methods of helping themselves did they ask for help from extended family, close friends, the monks, NGOs, FBOs, or GCPP. This attitude of *mai pen rai* was a common theme among these caregivers.

They also confirmed the findings of Knodel et al. (2009) as they shared that their local government and many other NGOs have produced and continued to provide HIV and AIDS educational programs within their villages. They expressed their gratefulness

for these projects, which have given them a better understanding of this chronic illness. The increase of programs by these organizations throughout Thailand, especially in the rural provinces, was the subject of research compiled by KFF (2010b), Knodel et al. (2009), UNGASS (2010), and Warachit (2011).

Simultaneously, the introduction of antiretroviral treatment in 2000 began the successful treatment of Thais living with HIV (AVERT, 2011b). As the interviewed caregivers whom have children orphaned by AIDS and PLHA shared, having this free drug intervention has brought health back to them. The caregivers shared their appreciation for Thailand's medical Gold Card, which has allowed them to quit worrying about covering medical costs.

They also shared their continued concerns over the rising costs of transportation to get to and from the hospitals. These concerns were reported in several studies (KFF, 2010b; Knodel et al., 2009; UNGASS, 2010; Warachit, 2011) where the researchers found Thailand's National Plan wanting of specific financial safety nets. Yet the financial hardships for the caregivers were clear from prior research (HAI, 2007a; Knodel & Chayovan, 2009a, 2009b, 2011; Lee et al., 2010), as they are from this research.

From the caregivers' sharing, it is clear that no matter what suffering life has given them; their cultural and religious beliefs have helped them through life's trials and tribulations. I heard strength in their voices and saw conviction in their bearing when they spoke about the unity of their two belief systems. Standing alone or working together, their unwavering beliefs gave them a sense of calmness and feelings of peace. This allowed them to provide love, protection, guidance, and comfort to the children in their

care, which in turn allowed the children the freedom to live life happily, knowing everything will be okay and if not, then *rok khong khon mee kam* explained it all.

Thailand's Beliefs and Erikson's Psychosocial Development Stages

I used Moustakas's (1994) psychological phenomenology process for this study. I listened to stories about the caretakers' daily lives as they tended to the needs of their deceased adult child's child. Two of the caregivers felt comfortable enough to share that the child they are raising is not their biological relative. The lengths to which these caregivers have gone to provide the daily needs and wants of the children in their care, as well as ensuring their future, was remarkable. With each additional interview, I fitted another piece of the puzzle for a deeper understanding about these caregivers' life experiences. My comprehension was framed within the precepts propounded in Erikson's theory (1950) of the eight ages of man.

This theory is based on the presumption that social experiences shape a person. From birth to death, humans change for good or ill in relation to their social activities and the knowledge gained from their experiences. These changes are based on stages of a person's psychosocial development. Each embodies a conflict that has the potential of allowing the person to cultivate strength and courage or succumb to weakness and fear. These personal developmental stages can also be explained through the Thais' belief of *dukkha*. The concept that all life is suffering is based on each person's own experiences, attitudes, and awareness. From these, each Thai must take personal responsibility for their actions and reactions to life's twists and turns. According to Erikson (1950), these also come with maturity, which generally is associated with growing older.

All the caregivers in this study assumed their roles as providers for their grandchildren, nephew, or nieces when they were in Erikson's stage of middle adulthood, which starts around the age of 40 and ends around 65 (Erikson, 1950). During this phase, a person is working to provide for a family. For these caregivers this meant taking care of their PLHA as well as that adult child's child. Two of the elderly caregivers shared a little about the past and the tough times because of their lack of understanding about HIV and AIDS. Listening closely, I heard degrees of frustration and disappointment as they shared. At almost the same time, they realized how they were sounding and with a quick smile, which allowed them to avoid conflict while maintaining *jai yen*; they changed their tone and storytelling. Their belief of *dukkha* allowed this quick turnaround to view the past with a positive outlook. Letting go of life's suffering in the form of the negative thoughts, feelings, and behaviors connected the Thai caregivers to Erikson's lifetime stages of moral, social, and spiritual development.

