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Losing Rice, Saving Corn: Grandparents Raising Grandchildren in the Wake of the AIDS

Epidemic in Vietnam

A dissertation submitted in partial satisfaction of the

requirements for the degree Doctor of Philosophy

in Social Welfare

by

Lesley Beth Maradik

2014

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ABSTRACT OF THE DISSERTATION

Losing Rice, Saving Corn: Grandparents Raising Grandchildren in the Wake of the AIDS
Epidemic in Vietnam

by

Lesley Beth Maradik

Doctor of Philosophy in Social Welfare

University of California, Los Angeles, 2014

Professor Albert E. Benjamin, Chair

Grandparent, or “skipped generation” caregivers are often overlooked and ignored in the global response to the HIV/AIDS epidemic. Grandparent caregivers are not only a vulnerable population due to age, frailty, and the decreased ability to generate income, but they are vital to the survival of younger generations. Caregivers are not only the providers of food, education and safety for grandchildren, but they are also the gatekeepers to testing and treatment for HIV + orphans. Previous studies on grandparent caregivers have shown that the stresses, challenges and trials facing this population cut across race, country, culture and ethnicity.

This dissertation explores and describes the lives of skipped-generation caregivers who foster their grandchildren orphaned by HIV/AIDS in Northern Vietnam. I investigated the challenges facing this population and the ways in which grandparents handled their trials on behalf of their families. Specifically, 1) what is the meaning of skipped generation caregiving in families affected by HIV/AIDS in Vietnam? 2) What is the context in which meaning is formed? 3) How do understandings of meaning and context relate to motivations for caregiving and coping?

An ethnographic approach was used to conduct in-depth, qualitative interviews with 21 older caregivers and seven key informants. I completed unstructured participant observations with five caregivers from the sample. Techniques commonly associated with Grounded Theory were used to analyze the interview transcripts and field notes.

Participants were mostly female and ranged in age from 55 to 78. I found that grandparents typically underwent four phases of their “caregiving career:” 1) caregiving for their biological child, 2) caregiving for their adult child because of drug abuse and HIV-related illness, 3) simultaneous caregiving for their adult child dying of AIDS and their grandchild, and 4) caregiving solely for the grandchild after the death of the parents. In addition, a framework is presented that describes the overarching themes related to phase four. This framework includes the central contextual, social and physiological processes that emerged during the period of caregiving following their adult child’s death. This model represents the overlapping understandings of disease, caregiving and coping held by grandparents who were raising grandchildren due to HIV/AIDS, and it illuminates contextual factors such as perceptions of culture and community that influence their coping and caregiving strategies.

The voices of grandparent caregivers must be a vital component to influence and inform service organizations and HIV sectors working in Vietnam. Based on a deeper understanding of the caregiving process, I offer suggestions on how home-based caregivers can help to support grandparents who are raising grandchildren. I present recommendations for programs at the local and government levels in Vietnam to support skipped generation caregivers and their families. I conclude by making recommendations for future research about grandparents who are raising grandchildren.

The dissertation of Lesley Beth Maradik is approved.

Laura Abrams

Ailee Moon

Donald Morisky

Albert E. Benjamin, Chair

University of California, Los Angeles

2014

DEDICATION

This dissertation is dedicated to my grandma, Marion Elizabeth Maradik. The most joyful, exuberant, loving and soulfully dedicated woman that I know. This dissertation was defended on the week of her 90th birthday, with the aid of her pilgrimage to Holy Hill...candles lit, intensions set...it finally happened.

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ABBREVIATIONS

AIDS: Acquired Immune Deficiency Syndrome
ART: Antiretroviral Therapy
FSW: Female sex worker
HIV: Human Immunodeficiency Virus
HSPH: Harvard School of Public Health
ICRW: International Center for Research on Women
IDU: Injecting drug user
MOLISA: Ministry of Labour, Invalids and Social Affairs (Vietnam)
MSM: Men who have sex with men
NGO: Non-governmental Organization
OVC: Orphaned and vulnerable children
PLWHA: Persons living with HIV/AIDS
SI: Symbolic interactionism
UNAIDS: Joint United Nations Program on HIV/AIDS
UNDP: United Nations Development Program
UNGASS: United Nations General Assembly Special Session
UNICEF: United Nations Children's Fund
WHO: World Health Organization

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CHAPTER ONE: INTRODUCTION

Since the 1980s, the HIV/AIDS epidemic has claimed the lives of many parents of young children and adolescents (Burnette, 1997; HelpAge International 2008; Joslin, 2002; Orbach & HelpAge International, 2007). The epidemic has resulted in an increase in older adults parenting grandchildren as "skipped generation" caregivers; i.e., grandparents raising grandchildren in the absence of either biological parent. Due to HIV/AIDS, the number of skipped generation caregivers in Vietnam is on the rise.

Skipped generation families are emerging as a global issue, given the increasing number of orphans affected by HIV/AIDS (Nyasani, Sterberg & Smith, 2009). At the global level, 15 million children under the age of 17 have been orphaned by AIDS (UNAIDS & WHO, 2008), and 40-60% live with their grandparents (HelpAge International & International HIV/AIDS Alliance, 2003). For grandparents caring for grandchildren, many adverse effects can be associated with their new role. These include increased financial burdens, problems with mental and physical health, insufficient access to emotional and instrumental support, social isolation due to the stigma of HIV/AIDS and, often, parenting strains associated with caring for children with neurological, emotional, and behavioral problems (Hayslip & Shore, 2000; Linsk & Mason, 2004; Mall, 2005; Poindexter, 2002).

Asia ranks second behind Africa in terms of the highest number of children who have been orphaned by AIDS, which exceeds 1.1 million (UNICEF, 2013). The number of persons living with HIV/AIDS in Vietnam more than doubled between 2000 and 2007, from 122,000 to 293,000 (Ministry of Health Viet Nam, 2007). Nearly 80% of the infected individuals are between the ages of 20 and 39 (UNAIDS, 2012), the most productive age group in terms of work and parenting. In 2012, an estimated 12,000 people died from AIDS related illnesses (UNAIDS,

2012), leaving behind the older and younger generations to care for each other. This affects the entire family unit in Vietnam, where there are multi-generation households, and where adult children are expected to provide financial support and care to their parents in the older stages of life.

In the most recent sentinel surveillance, data is not available on the number of children who have been orphaned by AIDS (UNAIDS, 2012). However, in 2007, 168,000 children in Vietnam were orphaned (abandoned children without families), 68,874 children were reported to be orphaned by AIDS (UNAIDS 2007), and 15,000 orphans were living in institutions (UNICEF Vietnam & MOLISA, 2010). An additional estimated 16,000 children are living on the street (HSPH, 2009), but the number of orphans living with older relatives or family members remains unknown.

Study Purpose

The primary purpose of this study is to explore and describe how skipped generation caregivers make sense of their role, and to identify how these meanings inform their coping strategies.

This research has three main research questions:

- 1) What is the meaning of skipped generation caregiving in families affected by HIV/AIDS in Vietnam?
 - a. What are skipped generation caregivers understandings of disease, caregiving and coping?
- 2) What is the context in which meaning is formed?

- a. How do skipped generation caregivers perceive Vietnamese culture with respect to parenting orphans affected by HIV/AIDS?
 - b. How do skipped generation caregivers affected by HIV/AIDS perceive the surrounding community's response to their situation and needs?
- 3) How do understandings of meaning and context relate to motivations for caregiving and coping?

Significance of study

While the area of caregiving has been well studied and discussed in the literature, little is known about caregiving in the context of HIV/AIDS, and much less is known about the role of skipped generation caregivers in families affected by HIV/AIDS, the “neglected role” of those caring for parentless grandchildren or familial orphans. There is a large body of literature on older caregiving roles. Much of the literature has focused on routine care, for example, caring for a spouse in old age, and this type of caregiving is also associated with health problems, strain, financial hardship, and lack of support (Brown, 2007; Schulz & Beech, 1999; Taylor, Kuchibhatla & Ostbye, 2008). Skipped generation caregiving differs from routine care because it is often an unexpected role that reverses the stages of the life cycle.

Caregiving by older adults in the context of HIV/AIDS creates many challenges compared to parenting during middle adulthood, including reduced energy, financial struggles, grief over the loss of an adult child, social isolation, and intergenerational issues. However, this role also has potential benefits and strengths, such as close relationships to grandchildren, renewed sense of purpose, and enhanced family identity (Giarrusso, Silverstein & Feng, 2000). In addition, grandparents and older relatives have been shown to be invaluable assets and reliable sources of care to children who have lost their parents (Hayslip & Kaminski, 2005).

Understanding both positive and negative aspects of the caregiving role can lead to stronger

recommendations for more effective programs to support caregivers in their new and unexpected roles.

These insights also can be useful for identifying the coping mechanisms used by skipped generation caregivers. Linking meaning and context to coping may help improve interventions for assisting older adults in caregiving roles. In the context of policy and program development, the study findings can be used to provide insight and evidence related to the needs of this often hidden population. There is a need to understand the experience of caregiving in later life in the context of HIV/AIDS in Vietnam, because older caregivers appear to be a growing population. Globally, there is increased attention in the social service literature and research on the issue of grandparents as primary caregivers for their grandchildren. Very few programs exclusively attend to the unique challenges that face the population of older caregivers who have been affected by HIV/AIDS.

The challenge of HIV/AIDS-related caregiving varies greatly among countries. Each country has its own strong cultural influences that affect how caregiving occurs, and ultimately, how caregivers cope. The main source of research on skipped generation caregiving in the developing world is in Sub-Saharan Africa, due to the high rates of HIV/AIDS there (Ankrah, 1993; Foster & Williamson, 2000; Oburu, 2004; Nyasani, Sterberg & Smith, 2009; Wangui, 2009). Many other studies have addressed the role of kinship caregivers, primarily within the African American community (Burnette, 1997; Cox, 2002; Grant, 2000). Researchers who study older caregivers argue that much more work is needed to understand the complex aspects of custodial relationships. HIV scholars recommend further research with participants about whom we know little, such as grandparents in different cultures (Hayslip & Kaminski, 2005).

To date, little research has focused on the meaning and context of the caregiving role among older adults and the impact of HIV/AIDS on the lives of older caregivers (Bullock, 2004). Even less research has been action-oriented in the sense that it seeks to provide evidence to inform programs aimed at improving the lives of older caregivers based on their voices and needs. The Ministry of Health in Vietnam (2004) released a National Strategic Plan on HIV/AIDS Prevention for 2004-2010 which calls for interventions that are evidence-based and carried out by community level organizations across multiple sectors. Many older adults, particularly in Vietnamese culture, have expectations of filial piety, defined as the responsibility to love, care for and respect parents as they age within the structure of a multigenerational household (Le, 1998). By understanding this growing HIV/AIDS caregiving group in a culturally grounded way, this study can offer new insights and contribute to the literature about elderly caregiving. This understanding may expand and improve existing theory and practice.

Study Overview

In this study, I utilized ethnography to gather descriptive and interpretive information about skipped generation caregivers through the examination of their observable and learned patterns of behavior, customs and ways of life (Harris, 1968; Agar, 1980). The caregiver stress process model (Pearlin, Lieberman, Menaghan & Mullan, 1981; Pearlin, Mullan, Semple, Skaff, 1990), along with the literature on skipped generation caregiving in the context of HIV/AIDS, informed this research. The caregiver stress process model views caregiver stress as a result of a progression of several interrelated conditions, including the primary and secondary stressors to which they are exposed, socioeconomic characteristics and resources of caregivers (Pearlin et al, 1990). This theoretical framework is viewed as a sensitizing concept that served as a lens to consider the data.

Ethnography is informed by Symbolic Interactionism (SI), which emphasizes the importance of understanding a situation from the person's point of view. The ethnographic approach has shown to be an effective way to study cultures outside of the researcher's native culture (Galibert, 2004). The use of ethnographic methods is especially pertinent given that the questions posed sought to explore the phenomenon of skipped generation caregiving in terms of meaning and context. Explanations derived from qualitative data provided rich descriptions and an in-depth understanding of skipped generation caregiving in Vietnam.

The sample for this study included 21 skipped generation caregivers and seven key informants from the two locations of Hai Phong and Hanoi in northern Vietnam. These sites were selected because of the high and concentrated rates of HIV/AIDS (Nguyen, Nguyen & Trinh, 2004). I conducted two phases of data collection in July to September of 2010 and April to July of 2011. During this time, I did semi-structured, in-depth interviews and unstructured participant observations with caregivers and their families. The research instruments included interview guides and ethnographic field notes derived from unstructured participant observation (caregivers only). For skipped generation caregivers, questions in the interview guides covered these areas: caregiver demographics, family demographics, basic information on HIV/AIDS, access to services, physical concerns, cognitive impairment, family life, role, contextual factors, psychosocial support, stigma/discrimination, coping mechanisms, planning, caregiving decision making processes, challenges, strengths/resilience and program support interests. I utilized two phases of data collection to gain a sense of how concepts and situations endure over time. This strategy allowed for follow up interviews, and for interviews and observations with new participants after data had been analyzed from phase one of the study. I analyzed interview data responses and ethnographic field notes using grounded theory techniques. The purpose of the

analysis was to identify significant patterns and constructs and to create frameworks that offered description and understanding related to the caregivers' meaning, context and coping.

Implications

This study has sought to expand our understanding of skipped generation caregiving in Vietnamese families affected by HIV/AIDS. It has aimed to understand the lived experiences, meaning of the caregiving role, and the processes of caregiving among skipped generation caregivers. Implications of this study include a better understanding of how skipped generation caregivers who cope well manage to do so. This evidence has the potential to inform and help those grandparents who are not coping well. The study will also be used to develop recommendations for humanitarian, HIV, and AIDS sectors on how to identify and support skipped generation caregivers and households in Vietnam.

This study seeks to understand the lives of Vietnamese skipped generation caregivers in a culturally grounded way. This research is informed by theory on caregiver stress in a different cultural context, in hopes of better understanding skipped generation caregiving. By providing a deeper understanding of family and HIV-caregiver dynamics in Vietnam, this study may also lay the groundwork for designing and testing new interventions aimed at families in need. I hope that these findings can be used to inform programs and policy and that can improve the well-being of caregivers.

In the next chapter, I present a review of literature concerned with skipped generation caregiving in Vietnam by describing the evolution of the HIV/AIDS epidemic in Vietnam, exploring the various meanings of the caregiving role in older adulthood, examining psychosocial and financial struggles associated with the caregiving role, exploring coping

mechanisms, examining the context of HIV/AIDS in Vietnam, and describing the impact of stigma and discrimination. Chapter 3 introduces the theoretical perspectives. Chapter 4 provides a detailed description of the qualitative methods informed by ethnography and describes the methodological perspective of symbolic interactionism. Chapter 5 is the introduction of the results section and presents two overarching framework entitled, “Alternating Flow if Caregiving in Later Life” and “Caregiving for Grandchildren after Adult Child’s Death.” Chapters 6, 7 and 8 present the results related to research questions 1, 2 and 3 respectively. Chapter 9 discusses the results in relation to studies of other researchers and offers implications, limitations and conclusions.

CHAPTER 2: LITERATURE REVIEW

Introduction

In this chapter, I review the relevant literature that relates to my three main research questions: What is the meaning of skipped generation HIV/AIDS caregiving in Vietnam? What is the context in which meaning is formed? How do understandings of meaning and context relate to motivations for caregiving and coping? In order to understand the meaning, context and coping mechanisms of these skipped generation caregivers, I will first explain the evolution of HIV/AIDS in Vietnam, and describe the current situation. Next, I will provide an overview of what is known about skipped generation families, including their psychosocial and financial needs and the coping strategies of older caregivers. Finally I will describe the context and landscape of skipped generation caregivers affected by HIV/AIDS in Vietnam, with special attention to cultural and environmental factors, such as the stigma that is attached to HIV/AIDS in Vietnam.

HIV/AIDS in Vietnam

Southeast Asia is currently ranked first for HIV prevalence in all of Asia, where significant variation exists in epidemic trends among different countries. In 2007, the number of HIV cases in Vietnam peaked, whereas in countries such as Thailand, Myanmar and Cambodia, HIV prevalence had decreased several years prior to 2007 (UNAIDS & WHO, 2007). At that time, more than 100 Vietnamese people become infected with HIV each day (UNAIDS & WHO, 2007). At the present moment, rates of HIV/AIDS in Vietnam are decreasing, although a tremendous impact on the country has been made. In 2011, HIV cases had been reported in all 63

providences of Vietnam, with a cumulative total of 249,660 people living with HIV, and a total of 52,325 AIDS-related deaths (UNAIDS, 2012).

In Vietnam, the HIV epidemic is considered to be in a “concentrated stage,” meaning that the HIV prevalence is over 5% in at least one defined subpopulation, i.e. either injecting drug users (IDUs), female sex workers (FSWs) and men who have sex with men (MSM), and less than 1% in pregnant women in urban areas (UNAIDS & WHO, 2004). The HIV epidemic in Vietnam is driven largely by high risk behaviors such as sharing injecting drug equipment and having unprotected sex, especially among the young adult male population (The Socialist Republic of Viet Nam, 2008). Although a high risk population has been identified, the epidemiological evidence suggests that Vietnam is at risk of a more widespread or “generalized” HIV/AIDS epidemic, meaning that country’s HIV-positive population is greater than 1% of the country’s entire population (UNAIDS & WHO, 2007). In the case of a generalized epidemic, some believe that serious economic, social and health consequences will be inevitable (UNDP, 2006).

Older adults in Vietnam are also growing in numbers; 7.5 million people (9% of the population of 85.79 million) are over the age of 60. It is projected that 12.6 million older adults will live in Vietnam by 2025 (HelpAge International, 2007). Furthermore, 2.5 million, or one-third of older adults now live in poverty (Knodel, Zimmer, Kim & Puch, 2007). The combination of increased rates of HIV/AIDS and the increasing numbers of older adults are factors contributing to the prevalence of skipped generation households in Vietnam. How the HIV/AIDS epidemic affects older adults caring for orphaned and vulnerable children (OVCs) is not well understood in Vietnam or elsewhere.

The term “OVC” was developed to address the incomplete definition of “orphanhood” in the scenario of HIV/AIDS (Smart, 2003). Among others, the term “OVC” includes children who live in a household in which one person or more is ill, dying or deceased; children who have caregivers that are too ill to look after them and children living with very old and frail caregivers (World Vision, 2002). These categories focus on factors related to HIV/AIDS (Skinner et al., 2006).

Why A Study in Vietnam?

The HIV/AIDS epidemic in Vietnam is now at a tipping point. The rates of HIV/AIDS could either be controlled or could become a leading pandemic within a decade (World Bank/Poverty Working Group, 2002). Although Vietnam is the country in Southeast Asia with the fastest growing rates of HIV/AIDS (UNAIDS, 2007), it is in a position to learn from other countries that have faced large scale epidemics of HIV/AIDS (UNDP, 2006). Vietnam also can learn from the experience of other countries, such as Africa, by piloting programs that target skipped generation caregivers. Because the Vietnamese culture embraces traditional family values about family care obligations, Vietnam is a natural setting for a study of skipped generation caregiving (Phinney, Ong & Madden, 2000).

Extended Family Care: the Role of the Older Caregiver

Psychosocial Strains

HIV/AIDS often causes a change or reorganization in the family caregiving structure. Extended family members often step into the role of primary caregiver when a child’s biological parent(s) have died. Older adults across the globe are responsible for the care of family members affected by HIV/AIDS (Poindexter, 2002). Grandparents are emerging as the greatest source of

support and the most reliable safety net for OVCs (Nyasani, Sterberg & Smith, 2009; Schatz & Ogunmefun, 2007). The potential reorganization of the family structure due to HIV/AIDS can cause a number of challenges to older caregivers including financial burdens, health related aging issues, lack of social support, and limited access to educational information (Nampanya-Serpell, 2002).

Studies in the United States examining the needs of kinship caregivers raising children who had parents with HIV found that multifaceted emotional and behavioral issues produced stress for the caregivers (Bullock, 2004; Burnette, 1997; Burnette, 1999a; Burnette, 1999b; Burnette, 2000; Emick & Hayslip; 1999). These issues included the children's behavioral problems, HIV-related health concerns, access to and costs of medical care, intergenerational strains and emotional difficulties. Grandparents raising grandchildren with higher levels of neurological, emotional and behavioral problems displayed higher levels of personal distress, lower role satisfaction, greater role strain, added health concerns, and more deteriorated grandparent-grandchild relationships than comparison groups not parenting grandchildren with these problems, which are often associated with HIV/AIDS (Hayslip & Shore, 2000; Linsk & Mason, 2004). Given that in Vietnam, older caregivers may have different experiences in raising OVCs, including poverty, health issues, and frailty, they may be more vulnerable than caregivers in the United States (Nyasani, Sterberg & Smith, 2009).

Recent research on extended family care and the role of grandparents has taken place mostly in Sub-Saharan Africa, where the extended family is the predominant system of care in communities affected by HIV/AIDS. These extended family units cross multiple generations, involve large networks of people with varying degrees of relationships with each other, and often cover large geographic areas. In communities with high rates of HIV/AIDS, a common

mechanism for survival is pooling material relief, labor and emotional support through the family network (Foster & Williamson, 2000). In Vietnam, the concept of extended family care in the context of HIV/AIDS may not hold the same meaning because this country has less experience with HIV/AIDS and because different cultural and societal expectations may apply.

Caregiving becomes a significant challenge during a time in the life cycle when older adults are typically free of childrearing responsibilities. Instead of having less responsibility, older adults become the primary caregiver to adult children or grandchildren battling a stigmatized disease. A study in Cambodia of older adults caring for persons affected by HIV/AIDS found that these caregivers endure poor physical and mental health exacerbated by increased workloads and caregiving responsibilities (Mall, 2005). Without social support, many skipped generation caregivers of families affected by HIV may experience isolation from their communities, which can contribute to intense stress (Poindexter, 2002).

In terms of the reported psychosocial needs of older caregivers, social isolation and inadequate social support are significant problems. In Vietnam, orphans are at risk for becoming “grand orphans” after the death of their older caregiver or grandparent. Awareness of this risk heavily impacts the psychological wellbeing of older caregivers with failing health (Foster & Williamson, 2000). When ill, older caregivers can experience great stress, amid uncertainty about who will take in the grandchildren if they die or become permanently disabled (Hayslip & Shore, 2000).

In a study of emotional support (e.g. friendships, empathy) and instrumental support (e.g. childcare, community services) among older caregivers, those with higher scores on both forms of support generally had better perceived health, less parental role strain, and less depression

(Gerald, Landry-Meyer & Roe, 2006). Numerous studies have found that psychosocial support appears to be crucial to the physical and mental health of grandparents, as well as to their ability to cope with the demands of parenting (Emick & Hayslip, 1999; Hayslip & Kaminski, 2005; Hayslip, Shore, Henderson & Lambert, 1998; Minkler, Fuller-Thomson, Miller & Driver, 2000, Jendrek, 1994; Minkler & Roe, 1993).

Some studies have asked older caregivers to reflect upon the reversal of the grandparent experience, meaning the role of raising their own children to adulthood, and then going back into the caregiving role for their grandchildren after the death or absence of their adult child. Taking on the role of being an older caregiver may have many negative consequences in the areas of personal, social and economic wellbeing. These consequences include poorer physical and mental health outcomes (Hayslip, Shore, Henderson & Lambert, 1998; Minkler, Fuller-Thomson, Miller & Driver, 2000), role overload and role confusion (Emick & Hayslip, 1999), and a greater sense of isolation and detachment from peer groups and other grandchildren not in their custody (Jendrek, 1994). Older caregivers are a high risk group for depression (Musil, 1998) and low self-esteem (Giarrusso, Silverstein, et al., 2000). These risks are heightened for older caregivers in the context of HIV/AIDS because the associated stigma and discrimination often perpetuate feelings of isolation in older caregivers, who say that they cannot relate to other parents and grandparents (Erhle, 2001).

Older adults in caregiver roles have reported stress and negative feelings such as frustration, resentment, and feeling taken advantage of (Wohl, Lahner & Joosie, 2003). These feelings can change or multiply among older caregivers in Vietnam, where many are caring for OVCs because their own children ran away and became sex workers or drug users (Orbach & HelpAge International, 2007). This can lead to shame and to resentment toward their adult child,

the child's spouse and the other set of biological grandparents, and potentially their grandchildren. Grief is a common emotion in older caregivers after being placed in the role of taking care of a grandchild, due to the absence of the child's parents (Hayslip & Kaminski, 2005; Joslin, 2002). Grief is exacerbated when older caregivers are also dealing with the grandchild's grief over the loss of their parent (Levine-Perkell & Hayslip, 2002; McKelvy & Draimin, 2002). Often, there may be few public outlets for this grief and fewer opportunities for social support (Miltenberger, Hayslip, Harris & Kaminski, 2004).

The physical and mental health status of the child also makes a difference in the overall caregiving experience. Research has shown that caregivers who categorize their grandchildren's emotional and behavioral problems as "none or minimal" have greater satisfaction in their roles than those who care for grandchildren with "moderate or severe" emotional and behavioral problems (Hayslip et al., 1999; Hayslip & Shore, 2000). Older caregivers and grandparents raising grandchildren who are HIV-positive face additional challenges in their caregiving roles, because these children are more likely to experience depression and stress as a result of their own HIV status and related health issues (Burnette, 2000; Joslin, 2002).

Psychosocial issues are often related to intergenerational conflicts. Research suggests that older caregivers often experience more intergenerational conflicts, including problems in disciplining and communicating with OVCs. This finding is the most common for older adults caring for adolescents. Generational definitions of norms and expectations further complicate discipline and communication (Sands & Goldberg-Glen, 2000).

Financial Strains

HIV/AIDS is extremely challenging as a disease, because of its epidemic proportions and the profound costs of treatment (UNAIDS, 2007). Despite efforts to provide universal access to HIV/AIDS treatment, access is low in many developing and transitional countries. In East, South, and Southeast Asia, 37% of people needing treatment are able to access it (WHO, UNAIDS, UNICEF, 2009). In Vietnam, this could be the result of multiple factors, including the distances and money needed to travel to health clinics, lack of HIV/AIDS education information, and fear of stigma. Older adults may be incurring the monetary cost of antiretroviral therapy (ART) themselves, but little is known about access among skipped generation caregivers. This financial burden makes these caregivers even more vulnerable to financial strains, because they often absorb the costs for treating family members. Additionally, the longevity of the illness makes treatment expensive. Persons living with HIV/AIDS can sometimes survive for decades with treatment and expensive antiretroviral medications, which can become very costly for low-income older caregivers. The high cost of medication, combined with elderly and financially-challenged adults in the caregiving role, create a cycle of HIV/AIDS and poverty (UNAIDS, 2007).

Prime-age adults between the ages of 20 and 39 have the highest rates of HIV/AIDS (UNGASS, 2007). This category of adults is the most financially productive and supports families and extended family network more than any other age group (UNDP, 2006). When older adults take on the caregiving role for their adult children and grandchildren, this is a role reversal; usually, older people expect to be cared for by their adult children (Mancini & Blieszner, 1989). This means that HIV is a double threat; contracting HIV/AIDS not only decreases life expectancy of individuals but also reduces the work force of many countries where

HIV/AIDS rates are high. In Vietnam, as indicated earlier, HIV/AIDS is considered to be a concentrated epidemic, mostly confined to cities such as Ho Chi Minh City, Hanoi, An Giang and Hai Phong (UNAIDS, 2007). The presence of HIV/AIDS can greatly reduce the economic capacities of communities (both in urban and the surrounding rural areas) that rely heavily on the economic power of working age adults. The negative economic and health impacts of HIV/AIDS create risks for families to fall into poverty and become vulnerable (UNDP, 2006).

Financial strains appear to be one of the greatest concerns for skipped generation caregivers. Economic factors play a crucial role in the extent to which an extended family network can care for OVCs. Studies have shown that the care of children affected by HIV/AIDS in developing countries falls on poorer people within communities, especially on women (Foster & Williamson, 2000). These caregivers face challenges including the costs of medications along with the loss of time at work, each of which can financially compromise the household. The majority of persons living with HIV/AIDS require the personal assistance of a caregiver, averaging five hours of care per day. Caregivers often are forced to quit their employment in order to meet caregiving responsibilities, resulting in a significant income reduction (UNDP, 2006).

In a survey of households with a person living with HIV/AIDS in Vietnam, 60% reported that they struggled financially because of basic needs such as food, education, healthcare, electricity and transportation (UNDP, 2006). For older caregivers, who have fewer family members to rely on financially, this effect may be even stronger. Indeed, the same study found that after the death of the family member with AIDS, only 50% of the families reported being able to fully financially recover after 9 months, and the financial recovery period ranged from 2 to 25 months (UNDP, 2006).

Coping Strategies

Being an older caregiver in a skipped generation family affected by HIV/AIDS often involves hardship over long periods of time, forcing caregivers to develop coping strategies. As described above, among the many challenges is the change in economic status due to the high costs of food, clothing, education (and often medicines) and the indirect costs of the loss of money, due to the time spent away from work in the caregiving role. The poor health and/or death of a family member and ongoing financial concerns result in significant levels of trauma and stress. The physical and emotional strain of providing care can have major consequences for the health of the older caregiver and the household (Orbach & HelpAge International, 2007). A focus-group study of older caregivers from Cambodia, Thailand and Vietnam showed that there are multiple roles and responsibilities in caring for people living with HIV/AIDS and OVCs (Orbach & HelpAge International, 2007). Caregivers spend a significant amount of time with daily tasks including obtaining food, water, and medicine, and assisting with feeding, bathing and dressing. Additional roles and responsibilities of older caregivers pertain to health, nutrition and education (Joslin & Harrison, 2002, Kipp, Kabagambe & Konde-Lule, 2002; Emlet & Poindexter, 2004; Orbach & HelpAge International, 2007)

Among the many ways that caregivers in Vietnam cope and survive in difficult circumstances, the most common reported form of financial coping was borrowing money, often at high rates of interest; second was reducing the consumption of food and healthcare; and third was selling assets (Orbach & HelpAge International, 2007). In many cases the older adult in the household was responsible for rejoining the workforce to make up for the loss of income that would have been earned by their working-aged, adult child with HIV/AIDS before he or she died.

What do older caregivers say they need?

Over the past 20 years of research on the topic of grandparent caregiving, the most persistent themes are the costs and benefits of caregiving for the grandchild, the need for social support, parenting issues, and recommendations for organizations working with older caregivers based on the reported needs of the population (Hayslip & Kaminski, 2005). In a study of households affected by HIV/AIDS in Vietnam, the families were asked what kind of support they wanted most over the next 12 months. The households reported that their greatest need was healthcare for the HIV-positive family member, access to medication, and treatment in hospitals. Monetary assistance was also expressed as a need by most households (UNDP, 2006), whereas this study reported on general households affected by HIV/AIDS in Vietnam, the specific needs of skipped generation older caregivers were not addressed.

One of the greatest challenges for older caregivers of OVCs is not having formal custody of their child/children (Adato et al, 2005). In many countries, including Vietnam, formal adoption, legal custody and guardianship come with monetary support from the local government. In Vietnam, a potential challenge for older caregivers, is that many people distrust the system and or/government and would rather give informal care to an OVC than to provide information about their family and work to the public (HelpAge International, 2008).

A study in South Africa found that the needs of rural and urban grandparents varied (Nyasani, Sterberg & Smith, 2009). Whereas rural caregivers' primary concern was meeting the child's basic needs, urban caregivers placed a greater emphasis on improving emotional and psychological support for the OVCs under their care. Other research, including studies of older caregivers in Zimbabwe, Malawi and South Africa found that older caregiver's primary needs

involved childcare, healthcare and psychosocial care (Halkett, 1999; Conteh, 2005). Across these studies of the needs of older caregivers, the results vary in terms of the caregivers' ratings of needs. Overall, social support, monetary assistance, assistance with social and legal issues and healthcare are the most commonly reported needs. Older caregivers and grandparents raising grandchildren who are HIV positive face additional challenges in their caregiving role, not only with respect to their own needs for support and community resources, but also because the children are more likely to endure hardship as a result of their own health status (Burnette, 2000; Joslin, 2002).

Strengths and Benefits of Caregiving Later in Life

Many people who undergo stressful life events such as caregiving in the context of illness report that they gain some kind of positive benefit from the experience, also known as "benefit finding" (Kim, Schulz, Carver & Charles, 2007). The concept of benefit finding might have meaning among skipped generation caregivers in Vietnam affected by HIV/AIDS. In an American study of the benefits associated with HIV/AIDS caregiving, benefit finding was related to seeking and utilizing social support, coping and problem solving (McCausland & Pakenham, 2003).

The close relationship that many older caregivers have with their grandchildren has been reported as the greatest benefit of this role, along with the heightened sense of purpose and family identity (Giarrusso, Silverstein & Feng, 2000). These sentiments might be even more significant in Vietnam, which is a more collectivist society than America, and where the family unit is highly valued. The vast majority of American older caregivers (90%) report that they would make the same decision again if they were asked to care for their grandchildren (Hayslip

& Shore, 2000). The most beneficial and important role that an older caregiver can have is to provide love, security and structure to a grandchild. In the context of the HIV/AIDS epidemic in Vietnam, a responsible older caregiver can be an invaluable asset to a child or family that has experienced the loss or absence of a family member to drug abuse, sex work or incarceration (Hayslip & Kaminski, 2005).

Culture and Caregiving

HIV/AIDS can be destructive to traditional support structures that sustain many families in Southeast Asia. Multigenerational households remain common. In 2007, an estimated 73% of older people lived with children and/or grandchildren in Southeast Asia with the expectation that adult children would look after them as they became older (Orbach & HelpAge International, 2007). As indicated earlier, the situation is often reversed in the context of HIV/AIDS, because current or future assistance from the adult children is likely to disappear. In addition, older people are faced with the prospect of providing care as their adult child becomes sick, coping with their eventual death, and becoming the primary caregiver to a young grandchild (Orbach & HelpAge International, 2007).

The caregiving responsibility for orphans and the position of the family caregiver vary by the cultural norms and the situation. For example, in a study of extended family safety net mechanisms, Foster (2000) found that for African orphans, the caregiving role falls upon the extended family, which is often a weakened safety net. Traditionally, aunts and uncles would be responsible for the care of their brother or sister's orphans. As a result of fragile family safety networks, more grandparents and distant relatives are being called upon to care for orphans. Only after all other relatives have declined to care for the orphaned child, are grandparents asked to

rear the child (Foster & Williamson, 2000). Studies in Africa can only offer clues about what similar research might find in Vietnam in terms of caregiving roles and extended family networks.

Studies have found that environmental factors influence extended family care. Nyasani, Sterberg & Smith's (2009) study of South African grandparents found dramatic differences, varying by location and environment, in the ways grandparents came into their caregiving roles. In the study, most of the rural older caregivers caring for OVCs reported that they had come into the caregiving role because there were no other options. This feeling of being forced into the role was supported by cultural and moral obligations to care for children in the extended family. In contrast, older caregivers in urban areas cared for children with whom they had no kin relations, but they felt a personal motivation and believed that they could offer help and protection to OVCs.

Many environmental factors influence the family structure and the care of orphans. In rural communities, where traditional values are maintained, usually a member of the extended family network would care for orphans. In urban settings, extended family networks can often become weakened, like in Africa. However, the role of grandparents and older relatives is growing, and the more traditional roles of aunt and uncles have lessened in terms of "orphan inheritance." Orphan inheritance is the norms and practices surrounding the care of a child who has lost his or her parents. Without a family safety net, children are at risk of becoming members of child-headed households, street children and exploited labor (Foster & Williamson, 2000).

When families are affected by HIV/AIDS, the caregiving burden predominantly falls on women. In a study of the caregiving roles in Vietnam, the results showed that 75% of caregivers

were women caring for people living with HIV/AIDS. Over 50% of the caregivers were mothers, and 16% were grandmothers (UNDP, 2006). Similar results are reflected in studies of older caregivers in South Africa; women were at the forefront of caregiving, particularly single women (Nyasani, Sterberg & Smith, 2009). Caring for OVCs affected by HIV/AIDS represents an enormous burden in the context of the traditional roles of women (i.e., child rearing, producing food, and working outside the home to generate income). In the context of HIV/AIDS, women's responsibilities also include finding HIV/AIDS information and medication, such as antiretroviral therapy (ART), while supporting themselves and their family members, and coping with discrimination from their community (UNDP, 2006). The care of children is largely in the domain of women and grandmothers in many cultures, and Vietnam is no exception.

When a household is affected by HIV/AIDS, older women fall into the role of caregiving, because of traditional gender roles and demographic imbalances caused by women outliving men (Barford, Dorling, Smith, & Shaw, 2006). There are more economic, health and social costs of caregiving for people affected by HIV/AIDS than in traditional caregiving situations. Low-income older women are less financially able than widowed men to carry out the caregiving roles, making them a more vulnerable population in terms of resources (HelpAge International, 2007).

Little is known about orphan inheritance in Vietnam and few have studied the consequences of traditional orphan inheritance practices (Foster & Williamson, 2000). The role of paternal and maternal grandparents may have meaning in Vietnam in terms of the differences in the context and caregiving for OVCs who have lost their parents to AIDS. In traditionally patriarchal societies such as Vietnam, the inheritance of orphans belongs to paternal relatives, and the marital status of the orphan's parents affects the inheritance (Oosterhoff, 2008).

The Role of the Political Situation in Vietnam & Local Initiatives

Vietnam is a single party state in which communism plays a central role in all areas of politics, government and society. In Vietnam, the government issues directives that are intended to guide, govern, or influence. It points lower authorities in the direction that the central government wants (Thuong et al., 2007). There have been recent acknowledgements from the Vietnamese government and nongovernmental organizations (NGOs) regarding the increasing number of children in need of special protection. Vietnam is now looking toward community-based and extended family options for caring for orphans, instead of the institutions that have historically absorbed their care. Children who spend extended amounts of time in formal residential care show greater risk for negative outcomes include stigma, isolation, low educational achievement, delinquency and homelessness (Foster, Levine, & Williamson, 2005; van Wijngaarden, 2006). Currently, there is a push by NGOs and the international aid community to have Vietnam adopt the UN Guidelines for the Alternative Care of Children. The guidelines make recommendations for policy and practice for protecting the well-being of children who do not have parental care (UNICEF Vietnam & MOLISA, 2010).

Vietnam's Decision 65 & Decree 67

A recent policy change that has taken place in Vietnam is Decision 65 and Decree 67. Decision 65 highlights the need to develop new policies that foster alternative models to institutionalization for children. The National Plan of Action on “community based care for children in difficult circumstances (2005-2010)” was passed in March 2005, and addressed the reintegration of OVCs into the community (UNGASS, 2005). Decision 65 was followed by Decree 67 in August of 2005; this outlines a detailed implementation plan with necessary

budgetary allocations (Duc, et al, 2008). Decree 67 states that any poor family with a registered HIV case is entitled to 120,000 VND per month (equivalent to \$6.28 US dollars per month) (Duc, et al., 2008). This effort on behalf of the Vietnamese government demonstrates the changing attitudes towards OVCs. It is a greater acknowledgement that they are not only the responsibility of their family and extended family, but the state is also responsible for offering financial protection outside an institutional environment.

The role of stigma and HIV/AIDS in Vietnam

A host of challenges affect older caregivers of persons affected by HIV/AIDS. Older caregivers endure the strain and struggle of being grandparent caregivers, but with the added challenge of HIV-stigma, which has been associated with social isolation and emotional stress (Poindexter, 2002; Orbach & HelpAge International, 2007). Erving Goffman (1963) describes the social nature of stigma as a “process by which the reaction of others spoils normal identity.” In Vietnam, there is a significant amount of stigma attached to being HIV-positive. Both older caregivers and OVCs are often socially and economically exiled from the community when revealing their status or the status of their family member. In Vietnam, HIV/AIDS is considered by some as a result of “social evils” that exist in society such as injection drug use, sex work and men having sex with men (Thuong, et al., 2007). The stigma attached to HIV/AIDS in Vietnam can be a significant barrier to implementing programs for older caregivers, because of the fear associated with revealing the status of their family member.

In one of the first studies of stigma, Goffman (1963) described the phenomenon as “an attribute that is deeply discrediting,” transforming the affected individual into a “discredited person.” Stigma serves a purpose in communities because it maintains power, and preserves the

economic and societal hierarchies created by humans (Link & Phelan, 2001). HIV/AIDS stigma plays out differently than many other forms of stigma, because people often believe that someone *did something* to contract the disease. HIV/AIDS is most commonly associated with men who have sex with men, sex workers and injecting drug users, populations that are already marginalized (Herek, 1999). In the case of older caregivers, the discrimination faced by these marginalized populations carries over into their lives, even when they and the OVCs they care for are not members of these groups (HelpAge, 2007; UNDP, 2006).

In Vietnam, stigma creates significant consequences for families affected by HIV/AIDS, because it permeates all aspects of social interactions with their community. In studies of stigma in Vietnam, family members have reported that they are required to borrow money from family and friends to support their HIV-positive family member. In the process of borrowing money, they do not reveal their family members' status to avoid stigma. If HIV status is known, caregivers will no longer be able to borrow money from community members and extended family. Instead they will need to borrow from moneylenders, at high rates of interest (UNDP, 2006).

Although little is known about how stigma affects older adults, we know that in Vietnam stigma within families is present during times when people are in the most need of support. A woman who tests HIV-positive often fears being blamed and rejected by her husband's family members, even when her in-laws were aware that their son was injecting drugs (UNDP, 2006). Studies show that women and men in Vietnam experience stigma differently. Women are blamed for HIV status more than men, and are held responsible for bringing shame upon their family, a finding related to patriarchy and the preference for sons in Vietnamese culture (Hong, Nguyen, Anh & Ogden, 2004; Oosterhoff, Anh, Yen, Hardon & Wright, 2008).

Stigma can create consequences for economic well-being for families and communities affected by HIV/AIDS. However, the consequences of HIV stigma in Asia have not been fully researched, so the full extent of the problem remains unknown (UNDP, 2007). It is known that stigma has social, physical and psychological implications. Stigma has been conceptualized as being a “matrix of influence” demonstrating the bidirectional nature of stigma and human development, which affects people at the individual, family, structural and societal level (UNDP, 2007).

Stigma in Vietnam and other Asian countries has resulted in people moving from their homes because of harassment and coercion, being refused food service, or not being allowed to do business with community members (Oosterhoff et al., 2008; Paxton et al., 2005). A study conducted by the International Center for Research on Women (ICRW) in Vietnam, found that even though family and community members were aware that HIV could not be contracted through casual contact, they still did not want to have contact with someone they knew to be HIV-positive. They justified their fears of sitting next to the person and sharing drinking glasses because they did not want to contract HIV “accidentally.” In Vietnam, the fear of being discriminated against is so strong that families affected by HIV/AIDS have reported quitting their jobs and moving to new communities to avoid stigmatization (Nyblade, et al, 2008).

Academics and practitioners alike have been interested in support groups for marginalized groups facing stigmatization, because of the collective power in raising awareness and also mobilizing and empowering group members (Evans, 1980, Gillis & Perry, 1991; Kling, Shilbey-Hyde, Showers & Buswell, 1999; Malhortra, Schuler & Boender, 2002; Schrijvers, 1985). For individuals and families affected by HIV/AIDS, joining a support group can offer

opportunities for older caregivers of skipped generation families to improve their quality of life, share personal experiences and access services such as micro-credit (Oosterhoff et al., 2008).

In Vietnam, self-help groups and empathy clubs for older caregivers and families affected by HIV/AIDS have emerged. The first support group was started in 1999 by the Women's Union, which is a government run organization under the Communist Party. Groups for persons living with HIV/AIDS, families and older caregivers have expanded rapidly in Vietnam over recent years and the number of non-governmental of self-help groups nearly doubled between 2006 and 2007, from 34 to 74 groups (Health Policy Initiative, 2007). Despite the growing visibility of support groups in Vietnam and their ability to offer access to AIDS medicines, psychosocial support and micro-credit, many persons living with HIV/AIDS and family members are still in hiding, reflecting of the fact that the stigmatization of these families remains strong (Oosterhoff et al., 2008).

There is a significant gap in the literature on skipped generation caregivers affected by HIV/AIDS in Vietnam. While research has identified relevant factors and processes, such as family structure, location, coming into the caregiving role, economic situation, psychosocial issues and various attributes of the child, we do not have a clear understanding of how these factors affect caregivers affected by HIV/AIDS in Vietnam. We do not know the meaning that skipped generation caregivers ascribe to their role and how this is affected by context and their environment. Because intergenerational caregivers represent a growing and disadvantaged population, research is needed that advances our understanding of their needs and experiences, in order to lay the foundation for the development of culturally relevant interventions to support older caregivers as they face the challenges of caring for their grandchildren.

CHAPTER 3: THEORETICAL REVIEW

In qualitative research, theory can be used in several ways and is dependent on the nature of the study. For example, in a grounded theory study, theory and theoretical tenets emerge from the data in the analytic process. In the case of my dissertation research, I wish to consider the theoretical framework of the caregiver stress process model as a sensitizing concept that might inform meaning, context and coping among skipped generation caregivers in Vietnam.

Researchers in the field of social science use sensitizing concepts as starting points in qualitative studies (Glaser, 1978; Padgett, 2004; Patton, 2002) and as background ideas that inform the overall research problem (Charmaz, 2003). Sensitizing concepts describe key aspects of social interaction and provide guidelines for research on specific populations, topics and settings. In this study, sensitizing concepts will be used to identify possible dimensions of caregiving and to provide a possible starting point for analyzing data.

As a researcher utilizing ethnography, I do not plan to test, improve or refine the concepts in the caregiver stress process model. While the concepts in the caregiver stress process model will inform the study of important categories related to caregiving, they might also steer the research away from other equally significant features of the research (Patton, 1987). The utility of a sensitizing concept is dependent upon which concepts emerge from the data; therefore the concepts that emerge from the data may displace the original sensitizing concepts altogether (Padgett, 2004).

The goals of this chapter are to provide a clearer theoretical context for my study and to elaborate on theories related to my research questions as an extension of the literature review. I

will summarize the caregiver stress process model as a beginning framework to identify preliminary sensitizing concepts. Then I will discuss the connection of this model to skipped generation caregivers affected by HIV/AIDS in Vietnam, and conclude with a discussion of how this research was not driven by the caregiver stress process model but was conducted ethnographically.

To establish a stronger theoretical grounding for this study, I focused primarily on two sets of literature. Since the population studied was grandparents raising grandchildren affected by HIV/AIDS, the first focus was elderly caregiving, and the second was caring for persons affected by HIV/AIDS. Within these two bodies of literature, caregiver stress, caregiver burden and the caregiver role emerged as the dominant theoretical concepts. The caregiver stress process model helped to illuminate the processes by which other researchers have examined caregiving in the context of HIV/AIDS and caregiving in older adulthood.

The Caregiver Stress Process Model

The caregiver stress process model views caregiver stress as a result of a progression of several interrelated conditions, including the primary and secondary stressors to which they are exposed and the socioeconomic characteristics and resources of the caregivers (Pearlin et al, 1990). The stress process was first introduced by Pearlin and his colleagues (Pearlin, 1975; Pearlin & Schooler, 1978; Pearlin et al, 1981) as a mechanism for the assessment of the caregiving processes and their influence on caregiver health (Morrissey, Becker & Rubert, 1990; Pearlin, Lieberman, Menaghan & Mullan, 1981; Pearlin, Mullan, Semple, Skaff, 1990). At its time of inception, the stress process approach was unique, because of the focus on micro- and

meso-level linkages among particular stressors, resources, and outcomes, while taking into consideration the social structural influences of these processes.

The original conceptualization of the approach centered around three major domains: 1) sources of stress (eventual life experiences, life strains), 2) intervening resources (social supports, coping), and 3) the manifestations of stress. Research and theoretical modifications over the past thirty years have led to enhancements in the basic model (Pearlin, 1999). The caregiver stress process model has been re-conceptualized to include mediators in the stress process that include internal mediators, such as coping, personality, hardiness, and external mediators such as social support. These resources, or lack thereof, have the capability to intervene at several points in the stress process. The levels of the mediators are influenced by the economic and social statuses of the individuals.

Older Caregiving, HIV/AIDS Caregiving and the Caregiver Stress Process Model

As suggested earlier, the caregiving stress process model has been employed in two kinds of research: studies that focus on caring for older adults, most often with Alzheimer's or a disability (Aneshensel et al., 1995; Pearlin et al., 1990; Pioli, 2005); and others that focus on caring for persons affected by HIV/AIDS (Pearlin, Aneshensel & LeBlanc, 1997). Considerable attention has been directed towards caregivers, particularly for spouses caring for older adults in old age (Pinquart & Sorensen, 2003). Because elderly caregiving is an emergent role that is inherently stressful, caregiving has been declared as a "risk factor for health" and an "independent risk factor for mortality" in leading medical journals (Schulz & Beach, 1999).

Previous research has shown that the demands of caregiving can have effects on those who occupy the role, due to high rates of anxiety, depression, lower well-being and poor physical

health (Pioli, 2005). Although the majority of the studies on elderly caregiving focus on caring for spouses affected by Alzheimer's, a population that represents very specific demands (Pearlin, Aneshensel, & Leblanc, 1997), other research has shown that caregivers of people affected by HIV/AIDS are similar to caregivers that experience severe and persistent stressors. However, in caregiving situations involving people with HIV/AIDS, there are significant differences compared to other long-term caregiving situations (Pearlin, Aneshensel & LeBlanc, 1997). Unlike caregivers of Alzheimer's patients, AIDS caregivers care for those who confront mortality at an age that violates normative life changes and expectations. Second, AIDS caregivers are more likely than others to experience stigma and discrimination from their community (Shilts, 1987; Sontag, 1989), making them less likely to reveal their caregiving experiences openly (Powell-Cope & Brown, 1992). AIDS caregivers then may experience challenges that go above and beyond typical caregiver burden.

The distinguishing conditions that are present in AIDS caregiving are mirrored in the stress process, but also give a unique perspective to the stress process model. Caregiver age, vulnerability to illness, relationship with the caregiving recipient, and the stigma experienced differentiates AIDS caregivers from other forms of caregivers. Adjusting to the knowledge that their loved one affected by HIV/AIDS will eventually die can be overwhelming and have a negative effect emotionally (Folkman, 1997). These kinds of distinctive conditions potentially influence the course of caregiving. Additionally, caregivers of persons living with HIV/AIDS may fear contracting HIV and can potentially live their everyday lives harboring this fear. Caregivers also worry about maintaining their own health while providing care to loved ones (LeBlanc & Wardlaw, 1999), which might be more prevalent in skipped generation caregivers who may worry about preserving their longevity to care for OVCs. In the case of skipped

generation caregivers in Vietnam, stigma can spread into their lives as well as the lives of their grandchildren with HIV/AIDS. Caregivers are frequently unprepared for this task as well as for the changes in their own lives related to the demands of caregiving. The stressors associated with this change can be significant and may negatively influence their well-being.

Therefore, it is reasonable to assume that older caregivers of OVCs affected by HIV/AIDS undergo similarly significant levels of stress. However, the difference is that skipped generation caregivers may have filled the role as caregivers for their adult child with AIDS, prior to assuming the role of caring for their orphaned grandchildren. Moreover, the grandchildren may or may not be HIV positive; in cases where they are HIV positive, this would likely create an even more stressful experience in the caregiving role.

Implications of Caregiver Stress Process Model for Cross-Cultural Research

A limitation of the caregiver stress process model is that it is a western model and has not been utilized in studies involving Asian populations. Culture plays a significant role in the way individuals interpret caregiving obligations and roles. Research shows that the way one appraises stressful events and copes with them depends on how the self is socially and culturally interpreted (Landrine, 1992). Culture influences what people consider stressful and how they react to stressors (Aranda & Knight, 1997; Horowitz & Reinhard, 1995). For instance, in their review of the literature on ethnic minorities and caregiver stress and coping processes, Aranda and Knight (1997) found important ethnic and cultural differences among caregivers' coping processes.