These caregivers are now in Erikson's maturity stage (65 to death), which has them reflecting on life and how good they feel about the life they have led or are living. This last stage is built on the other seven stages, assuming they have been competently dealt with. For example, the lesson of *krengjai* taught by Thai parents to their children established a bond of trust, behavioral guidelines, and self-control. These actions parallel Erikson's first three stages. They create attachment, love, and trust between the mother and child. Cooper and Cooper (1996) wrote, "The family makes a Thai" (p.82). Each of the caregivers has demonstrated this by meeting their children's basic needs of food,

shelter, and clothing. They are also providing structure and boundaries that protect and guide them to make positive life choices.

These combined beliefs helped guide the elderly caregivers through their daily lives to achieve a level of comfort for themselves and their family members. The Thai way was the term used by many of the caregivers to explain family relationships, structure, and their commitment to those who depend on them. Just as they were raised by their parents, they are raising the grandchildren, nephew, and nieces to understand the Thai hierarchical structure of respect and status within the family. Under this belief system, the caregivers are responsible for their charges' behaviors and guiding them to be good Buddhists and good citizens.

Erikson's theory explains life choices as life lessons, where self-control, resourcefulness, and usefulness are achieved. For a Thai, these lessons interconnect with *krengjai*, where respect and consideration begins at birth. This process helps develop the child's ego, which Erikson considered important for the child to successfully leave the comfort and safety of the family and attend school and to survive and thrive in other social environments. Hoare (2005) and Nevid (2007) supported Erikson's theory, stating that as children meet and rise above life's demands their ability to learn life lessons, emotionally and cognitively, expanded.

These life demands, referred to as life conflicts in Erikson's theory, can also be explained through the Thai-Buddhist belief of *dukkha*. Both philosophies agree that conflict is good for a person. It allows for choices between good and bad that can lead to positive or negative experiences. Yeshe (1998) stated "Each action has a reaction; this is

the concept of *rok khong khon mee kam and dukkha*” (pp. 5, 35, 36). Many of the children being cared for by their elderly caregivers were experiencing these demands and conflicts for the first time in their lives, as they were at the age of Erikson’s adolescence stage. These young people were stepping outside of their families and exploring new environments and relationships. Each of the caregivers interviewed shared that the children in their care have the integrity and morals to make wise choices when faced with life’s joys or disappointments.

The growth achieved from life’s positive and negative experiences benefited the caregivers when their adult child fell ill. It also helped them to let go of their feelings of anger and disappointment so that their journey as caregivers has been a positive one. They all shared that the guidance of Buddha’s teachings and meditation has given them the strength to walk through the fire and cope with the loss of their adult child due to complications of AIDS. Taking on the role of caregivers found them seeking the strength afforded by *krengjai*, self-control, and trust to struggle successfully through the crisis of HIV (Kittikorn et al., 2006; Phengjard et al., 2002). This period of loss and grief for the caregivers was what Erikson (1950) defined as the opportunity to grow psychologically. This growth paralleled their seeking understanding and peace for themselves and the children in their care through the “Buddhist belief of karma to create meaning and purpose” (Nilmanat & Street, 2007, p. 94).

The Thai way, as explained to me by many of the interviewed caregivers, was the Thai predisposition to concentrate on the family to help their children’s psychosocial development. This was especially true with the arrival of HIV as Bhana et al. (2010),

DeGennaro and Zeitz (2009), Richter (2010), and Richter et al. (2010) pointed out. This illness was a “family-based disease” (Bhana et. al., 2010, p. 1) and should be treated as such (JLICA, 2009; KFF, 2010b; Richter et al., 2009). Caregivers confirmed in this research that they first tried to manage on their own and then, as their caregiving duties took their toll, they sought help from their extended family members. Once this support was exhausted, they then sought outside resources, such as from their wat’s abbot and monks. This reaching out for help reflected the growth that is required in Erikson’s stage of young adulthood. Developing relationships outside of the family prevents loneliness and isolation, which could have led the caregivers to depression, guilt, and shame. Instead, their ego development supported them in asking for help.

The first case of HIV was acknowledged in Thailand in 1982, and though much has been done in the past 3 decades, the participants of this study found themselves still struggling with the financial side of caregiving (Liamputtong et al., 2009; Warachit, 2011). The caregivers in this study shared how conducting their daily chores while raising the children in their care gave them not only a sense of tranquility and acceptance in the face of life’s inexplicable and unforeseeable vagaries but also an understanding of life’s purpose. Leeper et al (2010) and Lee et al (2010) refuted this with their claims that Thailand’s caregivers had limited resources to help them with their responsibilities. I did not find any of the caregivers conflicted by sacrificing financially, physically, emotionally, and socially for the children in their care. On the contrary, their cultural and Buddhist belief of *krengjai*, *jai yen*, *dukkha*, and *rok khong khon mee kam* gave them the

self-esteem, self-control, and strong egos, which has allowed them to provide care with integrity and pride.

Limitations of the Study

Two major limitations of this study were that the data collected came only from the GCPP that is located in Chiang Mai, leaving out the other 76 provinces of Thailand. Depending on the size and wealth of each province, the caregivers found for this study may have different economic and social issues. Because Thailand shares its borders with Laos, Burma, Cambodia, and Malaysia, the caregivers in the bordering provinces may also have a different viewpoint due to the influx and influence of persons crossing the borders. A potential limitation had been the small sample population size of only eight caregivers, which did not materialize. In fact, I reached saturation at the 10th interview but chose to continue for the possibility to acquire new information. The literature review supported another limitation that also did not develop. All the caregivers consented to be interviewed, unlike Liamputtong et al.'s (2009) AIDS study, where many did not participate due to potential discrimination.

Recommendations

The validity of using phenomenological research methodology for this study was supported by the literature review. In the early years of Thailand's HIV epidemic, research was compiled by HAI (2005, 2007a), Kittikorn et al. (2006), Knodel et al. (2001), Knodel and Im-em (2004), Knodel and Saengtienchai (2002; 2005), Nilmanat and Street (2004; 2007), Phengjard et al. (2002), Songwathana and Manderson (2001), and Wacharasin and Homchampa (2008). These qualitative studies focused primarily on the

caregivers' narrative reports on caring for a PLHA, as well as their concerns related to this illness. The phenomenon of caregiving for the grandchildren and other children affected by AIDS was supplementary information. This continued to be true in later research conducted by Kuo and Operario (2009) and Lee et al. (2010).

The only article in the literature review that solely dealt with children orphaned by AIDS was Safman (2004). He conducted interviews through the health clinics located in the Chiang Mai province to determine if these children and their immediate caregivers needed any resources. He found that the caregivers had many concerns but the one that was consistently discussed was the finances needed to raise a child. This concern was also voiced by this study's caregivers raising a child orphaned by AIDS. Further studies that included a larger population sample of rural elderly caregivers that placed the limitation of only interviewing those that are the sole caregivers for their orphaned grandchildren, nephews, or nieces would help fill in the gap of what resources are needed to help them.

Moreover, a deeper understanding of Thailand's cultural beliefs relating to family duty and their Buddhist religious beliefs could be achieved by interviewing the elderly caregivers' abbots and monks. As was found in the literature review and supported in this study's findings, 94-95% of Thais follow Buddha's teachings (Kittikorn et al., 2006, Nilmanat & Street, 2007; Sethabouppha & Kane, 2005). This direction would add another dimension to the caregivers' stories, as well as ascertain what the wat is providing to them. This information could then be shared with the government, health department, and NGOs for possible community programs and interventions.

Implications

Positive Social Change

This study gave the GCPP rural elderly caregivers a platform from which to share their stories. For some, this was the first time they expressed their thoughts and feelings about their role as the primary provider for children taken in who needed to be cared for. This admission caused several of the caregivers to realize that talking gave them a positive feeling. Social change has already begun on an individual and organizational level, as GCPP caregivers have requested and now use the Center for monthly meetings to collaborate by sharing ideas and stories. Their empowerment has increased their social connections and given them a safe place to discuss topics with others who are in similar situations. I have encouraged the caregivers to take their conversations back for further dialogue with their village elders and wat abbot and monks. Including these leaders will enroll and engage the community to work together to address the issues facing all elderly persons caregiving for their relatives.

I have shared the findings of this study with the caregivers with the hope that they will be encouraged to push for increased pensions and programs that will help them with their material needs. All the elderly caregivers continued to work in the informal sectors, meaning Thailand's rising cost for food, gas, and transportation might force them to cut corners. These choices could cause them to fall ill or have other possible negative consequences. By not sharing this information with their local representatives, those in positions to create these changes cannot understand or even know they are in need of help.

The challenges of the elderly caregivers have been addressed by Thailand's government and health department with increased financial and educational programs for them. The caregivers, as confirmed in this study, agreed that these organizations are helping but more can be done. Financial concerns, especially in relationship to higher education, will need to be further explored with the elderly caregivers. I will request meetings with Chiang Mai's Minister of Education and leaders of various NGOs and FBOs to share this study's information. The implications for positive social change are that the leaders devote time and money in creating interventions that will improve the lives of Thailand's caregivers.