The Domains of Caregiver Stress as Concepts

A conceptual framework links various concepts and drives toward the formulation of theory (Seibold, 2002). The caregiver stress process model was identified in a review of the literature on older caregiving and HIV/AIDS caregiving. The literature indicated caregiving is a stressful process and stress is a result of a series of several interrelated conditions experienced by the caregiver and environmental factors and resources available to the caregiver (Pearlin et al, 1990). The domains of the caregivers stress process model represent broad theoretical concepts: (a) background and context characteristics, (b) primary stressors - objective and subjective (c) secondary stressors - role and intrapsychic strains, (d) internal and external mediators, and (e) outcomes of well-being. These concepts proved to be useful initially as I explored meaning, context and coping among skipped generation caregivers and developed my interview guide. The concepts also provided an analytic frame, serving as a point of reference and a guide in the data analysis. Below I will explain the concepts presented in the caregiver stress process model.

(a) Background and context characteristics

A caregiver's past and present experiences must be taken into consideration when examining the stress process, because caregiving does not occur in an isolated environment. The model addresses background and context constructs to account for the caregiving setting, with particular attention to the social and economic characteristics of the family. The background and context characteristics related to the caregiver influence caregiving and its consequences. Characteristics such as age, gender, socioeconomic status, living arrangements, stigma, and location have ascribed status that influences the everyday lives of caregivers and their relationship to the stress process.

(b) Primary Stressors - objective and subjective primary stressors

Primary stressors are defined as adversities and problems anchored in the caregiving role, directly related to the individual. These stressors are grounded in the caregiving role and can multiply into other aspects of caregiver's life (Pearlin et al., 1997). The potential “proliferation effects” of the stress involved in the caregiving role emphasize the reality of a complex stress model (Eicher & Barshaw, 1993; Raina et al., 2004). In the case of caregiving in older adulthood, the primary stressors can come from the burden and challenge of maintaining health and cognitive functioning, while battling perceptions of captivity and distress that pertain to the caregiving role.

(c) Secondary Stressors - role and intrapsychic strains

Secondary stressors arise from the demands of the caregiving role itself. Secondary stressors fall into two categories: the strains experienced in roles and activities outside of caregiving, e.g. family, work and social role strain; and intrapsychic strains, involving the weakening of self-concepts, e.g. self-esteem, mastery and self-efficacy. In addition, secondary stressors are often the result of the strains created by the consequences of the primary stressors. However, people exposed to the same level of stress are affected differently (Pearlin, 1989); therefore this model also takes into account individual differences between caregivers.

(d) Internal and external mediators

The stress process model includes numerous instances of mediators that impact the caregiving situation. Two types of mediators are identified in this model: internal and external. Internal mediators originate within the caregiver, are long-term characteristics that indicate

enduring patterns of coping and adaptation, and can help explain how the caregiver's approach changes, such as coping, personality, spirituality and life orientation, etc. External mediators are coping resources that are rooted in the environment of the caregiver therefore do not emerge from within the individual. Examples of external resources include social support, access to HIV/AIDS information and services and financial resources. Findings from other studies show that coping and social support can potentially intervene at multiple points along the stress process and that the availability of support may alleviate the impact of the stressors (Ensel & Lin, 1991; Lin & Ensel, 1989; Wheaton, 1985). The amount of support received may also determine the extent to which stressors can contribute to negative health outcomes among caregivers. Thus, the internal and external mediators may act as intervening variables when they alleviate the impact of the stressors; they may also interact with the stressors when a specific outcome is related to one of the internal or external mediators.

(e) *Outcomes of wellbeing*

In the caregiver stress process model, the manifestations of stress, such as well-being, physical and mental health and the caregiver's ability to sustain their own social roles are referred to as outcomes (Eicher & Barshaw, 1993; Caserta, Lund & Wright, 1996). A considerable body of literature supports each of these elements. Pearlin and colleagues recognize that the interrelationships among these variables change and develop over time. The caregiver stress process model suggests that life events can lead to negative changes in people's roles, changes whose persistence wears away desired elements of self-concept, and that through this set of linkages stress is provoked (Morrissey, Becker & Rubert, 1990; Sisk, 2000). This process of wearing away or deterioration in combination with the provoking of stress can lead to negative

outcomes. This model offers quality of life, depression, anxiety, physiological reactions and physical health as outcomes of wellbeing.

Conclusion

This theoretical review has identified several key gaps in research on older adults. Research to date has largely focused on caregiver role strain and burden in the context of Alzheimer's and AIDS caregiving. Research has not explored the experience of skipped generation caregiving in the context of HIV/AIDS from the perspective of older adults. There have been no published studies on the meaning of skipped generation caregiving in families affected by HIV/AIDS in Vietnam, including caregiver's perceptions of disease, caregiving and coping. Furthermore, there is little information on how the context of the meaning is formed and how these understandings add to our knowledge of caregiving and coping among skipped generation caregivers in Vietnam.

While existing theory offers hypotheses, ideas and concepts related to the process of caregiver stress and its outcomes, the limitation of this model is that it is a broad framework, which may not capture personal meanings associated with caregiving roles. It is also important to emphasize that the framework presented is a Western model and might not have the same application in the Vietnamese cultural context and is not oriented to studies involving Asian populations. As previously indicated, the caregiver stress process model has been incorporated into cross-cultural work, and this model provides one potentially useful framework for exploring the possible meanings of skipped generation caregivers affected by HIV/AIDS in Vietnam, and the context in which this population lives and provides care.

I used the sensitizing concepts from the caregiver stress process model as a point of departure for this study. From this point, I conducted this study ethnographically to determine the culturally based meanings of caregiving, contextual factors and coping. Since the study focused largely on meanings and context in a culture that is not my own, in many ways this research was exploratory. According to Lincoln and Guba (1985), when research is exploratory in nature, such as ethnographic research, social phenomena such as skipped generation caregiving should be studied with very few pre-constructed expectations to avoid creating explanations of phenomena ahead of time.

In conclusion, I have introduced the sensitizing concepts of the caregiver stress process model that reflect current theoretical ideas from the literature on older caregiving and HIV/AIDS caregiving. Ethnographic methodology provided a systematic approach to explore the personal meanings as well as the contextual factors that influence perceptions of caregiving and coping in skipped generation caregivers affected by HIV/AIDS in Vietnam. Staying true to ethnographic research, during the course of this study, I put aside preconceptions during the data collection and analysis processes, so that I was able to move beyond existing concepts in the literature. Ultimately, the goal of the analysis was to produce explanations, categories and frameworks of skipped generation caregiving in Vietnam in terms of meaning, context and coping.

CHAPTER 4: RESEARCH PARADIGM, CONCEPTUAL PERSPECTIVES AND METHODS

Ethnographic Research Paradigm

The primary purpose of qualitative description is to develop a clear depiction of an event or situation of special relevance, and an accurate account of meanings attributed to those events by participants. Sandelowski (2000) states that “qualitative descriptive designs are typically an eclectic but reasonable and well-considered combination of sampling, data collection, and analysis techniques” and can have overtones of other qualitative methodologies. Similarly, this study will utilize an ethnographic design with grounded theory techniques.

Ethnography is defined as a description and interpretation of a cultural or social group or system. The researcher examines the group’s observable and learned patterns of behavior, customs and ways of life (Harris, 1968; Agar, 1980). For this study, I used an ethnographic approach, meaning that I engaged in observations of skipped generation caregivers and their families in order to understand their everyday lives, and I conducted in-depth interviews with members of this population (Agar, 1980).

The origins of ethnography began in cultural anthropology in early the 20th century. Anthropologists such as Boas, Malinowski, Radcliffe-Brown and Mead set the stage for the use of ethnographic methods with their studies of comparative cultures (Creswell, 1998). Their early work borrowed from natural sciences methodology; however, they created their own methods through first hand data collection through the study of what they considered to be “primitive cultures” (Atkinson & Hammersley, 1994). Ethnography has moved from the study of other cultures to settings even within one’s own culture that are unfamiliar (Spradley, 1980).

Scientific approaches to ethnography have expanded to include many different environments such as schools, hospitals, and work places.

Ethnographers begin to study their area of interest by looking at people in interaction with ordinary settings and they attempt to distinguish patterns such as life cycles, events and cultural themes (Creswell, 1998). This consists of observing what people do (behaviors), what they say (language), and the tension between what they *say* and what they *do*, as well as what they make and use (i.e. artifacts) (Spradley, 1980). Thus, an ethnographer gathers artifacts and physical trace evidence, finds stories, rituals, and myths; and uncovers cultural themes to create a final “data set.”

In order to identify patterns, the researcher undertakes fieldwork by conducting in-depth interviews, gathering information through observations, and collecting materials with the final goal of developing a “portrait” and establishing “cultural rules” of the population studied (Wolcott, 1994). The goal of the researcher is to discover what a stranger would have to know to understand the daily lives of the population or to participate in the community in a more significant way. The way to access the study population is through gatekeepers and key informants who provide an introduction and entrance to the site and population. In the case of my study, I included key informants (e.g. staff at community organizations, NGO workers, home-based caregivers, government officials and religious leaders) as a subject group to provide useful insights and steer my research to the skipped generation caregivers in their network. Another interest of ethnography is the concept of reciprocity (Creswell, 1998). My research sought not only to study skipped generation caregivers, but also to inform programs that support this population through my partnership with Save the Children, an international NGO, that provides and funds psychosocial support groups, HIV/AIDS education, healthcare and economic

opportunities. The procedure of conducting a study using ethnographic methods entails thick descriptions of the population and an analysis of data involving themes and perspectives. Since ethnography is an interpretive approach, I searched for meanings of social interactions and generalizations about everyday life (Wolcott, 1994).

Rationale

In the summer of 2009, I conducted a pilot study in partnership with Save the Children's HIV/AIDS and Youth Health Program based in Hanoi, Vietnam. Save the Children is an international non-governmental organization that addresses the needs of older adults and orphaned and vulnerable children (OVCs) in developing countries through international fieldwork and needs assessments (Mall, 2005). This project enabled me to conduct an exploratory analysis of skipped generation caregivers of OVCs, which is linked to a larger program of psychosocial support groups and financial support for older caregivers that became operational in October 2010.

This pilot study was conducted using methods informed by grounded theory. However, after the data were analyzed, I realized the need to take a step back. Therefore, I approached the next phase of the study using ethnographic methods. Originally, I came into the pilot study with predetermined questions and categories that I wished to explore further (e.g. psychosocial support, coping, access to HIV/AIDS information, access to healthcare, government grants, etc). After returning to the United States, consulting with my committee and further analyzing the data, I concluded that I did not yet understand clearly the meanings of skipped generation caregiving and the context that surrounds this situation. Therefore, taking a broad perspective through ethnographic methods was a better fit for exploring concepts outside of my own culture.

From the perspective of many qualitative researchers (Denzin & Lincoln, 1994; Glaser & Strauss, 1967), meaning is socially constructed, and in order to understand the meanings of skipped generation caregiving in the wake of HIV/AIDS in Vietnam, one must include the perspectives of the skipped generation caregivers. In line with this approach, there is the constructivist-interpretive paradigm, in which the researcher's interpretations of events and situations involving local community actors provide the building blocks for the study (Denzin & Lincoln, 1994). Without participation by skipped generation caregivers, it is difficult to achieve a full understanding of meaning and its construction.

Methodological Perspective – Symbolic Interactionism

Symbolic Interactionism and ethnography go hand and hand, because symbolic interactionism interprets behavior as a result of the impact of community life, in which all meanings are intersubjective, or dependent on one other. Since symbolic interactionism is often thought of as a branch of ethnography, it is a useful lens to consider the data that will be collected in this study. In the process of collecting and analyzing qualitative data, researchers look for symbols which represent the importance of interaction and the meaning of self. Symbolic interactionism is a theoretical approach to study human behavior and social interaction. Methodological perspectives informed by symbolic interactionism rest on the idea that meaning is implied, therefore theories and frameworks must emerge from the everyday lives of the participants and how they interact with their community (Prus, 1995).

This study focused on the meaning, context and coping mechanisms of skipped generation caregivers. In order to understand the meanings that these caregivers ascribe to HIV/AIDS, stigma, and their own role, there was a need to interpret the social symbols that exist

in their lives. Social symbols disclose intersubjective meanings in the context of a community, such as a neighborhood in Vietnam. Understanding social symbols that relate to caring for orphans affected by HIV/AIDS was a good starting point to consider the data. In addition, negotiated order, a concept used in symbolic interactionism and ethnography describes the give-and-take of human interactions within communities defined by symbols. Negotiated order is expressed through expectations, norms and rules (Maines, 1982; Thomas, 1984; Maines & Charlton, 1985). For example, in the case of grandparent caregivers, their experience of stigma from their surrounding community might relate to the negotiated order experienced in their role.

Moreover, ethnography is an effective way to use symbolic interactionism, because of the focus on the community context. Symbolic interactionism and ethnography view isolated data on human behavior as uninformed, unless it can be understood in the context of the meaning ascribed to it by the surrounding community. Symbolic interactionism is often used to study small groups, e.g. skipped generation caregivers and their families (Thomas, 1984).

This approach was initially developed by pragmatist George Herbert Mead in the early 20th century. The foundations of symbolic interactionism can be found in pragmatism, with the view of reality as dynamic, ever changing and open to multiple interpretations. Symbolic interactionism is close to the pragmatist perspective, based on the belief that human beings are actively interpreting their environment, their interactions and themselves (Charon, 2007). The symbolic interactionist's perspective is that meaning comes through actions to solve problems. Through these actions, humans gain an understanding of their world (Charmaz, 2006). In addition, humans are active participants who define their environment, based on how they can best achieve their goals. In order to understand human processes, we need to understand and

study human action, including the causes and the consequences of this action and how individual perceptions affect this action.

Mead's student, sociologist Herbert Blumer (1969) said that symbolic interactionism is based on three simple premises: 1) human beings act on things on the basis of their meaning, 2) meaning derives from social interaction and 3) meanings are modified through an interpretive process. In summary, the concepts of self and reality are interpretive and created, constructed and co-constructed through an active interaction of symbols and language (Blumer, 1969; Charon, 2007). According to Blumer, symbols are the way humans make sense of everyday life. Human beings act towards objects based on meaning, and this meaning is derived from social interaction. Each individual creates meaning through social objects, through his or her own perspective. Humans are practical beings who interact with each other in groups or in social situations with the intention of meeting their goals. To study humans is to study interactions, which depend on the use of symbols, and individuals, society and the species are in a dynamic transition of process.

Something becomes a social object when it is given meaning. We come to understand symbols through social interactions that involve language. Language is words, which are symbols; in fact, they are the most important symbols of all. Words are a systematic way of using symbols, and words are categories, which make thinking possible. Language and thinking take humans beyond the concrete in the sense that they move us from past, present and future and this is how we create our own reality. Names help us to represent categories succinctly (Blumer, 1969; Charon, 2007).

Self-perception is a part of symbolic interactionism because self-concept is a process, self-judgment is an appraisal, and our identity is a name. Reality is an individual's perception, which is created through symbols. Symbols have shared meaning developed in interaction and used intentionally. The self is a social object, meaning the self is and continues to be socially created. Human beings actively and continuously define themselves. Symbolic interactionism directs us to the idea that it is just as important to unlearn as it is to learn, because philosophies become perspectives (Blumer, 1969; Charon, 2007). An example of the theoretical perspective that symbolic interactionism would take to this study is: what would a skipped generation caregiver want me to unlearn?

Symbolic interactionism suggests that the only way researchers can understand human interaction is to understand what their study participants believe about their world. Therefore, interaction and perception of reality allow us to understand the meaning that people ascribe to their lives (Charon, 2007). That is why scholars such as Blumer (1969) believe that qualitative, naturalistic inquiry is the appropriate way to understand how humans comprehend, make sense of, and act on the world. It is common for research that utilizes a symbolic interactionist perspective to conduct in-depth interviews and utilize participant observation to understand the everyday lives of the population studied (Charon, 2007). For this study, I adopted the symbolic interactionist perspective to study how skipped generation caregivers affected by HIV/AIDS create meaning and understand their world.

The rest of the chapter addresses the methods and procedures used in this study: sampling, information needed, research design, data collection, study procedures, interpretation and translation, data management, data analysis, ethical considerations, and trustworthiness.

Research Sample

This study's subject group was the skipped generation caregivers of orphaned or vulnerable children (OVCs) who reside in Vietnam, aged 55 and older. This is an appropriate definition based on the precedent set by other studies, whose inclusion criterion range from age 50 to 60 (HelpAge International, 2004a; Knodel, et al, 2001; Mall, 2005; Monasch & Boerma, 2004; Nyasani, Sterberg & Smith, 2009). This criterion is also supported by the notion that people experience more age-related health deterioration in the developing world (WHO, 2010) and the fact that people aged 50 and above are largely unrepresented in the international data on HIV/AIDS (Mall, 2005; Nyasani, Sterberg & Smith, 2009). At the time of data collection, the skipped generation caregivers included in this study were engaged as primary caregivers for OVCs, due to the death or illness of a family member from HIV/AIDS. The study's secondary subject group consisted of key informants who were involved with the interests of skipped generation caregivers e.g. staff at community organizations, government officials and religious leaders. The primary purpose of interviewing key informants was to gather contextual information related to the lives of skipped generation caregivers in Vietnam.

Inclusion Criteria

Participant Population One (Skipped Generation Caregivers):

The inclusion criteria were individuals aged 55 and over, married or widowed, in the role of raising grandchildren in the absence of both biological parents due to HIV/AIDS for over six months, of Vietnamese origin and living in Vietnam for at least one year prior to the interview.

Participant Population Two (Key Informants):

The inclusion criteria were individuals who work at organizations and/or serve the needs and interests of skipped generation caregivers in Vietnam. These organizations can be considered civil society organizations (CSOs), community based organizations (CBOs) or government supported organizations that have worked with skipped generation caregivers for at least two years. This population included staff members, volunteers working with the HIV/AIDS community, church leaders and government officials. Key informants offered deeper knowledge, context and insight on the viewpoints of skipped generation caregivers, because they had an insider perspective well beyond that of the researcher. Moreover, interviewing key informants provided continual clarification of ideas and information that was combined with other data gathered from interviews with skipped generation caregivers and participant observation (Ball, 1990).

Sampling Strategy

A purposive “snowball” sampling strategy was employed for this study. Purposeful sampling is a method that is typical in qualitative research and ethnographic methodology (Merriam, 1998; Patton, 1990; Silverman, 2000). The logic of purposeful sampling lies in selecting information-rich cases, with the objective of yielding insight and understanding of the phenomena under investigation. Unlike quantitative studies that utilize random sampling procedures based on statistical probability and that enable generalization, the intent of most qualitative research and certainly my study is to describe in-depth, context-based experiences. Therefore, generalization from the sample to the larger population was not the goal. The main purpose of this sampling strategy was to gather rich information about participants’ lives as skipped generation caregivers and about their communities in Vietnam.

In addition, the principle of maximum variation was applied to the purposive sampling strategy, which seeks to include a wide range of extreme characteristics into the final sample of skipped generation caregivers. Maximum variation is a sampling strategy that intentionally attempts to interview a widely varied selection of people, so that their collective responses can be close to the population as a whole. This strategy has been effective in studies that take place in locations where a random sample cannot be drawn, and is often utilized in qualitative research. Maximum variation is often considered an extension of the principle of regression towards to mean, meaning that a sample that is extreme in many ways will also have individuals who are close to the average in many other ways. Utilizing the principle of maximum variation in this study means that average skipped generation caregivers are automatically included in a sample of caregivers with “extreme” characteristics (Lincoln & Guba, 1985; Patton, 1990).

The maximum variation approach to purposive sampling was used to select a cross section of skipped generation caregivers in terms of gender, age, maternal/paternal, location, duration of caregiving, number of grandchildren, income, and other family involvement in caregiving. A screening instrument was be used in order to select individuals that represent each of the full range of categories (See Appendix A).

For this study, I located skipped generation caregivers from two locations in Vietnam. These caregivers were identified initially through lists prepared by HIV/AIDS self-help groups that serve as community partners to Save the Children. I identified additional participants through purposive sampling. Information from key informants about the location of other key informants and skipped generation households helped to locate more participants (recruitment methods will be described in a later section). A total of 28 participants, 21 skipped generation

caregivers and seven key informants, were sampled from two locations. Participants from both rural and urban areas were included at each location.

Sites

In an effort to increase variation in this sample and to capture skipped generation caregivers in different settings, participants were recruited from the northern cities of Hanoi and Hai Phong. The locations of the study were selected based on the high and concentrated rates of HIV/AIDS in those areas (Nguyen, Nguyen & Trinh, 2004). In addition, Save the Children's community partners who work in these cities reported that skipped generation caregivers in these areas had significant needs.

Overview of Information Needed

In seeking to understand how these skipped generation caregivers view the meaning of their caregiving role, context and coping, three research questions were explored. I focused on three categories of information: (a) contextual, (b) perceptual, and (c) demographic.

- a) Contextual information included information about the community where the skipped generation caregivers resided or worked. This information describes the culture and environment of the setting and the elements within the environment or culture that may influence behavior (Lewin, 1935). The primary method that I used to collect contextual information was to ask caregivers and key informants to explain certain organizational and institutional structures, such as how the local government is structured in terms of applying for and receiving government subsidies, such as Decree 67. I also gathered information from Save the Children about broad contextual issues that relate to Vietnamese culture. And, I attended larger events, such as conferences on HIV/AIDS and

older adult issues, which frequently take place in Hanoi, the capital city of Vietnam, where the majority of the non-governmental organizations (NGOs) reside. During my time working with Save the Children, I also ran workshops with skipped generation caregivers, conducted trainings with home-based caregivers on how to expand services to include skipped generation caregivers, and met with government officials to advocate for the extension of decrees to create greater eligibility for caregivers.

- b) I collected information about skipped generation caregivers perceptions of the caregiving role (meaning), the impact of their community and environment on caregiving (context), and how meaning and context affect coping.
- c) Demographic information pertaining to skipped generation caregivers and key informants was gathered. For caregivers this information included, age, gender, number of years in the caregiving role, family structure, number of children, number of grandchildren and/or OVCs cared for, income, occupation, etc. Information on key informants included their involvement with skipped generation caregivers, number of caregivers they work with who care for OVCs and persons living with HIV/AIDS (PLWHAs), and the number of years they have worked with skipped generation caregivers. Demographic information was needed to help explain what may be underlying an individual's perceptions. For example, prior to conducting the study, it was reasonable to posit that the caregiver's age might have explained some findings from the study, such as kinds of coping mechanisms used in the caregiving role. Demographic information was collected in the beginning of the in-depth interview. The information was displayed on a matrix (See Appendix B and C) which was later used to help analyze the data.

Research Design Overview

I will now summarize the steps needed to carry out this research, and I will discuss each briefly.

1. After the defense of this proposal, I acquired approval from the IRB at the University of California, Los Angeles before proceeding with the study.
2. The potential skipped generation caregivers and key informants were contacted through the community partners of Save the Children. I arranged a time to meet participants at their convenience to conduct the interview and or/participant observation (for skipped generation caregivers only). The interview guide was designed to collect demographic as well as perceptual data. Unstructured participant observation was used to collect contextual, demographic, and perceptual data.
3. Two phases of data collection took place: July to September of 2010 and April to July of 2011. During this time, semi structured, in-depth interviews were conducted with 28 participants, specifically 21 skipped generation caregivers and seven key informants that resided in two locations. In addition, participant observations took place with five of the families of skipped generation caregivers.
4. The research instruments used in the study were interview guides and ethnographic field notes were used to log data through unstructured participant observations. The interview guides underwent forward-backward-forward translation to ensure that they were translated from Vietnamese to English (see Appendix D & F in English and Appendix E & G in Vietnamese). The instruments were developed based on a pilot study that was conducted in the summer of 2009, when I interviewed ten skipped generation caregivers

and seven key informants from Hanoi, Ho Chi Minh City and Hai Phong to lay the groundwork for this dissertation research.

5. Interview transcripts and ethnographic field notes (see Appendix H for field note template) were analyzed between and after the two phases of data collection using techniques that are commonly associated with grounded theory but can be applied to a variety of qualitative methods.

Data Collection Methods

Phase One (July to September, 2010)

In-depth Interviews

Ethnographic approaches rely on symbolic interactionism, which focuses on the meanings that emerge as people define situations through interpersonal interactions, and on how interactions impact behavior. Thus, to understand the process of skipped generation caregiving affected by HIV/AIDS, we must understand what caregivers believe about caregiving in the context of their everyday, lived experiences. Personal interviews have the potential to draw out rich and thick descriptions and provide the opportunity and freedom to clarify statements and probe for more information. In-depth interviews allow us to secure an individual's perspective on an event or experience (Creswell, 1994; Denzin and Lincoln, 2003; Marshall and Rossman, 2006).

The interview is an essential tool in qualitative research (Kvale, 1996; Merriam, 1998; Seidman, 1998). Charmaz (1996) describes the interviewer's role as asking "the participant to describe and reflect upon his or her experiences in ways that seldom occur in everyday life." As Patton (1990) similarly claims, "qualitative interviewing begins with the assumption that the

perspective of others is meaningful, knowable, and able to be made explicit.” In this study, the logic behind collecting data through in-depth interviews with caregivers and key informants is to generate valid data through interaction with people (talking and listening to their stories).

Through this process, I was able to gain an understanding of the meaning of skipped generation caregivers’ experiences through their own stories and words. An interview protocol was used to provide structure on starting the interview, concluding ideas, ending the interview, and thanking the respondent (Creswell, 1998).

Participant Observation

The second form of data collection was unstructured participant observation, which was used to corroborate interview data and further allow the discovery of perceptions that were not revealed through direct interviewing.

Participant observation is the primary approach to data collection in ethnography. To collect data, the investigator must become a participant in the field, by immersing himself/herself in the culture-sharing group (Creswell, 1998). The "participant observer" field technique allows the researcher to obtain data about a community's values, dynamics, internal relationships, structures and conflicts based on their observed actions, rather than from their (normative) statements of what "is", as is the case in interviewing. In other words, one strength of participant observation is that it is an opportunity to document *what people do*, in comparison to *what people say*.