Recommendations for Practice

The findings of this study will also be shared with other stakeholders within the various NGOs and FBOs. The expectation is that the research will inspire the stakeholders to review and if need be, adjust their programs to meet the needs of the rural elderly caregivers. Another prospect is for the NGOs and FBOs to collaborate more in meeting the caregivers' needs. A meeting will be requested with Chiang Mai's governor, Mr. Tanin Subhasaen, where the study's findings will be shared to inform him of the needs of his elderly citizens. Policy recommendations that will improve the lives of the caregivers and their families will be the topic of discussion. I will publish the findings of the study in a peer-reviewed journal. Further presentations to appropriate stakeholders will be arranged as they present themselves.

Conclusion

“Who cares for the carers?” asked Berman (2002 as cited in Ogden et al., 2004). For the elderly caregivers interviewed for this study, their own care has long been forgotten. The Buddha taught, “Consider others as yourself” (Dhammapada 10.1, as cited in Borg & Riegert, 1999, p. 15), which is what these remarkable elderly caregivers are doing by caring for their juvenile charges having lost their parents to AIDS. Their needs and wants are only of concern after ensuring they have fulfilled their cultural and Buddhist beliefs regarding to family responsibilities. These duties are clearly stated in Buddha’s teachings when he put forth the following: “If you do not tend one another, then who is there to tend you? (Vinaya, Mahavagga 8.26.3, as cited in Borg & Riegert, 1999, p. 21). These beliefs gave the caregivers the strength and wisdom to meditate on Buddha’s moral teachings to find comfort, peace, and compassion as they cared for their adult children dying from AIDS. These attributes continue to aid the elderly caregivers as they maintain a home for their grandchildren, nephew, or nieces. They have also learned how to seek outside help from other family members, the Thai government, NGOs, and FBOs. While life has not been easy for these caregivers, they continue to live by Buddha’s teaching: “May fear and dread not conquer me” (Majjhima Nikaya 6.8, as cited in Borg & Riegert, 1999, p. 83). Through the evolution of HIV treatment and the lessons that came along with this illness, the elderly caregivers have adjusted their way of life, physically, financially, socially, and emotionally, to ensure the successful future of their wards.

In the discussion with the elderly caregivers' about the adjustments they have made over the years, the familiar words of “*mai pen rai*” were heard as many gave a short laugh, while others gave a quick, subtle smile. These behaviors supported their unquestioning responsibilities of providing a family for these children without a thought for themselves. The acceptance of their roles is linked to their Buddhist beliefs. His principles, *dukkha*, *rok khong khon mee kam, bun*, and *baab* are coupled with Thailand's cultural beliefs of *krengjai*, *naa*, *hai*, and *siasala* (Kamnuansilpa & Wongthanasu, 2005; Nyamathi et al., 2007; Sethabouppha & Kane, 2005; Sorajjakool, 2006). They are the bricks that compose the foundation for these caregivers to continue to thrive and live life fully. These cultural and religious beliefs gave the elderly caregivers the self-discipline, calmness, and unconditional love to provide for their grandchild, nephew, or nieces orphaned by AIDS.

Yesterday is but a dream, tomorrow but a vision. But today well lived makes every yesterday a dream of happiness, and every tomorrow a vision of hope. Look well, therefore, to this day (Sanskrit Proverb).

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Appendix A: Interview Questions for GC's Caregivers

Specific Aims: To explore and describe the lifestyles of the rural elderly caregivers who care for their grandchildren, nephew, and/or nieces affected by AIDS.

Date: _____ Participant's Pseudonym: _____ Sex: ___F ___M

Introductions and opening of interview: Tell us a little about yourself and your family, such as marital status, number of grandchildren, and who else lives in the home.

Questions:

1. How is it that you became your grandchild's caregiver?
2. What part did your belief in family support this decision?
3. How do you see your Buddhist belief supporting or interfering with your caregiving?
4. What changed when you became the caregiver? Tell me about your daily activities?
5. Please describe your feelings and thoughts about these changes in your life.
6. What physical changes have you undergone as the caregiver?
7. How has this affected your financial status?
8. What about social commitments with family and friends?
9. What about the rest of your community? How do they treat you? Your grandchild? The rest of the family?
10. What community programs have helped you and your family?
11. What else would you suggest to help you successfully raise your grandchild?
12. These are all the questions I have, is there anything you would like to ask or add before we end this interview?

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Appendix C: Back Translation of Interview Questions for Caregivers of GC

Specific aims: to explore and explain the way of rural elderly caregivers who care for their grandson affected by AIDS.

Date: _____ Alias of _____ Sex: F ____: M ____

Introduction and interview: tell us a little about yourself and your family as the marital status, who lives in the house .

Questions:

1. How do you feel that you are a caregiver for your grandchild and how long?
2. How did your faith in supporting the family decides?
3. How has Buddhist support or interfere with your caregiving?
4. Things change when you start as caregiver, tell me about you your daily activities?
5. Please describe your feelings and ideas about these changes in your life.
6. What physical changes?
7. Affected the financial status?
8. Social commitments with family and friends?
9. The rest of your community? Treat you and your family how?
10. How has the community to help you and your family with health problems?
11. What else would you suggest to help make you successful raised your grandson?
12. These are all questions that I have, anything you want to ask or add before we end the interview?

Appendix D: Letter of Cooperation from a Community Research Partner

Grandma Cares Partnership Program
412/1 Chiang Mai Lampang Rd
Nongprakrang Chiang Mai 50000 Thailand

February 26, 2012

Dear Sarah-Kate,

Based on my review of your research proposal, I give permission for you to conduct the study entitled, *The Impact of HIV and AIDS on the Rural Elderly Caregivers in Chiang Mai, Thailand*, within the Grandma Cares Partnership Program (GCPP). As part of this study, I authorize you to meet with interested caregivers, arrange times and meeting places for interviews, follow up meetings for members checking, and to facilitate a workshop where you share your findings and conclusions. Individuals' participation will be voluntary and at their own discretion.

We understand that our organization's responsibilities include: allowing the use of GCPP Center for interviews and a workshop to explain the results of study. I or our office manager, Temduan, will translate during the interviews and if needed she will transcribe the audio interviews. We reserve the right to withdraw from the study at any time if our circumstances change.

As GCPP Director, I confirm that I am authorized to approve research in this setting.

We understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the research team without permission from the Walden University IRB.

Sincerely,



Hope Watchameitick

Appendix E: Consent Form

You are invited to take part in a research study to explore the social, religious, and familial consequences and obligations associated with caring for the grandchildren orphaned by AIDS in Thailand. The researcher is inviting caregivers who are part of the Grandma Cares Partnership Program (GCPP) and are the main caregivers for their grandchildren to be in the study. This form is part of a process called “informed consent” to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named Sarah-Kate Hawkins, who is a doctoral student at Walden University. You may already know the researcher as a volunteer at GCPP, but this study is separate from that role.

Background Information:

The purpose of this study is to explore the social, religious, and familial consequences and obligations associated with caring for the grandchildren orphaned by AIDS in Thailand.

Procedures:

If you agree to be in this study, you will be asked to:

- Meet with the researcher two times, to be audiotaped.
- The first meeting will take about 60 minutes to answer the interview questions.
- The second meeting will take less than 30 minutes to clarify your recorded and written words.

Here are some sample questions:

- What part did your belief in family support this decision?
- What changed when you became the caregiver? Tell me about your daily activities?
- Please describe your feelings and thoughts about these changes in your life.
- What physical changes have you undergone as the caregiver?

Voluntary Nature of the Study:

This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. No one at GCPP will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind during or after the study. You may stop at any time.

Risks and Benefits of Being in the Study:

Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as becoming upset. The study's potential benefits could motivate Thailand's government to invest in creating policies that will improve the lives of the caregivers and their families.

Payment:

The participants will receive a certificate of appreciation.

Privacy:

Any information you provide will be kept confidential. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. Data will be kept secure by locking all paperwork and the computer, which is password protected, in the researcher's office file cabinet. Data will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions:

You may ask any questions you have now. Or if you have questions later, you may contact the researcher via 08-08-588-119. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is 1-800-925-3368, extension 1210. Walden University's approval number for this study is # is 06-21-12-0065746 and it expires on June 20, 2013. The researcher will give you a copy of this form to keep.