To engage in participant observation, I immersed myself in the daily lives of caregivers to the extent permitted within the families in order to gain a deeper understanding of local life and document “how things work” (Spradley, 1980). During the participant observation, I used an

observational protocol to record information about the observational session. This information included field notes to record descriptions of activities and drawings of the physical setting and reflexive notes about the process, reflections on activities, and conclusions about activities. This information was used during the analysis for further theme development (Creswell, 1998).

Phase Two (March to June, 2011):

In-depth Interviews, Ethnographic Field Notes & Focus Groups

Phase Two of the data collection served as an opportunity to re-contact participants who had agreed to be interviewed a second time, and to recruit new participants to the study. For the Phase One participants, the purpose of this phase of data collection was to understand how their perceptions may have changed over time. The same procedures took place as in Phase One, except new participants were not asked if they would participate in another phase of the study.

After data from Phase One had been analyzed, I was able to present the findings to two groups of caregivers and key informants. The purpose of these focus groups was to report initial findings from the interviews and field notes to review and confirm the results. The focus group did not serve as a stand-alone method for data collection, but allowed for feedback on the initial results of the study. The participants of the focus group were the not the same individuals that participated in the interviews and/or participant observations, due to logistical, transportation and childcare limitations of the sample. Instead, I was also able to conduct member checking interviews, i.e. sharing the findings with the participants involved, with two older caregivers and two key informants.

During the two focus groups, I first presented the study's initial results and asked for their comments and feedback on those results. I also discussed with them the practical consequences

of these findings in terms of how they will be used to inform programs involving skipped generation caregivers in partnership with Save the Children. At the end of the group, I had a list of comments and suggestions from the group, which were then compared and analyzed as a part of the study.

Detailed Study Procedures

Recruitment

In order to identify the study's participant population, I first contacted community partner organizations that work with skipped generation caregivers in Hanoi and Hai Phong. I visited the sites and introduced the purpose of the study to the key informants and organizations. I then asked the community partner organizations to allow me to hold two information briefing sessions. The first session was for interested skipped generation caregivers and the second was for key informants. We designed the sessions so that they were culturally sensitive and emphasized that the study is completely voluntary. I presented the purpose of the study and explained the study's design and procedures. I also explained that there are two different methods of collecting data, in-depth interviewing and participant observation. I informed the caregivers that if they were interested in participating in the study, they could participate in either the interview or the observation or both. Key informants were invited to participate only in the interview. From that point, I met individually with each caregiver and key informant to consent to participate in the study. Private conversations began with my self-introduction, followed by a brief re-introduction of the study. Detailed information about voluntary participation was emphasized during recruitment for the study.

For caregivers who lived in rural, remote locations who could not travel to an information session, the procedure was altered. First, a representative from a community partner organization would ask them if they would like to learn more about the study. If they agreed, then I would travel to a location of their choice and do a one-on-one information briefing session with them, using the assistance of an interpreter. If they agreed to participate then we would arrange a time for the interview or observation at their convenience.

Informed Consent

The method of obtaining consent from participants was through signed consent. I obtained the consent forms from the caregivers and key informants at the time of recruitment, after the information briefing sessions. During these sessions, I introduced the background, main research questions and study design for the participants. The sessions were arranged at the convenience of the caregivers and key informants. Participants who agreed were then asked to sign a consent form and indicate, by checking a box on the consent form that they were interested in participating in the interview or the observation or both.

Comprehension

Special steps were taken to ensure that the participants understood the information that was provided to them. While many people living in Vietnam speak English the large majority of enrolled participants were unable to read, speak or understand English, so I explained the study to them through Vietnamese interpreters. The interpreters were experienced professionals who have worked with Save the Children in previous studies and maintained highly professional levels of rigor, expertise and skill. When describing the study, I used lay language and visual aids. I answered all questions and addressed any doubts that participants expressed.

Interview Guides and Pilot Study

The original interview guides were altered and improved after the pilot study. These changes were based on contributions of my dissertation committee, Save the Children staff, community partners, skipped generation caregivers and interpreters.

During the 2009 pilot study, ten older caregivers and seven key informants were interviewed. The preliminary themes that emerged from the pilot interviews revolved around the relationship between family strengths, challenges and coping mechanisms. Based on the pilot interviews, I developed a new series of open-ended questions that were informed by the domains of the caregiver stress process model (Pearlin, 1975), but offered flexibility and allowed new directions to emerge during the interview process.

With the guidance of two UCLA professors of nursing as a part of a qualitative research course series, I developed a framework was developed for the three research questions described earlier. Matrices were constructed to illustrate the relationship between this study's research questions and the interview questions as they were being developed. Two doctoral colleagues and two supervisors at Save the Children were asked to provide feedback. Their comments were incorporated into the final interview guide.

The interview guides for the caregivers and key informants were designed so that questions were open-ended in order to introduce a topic and encourage the participant to talk about their experiences. The guide included prompts for the interviewer to encourage more in-depth exploration of ideas and topics. Topics covered included, but were not limited to, perceptions of the meaning of their role as skipped generation caregivers, involvement in decision-making and their family, how their environment influenced their everyday lives, their

perceptions of life experiences, views and beliefs related to caregiving and managing their everyday lives, sources of information and beliefs about HIV/AIDS. Prompts such as “please tell me more about that” or “can you give me an example?” were used to gain a deeper understanding of the process experienced by the participants. The topics covered in the key informant interviews included their perceptions of the everyday lives and challenges of skipped generation caregivers, their perceptions of their organization’s needs and the needs of skipped generation caregivers in their community.

Translation Plan and Process

The translation plan of this study included two different steps. First, the interview guide and the consent forms were translated using the forward-backward-forward translation method. Second, the in-depth interviews were translated using live, staggered translation. Below I explain the methods and rationale for using these two approaches.

Forward-Backward-Forward Translation

The interview guide underwent a forward-backward-forward translation process with two professional bilingual translators. This was important for maintaining the meaning and intent of the questions. This method states that the guide must first be translated from English to Vietnamese by the one translator, who is a native Vietnamese speaker. Then the interview guide must be translated back to English by a second translator, a native English speaker who is also fluent in Vietnamese, and who has not seen the original questionnaire. This two-step process improved the accuracy of the translation process and decreased error. At this point, discrepancies in the translation process were discussed and revised with the assistance of the second translator, to create the final interview guide in Vietnamese (Ponce, et al, 2004).

Staggered Translation

Squires (2008) has studied the best practices for the use of interpreters in cross-language qualitative research, and makes several methodological recommendations for the translation/interpretation process. The term “cross-language” research can be defined as a study in which there is a language barrier between the study participants and that researcher (Larson, 1998; Temple, 2002). The distinction between interpreters and translators is that interpreters provide oral translation services, and translators provide the direct translation of documents. Because I conducted live interviews with study participants, I required the services of an interpreter who conducted oral translation during the interview process and thus addressed the problem of the language barrier. Although I speak a conversational level of Vietnamese and can collect demographic data, the in-depth nature of the interview required a professional interpreter.

The use of interpreters during cross-language studies requires strategic planning in advance, to ensure the credibility, transferability and dependability of the qualitative study (Squires, 2008). This study required “live” oral or translation, so my interpreter and I decided to use staggered translation (also known as consecutive or sequential translation). This method entailed that I asked the question in English, the interpreter asked the participant the question in Vietnamese, the participant responded in Vietnamese and then interpreter told me the response in English. Both the interpreter and I wrote notes during the interview, and cross-referenced these notes to provide another level of validity to the research findings. Furthermore, all participants agreed to be tape recorded during their interview.

An important methodological consideration in using an interpreter is the level of involvement of the interpreter in the research process and their role (Squires, 2008). When

interpreters make clarifications about the word choice of the research participant, their role changes in the research process, because they are now creating subjective meaning. In this study, I used the strategy that requires the interpreter to interpret words and phrases in a subjective, culturally-bound way, which is more important for contextual meaning than word-for-word interpretation (Twinn, 1997).

Interview Process

The interviews took place between July and September 2010 and April and July 2011. All interviews were conducted in person and were tape recorded in their entirety. All of the interviews took place in private and the participants were given a choice of where they would like the interview to occur. Each interview took approximately 60 to 90 minutes.

Before beginning the interview, I provided a written consent form (approved by the University of California, Los Angeles – IRB) to the participant in his/her preferred language and reviewed it with the participant. I provided the opportunity for questions and then asked the participant to sign if they agreed. The participant was given a copy of the consent form for their records.

Permission was requested to contact the participants a second time in the case that there were any questions or areas in need of clarification relative to their interview, approximately one week after the interview or after the interview had been transcribed. This allowed me to check themes and categories to assure relevance to participants' experiences and accuracy in representing that experience, and to conduct a second interview during the second phase of the study if needed.

After the interview was complete, I asked the caregiver participants who agreed to be in the participant observation part of the study if they would still be interested in participating, and reiterated that “participant observation” entails spending approximately 2 to 3 days of observing them interacting with their family and carrying out their daily routine.

If the caregiver participant agreed, then I arranged a time or series of times that were convenient for the participant to meet. The observation periods included daily routines such as the care of children and preparing meals, and caregiving tasks outside of the home such as going to the market and running errands. If the participant did not agree, then he/she was excluded from the participant observation portion of the study.

Following each interview, I recorded observations of each participant’s appearance, facial expressions, body language, environment, and comfort during the interview along with my observations about their feelings of comfort/discomfort during the interview and my thoughts on the interview process. This information provided context for the interview transcripts and an opportunity to establish interviewer and environmental factors that may have colored the interview. All identifying information was removed from all transcripts and each participant was assigned an identification number and a code name.

Translation in the interview process

The interpreter and I met at the designated place, prior to the interview, and then entered the interview space together. When greeting the participant, I introduced myself in Vietnamese and explained the purpose of the interview. The consent form was signed with the language assistance of the interpreter. I then began the interview by collecting demographic data in Vietnamese in order to develop rapport with the participant. We then shifted to the open-ended,

in-depth questions with the interpreter translating between the participant and me. During this time, I asked a question in English, the interpreter translated the question into Vietnamese, the participant answered in Vietnamese, and the interpreter translated the response back to me. On completion of the interview, I transcribed the audio-tapes into English. After the transcription, the transcript and the tape recording were electronically sent to the interpreter, who then cross checked the tape and the transcript to ensure that all of the information was accurately captured.

The ideal situation would have been to hire a professional translation team to conduct this research; however the reality was that this was not feasible due to my limited budget. Squires (2008) recommends and confirms that a socio-linguistically competent, bilingual, native speaker from the same country of origin as the participants is the best option in this case. I also hired interpreters that were recommended to me by Save the Children, and who had been involved in interviews with participants who have been affected by HIV/AIDS, which ensured that they were also sensitive to HIV/AIDS issues.

Payment

Study participants were paid 70,000 Vietnam Dong (equivalent of \$4.00 U.S. dollars) for participating in this study. This payment was in accordance with Save Children's local rate for participation in research. This was the total amount that one participant can receive in Vietnam for one interview or participant observation. All participants were paid upon completion of the interview or observation.

Data Management

Due to the stigmatized nature of HIV/AIDS in Vietnam, there were specific plans for managing the identifiable private information of the participants. I maintained privacy in the

research setting by conducting interviews in a private room at a location chosen by the participant. The only identifying information that was collected from each participant was their name and place of residence. These identifiers were removed from all transcripts and replaced with identification numbers. The interviewees' personal identifying information was coded using letters and numbers to represent skipped generation caregivers and key informants. For example, OC-1 – OC-21 represented the 21 skipped generation caregivers and KI-1 – KI-7 represented the 7 key informants.

Data were collected in both paper and electronic form. Personal information, audio recordings, and the master list were stored in a secured office at the headquarters of Save the Children in Hanoi, Vietnam. After the data collection was completed, the identification information was moved to the United States to my secure office at the University of California, Los Angeles (UCLA).

Computer-based files were also used. The key to the code was encrypted in a password protected file. The coded data file was and still is maintained on a separate computer/server. After the study was completed, all data files were stripped of personal identifiers and the key to the code was destroyed. Audio recordings have been transcribed and then destroyed to eliminate the possibility that study participants could be identified.

Digital versions of the master list of identifying information and all audio-recorded interviews have been stored in a file secured with a password in my laptop computer, which is also secured with a password and stored in my secure office.

Methods for Data Analysis and Synthesis

The goal throughout data collection and analysis was to organize and make sense of volumes of data, decrease the size of the information, identify significant patterns and constructs and create a framework. Merriam (1998) suggests that scholars conduct their research so that data collection and analysis are a concurrent process to avoid the risk of unfocused and overpowering amounts of data.

Transcripts and field notes were entered into Atlas.ti, a qualitative data software package, and quantifiable data was entered into a statistical software package (SPSS). Computer software programs such as Atlas.ti enable the researcher to store, categorize, retrieve and compare data. Using a grounded theory approach (described in the next section), the analytical procedures included opening coding, focused coding, axial coding and theoretical coding for both interview transcripts and observational field notes (Charmaz, 2006). SPSS allowed me to conduct some basic analysis on quantifiable data such as age, income, and number of caregiving years for skipped generation caregivers.

After each in-depth interview or observation, I conducted a preliminary analysis to extract key points, and this informed subsequent data collection. All data from in-depth interviews, key informant interviews and observational field notes were analyzed together. Segments of coded data were later brought together into matrices created in Microsoft Word, which allowed for identification of themes and comparison across the participant groups. Description and interpretation followed while making attempts to identify similar and differing views among both sets of participants (skipped generation caregivers and key informants).

Open and Focused Coding

I first read each interview transcript and field notes in their entirety and wrote a brief summary of the overall message conveyed in the interview or observation. Beginning with open coding, key phrases were highlighted in the transcripts and then paraphrased into condensed open code, capturing the essence of the phrase. A coding-partner approach was employed for initial coding. One other independent coder, who is trained in qualitative analysis and culturally competent, coded five of the interviews with me. After completing analysis and hand coding, I developed a preliminary codebook, meaning a list of the most recurrent initial codes and categories (Charmaz, 2006). All of the emerging interview transcripts and observations were analyzed using the codes established in the codebook. During this process, the codebook continued to be developed to mirror emergent categories and concepts. In order to visually present the data for further analysis, data matrices were used. The matrices assisted in the comparison of themes across and within participants (Miles & Huberman, 1994).

Axial coding

Axial coding further develops the dimensions of each category and subcategory, but also begins to show how these dimensions and categories are related. Analysis begins to move away from the pure description of concepts in focused coding, towards analytic, more abstract conceptual development. To accomplish this and to visually present the data for further analysis, I used the focused codes to create data-family matrices in Atlas.ti. As I subsequently looked within and across cases and coding categories of the families, I constructed several overriding themes, or axial codes, related to perceptions about meaning, context and coping. At the axial level of coding, I continued to compare data and interviews for variations and nuances to create

descriptive categories within each theme. Subcategories that described the characteristics and dimensions of the categories were articulated. As the analysis proceeded concurrently with data collection, the interview guides were adjusted to obtain more complete information for each category and to add new categories as they emerged from the data.

Theoretical coding

Theoretical codes conceptualize how categories are related and facilitate explanations about variations within a certain core category (Charmaz, 2006). Again, the core categories and central themes of the data related to the meaning, context and coping mechanisms of skipped generation caregivers were examined. In addition, throughout the process of data analysis, I maintained memos related to analytic decisions, consultations with my dissertation committee, and relationship questions posed of the data (Morse & Richards, 2002).

Ethical Considerations

Ethical issues related to protection of the participants in the study are critical to the research process (Berg, 2004; Marshall & Rossman, 2006; Merriam, 1998; Pring, 2000; Punch, 1994; Scharm, 2003). As a researcher, I was responsible for informing and protecting caregivers and key informants who chose to participate in this study. To this end, the study utilized voluntary cooperation, informed participants about the study's purpose, treated information collected from participants with respect, and protected any identifying information.

Cultural Considerations

This study involved some participants who were illiterate or insufficiently literate to be able to comprehend a conventional written informed consent form. In addition, this study

included cultural groups in which there was a reluctance to sign a written informed consent form and/or groups in which it is considered impolite to refuse a request. To address these concerns, I worked closely with Save the Children to gain knowledge about Vietnamese culture and social norms regarding participation in research. Save the Children has had experience in conducting research studies and program evaluation since 1990, has 95% Vietnamese staff, and is knowledgeable about Vietnamese culture and its influence on people's decision making.

Risk/Benefit Analysis

During the interviews, there was potential for risk and discomfort in the research procedures. The interview guide required caregivers to recall some unpleasant memories regarding the illness or death of a family member from HIV/AIDS. These caregivers may also have undergone some stress when talking about their life experiences. Key informants who serve the interests of skipped generation caregivers may also have recalled some unpleasant memories regarding the struggles of the caregivers that their organization serves. They may have also undergone some stress when talking about the life experiences of the caregivers that they served.

Throughout the research process, I made myself available for follow-up conversations with both caregivers and key informants to help soothe the psychological tensions or frustration due to some unpleasant memories. There were some potential benefits for participating in this study, but participants may or may not have benefited directly from the interview process.

The research itself was aimed to improving psychosocial support programs for skipped generation caregivers in other communities. Utilizing insights from this research, Save the Children was able to exchange information with other organizations serving these caregivers, people living with HIV/AIDS and orphans and vulnerable children in Vietnam and other

countries in Southeast Asia. Ultimately, the benefits of this study appeared to outweigh the potential risks to participants. Toward that end, I have sent copies of the results of this research to interested parties in Vietnam.

Issues of Trustworthiness

In order to address issues of trustworthiness in conducting a qualitative study, I have considered several ethical issues related to the trustworthiness of my data. I have taken necessary steps to address these issues through criteria described by Lincoln & Guba (1985) and Guba & Lincoln (1998) on evaluating trustworthiness in qualitative research.

Issues of trustworthiness in this study were addressed through addressing validity and reliability, which are also familiar to quantitative research. To examine issues of trustworthiness, I focused on credibility, dependability and transferability (Guba & Lincoln, 1998). My goal was to control for potential bias throughout the research process in the areas of design, implementation, and analysis.

Credibility

The criterion for credibility (or validity) is determined by whether the findings are accurate and credible from the standpoint of the researcher, the participant, and the reader (Creswell, 2003; Creswell & Miller; 2000, Mason, 1996; Maxwell, 2005; Miles & Huberman, 1994). A study is methodologically valid when the logic of the methods is linked to the kinds of research questions being asked. In order to enhance the methodological validity, I gave careful consideration to the interrelationship of the study's purpose, the conceptual framework, the research questions and methods. I continued to focus on methodological and interpretive validity throughout the course of the study.

To enhance this study's methodological validity, I triangulated data sources as well as used two data collection methods (in-depth interviews and participant observation) and two study groups (skipped generation caregivers and key informants). Gathering data from multiple sources and by multiple methods yielded a fuller and richer picture of the phenomenon under review. To enhance the interpretive validity of this study, I employed various strategies.

First, I clarified my assumptions, and the steps through which interpretations are made were charted through journaling or memo writing (Charmaz, 2006). Memo writing was used from the beginning of sampling through the entire analytic process to assist and record the conceptual development of the final results (Charmaz, 2006; Miles & Huberman, 1994; Morse & Richards, 2002; Strauss & Corbin, 1998). I included segments of raw data to stay grounded in the participant's language, and my memos moved beyond descriptive notes. I found that my memos helped to expand and refine codes and categories, and helped the analysis move toward a more integrated understanding of the process of caregiving in skipped generation families.

Second, I used collaborative modes of research, including the search for discrepant evidence and peer review (Guba & Lincoln, 1985). This included searching for variation in the understanding of phenomena, and actively seeking situations and perceptions that challenged my expectations of the emergent findings. To further ensure that I addressed the realities of the caregivers and key informants, I reviewed and discussed my findings with professional colleagues. Thus, throughout the analysis process, I sought opportunities for consultation: 1) I attended meetings of the Qualitative Research Interest Group, a group of researchers who meet every other month to discuss issues in their research processes; 2) I continued my education through enrolling in the Nursing 205 Qualitative Series; 3) I took part in the Qualitative Dissertation Writing Boot Camp, and 4) I participated and attended the 2013 International

Congress of Qualitative Inquiry; 5) I consulted with committee members throughout the research process and data analysis; and 6) I partner-coded with another doctoral student colleague to help ensure that the perspectives of the participants was properly addressed and reflected throughout the data analysis and the findings.

Dependability/Reliability

In quantitative research, reliability refers to the extent to which the findings can be replicated by other studies. In most qualitative research, including this study, there is insufficient breadth of subjects and experience to provide adequate degrees of reliability. However, in qualitative research, the more significant concern is that the findings be dependable and consistent with the interviews and observation (Guba & Lincoln, 1985). Therefore, the goal is not to rid the research of discrepancies in the data analysis, but to be able to explain why the discrepancies occur. To achieve this, it was crucial to document all of the study procedures, coding schemes and categories, and to demonstrate that these have been used consistently throughout the research process.

To further address dependability, inter-coder reliability (Miles and Huberman, 1994) was considered through the use of a coding partner for data analysis. In addition, I maintained an audit trail (Lincoln & Guba, 1985) that recorded the development of my thoughts throughout the research process and documented the rationale for all of the choices and decisions that I made in the field and in the analysis. The audit trail created a “transparency of method” (Merriam & Associates, 2002) which makes me accountable to others by granting access to my journal and memos on how the transcriptions and field notes were analyzed and interpreted.

Transferability

Although generalizability is not the intended goal of this study, the issue of transferability must be addressed (Lincoln & Guba, 1985). Transferability means the extent to which the results of studying a particular phenomenon, such as skipped generation caregiving in Vietnam, can be transferred to another context. Patton (1990) promotes the term “context-bound extrapolations” which is defined as the assumption that the findings of the study can have applicability to other situations that have comparable, but not matching conditions. In the case of this research, the focus is on a particular culture at a particular historical juncture, of which there is great value. However, the depth and the richness of the description may also provide transferability of the findings to another context. In Chapter 9, I compare these findings to other contexts, such as resource deprived countries, and grandparents who are raising grandchildren in Southeast Asia.

Chapter Summary

This chapter presented a detailed description of the methods used in conducting this dissertation research. Ethnographic methods were employed to illustrate the phenomenon of skipped generation caregiving, its meaning to caregivers affected by HIV/AIDS, and the context and the coping mechanism employed by caregivers. The participant sample was made up of 28 purposively selected individuals. Two data collection methods, including in-depth interviews and unstructured participant observation, were employed throughout two phases of the study. Those data were reviewed in the context of the literature and the emergent themes.

CHAPTER 5: THE ALTERNATING FLOW OF CAREGIVING IN LATER LIFE AND CAREGIVING FOR GRANDCHILDREN AFTER DEATH

This chapter briefly presents two conceptual models which are derived from notes, records and interviews from grandparent caregivers and key informants, and which respond to the study's three questions. The first conceptual model addresses the alternating flow of caregiving in later life, while the second model conceptualizes caregiving for grandchildren after the adult child's death. These models highlight the importance of context, caregiving and coping, and present the themes which are the basis for organizing the findings in chapters 6-8 to follow.

The model in Figure 5-1 illustrates the alternating flow of care that grandparents experienced in their careers of providing care to both their adult children and grandchildren. This long journey is described by four main phases or sub-processes. The caregiving career started in a very traditional way for their biological child (Phase 1). As their child grew up, caregivers moved to caregiving for their adult child battling drug abuse (Phase 2). After the birth of their grandchild(ren), caregivers became responsible for the care of both generations, their adult child as they were addicted to heroin and dying of AIDS, and their grandchild (Phase 3). This process ended with caregiving for the grandchild after the death of their adult child (Phase 4). These four phases highlight grandparents' experiences with the long process (career) of caregiving on the road to raising their grandchildren in the context of HIV/AIDS.

The caregiving path was "multidimensional" for grandparents, because it included contextual, social, psychological and health-related factors. The process took place over several years, and was continuous, sequential and iterative in the sense that the grandparents often moved back and forth between phases depending on their family situation (for example,

grandparents could move back and forth based on their adult child's experience with injecting drugs and sobriety). Lastly, there is not a clear end to the caregiving career. This reflects the complex reality for these grandparents, who were struggling with unknown futures, limited resources for their own elder care, and the loss of extended family care or filial piety.

<<Insert Figure 1: Alternating Flow of Caregiving in Later Life>>

Phase 1: Caregiving for biological child

Phase 1 of caregiving took place during the time when the grandparents were mothers and fathers for the first time and raising their biological children (the second generation). This phase encompassed very typical caregiving roles. Many had large families of five to eight children and had husbands who migrated for work, were in the Vietnam (or "American") War or battled addiction themselves. Therefore, this caregiving role was demanding and often occurred without the help of a spouse. However, according to Vietnamese tradition at that time, study participants were daughter-in-laws and therefore lived under one roof with their mother and father-in-laws. This often provided help in the caregiving role through the assistance of the older generation.

Phase 2: Caregiving for adult child

The second phase was the period when older caregivers were caregiving for their adult child battling drug abuse and HIV related illness. Moan described her son's behavior during his heroin addiction, "When he was hungry for drugs and he had no drugs, then he was like a horse; no one could control him." Huan and Tuan reflect on the emotional stress that this phase caused their family, "When you have a child, however she is, you still love her, you witness her craving for drugs, and it is terrible, and at that time she is not conscious, and she can't control her behavior at that time." This time, prior to the births of their grandchild(ren), was marked by high

anxiety, confusion and stress over the mental and physical health of their children, the mystery of a new and incurable illness, and uncertainties about the future and about the spread of the disease.

Phase 3. Simultaneous caregiving

Many grandparents had experienced several years of caregiving for their children as they battled drug addiction and HIV/AIDS, while simultaneously caring for their grandchildren. This represents the third caregiving phase after the grandchild(ren) were born. At this point caregivers began raising their grandchildren, while simultaneously providing “full-time care” for their adult children dying of AIDS. In Vietnam, as in many Southeast Asian countries, there are expectations of filial piety. These expectations were often violated when grandparents were placed in the role of caregiving for their children and grandchildren. In general, grandparents reported that the traditional caregiving arrangement should be that the adult child(ren) of the family would provide care and support for their aging parents. The absence of the middle or parental generation directly affected the grandparents’ plans, financial situation and emotional state during older adulthood. Grandparents saw the middle generation as traditionally the most productive in terms of work, parenting children, and providing care and financial support to grandparents as they age. However, that filial support was absent in the lives of these grandparents. Caregivers reported that this stage was the most complicated caregiving phase, and the most emotionally troubling period of their lives.

Phase 4. Caregiving for grandchildren, after adult child’s death

This research took place during the final phase of care (Phase 4) and has focused on this phase of care: caregiving for grandchildren, after the adult child’s death. I thus met the grandparents while they were caregiving solely for their orphaned grandchild(ren). Caregivers

reported that their caregiving roles became less complicated, less demanding, and less conflicted after the adult child's death. Grandparents also reported improvements in their health and wellbeing, following this stressful event.

Although the caregiving roles became easier during the final stage of care, this phase presented grandparents with a different set of significant and daunting challenges. Grandparents often faced financial troubles, became isolated, worried about the future, and struggled with their own failing health and the loss of the freedom that traditionally comes with being the elder of the family. Hoa, an adoptive grandmother described the changes in lifestyle that she experienced after taking over the care of the 5-year-old grandson of her ex-husband. Before caregiving, she had more freedom to move around and more security, but after taking on the caregiving responsibility, she was unable to provide for herself and the grandchild, and was more reliant on support from others.

Based on the overall findings from this research, the final phase (4) of the model was expanded to include the central contextual, social and physiological processes that emerged during the period of caregiving for grandchildren, after the adult child's death (Figure 5.2). This framework represents the overlapping understandings of disease, caregiving and coping held by grandparents who were raising grandchildren due to HIV/AIDS, and it illuminates contextual factors such as perceptions of culture and community that influence their lives and the link between meaning and context, on the one hand, and coping and caregiving behaviors on the other. Figure 5.2 also frames the discussion of findings related to my three research questions, which are the subjects of Chapters 6, 7 and 8.

<<INSERT FIGURE 2>>

Chapter 6 addresses caregiver understandings of caregiving, coping and disease.

Grandparents believed that their caregiver burden decreased and shifted after the death of their adult child, when they were left alone to care for their orphaned grandchild(ren). They also viewed their caregiving role as temporary, due to their age and/or the HIV+ status of their grandchild. Caregiver understandings of coping¹ included having a future orientation for their grandchildren's care, such as: making plans with extended family, investing in education, not having options for future care, and seeing an orphan village as the final option. Grandparents generally understood HIV as a social disease related to criminal behavior and lacked medical knowledge about HIV. As suggested by the arrows in Figure 5.2, these knowledge deficits combined with their beliefs about HIV as a social disease led many grandparents to either hide the HIV status or remain uninformed about the HIV status of their grandchildren.

Chapter 7 addresses the second research question, which has two parts: first, how do skipped generation caregivers perceive Vietnamese culture with respect to grandparenting orphans affected by HIV/AIDS?; and second, how do these skipped generation caregivers perceive the surrounding community's response to their situation and needs? The context of caregiving is heavily influenced by Vietnamese cultural values about family responsibilities and roles, and beliefs about whose responsibility it is to parent familial orphans. The context also includes grandparents' perceptions of their community, which consisted of feeling isolated by the community, feeling compensated by the community, viewing family responsibility as being greater than community responsibility, and experiencing the paradox of both feeling supported and stigmatized as a family affected by HIV/AIDS.

¹ The many dimensions of coping are presented in greater detail in Chapter 8

Chapter 8 considers the third research question: How do understandings of meaning and context relate to motivations for caregiving and coping among skipped generation caregivers in Vietnam? I describe grandparents' motivations for assuming caregiving roles, and explain how grandparents managed their everyday lives through problem-focused coping. Problem-focused coping includes: existing one day at a time, understanding limitations and rules, getting used to a hard life, relying on others, borrowing money, rationalizing with grandchildren, balancing hope and realism, and finding the benefits of their roles.

In this chapter, I have described the four phases depicted in Figure 5-1: caregiving for their biological child, caregiving for their adult child because of drug abuse and HIV-related illness, simultaneous caregiving for their adult child dying of AIDS and their grandchild, and caregiving solely for the grandchild after the death of the parents. I have also introduced the overarching framework for caregiving for grandchildren after the adult child's death, which includes the meaning of skipped generation caregiving, the context in which meaning is formed, and how understandings of meaning and context are related to coping and caregiving.

Figure 5-1: Alternating Flow of Caregiving in Later Life

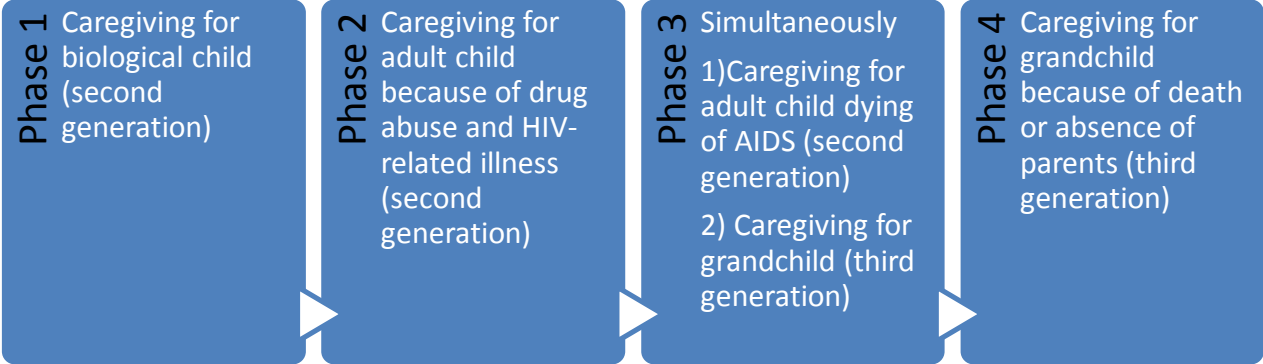
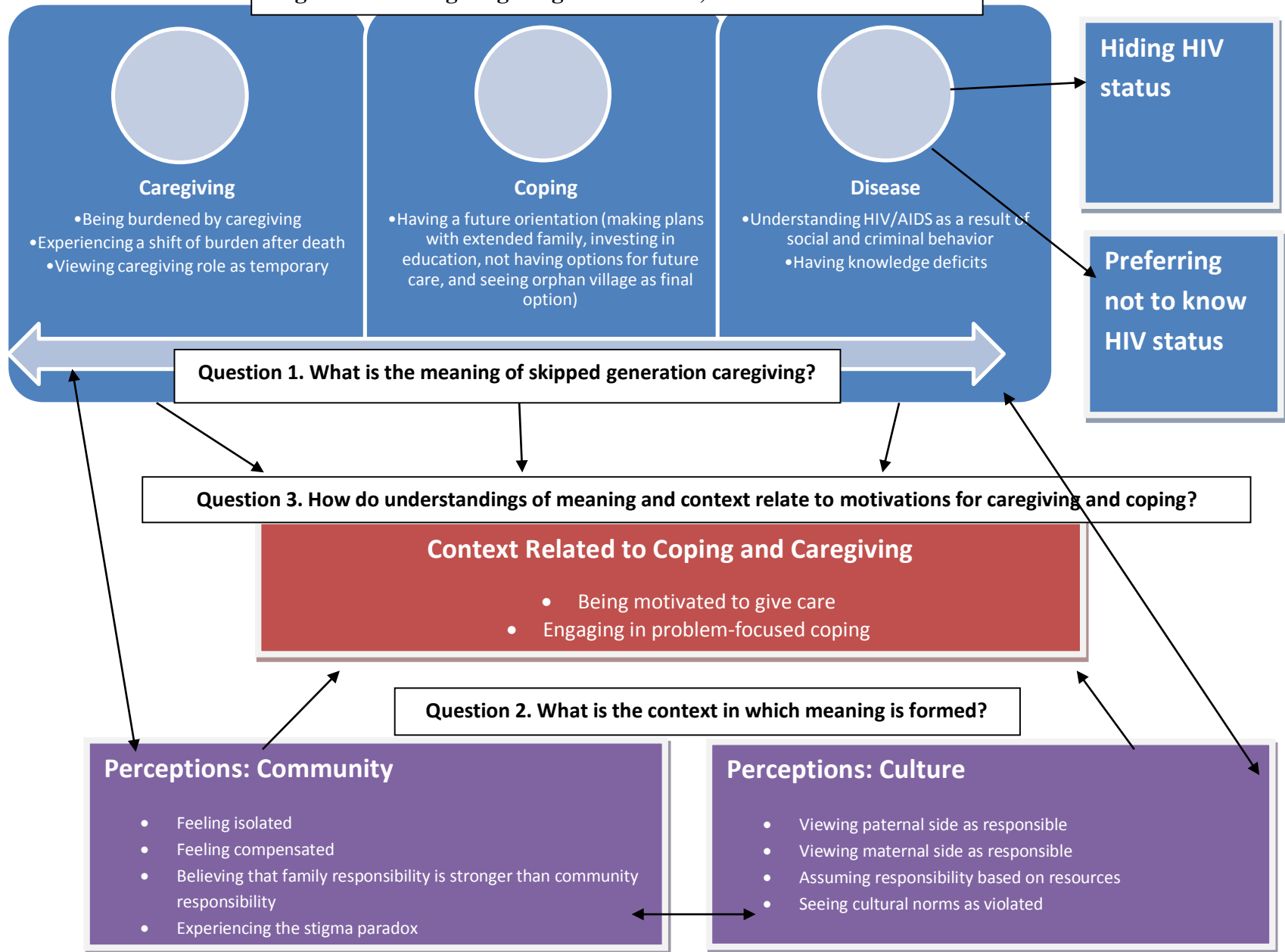


Figure 5-2: Caregiving for grandchildren, after adult child's death



CHAPTER 6: UNDERSTANDINGS OF CAREGIVING, COPING AND DISEASE

Before addressing the first study question related to meanings of skipped generation caregiving in Vietnamese families affected by HIV/AIDS, I begin with a description of the study population's demographic characteristics. Next, I present findings related to local understandings of caregiving, coping, and HIV/AIDS as a disease from the perspective of these grandparents raising grandchildren in Northern Vietnam.

Characteristics of Caregivers

Caregiver demographic characteristics are presented in Table 6-1. At the time of the 21 interviews, the average age of the skipped-generation caregivers was 64 years (SD = 6.8, range =55-78). Five couples and 16 single grandmothers participated in the interviews. The participants' estimated mean monthly household income was 1,170,000 Vietnam Dong (about \$55), considered low in Vietnam. However, the range in income, from 0 to 4,000,000 Vietnam Dong (\$0 to \$190.40), was relatively wide. Regarding marital status, a third (n = 7) were married, nearly half (n = 9) were widowed, three were divorced, and two were in other situations, such as a missing husband due to alcoholism. The caregivers had spent close to an average of 9 years as caregivers for their grandchildren, with a range of six months to 17 years. About half (n = 11) of the caregivers were paternal grandparents, eight were maternal grandparents, and two were "adoptive" grandparents. The grandparents cared for 1 to 4 grandchildren, with most caring for between 1 and 2 grandchildren. The majority of the caregivers lived in rural areas, while just over a third lived in urban locations.

In terms of the grandparents' self-reports of their grandchild(ren)'s HIV status, thirteen reported HIV positive, ten reported HIV negative, and seven reported that they did not know.

There were four reasons mentioned for not knowing the HIV status of their grandchild: they assumed that the grandchild was HIV positive; they were afraid to learn the HIV status of the grandchild; they did not seek testing because of limited resources; and, they lacked trust in the results of the test. In terms of assistance from the government and organizations, the majority of the caregivers were unable to access government grants, while just over a third were successful in receiving a monthly grant. Just under half were receiving financial or material assistance from a public or private organization (n = 9) while more than half were not (n = 12). A greater number were receiving services from an organization (n = 12), while the remainder of the grandparents were not (n = 9).

Table 6-1: Caregiver Demographics

	Number	Percent
Age* (n=26)		
55-60	8	31
61-69	12	46
70-78	6	23
Gender*		
Female	21	81
Male	5	19
Marital Status of Main Caregiver		
Married	7	33
Widowed	9	43
Divorced	3	14
Other	2	9
Grandparent Relationship to Family		
Paternal	11	53
Maternal	8	38
Adoptive	2	9
Location		
Urban	7	33
Rural	14	67
Monthly Income (VND)		
0	1	5
7,000 - 1 million	11	53
1 - 2 million	5	24
2 - 3 million	2	9

3 - 4 million	2	9
Number of Grandchildren Receiving Care (n=30)		
One	14	66
Two	6	29
Three	0	0
Four	1	5
HIV Status of Grandchildren (n=30)		
Positive	13	43
Negative	10	33
Unknown	7	23
Years of Caregiving		
6 months – 3 years	2	10
4 years – 8 years	8	38
9 years – 13 years	8	38
14 years – 17 years	3	14
Receiving Government Subsidies		
Yes	8	38
No	13	62
Receiving Financial or Material Assistance from an Organization		
Yes	9	43
No	12	57
Receiving Services from Organization*		
Yes	12	57
No	9	43

*age includes 21 female caregivers and 5 caregiving spouses

*gender includes 21 female caregivers and 5 male caregiving spouses

*services included psychosocial support, empathy clubs, etc.

Characteristics of the Key Informants

Seven key informants were interviewed for this study. The seven included four women who ran self-help groups for older caregivers, one community medical worker, one community organizer, one government agency worker, and one nun who worked in an orphanage for children living with HIV/AIDS. These key informants had worked with skipped-generation caregivers for about 5 years. Interestingly, key informants varied widely when estimating the number of grandparents in their community who were skipped generation caregivers, with

estimates ranging between three and 689 individuals in their community who were grandparent caregivers².

Findings

The first research question addresses skipped generation caregivers' understandings of (1) caregiving, (2) coping, and (3) disease. I will now present findings on each in turn, organized in terms of the dimensions in the Table below, beginning with an introduction of a grandparent-headed household living in Northern Vietnam.

Table 6-2: What is the meaning of skipped generation caregiving in families affected by HIV/AIDS in Vietnam?

Sub-question	Theme	Dimension
What are skipped generation caregivers understandings of caregiving, coping and disease?	Understandings of Caregiving	<ul style="list-style-type: none"> • Being burdened by caregiving (material, psychological, social/environmental) • Experiencing a shift of burden after death • Viewing caregiving role as temporary
	Understandings of Coping	<ul style="list-style-type: none"> • Having a future orientation (making plans with extended family, investing in education, not having options for future care, and seeing orphan village as final option)
	Understandings of Disease	<ul style="list-style-type: none"> • Understandings HIV/AIDS as a result of social and criminal behavior • Having knowledge deficits • Hiding HIV status • Preferring not to know HIV status

² Grandparent caregivers was defined as providing care due to the death or absence of parents due to HIV/AIDS

Linh and Cai

During the time that I spent with Linh, a 60 year old grandmother living in rural Hai Phong, I learned that she was a full time caregiver to her 14 year old granddaughter, Cai. She had been providing full time care to Cai since she was 5 months old. Linh also provided care during the day time to her middle son's 4 year old son and 1 year old daughter, while their parents were at work. Linh had been raising her granddaughter without the help of any other relatives in her family, except for the help of her husband. All of her husband's relatives had died, but when they were younger, they had all lived in the same town. Similar to many grandparents who participated in this study, Linh was geographically separated from her family of origin. She was originally from the south, but moved to the north when she married her husband, leaving her relatives behind.

Linh gave birth to three sons; the eldest died of AIDS 14 years ago, and was Cai's father. Her second son was married and lived next door with his 4 year old and 1 year old children, and her youngest son was 23 years old. The youngest son had bought the home from Linh and her husband and was currently residing with them because he was single.

Cai's father died of AIDS and her mother fled shortly after her birth and they had not heard from her in 14 years. Before his death, Linh's eldest son battled addiction to opiates and was an injecting drug user. Linh's hometown was heavily affected by the HIV epidemic, due to its geographical location. Hai Phong is home to the largest and busiest port in Vietnam. A common occupation for young men was to work on the ships, where they were given opiates and taught how to inject them. When they returned to their home town, many of the young men transmitted HIV to their wives and children. At the height of his addiction, Linh's son stole nearly all of their household items, including their furniture, to buy drugs. Linh's household was

running low on supplies and finances, but she could not leave the house for work, because she was taking care of and trying to protect her granddaughter, Cai. Linh explained that the most difficult time in her life was when Cai was a baby, due to the complicated role that she had to fill of raising her granddaughter, dealing with her son's addiction and protecting her granddaughter from harm. This simultaneous caregiving role seemed to be the most difficult time period in the lives of all of the grandparents. Dealing with the addiction, illness and eventual death of their adult children, combined with caregiving for a young child(ren), was an overwhelming burden for grandparents. Linh reported that her life became easier after the death of her son. She could now focus solely on raising her granddaughter Cai.

Throughout my time interviewing and observing Linh, she continuously explained that she was filled with worry. Her primary concern was her financial burdens, particularly earning enough money to pay for her granddaughter's education and fees. Her secondary concern was her granddaughter's health, and her third concern was her granddaughter's future after she and her husband passed away. This concern about her granddaughter's future was shared by many of the other grandparents in the study, who saw their caregiving role as temporary due to their age and failing health. Linh and the majority of the grandparents said that they had no other caregiving options. Despite the fact that Linh had two living sons, she did not think that she could ask them to share caregiving responsibilities, due to poverty and lack of resources.

Money was unstable for Linh's family, and they earned the majority of their income during rice season, and this money had to last for an entire year. Her husband also earned money through working at the "recycled iron and bottle market," which was a common occupation in her town located in rural Hai Phong. This job entailed going through people's garbage and collecting recyclables and traveling to the market to sell the items. Linh used to work alongside

her husband in recycling, but she said that she is now too old and weak to make money in the recycling industry, so she stayed behind and tended to the rice paddies, chickens and vegetables in their back yard.

Due to Linh's financial status and the fact that she was caring for a child orphaned by AIDS, she was entitled to government subsidies. However, she had not been able to access subsidies, even though she had tried on several occasions. She said that when she applies, the government representatives say "yes" to her requests and then she never hears back from them. Linh believes that the representatives are simply ignoring her requests to access subsidies, even though she is entitled to them. This situation was very frustrating for her, and it left her feeling as though she was constantly "chasing" subsidies with no results.

Linh reported that she did not know Cai's HIV status, but believed that Cai was HIV positive. Cai was often very sick from an unidentified illness and pain in her joints. In order to ease her granddaughter's pain, Linh often massaged her throughout the night. Cai was constantly trying to help Linh around the house with chores and farming in their back yard, but Linh often refused her because of concern about her health. Linh had never received any formal HIV education, but reported receiving information from mass media like radio and TV.

Linh suffered from several health problems, but had not gone to a doctor in over a year and said that she deliberately avoided the doctor at all costs because she did not have health insurance and was afraid of the expense. She said that she was constantly fatigued because of her health conditions and her granddaughter's illness. Linh's ailments included poor eye sight, memory loss, and what she described as a breathing problem that caused her heart to beat faster when she breathed deeply.

Linh said that she was able to manage her difficult life by becoming a mother again to her grandchild, and fully identifying her maternal role. Linh often referred to herself as Cai's "replacement mother" and referred to Cai as her "daughter." Linh was familiar with hardship and loss due to the impact of HIV/AIDS on the middle generation. She comforted herself by thinking about other families whom she perceived to be in similar or more difficult situations than hers. Because Linh lived in a neighborhood with a concentrated epidemic of HIV, she knew several other grandmothers who had experienced even more trouble from HIV positive sons and were in more difficult financial circumstances than her family.

Understandings of Caregiving

As illustrated through Linh's story, for Vietnamese grandparents raising grandchildren in the context of HIV/AIDS, the meaning of caregiving included a cross-generational caregiving role that extended beyond "skipped generation caregiving." This caregiving role embodied a career of many years, and was fluid, porous and continually-evolving throughout the caregiver's older adulthood. Three dimensions emerged related to "understandings of caregiving": caregiving was a burden; the caregiving burdens decreased and shifted after the death of the adult child; and the caregiving role could be a temporary one.

Caregiving as a Burden

Although grandparents discussed and demonstrated their intense love for their grandchildren, they were burdened by their caregiving role. Faced with significant challenges for a long period of time, grandparents frequently used phrases like, "I had many burdens even before taking care of this child" and "I have a very miserable and hard life." The ways that

grandparents were burdened included three different dimensions: material, psychological and social/environmental.

The primary burden defined throughout the interviews was financial. Grandparents did not have the resources to provide financially for themselves and their grandchildren. Key informants agreed that there were significant trials that faced the skipped generation caregiving population. These problems increased if the grandparent cared for a child who was living with HIV/AIDS. Phoung, a key informant, reflected on the material burdens that she observed in her work with grandparent caregivers in a home-based care program. She said,

Their grandchildren fall sick frequently. If grandparents only had to provide income for every day food, then I think that they would be fine. But they also have to take care of the medical treatment and this is very expensive. They struggle to bring the children very frequently to the hospital because they do not have the means of transportation to bring the children for their periodical check-ups. (Phoung, orphanage care worker, urban Hanoi)

The majority of the grandparents also carried a psychological burden due to the demands of a caregiving career. The uncertainty of the future of care of their grandchildren and themselves created worry and depression. The longevity of the caregiving career psychologically taxed the grandparents. One respondent (Loan) shared that her caregiving burdens were often overwhelming, “Sometimes I feel very bad. Sometimes I am full of tears and it is very large. Sometimes I cannot remember the best feeling that I have had in my life.”

In addition to psychological burdens, grandparents experienced social and environmental burdens in the form of negative interactions with family and community. Tragically, after going to the funeral of his son, Duong’s husband committed suicide by hanging himself from the ceiling of their small one-bedroom apartment. His rural family had humiliated him for not raising his son properly and bringing shame to the family. Duong reported that he felt as though there

were no alternatives and could not deal with his shame in any other way. Key informants frequently discussed stigma and discrimination among the major burdens for grandparent caregivers. Phuong, who worked in an orphanage for children affected by HIV/AIDS, spoke about social burden for grandparents in their home based caregiver program:

The problem is the discrimination that they face in the community. Their children cannot go to school and if they do, they face discrimination. Another thing is that the children are depressed. Children and caregivers often become depressed and live in isolation. This is a large difficulty for the children because often the community does not accept their disease. (Phuong, orphanage worker, urban Hanoi)

There was significant overlap between the categories of burden: material, psychological and social/environmental. For example, Ngon, a key informant who worked with grandparent caregivers in a self-help group identified finances, stigma, and the connection between finances and discrimination as the main burdens facing grandparents:

One of the challenges is that they face discrimination and stigma from the community. For example if the caregiver is selling noodles, once the people in the community find out that they have a person with HIV in their family, then they no longer will buy the noodles from them, and they can no longer sell them. They want to keep everything a secret. (Ngon, self-help group worker, urban Hanoi)

Ngon observed that grandparents material burdens could not be remedied without their social burden of stigma being resolved. Ngon echoed grandparents' primary concern of not being able to continue to finance their grandchild's education. She said, "Many of the grandparents have a low education level and do not have enough money to support their children's study."

The views of the key informants matched those of the grandparents in the sense that they both considered caregiving roles to be burdensome, and they described similar and overlapping properties of material, psychological and social/environmental burdens; however, they prioritized them differently. Grandparents continually referred to material burden as their central

concern, whereas key informants cited “stigma and discrimination” as the primary concern facing this population because of its impact on psychological and material burden.

Caregiving Burdens Decreased After Death

The majority of the grandparents felt that caregiving burdens decreased after the death of their adult child, and that the caregiving role then became less demanding. Reflecting on the time when her HIV positive son was still alive and her granddaughter was a toddler, Linh described how her son continuously stole household items and sold them for drugs. She said,

It was the most difficult when she was small, so I couldn't go to work. Her father was like that and it was very difficult. Furniture pieces in the house went missing one by one; most of them were gone. That was the period when I was most mentally and emotionally miserable and worried. (Linh, 60)

Although the death of her son was a tragic event, prior to his death, Linh experienced a double burden of caregiving tasks because she was simultaneously caregiving for her son and granddaughter. Duong, who was raising an eight-year-old grandson, explained how her life became less stressful after her son died and his brother was sent to a rehabilitation camp:

My biggest difficulties were in the past when I not only had to take care of him [the grandson]; I also had to take care of his father and uncle, who were both drug addicts. My husband, after his retirement, had to ride the cyclo to earn money to keep the family with two sons and a daughter in-law. My son went to work but he didn't bring the money home; he spent all of his earnings buying drugs. (Duong, 64)

After the death of the adult child, grandparents found themselves providing care only for their grandchildren, and this was considered “easier” even though there were emotional costs associated with losing an adult child.

The Temporary Nature of the Caregiving Role

Despite the fact that grandparent caregivers were “career caregivers” and had been in caregiving roles for many years, the theme of caregiving as a temporary role emerged from the interviews. Many grandparents acknowledged that their caregiving role would soon come to an end based on their age and inability to continue to provide care. The majority of the grandparents were living in poverty, because they did not have the means to sustain themselves and their grandchildren. Hien was providing care to two grandchildren in rural Hai Phong. She said, “This is not enough for them when they grow up. I just have simple food and can’t subsidize them in the long term.” Other grandparents viewed their roles as temporary because they either thought that their grandchildren would eventually die of AIDS, or did not believe that they themselves had much longer to live due to failing health.

Understandings of Coping

Grandparents coped with their “temporary role” through thinking about the future, a time when they would no longer be able to or have to continue their care. Grandparents’ resources dictated their future hopes and dreams for their grandchildren’s future. Four properties illustrate grandparent’s understandings of coping, and their future orientation for their grandchildren. These four properties include: (1) making plans with extended family, (2) investing in education, (3) not having options for future care, and (4) seeing orphan village as final option. Whether and how people planned and dreamed was affected by key contextual factors such as the HIV status of the grandchild, the family financial situation, the family network, the health status of grandparent(s), and the extent of community resources.

Making plans with extended family

Some grandparents had already devised a plan about who was going to take over the caregiving responsibilities when they could no longer raise their grandchildren. Often grandparents planned to rely on their extended family networks, but acknowledged that these arrangements were uncertain, not ideal, and could cause harm to the grandchildren.