Additional note:

If you want to speak to someone about your feelings and ideas that came from this study, you can contact:

Dr. X XXX

The Thai Red Cross Society
369-371 Witchayanon Road,
T. Chang Moi, A. Muang-Chiang Mai
Telephone: 053-235161

HelpAge International
Nimmanhemin road 6 SOI 17,
Suthep Muang Chiang Mai
Telephone: 53-225440
Email: hai@helpageasia.org

Sriphat Medical Center
110/392, Inthavaroros Road,
Tambon Mueang Chiang Mai
Telephone: 53 Sriphum 946900/1

The information shared with these sources will be kept confidential and will not be part of this study.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below, I understand that I am agreeing to the terms described above.

Printed Name of Participant

Date of consent

Participant's Signature

Researcher's Signature

Appendix F: Confidentiality Agreement

Name of Signer: Temduan Cha-Em

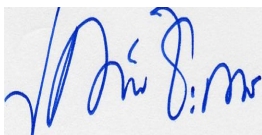
During the course of my activity in collecting data for this research: “The Impact of HIV and AIDS on the Rural Elderly Caregivers in Chiang Mai, Thailand” I will have access to information, which is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

By signing this Confidentiality Agreement I acknowledge and agree that:

1. I will not disclose or discuss any confidential information with others, including friends or family.
2. I will not in any way divulge, copy, release, sell, loan, alter or destroy any confidential information except as properly authorized.
3. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant’s name is not used.
4. I will not make any unauthorized transmissions, inquiries, modification or purging of confidential information.
5. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
6. I understand that violation of this agreement will have legal implications.
7. I will only access or use systems or devices I’m officially authorized to access and I will not demonstrate the operation or function of systems or devices to unauthorized individuals.

Signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature:



Date:



Appendix G: Confidentiality Agreement

Name of Signer: Dylan Jan Hartmann

During the course of my activity in collecting data for this research: “The Impact of HIV and AIDS on the Rural Elderly Caregivers in Chiang Mai, Thailand” I will have access to information, which is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

By signing this Confidentiality Agreement I acknowledge and agree that:

8. I will not disclose or discuss any confidential information with others, including friends or family.
9. I will not in any way divulge, copy, release, sell, loan, alter or destroy any confidential information except as properly authorized.
10. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant’s name is not used.
11. I will not make any unauthorized transmissions, inquiries, modification or purging of confidential information.
12. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
13. I understand that violation of this agreement will have legal implications.
14. I will only access or use systems or devices I’m officially authorized to access and I will not demonstrate the operation or function of systems or devices to unauthorized individuals.

Signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature:

Dylan Jan Hartmann, BA



Date: March 9, 2012

Curriculum Vitae

Sarah-Kate Hawkins

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Licenses:

Marriage and Family Therapist License (MFT), Commonwealth of Virginia, 1998
Professional Counselor License (LPC), Commonwealth of Virginia, 1997

Education:

PhD Candidate in Public Policy and Administration, International Non-Government Organization (NGO) Specialization, anticipated completion May 2013
Master of Education (Med), Agency Counseling, Lynchburg College, 1991
Bachelor of Arts (BA), History and Communications, Randolph Macon Woman's College, 1985

Experience:

- **Program Coordinator**
Grandma Cares Partnership Program, Chiang Mai, Thailand, 2009 to Present
- **Volunteer**
The Gate Theater Group, Chiang Mai, Thailand, 2011 to Present
The Rotary Club of Chiang Mai ThinThaiNgam, Chiang Mai, Thailand, 2009 to Present
- **Consulting Counselor** for Grades 7 – 12
CMIS, Chiang Mai, Thailand, 2009
- **High School Coordinator/Counselor** for Grades 7 – 12
CMIS, Chiang Mai, Thailand, 2008 - 2009
- **Principal** for Grades 6 – 12
Narmer American College, New Cairo, Egypt, 2007 – 2008
- **Counselor** for Grades 3 – 12
Kodaikanal International Boarding School, India, 2005 – 2006
- **Crisis Counselor** for Battered Women and their Children
Outer Banks Hotline, North Carolina, 2005

- **Special Education Teacher** for Autistic children
Ideal Education School, Kuwait, 2002 – 2005

- **Peace Corps Volunteer** for AIDS Awareness, Prevention, and Education
Bhairahawa, Nepal, 2000 – 2002

- **Clinical Coordinator/Therapist**
Kindred Homes of Central Virginia Community Services, now known as Horizon Behavioral Health, Lynchburg, Virginia, 1992 - 2000