Khuyen was a paternal grandparent. She had developed a mutual agreement with the maternal grandparent of their grandchild:

I have always said that if I pass away, then I will send her back to her mother's mother and we have talked about this and have an agreement. Her maternal grandmother is 60 years old. She is still in good health and she has agreed to my proposal. (Khuyen, 78)

However, even if grandparents had a plan in mind for the future care of their grandchildren, these plans were often complicated, less than ideal and created burdens for others.

Hien expressed doubts about future plans for her two grandchildren:

I have to lay my hard responsibility on their uncles and persuade them to bring them up until their niece and nephew are mature. I don't want anyone, not even their relatives to say bad things about them when they have to spend their money for those children after I pass away. If I pass away, then I will ask their uncles to bring up the children but it will put both the uncle's family and the children in a difficult situation. The partners of the children's uncles will find it difficult to accept and will talk badly to the children, like say --it is this way because of your drug-addicted father and now I have to take responsibility for you. (Hien, 63)

Grandparents who had solid and stable plans for the future were those who felt supported by their family networks, had family in close proximity, and were relatively financially stable.

Investing in education

When there was not a solid plan in place for the future care of the grandchildren, grandparents often coped through relying on hopes and dreams about the futures of their

grandchildren. Often these dreams involved the hard work and money that the grandparents had invested in their grandchildren's education in hopes that these investments would be able to carry the grandchildren forward in life. Binh said, "I hope maybe in the future when my children grow up that they can make money for all of the debts that I have collected to pay for their school."

Hien hoped for the continued support from her eldest grandson's mentor/benefactor; this was a relationship arranged by his mother before she left her children to remarry after her first husband died of AIDS. The grandmother hoped that her grandson's mentor would continue to offer financial support after her death so that he could continue his education. She said, "I hope my first child who is in 12th grade continues to be supported by his adopted grandfather and continues going to school through his support and encouragement."

Not having options for future care

The majority of the grandparents, especially those with extremely limited resources, were not able to provide a plan of care for their grandchildren's future. These grandparents were limited by poverty, age, and capital which prevented them from devising a plan for their grandchild's future after they were gone. My and Huan, a caregiving couple, said, "We have no plans because we have no money. We just hope that we have enough money to maintain his study and bring him up until he is old enough." My and Huan were a retired couple living in urban Hanoi and the paternal grandparents of a 12-year-grandson named Long. Their son died of AIDS seven years ago. My and Huan were taking care of Long without any financial assistance from the government. In addition, they did not have any support from their relatives, all of whom lived in the countryside. Long's mother had abandoned him, and she remarried shortly after the death of her husband. His father was addicted to drugs and married in 1997, became infected

with HIV in 2003, and died in 2005. For several years, their son and his wife, both unemployed, lived with My and Huan and relied on their support and care. Throughout my time interviewing and observing My and Huan, they revealed that they had suffered numerous losses including the deaths of all four of their children to accidents and illness. The grandparents were also concerned about Long's health problems, and described his physical condition as being "weak" and "having twitching eyes." They also described his mental condition as being "retarded" and "not good in school." Their view of Long's health and the numerous tragedies that they had been forced to face directly contributed to their sense that they could not plan for the future.

For grandparents who were not able to provide a plan, they dreamed of future situations which would help carry their grandchild forward in life after they were gone. For Tam and Kien, this dream was a house. Tam was an adoptive grandmother who was living with HIV and caring for four HIV+ orphans who were previously living in the street. She also did not have any options for the future care of her grandchildren. Instead of devising a plan with no resources, she hoped to secure housing for her grandchildren. She said,

My only wish is that I can have a house, a simple house so that there is enough space for the children. So they are free to play and have plants. That is my only wish. The children would have a place to live and that there is someone who can care for them, just like I do now. (Tam, 55)

Kien was also concerned about providing a residence for her thirteen year old grandson. She did not have resources to build the house, but she thought that being able to provide her grandson with a house would ensure a future which was different than this father's. She said,

If children don't have a solid foundation, then they will be dropped into social evils and they will destroy their lives. I just wish that I had some money to build just a little house so that we can stay there. That little house would be his foundation, and that way, he will only have to worry about finding a job but that little house will be his accommodation. That is the most important wish for me. (Kien, 74)

The concept of “not having options for future care” of their grandchildren violated normative roles of grandparents. In typical grandparenting situations, grandparents would not have to worry about the future of their grandchildren, knowing that the parental generation would provide care. In Vietnam, it is also the expectation that the parental generation will care for their aging parents as well as provide for their children. With the elimination of the parental generation due to HIV/AIDS, the grandparents have had to struggle to figure out ways in which their grandchildren could survive after their deaths. Above all, every grandparent hoped that they would be able to live long enough to see their grandchildren grow up and be able to support themselves.

Seeing orphan village as final option

Some of the grandparents tried not to expect too much for their grandchildren’s future and would not allow themselves the freedom of dreaming about the future. Bich recognized vulnerability in her caregiving situation: “There are no strengths in my family. My life is breakable like glass because I am old enough to pass away. So I do not think about the future.” In situations where grandparents could not provide a desirable option for future care, they relied on the orphan village, which was located in Ba Vi, a rural area outside of Hanoi. The orphan village was an institution founded in 1984 by the Department of Labour, Invalids and Social Affairs of Hanoi. This were known to the grandparents as a place that accepted “disabled” children and orphans of the AIDS epidemic. They also gave care to elders without family and homeless people. Grandparents considered the orphan village because of their grandchild’s HIV positive status, along with their own age, poverty and failing health. Poignantly, many grandparents simultaneously considered their own deaths and their grandchildren’s deaths.

Hoa was the oldest caregiver in the study, and was deeply concerned about what would happen to her 5-year old adopted grandson named An. She said, “I hope that he can grow up and he can take care of himself. That is all. I never dream of the day when he gets married, or has children. I am too old.” Hoa expressed on several occasions that she was very worried about the future of her grandson, so she prepared her grandson by testing his reaction to orphanage care. She said, “I am now 80 years old. When I die, the child will be sent to an orphanage. This morning I pretended to frighten him that you are coming to take him to the orphanage. He was really scared, but it’s the only way when I die.” She also did not have a desirable plan in place, so she thought that the only alternative was to place him in an orphanage, which was deemed the least desirable caregiving situation by the grandparents. As suggested, Hoa also used my data-collecting visits and observations as opportunities to test her grandson’s reaction to institutional care. She included him in the conversations about future care, which may have seemed cruel, but Hoa justified this by wanting to prepare her grandson for the worst so that he would be strong in handling the inevitable. While Hoa’s actions were intentional with respect to considering the future, she did not allow herself to dream of a future for the two of them together, and saw the orphan village as their only option.

Cam was another grandparent who considered the orphan village as a worst-case scenario. She hoped that her son would be able to defeat his addiction to heroin and come home to care for his 9-year old son who was HIV positive, but she had her doubts. She said, “I am hoping that if the father comes back from the rehabilitation center, he can care for him after I am gone.

Otherwise, I will bring him to the orphan village.” Bich agreed that the orphan village was her last choice for her 9-year old granddaughter who was living with HIV. She explained the options that she had considered, “My expectation is that I would love my grandchild to go to

school and finish and complete her studies. If I pass away, I am hoping that social support will come. When I am unable to care for the child, I will bring her to the orphan village.”

Understandings of Disease

Four themes emerged that pertain to the grandparents’ perceptions of disease: (1) understanding HIV/AIDS as the result of social and criminal behavior, (2) having knowledge deficits, (3) hiding HIV status, and (4) preferring not to know. Grandparents understood HIV as a social disease, which for them was the result of criminal behavior that was “brought about by social evils.” This understanding was coupled with significant deficits in knowledge about HIV/AIDS and its transmission or, “I don’t know anything about HIV.” Both of these understandings often led grandparents to hide the HIV status of their family members and to avoid getting their grandchild tested for HIV.

HIV/AIDS as a social crime

From the grandparents’ perspective, HIV-related stigma continued to exist among both the older and younger generations. Duong explained the events that led her husband to commit suicide after returning home from his son’s funeral. The older members of her husband’s family had held him responsible for “the social crimes” that their son had committed, “After our son’s death, he went to the countryside where he suffered from insults from relatives. They blamed him for not educating his son well, and then he could not bear to live with the failure and insults from his relatives.” In addition, grandparents reported that their grandchildren were bullied at school for being from an “HIV family.” Khuyen shared her concerns about her nine year old granddaughter, “There is a lot of stigma against my grandchild. I know this because sometimes

she comes back from school and she is very sad because other children do not want to play with her because they knew that her parents were HIV positive.”

Grandparents explained that their children had a “social disease” or were involved in “social crimes” when referencing how their adult child became HIV positive. When asked how they defined social evils, grandparents and key informants identified drug use and prostitution, which they believed were related to a deep moral character flaw. Moan said, “a social disease means that you use drugs, that you are a playboy, and you are involved in social evil activities, so that is a social disease.” Kien said, “HIV is because you play around too much, try bad things, inject drugs and you are addicted and then you have HIV. HIV is something that you get when you are a playgirl or playboy and you get together with bad people.” When I asked Kien what she meant by being a “playboy or playgirl” she replied, “It’s that you “work” (uses Vietnamese word for prostitution) and hang out with other people who are drug users and then you try and you are addicted too. A playboy is a drug user.”

Although the grandparents reported that stigma had decreased in their community over time, the concept of social evils continued to lead to stigmatization for individuals who were living with or had been affected by HIV/AIDS. The majority of the grandparents used the word, “social evils” or “social disease”³ instead of “HIV/AIDS” in their interviews. When telling me the story about how her adoptive grandson’s father died of AIDS, Hoa said,

He caught the social disease. People said that the father caught HIV first, then gave it to his wife. He was so weak that he could not drive *xich lo* (bicycle taxi) anymore. When the child’s mother died, she lived so far away that we did not know how she died. Yes, this is their father. (Hoa, 78)

³ As suggested, “social evils” and “social crimes” were common terminology in the interviews and observations. However, the key informants always used the term “HIV/AIDS” because they were trying to decrease stigma in the communities where they worked.

Cuong, raised was raising his 10-year-old grandson along with his wife Hanh. He was retired from the military and had his own struggle with “social crimes.” Cuong was disabled in the American War, because of shrapnel embedded in his arm. As a result of the trauma he experienced in the war, he had begun injecting heroin 25 years ago. Although he was recovered at the time of the interview, his sons also became addicted and died of AIDS. Cuong shared his view on the AIDS crisis, “Social crimes are a common problem for the whole world rather than any single country. My family is also affected by social crimes. One of my children was seriously involved in a social crime. He’d been using drugs for over 15 years, nearly 20 years.”

Cuong reflected on his son’s experience with addiction, and how being involved in high risk behaviors led to his death,

He died of social crimes; he was a drug addict. After coming back from the rehabilitation center, where he had been twice or three times, he could not get rid of drugs. When it became so severe, he asked to be taken home. At that time he was too weak to use more drugs. After two months, he passed away, died of HIV. (Cuong, 69)

Duong shared her concerns about her grandson’s future based on her beliefs about his father’s character, “I don’t know if he (my grandson) can grow up into a good person or not. His father was corrupt; he was addicted to drugs.” Moan also explained her fears about the future of her two grandsons, “There are many risks around them so if they do not have a job, then they may fall into social evils.” Yet, other grandparents viewed their grandchildren as being very different from their parents, and believed that the grandchild would learn from the mistakes they witnessed in their parents, or “they look at their father as an example and they will never make that mistake again.”

Although grandparents had significant knowledge deficits when it came to HIV/AIDS, they were very familiar with the behavior and patterns of drug addicts. Grandparents blamed

drug addiction for HIV coming into the family. Since injection drug use was the most common method of transmission of HIV among this population and in Northern Vietnam, grandparents were knowledgeable about not only the process of obtaining heroin, but also the behaviors that were related to heroin withdrawal and the cycles of their children seeking more heroin. Boi was the one of two grandparents who still had a living son, although he had been absent from her life for several years while he was imprisoned in a rehabilitation camp. He had recently escaped from the camp, along with 1,000 other prisoners, and was wandering the streets and injecting heroin. Boi shared the stories that she had heard from her community about her son's drug abuse cycles,

He is injecting. People have told me that they have seen him eating dirty things on the street, like dirty food. When they tell me that, I feel so bad because he is my son and I feel so sorry for him. My other children, my daughters told me that they went out to find him and ask him to come back home but he refused. He won't come back to me; he does not want to come back. (Boi, 63)

Hue and Tuan shared their experience in trying to help their daughter through periods of heroin withdrawal:

Before when Hung was still alive, if you would have visited us then, then you would see nothing in this house, because a drug user would never agree to see anything in the house. Because you know, when you have a child, however she is, you still love her, you witness her craving for drugs, and it is terrible, and at that time she is not conscious, and she can't control her behavior at that time. (Tuan, 71)

Grandparents faced manipulation through their adult children when they were going through heroin withdrawal. Hien said, "My son would often come back for money. He would often come back and threaten to put his head in the wall. He would sell everything! So I gave him money when he asked." Grandparents also observed that their neighbors were always on high alert, needing to protect themselves and safeguard their possessions when adult children and their friends were in town.

Knowledge deficits about HIV/AIDS

Although grandparents were very familiar with drug addiction, many lacked knowledge about HIV and its transmission. Thuy was a grandmother raising her 12-year old granddaughter named Dung in a very isolated rural town outside of Hai Phong. She did not have access to any support clubs or home-based caregivers, and therefore was never able to receive information about HIV/AIDS. She had seen commercials produced by the government on television but had never received one-on-one educational information. Throughout our interview, Thuy revealed a great deal of medical misinformation about HIV/AIDS. For instance, she told me that because she thought that Dung was HIV positive, she intentionally kept her from the clinic. Thuy also believed that because both of Dung's parents had died of AIDS, Dung was automatically HIV positive.⁴

She said,

But I know from the television that 30% of the children with HIV positive parents are because they know their status and avoid natural childbirth by surgery. In this case, the children can be protected by avoiding the blood of the mother. At the moment, I still believe that my granddaughter is living with HIV. I am scared to really know the truth. She often vomits after having a meal like her mother, and she is sick for months at a time. So, I believe that I know her status, even though I have never taken her to get a test. But many people tell me that she looks like she has good health, but actually maybe she is like her paternal family, "fat but sick." (Thuy, 62)

⁴ At this point in the interview, my interpreter and I decided that it would be unethical to not provide a basic understanding of HIV/AIDS and reasons for transmission after the interview. We also wanted to urge Thuy to get Dung tested and give her some resources for treatment. My interpreter, who worked for an NGO in Hai phong that worked with communities affected by HIV/AIDS thought that it would be more appropriate if he intervened with HIV information, and I agreed. Below is a transcript from this conversation. The interpreter said, „I have to explain to you that only 30% of children who have a mother living with HIV will be infected from their mother, so I would like to highly encourage you to go get her tested to be sure. That way if she is negative, you no longer have to worry and if she is positive then you will be able to get her on the proper medicine, ARV.”

Interviews with participants illuminated the fact that most of the grandparents did not have access to adequate HIV/AIDS information related to the transmission, symptoms and treatment. As a result, these knowledge deficits led to reluctance to seek testing and treatment for their grandchild(ren).

Grandparents who were knowledgeable about HIV were usually involved in social welfare programs such as self-help groups, sharing clubs, empathy clubs, or had a home-based caregiver coming to their residence. One grandmother named Sa became highly involved in communication campaigns about HIV, as an educator and home-based caregiver for families (like hers) who had been affected by HIV/AIDS. Sa explained her passion for educating others, “I have gone to various workshops and trainings on how to prevent the transmission of HIV/AIDS and how to reduce stigma and discrimination, and so I became a communicator to disseminate information to other people, to help people to understand more about HIV/AIDS.” Tam was another grandmother who was an educator and outreach worker in the community with a particular interest in hard-to-reach populations, such as male sex workers. Through her work, she had adopted four street children who were HIV+, and had been abandoned by their parents. Tan shared that she had used many sources to access HIV information:

I have studied so much about AIDS that I am a trainer already. I have conducted many trainings for various organizations in Vietnam. So whenever I want to update any information, I just contact the Center of Health and Communications. So now I have all kinds of illustrations and instruments like condoms, for both male and female and the penis models, everything. I go everywhere. I can access every place and communicate with people about HIV, with MSM [men who have sex with men] in their working place. No one can access these places and no one can go there, but I can go there, because they trust me. I also receive monthly subscription to the magazine “AIDS and Community.” (Tan, 55)

Sa and Tan were the exception, because most grandparents were isolated, either geographically or socially, and had little to no knowledge about HIV/AIDS.

Hiding HIV/AIDS status

The connection between HIV/AIDS and social evils combined with knowledge deficits about the nature and transmission of the disease, led grandparents to hide the HIV status of their family members from the community. Grandparents hid their family members' disease in two ways: concealing the HIV status of their adult child in the past; and hiding their grandchild's HIV status currently from the community. Hanh reflected on her son's experience of veiling his HIV status prior to his death:

My son hid his case as a patient. When Mrs. Lien [the social care worker] came to visit him, he refused to meet. Not until he became too emaciated did he let her take him to treatments, but it was too late. She came and helped him to do cleaning just a few days before he died. She and I did all of the procedures of care. (Hanh, 63)

Those who did not currently hide information about their family nonetheless had periods in the past when they had not disclosed information or had kept secrets about the HIV status of their family member(s). Caregivers revealed that they had kept secrets about 10 years ago at the beginning of the AIDS epidemic. However, there were grandparents who still believed that it would be in the best interest of their family to withhold information about their grandchildren. Hoa hid her grandson's status out of fear of the community's response. She worried about her grandson based on rumors that she had heard from her friends:

In my opinion, I don't want people to know about him and the origin of his social disease! In other areas, they burn all of the belongings of dead HIV patients. Especially in the high lands [where her grandson had been living before she adopted him], they have heavy discrimination when it comes to the social disease. (Hoa, 78)

Preferring not to know HIV status

In addition, some grandparents were so fearful of the truth of their grandchild's HIV status that they preferred to remain unaware. My and Huan, an urban grandparent couple, shared

that they were not interested in having their grandson tested for HIV. My said, “I don’t dare to take him to the testing center so we don’t know whether he has HIV or not. We are scared so no testing yet. If he had HIV, it would be very awful; we would be very depressed.” Another group of grandparents said that they feared the truth, which caused them to avoid having their grandchildren tested for HIV, despite having access to an HIV testing facility and free anti-retroviral treatment. According to Linh, a rural-based grandmother,

I have taken my grandchildren to the clinic to get tested for hepatitis, but I did not ask them about her HIV status...Many nights I can’t sleep because I stay awake thinking and being scared about that. If this happens and she has HIV, then I do not know how to resolve this problem. (Linh, 60)

Another grandmother was unaware of the free HIV testing and care available in Vietnam. When I asked if she ever had her grandchildren tested, she said, “I’m old and I don’t have money to take them to the test.” Other grandparents were uncertain about the HIV status of their grandchildren and did not fully trust the doctor or the results of the test. Khuyen, who was raising a nine-year-old granddaughter in the same coal-mining town as Thuy said that her granddaughter was presenting signs of an illness:

Her dad took her for an examination and for an HIV test when he was alive. We were told that she is negative. I do not know if she is infected; I think there is a chance that she might be because she is very weak. She is sick a lot. She had some swelling in the lymph nodes of her neck from the beginning of the year and was given medicine at K6 [her school]. We were told that adults have to take the medicine for six months and children do it for four months. One tablet a day for this illness. (Khuyen, 78)

For grandparents, not having their grandchildren tested led to uncertainty and anxiety about their grandchildren’s status, and prevented the grandchildren from receiving treatment if needed. Yet the fear of knowing that their grandchild might be HIV positive led grandparents to choose inaction over testing.

Feedback from participants: source of AIDS, stigma, and economics

I learned more about the perspectives of these grandparents about disease through member checking and focus groups, as the grandparents commented on the phases of caregiving (Figure 1). They provided more insights into how AIDS was related to stigma and economic issues, and other insights on the four dimensions related to grandparents' understanding of disease. They suggested that my original model (Figure 5-1) was accurate for grandparents who had children that were injecting drug users, but agreed that the figure should be adjusted if the adult child had contracted HIV from sex (N=2). The first scenario involved having a son who contracted HIV from a sex worker, and the second scenario involved having a daughter who contracted HIV from her husband. In the opinions of key informants and grandparent caregivers, having intercourse with a sex worker was much more socially acceptable, less financially draining to the family, and less shameful to the family than being addicted to drugs. This was related to the socially "semi-acceptable" practice of wealthy businessmen who were clients of sex workers, who hid their HIV status from their co-workers, and who supported their families financially before and throughout their illness.

According to the participants, instead of robbing the family of all possessions, the sexual encounters that led to contracting HIV were considered flukes, and these men were still able to live "normal" and often secretive existences until symptoms started to emerge. While illness related to HIV/AIDS resulted in a great financial loss for the family, these families did not experience the same level of chronic stress, chaos and worry that came from caring for a troublesome drug user over time. One key informant reflected on her experience in working with grandparent caregivers who did not have drug addiction in their families:

In the old times, most people caught HIV by using drugs but for many people who caught HIV recently, the reason is because of sex work. With people who are not using drugs, when they find out that they have HIV, they are ten times more shocked than people who use drugs and so is their family. After that, they still hope for some cure to continue living and so do their parents. In these cases, finances are not a big problem for them, they only need silent support from someone. (Tuyet, self-help group worker, Hai Phong)

Grandparents who had not faced drug addiction and injecting drug use in the family also wanted Figure 1 to reflect this difference in the source of HIV/AIDS. They disagreed that their “caregiving burdens decreased and shifted” following the death of their adult child. Instead, it was their perspective that their caregiving burdens “increased.” Thuy, whose daughter became infected with HIV from sex with her husband, reflected, “Actually, when her mother was still alive I felt better. When she became sick I felt very sad.” The member-checking interviews and focus group conversations revealed that the mode of HIV contraction was one of the most influential factors in terms of how caregiving patterns and processes emerged.

For skipped generation caregivers affected by HIV/AIDS, individuals thought about the future in ways that were very different from typical grandparent experiences. Grandparents in this study had experiences that were shaped by their difficult circumstances as well as by their understanding of HIV as a disease. These experiences and understandings are influenced by the environment in which they occur, so the next chapter will address the contexts of both the Vietnamese culture and the local communities in which grandparents lived.

CHAPTER 7: REFRAMING ROLES AND EXPERIENCING CONTRADICTIONS

The second research addresses the contexts in which grandparents form their understandings of caregiving roles in their lives. The contexts include both their perceptions of Vietnamese culture and its impact on defining whose responsibility it is to care for the orphaned grandchildren, and their perceptions of their extended families' and surrounding community's response to their caregiving situations (See Table 7-1). First, this chapter describes the theme of "reframing traditional roles" within Vietnamese culture and how such reframing differs from normal traditions of Vietnamese caring structures. Four dimensions emerge within this theme and involve grandparents' understandings about issues of responsibility toward their orphaned grandchild(ren): (1) viewing the paternal side as responsible, (2) viewing the maternal side as responsible, (3) assuming responsibility based on resources, and (4) seeing cultural norms as violated. Second, I discuss the community in terms of experiencing the contradiction of the community's reaction, encompassing grandparents' shared impressions of family and community reactions to their caregiving roles. The theme has four dimensions: (1) feeling isolated, (2) feeling compensated (3) believing that family responsibility is stronger than the community's responsibility, and (4) experiencing the stigma paradox. Again, these categories and dimensions are important because they relate to the context in which grandparents understand their caregiving roles.

Table 7-1: What is the context in which meaning is formed?

Sub-question	Theme	Dimension
Perceptions of Vietnamese culture with respect to parenting orphans affected by HIV/AIDS	Reframing traditional roles	<ul style="list-style-type: none"> • Viewing paternal side as responsible • Viewing maternal side as responsible • Assuming responsibility based on resources

Perceptions of Surrounding Community's Response	Experiencing the contradiction of the community's reaction	<ul style="list-style-type: none"> • Seeing cultural norms as violated • Feeling isolated (geographically, socially) • Feeling compensated • Believing that family responsibility is stronger than community responsibility • Experiencing the stigma paradox(changes over time, differences by area, blame, fear, pity)
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Through Figure 5-2, I highlighted the forces that influence caregiving for grandchildren, after the adult child's death, and the intersection between grandparents' perceptions of their culture and their perceptions of their community. These perceptions affected the personal meanings that grandparents held about understanding caregiving, coping and disease (see Chapter 6). Figure 7-1 described, "The context in which meaning is formed" and the connection between traditional Vietnamese familial roles (culture), and the grandparents' experiences of the perceptions of others (family and community). Through "reframing traditional roles" (theme one) grandparents redefined traditional roles based on their own personal narratives. This reframing caused grandparents to embrace beliefs about the differences between the roles of paternal and maternal grandparents. Often their relationship with the other side of the family, especially their daughter-in-law, caused grandparents to see that cultural norms have been violated. And often grandparents cast aside traditional family roles and became pragmatic in assuming the caregiving role based on available resources. Grandparents often experienced a "contradiction of their community reaction," (theme two) which led to grandparents feeling isolated or compensated in their caregiving roles, which related to experiencing a paradox when it came to stigma in their family and community. In addition, although grandparents appreciated

the community's efforts to support them, in the long run, they relied more on their family roles and responsibly than on community support.

<<INSERT FIGURE 7-1>>

Perceptions of Vietnamese culture with respect to parenting orphans affected by HIV/AIDS

One of the more surprising results of this research was that grandparents did not perceive a single set of cultural rules stemming from Vietnamese traditions and values about caregiving. Instead, grandparents “reframed traditional caregiving roles” and constructed cultural values based on their personal caregiving stories. This led to a variety of grandparents’ perspectives on how Vietnamese culture views caregiving responsibilities. Figure 7-1 provides a framework to discuss the relationships between the themes and dimensions that have emerged from this study.

Viewing the paternal side as responsible

Traditionally in Vietnamese culture, it is the responsibility of the paternal grandparents to care for the grandchildren if anything happens to the parents. After marriage, women move into the homes of their in-laws and become a part of that family. It is understood that a woman will move away from her parents’ home after marriage to fulfill her obligations to her new family. In the Vietnamese language, after marriage, a woman refers to her in-laws as her "inside" family, and to her biological parents as her “outside” family. Moan elaborates on this tradition when she describes the home that she lives in:

This is my own house, but actually in Vietnam when you get married to a man, you have to follow him to his family. If he lives with his parents, then you have to live with his parents too, under the same roof, in the same house, so this is my case, and my husband is the eldest son of my in-laws. So that means that he will inherit all of the assets, not all, but he will stay in the house of his parents. (Moan, 60)

Traditionally, it is the obligation of the son to stay in his hometown living within his parent’s home. In the rural areas it is most likely that he will have to travel to bigger cities for

work. This means less frequent contact with elders and children. It is the daughter-in-law's responsibility to care for her mother- and father-in-law as they age, and it is the responsibility of the son to care for his parents financially as they age. Although maternal grandparents have significant roles in the lives of their grandchildren, it is the paternal household where the grandchildren reside. Often maternal grandparents with no sons were in a more vulnerable position when it came to their future care. Thang Thang, a maternal grandmother, explained that she had five daughters and this was a challenge because the paternal side was her daughters' priority. She reflected on Vietnamese culture when it comes to caregiving for the paternal side, "I have five children. All of them are daughters, so they have their in-laws to take care of. Their main responsibility is their husband and their husband's family, so I have very little help from them."

About half of the grandparents in this study were paternal grandparents (52.8%). Many believed that it was their responsibility to care for the grandchild, and that they were fulfilling that obligation. Cuong, a grandfather who was raising his grandson with his wife Hanh, said, "In general, we give him our best care. Because he is the first paternal grandson, especially since his mother left. We, the grandparents have done our best; we never let him down or have any trouble." When asked who should be the rightful caregiver of the grandchild, most of the paternal grandparents said that it was their role to fill.

My said,

The paternal side is always the first to take responsibility. Paternal grandparents should be the main caregivers. The maternal side only gives a hand, and sometimes they may take him to stay with them but not permanently. The maternal grandparents may show their affection towards the child but according to social customs, the paternal should take on the role, unless they can't do it. (My, 68)

Grandparents who were able to provide care to their parental grandchild felt pride in their caretaking responsibility and their ability to fulfill that obligation. When I asked Cuong about how he dealt with stress and fatigue, he said, “We don’t think too much.” He went on to explain his role in his grandson’s life: “When his father died, he is still my grandson and receives all of our care. Since his mother left, his grandma and I have taken care of him, and I have always felt good about that.”

Viewing the maternal side as responsible

Of the participants in this study, 40% were maternal grandparents (the remaining 10% of grandparents were adoptive grandparents). This group of maternal grandparents redefined their ideas about caregiving roles and many willingly took over the care of their grandchild, but were also faced with a lack of options. Thuy, a maternal grandmother assumed the caregiving role because her religious beliefs overrode traditional Vietnamese cultural beliefs. Thuy shared that although she was not the rightful traditional caregiver, she felt obligated to care for her kin: “I’m Buddhist, and she is my descendant. Although she is not my paternal grandchild she is a maternal grandchild; she is of the same blood as me.” Kien was the maternal grandmother of a 13 year old grandson named Son. Kien had not heard from her daughter in several years, but knew that she was HIV positive and was working as a “prostitute” in another province. She described how she became the rightful caregiver of Son: “After the birth of my grandson, my son-in-law started using drugs. So my daughter brought Son back here for us to raise together. We ran out of money, and she moved away to work.” I asked Kien if she has ever had contact with the paternal grandparents, she replied,

No. It’s been 10 years and I don’t know anything about them, just know that they lived in Do Son, I don’t even know whether they are still alive. There was no wedding. My

daughter and him loved each other and then she was pregnant and then he left her. That is a common story in Vietnam, after the girl gets pregnant, the man leaves her. (Kien, 74)

Paternal grandparents frequently held negative views of their daughters-in-law, many of whom had abandoned their child and their caregiving responsibilities. The majority of paternal grandparents told similar stories: their son had become addicted to heroin, destroying his marriage and often infecting his wife with HIV/AIDS. Unaccountably, the grandparents struggled with feelings of anger and animosity not toward their son, but rather their daughter-in-law.

My and Huan were paternal grandparents, but they believed that their daughter-in-law along with her parents should take care of the grandson, because she was still alive. Throughout multiple interviews, My described the frustration and betrayal that she felt from the maternal side of her grandson's family. She said, "At first the child was sent to live with his maternal grandparents, but then the child was sent back to us by the grandparents who did not want to care for him." My also explained her perception on the role of Vietnamese culture in caregiving roles:

In Vietnamese culture, it must be the mother and the grandmother who must be in charge of grandson, the maternal grandmother. But the mother has left and her mother did not want to be in charge of the grandson. So, when the child's mother left she sent the grandson to go and live with her parents. They soon sent the grandson back to live with us, the mother and father of the son. This is against Vietnamese culture. (My, 68)

Most grandparents fully accepted their caregiving role, but only if the daughter-in-law had died. In many cases, the daughter-in-law was sick or very poor and living back with her biological family. (These scenarios will be examined in more depth in the last section, "caregiving norms have been violated.")

Assuming responsibility based on resources

In general, grandparents were forced to have fluid expectations of caregiving roles. Their experiences with HIV/AIDS within their families had altered their adherence to the norms of

Vietnamese culture. Based on the numerous tragedies they had encountered, and their need to ensure the survival of their families and grandchildren, they re-interpreted traditional Vietnamese values for a more pragmatic approach to caregiving.

Sa, a paternal grandmother, explained the hierarchy of Vietnamese caregiving roles while she also described how grandparents often used pragmatism to adapt that hierarchy in the face of HIV/AIDS:

Usually in Vietnam it is the paternal grandparents who take the primary responsibility to raise the grandchildren. But it is also up to the different economic situations of the grandparents. The grandparents with better economic conditions will tend to take care of the grandchildren. The general trend is that the paternal grandparents will take care of the grandchildren but in cases where the paternal family is so poor that they cannot raise the grandchildren, then the maternal family will take care of the grandchildren. (Sa, 65)

Khuyen, another paternal grandmother explained her decision to provide care for her granddaughter, Ha:

Ha's paternal and maternal grandfathers have passed away and Ha's maternal grandmother does not have a pension. I have a pension and my brothers and I were workers. So if I have any difficulties, my brothers can help me. Since Ha's grandmother has never had a pension, no one from that side can help her. Also, I am the one that has the stable income, because of my pension. This enables me to take care of my grandchild. On the maternal side, her grandpa died, and her grandma has no stable income, no pension, so she has to work now to make a living, so she can't care for her like I do. Also another reason is that I live very close to my children, and sometimes the children can support me. (Khuyen, 78)

Mai, a maternal grandmother shared a similar viewpoint in her caregiving role for her granddaughter, Lan:

Personally I don't differentiate maternal from paternal. In my situation, Lan's paternal grandmother is older than me and she is weaker than me. I think that I even have better conditions than her to take the responsibility of caring for Lan. So I have taken that responsibility. (Mai, 61)

Thuy was a maternal grandmother who had assumed the caregiving role because this was the best option for her granddaughter, due to poverty, mental health and violence from the paternal side of her granddaughter's family. She described the family:

In fact, her grandparents are so difficult too. Her paternal grandmother has passed away, and her paternal grandfather has schizophrenia, and he cannot eat by himself. Sometimes, he wanders and walks the streets. They cannot offer any support to her. Their family did not like my daughter; they beat her because they believed that she told other people in her commune about her husband's HIV status, and after that they drove her out. She was a very virtuous woman, and that is why she was bullied by her husband's family. Her husband was born in 1972, and he died before his daughter was 3 years old. (Thuy, 62)

Other grandparents shared the viewpoint that the dysfunction on the other side of the family was too difficult to share with their grandchild and family. Mien and Hieu were raising Bao, a five-year-old grandson. Although they were the maternal grandparents, they had no contact with the paternal side of the family and did not want contact with them:

We do not know where Bao's paternal family is, because we do not know who the father of our grandchild is, so we have no access to his other grandparents. When my daughter was alive she had relations with a man who was a drug user, and he was homeless, and he was parentless. So we did not want to look for him or find him, because if we looked for him and found him, our lives would be even worse and worse. I heard that the parents of that man (Bao's father) died when he was just a little boy at the age of four or five. He then became a street child, so he was living on the street and he used drugs, and he met my daughter and they had a relationship and they had a baby-- that's Bao. So you see, he came from a very complicated background and he has a complicated life. Having a father for Bao will be worse than having no father for Bao. So what would be the reason to find him and bring him here, because why would we want to add more burden to this family? (Mien, 57)

This group of grandparents believed that family resources and finances should dictate which side should assume the caregiving role. Grandparents weighed their resources and support networks against those of the other side of the family. Collectively (and sometimes individually), they made the decision about who would provide care based on who had more, and this often forced them to alter their beliefs about traditional Vietnamese caregiving roles.

Seeing cultural norms as violated

Regarding skipped generation caregiving in the context of HIV/AIDS, there were often times defined responsibilities that were considered violated by the grandparents. Findings from this study showed that grandparents experienced a need to reorganize the family structure due to years of drug addiction, poverty, separation and alienation from their family members.

Throughout this reorganization of the family, many grandparents still believed that caregiving for the grandchild was the obligation of the paternal grandparents or the daughter in-law and her family, and often times norms has been violated.

Hoa was one of two adoptive grandparent caregivers in this study with a caregiving situation very different from those of other study participants. Her husband had passed away, after leaving her for another woman who was a part of a hill tribe. They had not had any contact in over 25 years. However, six months before I met Hoa, her daughter found a five-year-old boy named An who was living in a garbage dump and trying to gather cans and recycling in order to earn money to survive. Hoa's daughter recognized the boy as her father's grandson from his new marriage. This situation broke her daughter's heart, so in desperation, she brought the little boy to Hoa in order to be cared for. Hoa explained her situation,

When I took his grandson here, if I were bad I would have told him to go away, because we were not relatives, while his grandmother is still alive! I was cursed! At that time I was 40 years old, my husband left me after 26 years, and I brought his grandson back and took care of him! My husband left me after 26 years! (Hoa, 78)

Although An was only five years old, half of the teeth in his mouth were black with decay. Hoa and An were living in a shack in the back of her biological son's house, with no running water, and a campfire for cooking meals. Hoa told me that she had previously lived in her son's home, but she had been demoted to the shack by her son due to her decision to care for An. She believed that her son thought that An had HIV and was afraid that he would infect his

children. Although Hoa was loving and diligent in her care of An, she harbored feelings of resentment and animosity. She was dealing with a lot of health issues, had undergone two surgeries to remove her kidney, was going blind, and had recently fallen, injuring herself. She endured constant fatigue, pain and weakness. She made it clear in our interview and observations that she was not the rightful caregiver for this child. She said, “Sometimes I am very angry with the second wife of my husband. The other wife should be the rightful grandparent of the child, but she refused to care for him and rejected her responsibilities of caring for her grandson.”

The majority of grandparents with daughters-in-law who were still alive harbored bitterness and hostility toward them. They felt that it was “unacceptable” and “unbelievable” that the daughter-in-law would abandon her child. This sentiment prevailed even when the daughter-in-law had been infected with HIV from their son and had suffered through the son’s drug addiction and abuse. Grandparents felt that it was tolerable for the daughter-in-law to move on with her life and potentially marry another man, but that she had violated Vietnamese cultural norms when leaving the child behind. Duong shared her negative feelings:

It is unacceptable for a mother to desert her child. Even when the couple broke up, she should have brought the child with her. No one deserts their child and leaves him to his grandmother like this. There are old sayings that a woman could leave her husband but never abandon her son, but she left him when he was only one year old. It seems like he doesn’t have a mother, just like both the father and mother are dead because she hardly cares about her son. I am very upset and feel sorry for him. (Duong, 64)

Duong also reflected on the fact that cultural norms had been violated concerning her caregiving role in her grandson’s life: “His parents were supposed to raise him but we had to do this. It is sad and difficult, mentally and physically.” She also often compared her situation with situations of families living around her and this reinforced her feelings about violated cultural norms: “I feel very upset, especially when looking at other families, their sons are living well. I think about myself and I’m very depressed.”

My and Huan also believed that cultural norms had been violated in their caregiving arrangement. Although they were the paternal grandparents to their grandson, Lap, they believed that Lap's mother still had an obligation to care for her son, and they were the only participants who took their case to court in order to get legal assistance with the custody of their grandson. They did this hoping to force the daughter-in-law to take some responsibility for their grandson:

Two years after the divorce, Lap's father died from AIDS. The court announced that the mother was responsible for bringing up Lap but she refused, pleading that she had no home and had to live on her parents. Then she moved into her parent's home and left Lap for us to raise. She is living with her parents. She does hair washing at a hairdresser's to earn the living for herself and her parents. (My, 68)

Although few grandparents had the means to take their cases to custody court, this example illustrates the complicated relationship the skipped generation caregivers had with Vietnamese culture in terms of assigning responsibility for orphaned grandchildren. There were no clear traditions and rules that every family followed. The grandparents' lives were in a state of flux, as they were constantly trying to redefine their roles according to larger cultural and community values.

Boi, a parental grandmother, had one son who had died of AIDS, and another who was living in a rehabilitation camp. She also harbored negative feelings toward her daughter-in-law and the maternal grandparents, based on their lack of support of her son, because of his addiction. She reflected that caregiving norms had been violated by the maternal grandparents, and that the traditional caregiving role of the wife has been violated by her daughter-in-law:

They refused to raise the children because they are the children of a drug user. They said that they have origins of using drugs so they said that they refused to raise them. In Vietnam, they do not go to their maternal grandparents. In Vietnam is it believed that grandchildren belong to the responsibility of the paternal grandparents. And if your husband is in the rehabilitation camp, then most women will visit every one month or every 2 months, you will go and bring him food, you encourage him to focus on drug

treatment, but she does not do that and she complains that we did not look after him and we did not raise him properly so her husband fell into drugs. (Boi, 63)

The families were desperately trying to get by and restructure their lives in the face of family tragedy, lack of finances, emotional stress, drug addiction and disease. Often grandparents were pragmatic when deciding which caregiving situation would be best for the grandchildren; however, many still harbored emotional attachments to “the old ways” of organizing family life based on Confucianism and tradition. They therefore saw caregiving norms as being violated when the rightful caregiver abandoned the child.

Grandparents’ perceptions of the surrounding community’s response to their situation and needs

Caregivers had a wide range of perceptions about community responses to their situation. These perceptions supported the theme of “experiencing the contradiction of the community’s reaction” and included four dimensions: feeling isolated, feeling compensated, believing that the family rather than the community was responsible to give care to orphaned grandchildren; and feeling stigmatized. Conversations about the surrounding community’s response to their situation and needs included much discussion about relationships with extended family members. With this generation of caregivers, they most likely grew up in communities where their extended family also resided. Over time, their adult children and other family members had migrated for work or for marriage, creating a disconnect between the “family community” and the “community of neighbors.” This situation impacted caregiving relationships within the community and family networks. Grandparents explained that the more support and resources that were available from their family, the less dependent they were on the community.

Feeling isolated

When asked how they felt about their surrounding community's response to their situation and needs, grandparents reported that they felt isolated based on a) geographical location and b) a lack of supportive relationships. In most instances, grandparents felt that the experiences of being isolated both geographically and within relationships were intertwined. This led to being marginalized in their communities, being separated from family, being abandoned by family members (particularly, husbands and daughters-in-law), and being "the only one" able to care for their grandchild(ren).

In traditional Vietnamese families, there are often multiple generations living under one roof, and several extended family members living in close proximity. The lives of the caregivers in this study challenged that norm, as they were left alone in their caregiving roles without help from extended family members. One grandparent, My, reflected on the reasons for her geographical isolation and the challenges that this isolation posed in her everyday life: "The most difficult thing is that there's no one for us to count on when we have problems with health, as we don't have any relatives here, they are all in the countryside and are very poor." Binh shared a similar experience: "I have brothers and sisters, but they live quite far away, in distant villages from this village. They live in other provinces." Although Hoa had eight children, she was separated from them all: "They are all living far from here; each person is in a different province. Because of the poverty, they have moved far away to go look for the means to sustain themselves and their families." When I asked Hien about her family and other children, she replied,

My children live quite far from here. My two daughters both live with their husbands in other districts, not here. My children are farm workers. They don't have stable jobs or stable crops. How can they subsidize their nephew and niece? They are only able to

sometimes give them a little money, a couple thousand *dong* for their breakfast. The siblings also find it difficult to bring up their own children. (Hien, 63)

In general, grandparents who were isolated identified poverty and distance as the reasons why their extended family members could not offer support. And, grandparents with daughters who were also living in poverty acknowledged that it was the daughter-in-law's duty to serve her husband's family and earn money for the household where she was residing.

Tam felt isolated because she did not know other caregiving grandparents like her, which was a finding that was more common in the urban areas. She said, "At the moment, I do not know any caregivers who take care of the orphans. I know parents, but they take care of their own children. So I do not think that there is any caregiver group for orphans."

Several grandparents told me that the geographical isolation led to social isolation in their lives. The recurring theme of having strained relationships with their daughters-in-law contributed to this isolation. The damaged relationship from having a son who was injecting drugs, and was often abusive and unfaithful, led paternal grandparents to be estranged from the care of their daughters-in-law. Linh shared that she was isolated both geographically and socially because her daughter-in-law moved away after the death of her husband, Linh's son:

Our situation is generally rather troublesome. If the child had both her father and mother, it would not be so tough on me. But her parents are no more. Her mother has gotten married somewhere else. I receive no news from her and don't know whether she is still alive or dead. (Linh, 60)

The dimension of isolation was very apparent from my interviews with Duong over three years. Duong was a former school teacher living in urban Hanoi. She often reflected that no one really knew her or understood her current caregiving circumstances. During my observations with Duong and her grandson, we often went to her new place of work. After she retired as a

teacher, buried her son, and lost her husband, she had to go back to work to support her grandson. She had a job washing dishes at a street food stand which sold *pho*, a rice noodle soup.

Duong was very well-liked by the customers and her co-workers. However, she told me that on the rare occasion when she opened up to someone at work, they were “very surprised by her misfortune.” They told her that she looked like a “normal” person, and one would never be able to see the heartbreak and tragedy that she had endured just by looking at her. For the most part, Duong kept that part of her life a secret and had few people around to support her. Even her brothers and sisters could not support her, because they lived far away. One time, I shared with Duong my observation that she had been taking care of people her entire adult life. I asked her, “Who takes care of you?” She shared, “No one. My other son now is still in the rehabilitation center; I have no hope for him. Even when I’m sick, my brother and sister can only pass by for a few minutes, they cannot stay all day to care for me. I have two sons but both of them are hopeless.”

In general, most grandparents experienced some kind of isolation in their lives, either geographically, socially, or both. There were also some positive feelings; however a small number of grandparents felt compensated in their caregiving roles.

Feeling compensated

Often, grandparents felt supported and compensated by their surrounding community. This support came in the form of formal sustenance from NGOs and local organizations, and informal support from their spiritual community and neighbors. They considered the most helpful forms of support to be emotional or “in spirit” support, as well as financial support or support for their grandchildren’s education. Despite experiencing isolation, grandparents often

felt compensated by their community. Although Hue and Tuan reflected on being apart from their family due to distance and poverty, they felt greatly supported by their neighbors:

Our neighbors are very kind-hearted. They visit us and even donate a little money to our grandchild. Sometimes when our grandchild is severely sick, they come to visit and give us money, and of course the people from the Mother and Wife Club also come to visit us to give us money. Yes, of course the club members are the ones who come to visit us most often. But you see, our neighbors who do not have children living with HIV still come to visit us and help us without discrimination and stigma. We live in a very close relationship with this neighborhood. If you live in the countryside, you may see the stigma and discrimination there is more severe. But here in city, it is quite the opposite.” (Hue, 65)

Out of the grandparents who participated in this study, less than half received some form of financial assistance from a private or public organization, even though most of the families were eligible for government decrees, such as Decree 67⁵. Most grandparents felt let down by the government and had struggled to access government “decrees.” Two grandparents were receiving a government pension and felt that this money was enough for them to live on. However, this money was barely enough and they struggled to take care of themselves and their grandchild on a pension meant for one person. Caregivers who were involved with an organization (either community or nongovernmental) felt that the support was excellent. The community groups helped them to reclaim their dignity, connected them to other families who had been affected by HIV/AIDS, and helped them to generate extra income.

Cuong felt compensated by his surrounding community through the formal support of organizations:

I just consider that the loss of my son is in the past, and of course, it remains hurtful for the whole family. But I feel compensated for this loss by the help of the community. I

⁵ In Vietnam, Decrees are rules or laws issued by the government. In the case of Decree 67, it is a provision of welfare services in the form of cash for disadvantaged groups, such as orphans, frail older adults with no pensions or people living with HIV/AIDS.

mean the Red Cross and World Vision both used to give care to us. We really appreciate it. (Cuong, 69)

Hoa felt compensated and supported by her Buddhist religious group:

I go to several pagodas...I made friends with some kind-hearted women at the pagodas; they often come here to visit, and buy books and gifts for the child. Sometimes the pagoda master comes here. I often go to the local pagoda, but on special occasions I go on a pagoda-tour for two days. I took him with me once. (Hoa, 78)

Regardless of the support that grandparents received from the community, they believed that it was the responsibility of the family to take care of their grandchild(ren). And this familial responsibility overrode any available support from the community.

Believing that family responsibility is stronger than community responsibility

Although many grandparents experienced support from the community, they acknowledged that community support had its limitations. Grandparents had seen international programs come and go, with funds that provided helpful but short-term support. They had hoped that such programs would be sustainable, but without long-term funding, they no longer believed that international NGOs would solve their problems. Grandparents said that they appreciated the NGO support for the time being, but at the end of the day, they relied heavily on their families, believing that familial support was more reliable than community support.

Through NGO support was perceived to be helpful, My and Huan believed that family should be primarily responsible for their orphaned grandchild. My stated, "Only when no one can afford to raise him, the child should be sent to the orphanage. The family, people of the same blood, have to take on this responsibility first. If this is impossible, then there's no choice but to rely on society."

Cuong told me about asking relatives for help when his family was in financial trouble. He relied on this help, before going to the community or organizations for assistance:

“Sometimes when we have financial difficulties, they support us through giving us money when we need it.” Grandparents also agreed that their neighbors shared the perception that it was primarily their family’s responsibility to provide care. The community’s reaction to the caregiving role was that they “pitied them” and would help when they could, but they could not provide long-term resources. The majority of grandparents believed that although the assistance from the community was important, community people were not as obligated to care as the family unit.

Experiencing the stigma paradox

Grandparents reflected upon the complicated relationships between family and community in terms of stigmatization. Although stigma was never identified as being a primary concern (compared to financial issues, food, education and the future care of grandchildren), the theme of being stigmatized was recurrent throughout all the interviews and observations. However, being stigmatized was often brought up in the context of the past and/or partnered with feeling supported by the surrounding community, thus creating the “stigma paradox.”

Grandparents reported that experiences of stigma followed several patterns: 1) Stigma changed over time, so that ten years ago it was worse, but government intervention made it better; 2) Stigma was less burdensome in rural areas where many more people were afflicted; 3) Blaming the grandparents was one element of stigma; 4) Being feared by the community based on having an HIV+ family member was another element, and; 5) Being pitied by the community was also common, and was perceived as one motivation for care. This reflects the paradox surrounding stigmatization in the sense that examples involve positive overlaid with negative reactions.

Stigma changes over time. Most of the caregivers had experienced an overwhelming amount of stigma in the past, but presently felt comfortable and secure in their own communities, thus creating the stigma paradox. Grandparents' explanations of stigma involved the old wounds from their experiences while caring for family members battling drug addiction and dying of AIDS. However, they experienced a contradiction because many currently felt supported in their communities. Still, they acknowledged that the "support" that they currently felt from their community was offered because of pity.⁶

Grandparents consistently spoke about the difficulties that they experienced "ten years ago" during the initial outbreak of HIV. Grandparents took comfort in seeing the positive transition in community in terms of stigma over the past ten years. However, experiencing stigma in the past, not only from the community, but also from extended family members, was not easily forgotten.

Most caregivers revealed that life has improved for families affected by HIV/AIDS in the past ten years. Campaigns led by the government and community organizations and education programs had raised awareness about HIV that for the most part ended misconceptions about HIV transmission. This effort helped families interact with their community without fear. However, this situation created a complicated and inconsistent relationship between families affected by HIV/AIDS and their communities.

Hien explained her complex and shifting relationship with her community:

Before there was a lot of stigma in the community against people that have HIV and their families, but the community organizations came in with behavior change communication programs that talked about stigma on HIV infected children. They invited the community

⁶ In the Vietnamese language, the word "pity" or "đáng tiếc" (what a pity/it's a pity) does not have a double meaning, like it does in the English language. In Vietnam, pity is given out of sympathy, and not because of contempt.

to join in on workshops that gave information about HIV and its transmission. Still, there was stigmatization, but after repeated projects attempting to talk about HIV and stigma, the community is now normal, which has reduced a lot of stigma on my children and my son. (Hien, 63)

My and Huan spoke about how they had experienced fear from their community in the past, but that this fear had subsided over time, creating a shift in their environment:

At the time of my son's death there was no information available for people to be aware of HIV patients. We had no relationships because everyone is scared. Now, thanks to the club and the mass media, we have become more acceptable to society. It is easier for us to move on with life. (My, 68)

Stigma differs by area. Contrary to the conventional view that rural areas are more conservative and less tolerant, grandparents in rural areas reported less stigmatization than grandparents in urban areas. This was due to the high, concentrated rates of HIV in these small, sea-faring communities, which led to more familiarity with HIV. In several of the villages that I visited in rural Hai Phong, almost the entire parental generation had died of AIDS, leaving behind the grandparents and grandchildren to care for each other.⁷ HIV has spread because all of the young men once worked on ships and had found heroin in the cargo brought into the Hai Phong port. Heroin use, addiction and HIV/AIDS spread rapidly through these areas, making HIV/AIDS a familiar experience for almost every family in the village. This decreased the stigma, but it still existed. Binh, another caregiver living in rural Hai Phong, had lost two sons to HIV/AIDS. She experienced the paradox of both stigma and support from the community: "From the beginning there is a small stigmatization, but after that, they all knew that my two sons were infected with HIV and died. When they knew, they still tried to treat them well without prejudice."

⁷ The benefits of the mutual caregiving role are discussed in depth in Chapter 8

Blame. While most of the perceived stigma had occurred in the past, feelings of shame, being gossiped about, and isolation still crept into everyday life. Interactions with the community often reflected a mixture of blame, shame, acceptance and support. Blame was a commonly talked about throughout interviews and informal conversations during observations with grandparents.

Hien talked about her neighbors' current reactions to her family. Although she now felt more accepted by her community and had characterized her community's reaction as "normal" in an earlier conversation, her caregiving situation and poverty still caused neighbors to gossip about her and avoid her:

They say that we are such a bad family, and we created a bad boy, a drug user. They were always on high alert of my son, because they were afraid of losing their property if he stole. In addition to this, they are afraid that if they visit my family then I will ask for some money to borrow. Of course, they are also afraid of the disease, and they try to be far away. (Hien, 63)

When I asked Binh about the typical reaction from people when she revealed that both of her sons died of AIDS, she said that she felt unsupported by the community, although government policy was helping:

From the beginning many people had a bad reaction. They said that it was my own fault that my sons were addicted to drugs and had HIV, and that we were so poor. They told me that I could not blame anyone else for my troubles. At first, my sons were stigmatized but after some good advocacy and communication campaigns, things became better. They also made a law about HIV people, which helped to significantly lessen the stigma on my sons. (Binh, 60)

When I further questioned Binh about what "a bad reaction" entailed, Binh reflected on the gossip that occurred behind her back. She said, "They often talk to each other about the disease and they whisper."

Fear. Hoa also shared that she had experienced a complicated relationship with her neighbors and family, which she experienced as two conflicting experiences of 1) being cared for and 2) being feared. She said that, “My neighbors and children sometimes cook and bring us foods, but they still keep their distance and worry. I feel pity for myself, too.”

Many grandparents shared stories of stigma and discrimination that they knew were present in *other* communities, and much of that stigma was based on fear. Thuy said,

In my community, I don't know of any discrimination against people living with HIV, but in Cua Ong, when a child has been infected with AIDS, they cannot go to school, they are not allowed to go to school or play with other children. I know one woman in Cua Ong commune who said that children who have HIV will be dead soon, so it is not really necessary for them to go to school. But in my community, I think that everyone is treated normally when it comes to children who have HIV. (Thuy, 62)

Pity. Grandparents often shared their conflicting feelings about experiencing both stigma and support due to being a family affected by HIV/AIDS. In fact, grandparents never identified stigma as their immediate concern, but instead, admitted that they sometimes questioned their neighbors' motives of support. Even if people acted friendly to them, they were unsure if it was genuine or due to pity based on all of their misfortunes.

Grandparents who experienced positive reactions to their caregiving situations often framed their neighbors' motives as “pity.” Thuy, who lived in rural Hai Phong and cared for 12-year-old granddaughter, described her experience:

She is an orphan, so not only me, but also everyone takes pity on her. When I take her out of the house and we go out, many people know her situation and take pity on her. For example, Sam this elderly women who sells star fruit, donated 50,000 *dong* for my grandchild. These amounts of money are so big for a star fruit seller. (Thuy, 62)

Thuy also reported support from the local government, but again characterized the support that she received for her granddaughter as “pity”:

Sometimes the commune committee's staff gives her a donation of a small amount of their individual money. For example Mr. Nam-- who works at the Commune Committee -- gave her 50,000 *dong* when he met her at his office. He did that because he takes pity on her. (Thuy, 62)

Kien, whose daughter had died of AIDS while working as a "prostitute" in a distant province, said that sometimes she catches her neighbors talking about her situation and her grandson. I asked her how it made her feel when she overheard people talking, and she said,

I just feel sad and sorry about my daughter. But actually the neighbors, they feel sorry for me because they know about my situation and they know that everything that has happened has upset me a lot already. When I overheard the story, I feel sorry for myself, I feel sad. And I know that they feel sorry for me, because they know that I have a difficult life, and my daughter went far away and she got a disease and she left her son behind for me to take care of, and I know that the neighbors just feel sorry for me. (Kien, 74).

Although grandparents identified social crimes as the cause of HIV in their families, they still felt supported by "their communities." Khuyen described her relationship with her neighbors and her community, and how they had not blamed her for her son's addiction to injecting heroin and HIV status. When I asked her how the community reacted to her son, she said,

They knew that he was addicted to drugs. They never blamed me for that. They just said that this happened because my child followed the bad people the society and committed social evils. He did not listen to his parents and now he has to accept the consequences. They have never blamed me. (Khuyen, 78)

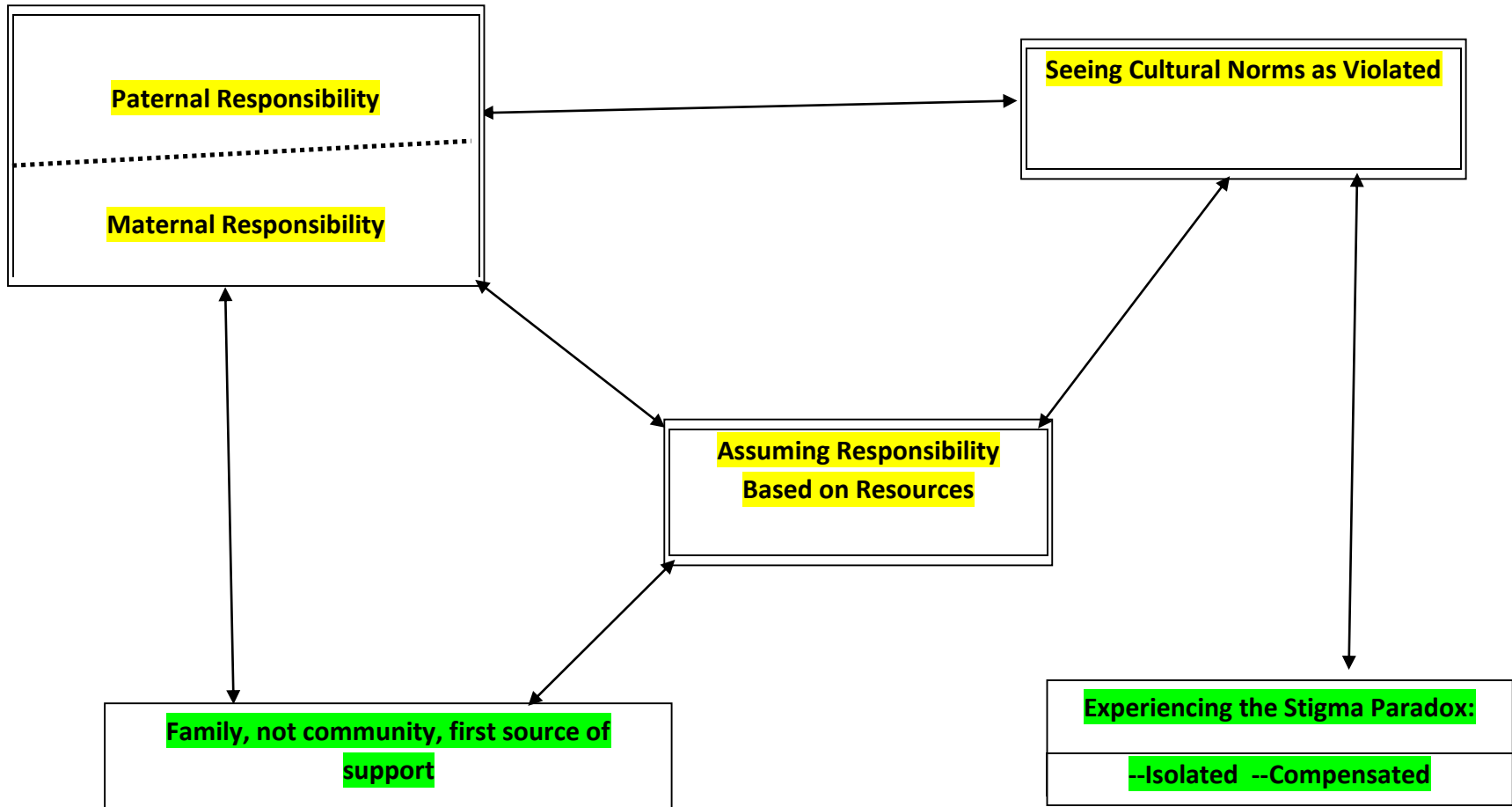
Although grandparents often categorized compassion and support as "pity" they shared that they also felt pity for themselves and their grandchildren, and therefore understood the perspective of their neighbors.

So far the results section has explored grandparents' understandings of meaning related to caregiving, coping and disease (Chapter 6), as well and the context in which this meaning is formed (Chapter 7). Next, Chapter 8 will expand upon those local understandings to explore how understandings of meaning and context are related to coping and caregiving among skipped generation caregivers in Vietnam. For caregivers, the dissonance experienced in the stigma

paradox might be another way of managing or coping with the disconnection between stigma and support.

Figure 7-1: The Context in Which Meaning is Formed

Culture: Reframing Traditional Roles (Theme 1)



Community: Experiencing the Contradiction of the Community's Reaction (Theme 2)

**CHAPTER 8: MEANING, CONTEXT AND COPING: MOTIVATIONS FOR CARE
AND PROBLEM-FOCUSED COPING**

My third study question addresses how understandings of the context and meanings of caregiving relate to motivation for and coping with caregiving. As described in earlier chapters, personal meanings of the caregiving role were informed by contextual understandings. This chapter first explores how the combination of a) meaning and b) context is related to motivation for and coping with caregiving in the lives of grandparent caregivers. For grandparents, their understandings of their caregiving roles combined with contextual factors motivated them to continue providing care for their grandchildren, as seen in Table 8-1. In considering the theme of “being motivated to give care,” three dimensions emerged: being dedicated to the grandchild; pitying the grandchild; and leaving behind a legacy.

Table 8-1: How do understandings of meaning and context relate to motivations for caregiving and coping?

Theme	Dimension
Being motivated to give care	<ul style="list-style-type: none"> • Being dedicated to grandchild • Leaving behind a legacy • Pitying the grandchild
Engaging in problem-focused coping	<p><i>Managing Material Challenges</i></p> <ul style="list-style-type: none"> • Borrowing money • Existing one day at a time <p><i>Managing Psychological Challenges</i></p> <ul style="list-style-type: none"> • Getting used to a hard life • Relying on others • Rationalizing with grandchildren • Balancing hope and realism • Finding benefits through role <p><i>Managing Social/Environmental Challenges</i></p> <ul style="list-style-type: none"> • Understanding limitations & rules (familial & formal)

This chapter also addresses the ways in which grandparents managed their caregiving roles and responsibilities by engaging in problem-focused coping. Local understandings of the caregiving role and the context in which meaning is formed led grandparents to engage in problem-focused coping strategies, rather than other strategies such as avoidant coping (using any means to prevent stressful situations) or emotion-focused coping (changing one's emotional reaction to a stressor). Throughout the course of the interviews, grandparents questioned the meaning of the word "coping;" a more appropriate word for them might be "managing." Through discussions surrounding the management of the caregiving role, I identified eight themes related to the problem-focused coping strategies used by the skipped generation caregivers.

Figure 8-1 attempts to describe the relationships among coping and caregiving motivation, meanings (understandings of caregiving, coping and disease), and contexts (culture and community). This chapter is designed to connect Chapters 6 (meanings) and 7 (context) by further exploring the relationship between these two, and analyzing how meaning and context guided grandparents to take care of their grandchildren and survive. As seen in this framework, meaning and context may be considered distinct, yet they also overlap and influence each other. Meaning and context combine to influence caregiving in the sense that grandparents were motivated to provide support and care to their grandchild(ren) based on their personal understandings of their roles within Vietnamese culture and community. As indicated, grandparents described the process of "managing," rather than coping with, their everyday lives and the care of their grandchildren through hard work, determination and strategizing. Usually, the goal was to achieve educational opportunities to ensure a bright future for their grandchild(ren). The Vietnamese cultural and community values of educational success

combined with grandparents' personal understandings of struggle, family history and loss led grandparents to engage in problem-focused coping. In addition, coping and caregiving influenced each other in the sense that motivations and coping, particularly the dimension of "finding benefits through role" were intertwined.

<<INSERT FIGURE 8-1>>

Being Motivated to Give Care

The grandparents in this study were "abandoned" to the caregiving role due to an AIDS-related death, drug addiction, migration for sex work, or a combination of these factors.

Although the caregiving role was a selfless one that often involved poverty, isolation and hardship, grandparents had several motivations to care: dedication to the grandchild -- "I do not want to go anywhere"; the desire to leave behind a legacy -- "I hope that he remembers my heart"; and sympathy for the grandchild -- "I feel pity for him". These dimensions were not exclusive and there were significant overlaps between them.

Being dedicated to the caregiving role

Dedication to preserving the life and the wellbeing of their grandchild(ren) was the most common motivating force influencing the roles of the grandparents. Mien shared that her dedication to her role as the primary caregiver for her twelve-year-old granddaughter was inspired by her Vietnamese cultural values. She explained how her belief system helped her face the challenges:

Generally, I just try to work the hardest and try to do the best that I can for my children, and my grandchildren. I don't know what other women think, but as a Vietnamese woman, I think that women should be patient and should sacrifice for their families, their

husbands and their children. Because of that philosophy, I am tolerant and I accept things and I just try to overcome everything. (Mien, 57)

Boi explained that it was her duty to care for her grandchildren and that there were no other caregiving options. She said, “I have no choice. I just know that it is my responsibility to take care of the grandchildren. I have no right to refuse that responsibility, so I just accept this.”

Grandparents were dedicated to work under the weighty physical challenges of caregiving, and their perspectives of on caring were based on love and devotion. Linh shared that she planned to provide care for as long as possible: “It is the affection between a grandmother and a grandchild that keeps us together. I don’t want to go anywhere.” The love shared between a grandchild and grandparents fueled the commitment to continue on the long journey of care. Mien said, “The most important thing that helps me to get over difficulties in my life is my love for my children and my love for my grandchildren.” Other grandparents indicated that this dedication was reciprocal and mutual⁸. Tam reflected on the dedication that she felt through the relationship that she had with her grandchildren: “I need the love of a family and the children also need the family attention, so we lean on each other to build up our lives. Now our lives fit together like a puzzle put together.” For grandparents the meaning of their caregiving role was to be a loving support system in their grandchildren’s life. Devotion and sacrifice was also expressed as an aspect of Vietnamese culture that impacted the caregiving role and was valued by grandparents.

Sa’s daughter-in-law was still alive and had remarried after her son had died of AIDS. When I asked Sa why her grandson’s mother did not take her sons with her into her new marriage, she reflected on the contextual factors related to Vietnamese culture and children from

⁸ Evidence of this will come later in the Chapter under the sub-title of “Finding Benefits through Role.”

previous marriages. She said, “In Vietnam, the couple does not want to bring any distractions into the happy home or other things so she did not take her son with her. And also we have lost both of our sons so we want to keep one grandson to stay here with us to make us happy.”

Despite the non-traditional living arrangement and the abandonment of her grandsons by their mother, Sa like many other grandparents saw her caregiving role as mutually beneficial, and was committed and enthusiastic to continue to provide love and support to her grandchildren. In this case, her daughter in-law lost motivation to provide care to her sons based on the cultural values of wanting to start a new marriage without “distractions.” Because the Vietnamese culture dictates a happy home, this motivated Sa to take over as the primary caregiver for her orphaned grandsons.

Leaving behind a legacy

The second motivation for providing care was the grandparents’ desires to leave behind a legacy. This legacy related to Vietnamese culture in the sense that grandparents wanted to be remembered as ancestors for their grandchildren after they passed away. Often grandparents were concerned that there would be no one left to look after the sacred altars of their ancestors, including the altars of their deceased adult children. Wanting to be thought of either formally or informally was a motivation to provide care for orphaned grandchildren.

Hoa reflected on the legacy that she wanted her grandson to recollect after she passed away: “So, you see, I just brought him up with the hope that he will grow and remember my heart.” For many of the grandparents, raising the grandchild was a second chance to correct the past mistakes of the family.

Mien reflected on her caregiving role as being her “mission.” Moan also wished to fulfill her role long enough so that her grandsons could be successful and make a valuable contribution to society. Many grandparents explained that their grandchildren’s success would become part of their legacy and that all of their sacrifices would pay off. When asked how she had overcome so many difficulties in her life, Moan described her behavior:

The answer is because I have no choice. I only have one choice, one option, to go on, go ahead and carry on. I don’t care about my life; I am old. Maybe I will survive for some more years. So what I can do now is to maintain and go on with this family, with the grandsons. Sometimes I am exhausted, but I think about a near future day, when my grandsons will grow up and they will have a job and they will have their own life, and be responsible for their own life. Then I will die, but I will die in happiness. (Moan, 60)

Grandparents wanted to be remembered and to feel significant. They acknowledged that caregiving for their grandchild was their most important undertaking and main goal. This was particularly true for grandparents who had lost an adult child to drug addiction and HIV. For grandparents who had raised and lost a child, having a second chance to leave a positive mark on the world and acquire a positive legacy through their grandchild was considered a privilege.

Feeling pity for the child

The final dimension within the theme of “being motivated to give care” was “feeling pity for the child.” For grandparents, their feelings of pity were driven by the “bad luck” or “misfortune” that their grandchild(ren) had experienced at a young age in losing their parents and/or contracting HIV/AIDS through mother-to-child transmission. As mentioned in Chapter 7, feelings of pity that grandparents felt for their grandchildren arose in part from the stigma placed on their grandchildren based on being from an “AIDS family,” a key aspect of the context in which caregiving exists. The majority of the grandparents in this study considered their grandchildren to be “disadvantaged” and wanted to compensate for the hardships in their lives.

Bich shared the intense sympathy that she felt for her nine-year-old granddaughter who was living with HIV.

I feel very sorry and much pity for my grandchild because she had such a bad start and was very sick. There is so much stigma attached from having HIV/AIDS in Vietnam that the children are kicked out of school if they find out. It costs one million dong a year to go to school, which is a significant amount of money compared to what we are able to earn. I was retired at the time, but because I have to support the children, I had to go back to work. (Bich, 64)

Not only did Bich feel pity toward her grandchild, but that pity motivated her to continue to strive to protect her from stigma and provide an education for her. When I asked Sa how her caregiving role had changed from raising her children to raising her grandchildren, she reflected that she wanted to provide her grandchildren with more because she felt sorry for them, and wanted to compensate for the mistakes of their parents. Sa said, “Yes it is different, because I tend to give more care and support to my grandsons, because they are disadvantaged children.”

Sympathizing with a child’s misfortune affected not only biological grandparents, but also adoptive grandparents. Both adoptive grandmothers in this study, Hoa and Tam, assumed the caregiving role for non-relative orphaned grandchildren. Hoa and Tam had similar experiences because they had to confront the opportunity to care very suddenly; it was not premeditated or planned. Each had to make a spontaneous decision to assume the caregiving role, since there were no other options for the orphaned children.

Tam’s story is unique because she was already involved in the effort to prevent HIV/AIDS in her community. She was a former street child who had survived the Vietnam War by becoming a sex worker to earn money. Tam explained her past: “I used to have a step-brother and sister but we were separated, but we all lived on the streets. Just like these children I lived on the streets when I was young too. So I do not have much connection to my family.” A year and a

half before our interview, Tam was also diagnosed with HIV. She explained the process of learning about her HIV status:

I have always been involved with people living on the street and people who have HIV/AIDS, so I started joking with people and telling them that I had AIDS. Because I am very small and I look sick, people always thought that I had AIDS anyway, so I just started joking with them and telling them that I had it. In fact, I did. (Tam, 55)

At the time of our interview, Tam worked with a local HIV/AIDS prevention organization as an outreach worker and as a tour guide in urban Hanoi. During her outreach work, on separate occasions, she came across four young children who were living on the street. She could identify with their mothers who were addicted to heroin and dying of AIDS:

At first I tried to approach their parents to offer help, like I do to others who are living on the street. But when I introduced myself and referred them to social services, they told me that unless I took their children into my care, then they would not go to the houses to get rehabilitation. Their parents felt very hopeless. They told me that if I did not take care of the children, then they will continue to wander on the streets. So I accepted that I would take care of the children. (Tam, 55)

She decided in the moment to take over the care of the children as their adoptive grandmother. Tam also reported that none of her four grandchildren's biological parents recovered from addiction and AIDS, and all were now dead. Although Tam identified with the children and their mother based on her own life and experiences, she also felt pity for the children and their situation and could not turn her back on them. Because Tam experienced AIDS-related discrimination firsthand, she was even more aware of the cultural context of stigma that affected the children.

Hoa, the other adoptive grandparent in the study, echoed Tam's motivation for taking care of five-year-old An. Although she questioned her own ability to care based on her age and frailty, she said, "From the bottom of my heart, I have to tell you I am now too old to take care of children. It was just that I felt, and I feel pity for him."

Biological and adoptive grandparents shared the sentiment that pity had motivated them to establish and maintain their caregiving roles. As reflected in this chapter, being dedicated to care for their grandchildren and leaving behind a legacy also motivated grandparents to provide care. This motivation was influenced by grandparents' understandings of their role within the context of Vietnamese culture and community. The next section describes how grandparents engaged in problem-focused coping to more effectively manage and execute their caretaking roles.

Engaging in Problem-Focused Coping

The grandparents who participated in this study were highly stressed. The major types of stress defined throughout the interviews were material, psychological and social/environmental (see Chapter 6). In order to cope with many challenges, grandparents tended to face problems head on and devised daily solutions in order to ensure the survival of their families. These problem-focused coping strategies involved action, daily adjustments, and sacrifice. For example, My said, "We have adapted because of the love of the child, and for the life of the child. For example, we can stay hungry as long as the child is full."

Eight main dimensions emerged within the theme of "engaging in problem-focused coping", and these aligned with the three dimensions of burden just mentioned (material, psychological and social/environmental). Grandparents coped with material burdens by borrowing money and existing one day at a time. To deal with psychological burden, grandparents got used to a hard life, relied on others, rationalized with grandchildren, balanced hope and realism, and found benefits through role. Lastly, grandparents coped with social and environmental burdens by understandings limitations and rules.

Borrowing Money

Being left alone to support and care for grandchildren in older adulthood presented several financial challenges for grandparents. In Vietnam, there are expectations of filial piety, including the assumption that as they aged, grandparents would receive care from their adult children. However, these grandparent caregivers struggled financially. They did not plan ahead for the death of an adult child or for their subsequent caregiving responsibilities. Both grandparent caregivers and key informants were primarily concerned with finances, particularly being able to fund their grandchild(ren)'s education. Quyen, a key informant, was a volunteer and retired medical worker who worked with an empathy club that supported women affected by HIV/AIDS. Quyen said, "Their role is very important in raising children. Many children get HIV from their parents. When their parents pass away, they leave behind a big financial issue that grandparents have to bear by raising the children."

To resolve the problem of insufficient money for the household, these caregiving grandparents often re-entered the workforce after retirement, borrowed money from individuals in the community, and used multiple forms of loans. Binh, a single grandmother caring for her two teenage grandchildren, described her multiple strategies for financing the education of her grandchildren: "Ideally, I prefer to borrow money from neighbors in the same situations. You know they also have families affected by HIV so they understand. I also wait until *Tet* (Vietnamese New Year) and then I receive lucky money from my relatives."

Grandparents always preferred to borrow from close friends and family, but their last option was to go to community loan sharks to borrow money, a practice known as "black credit" or "neck-cutting credit" in Vietnam. The primary motivation was to continue to provide funding

for their grandchildren's education, which reflected the larger context of the value placed on education within the Vietnamese culture. Binh reflected about the practice:

I have had to go into black debt, through black credit. I had to pay a very high interest rate. I borrowed one million dong, and then I had to pay more than 50,000 *dong* per month. For me, those debts are incredible. But I had to do it. If I didn't pay the tuition fee on time, my children would have to drop out of school. (Binh, 60)

The ability to earn money and support the household was the main concern for the caregivers and key informants. For example, when asked what makes the biggest difference between grandparent-headed households that are coping well and those not coping well, a key informant responded, "The main difference is the health status of grandparents, if the grandparents are able to work, then raising children is easier for them. It is more difficult for grandparents who are too old and weak to be able to work to earn money to raise their grandchildren." Throughout all of the interviews and observations, regardless of socioeconomic status, being able to generate income and sustain income throughout their older adulthood was a primary concern of the grandparents. Most grandparents managed their finances primarily through a combination of work and borrowing.

Existing One Day at a Time

To cope with their current financial struggles, caregivers reflected on living moment-to-moment, existing one day at a time, and "only caring about today." The grandparents often used the money made over the course of the day to determine the outcome of the day. For instance, I observed that the caregivers used the money that they made in the early morning market to pay for breakfast, and then used the money that they earned mid-day or after harvesting crops to provide lunch and dinner. Hoa, a single grandmother caring for a five-year-old grandson, said, "Basically, we just earn and eat on a daily basis. In the early morning, I sell five bunches of

vegetables for 10,000 *dong*, then this money is for his breakfast. I wake him up and give him the breakfast.”

To add to their challenges, older and frailer grandparents had to handle multiple health problems that prevented them from earning adequate money for sustenance. Many grandparents had to continue working despite pain while also having to assess their health limits. Hien, grandmother in rural Hai Phong said,

When I am healthy, I work; when I am sick, I lie on my bed and try to relax. I don't have a nap during the work day, because I am working all day long. I work to overcome. I never enjoy a lunch break. After my family responsibilities, I often go snail catching and I sell them at the market. I often collect them at night and I sell them in the market. (Hien, 63)

This relates to an earlier discussion of grandparents' perceptions of the meaning of their caregiving role (see Chapter 6). Even though they were devoted to their grandchildren and providing care for as long as they could, grandparents found that the caregiving role was a heavy burden to carry. Grandparents caring for children who were HIV positive had the extra tasks of providing medical care and maintaining a hygienic environment for their grandchildren to prevent opportunistic infections. Tam, an adoptive grandmother who was raising four HIV positive children, discussed the challenge:

I have to be very careful about the hygiene. I have to wash all of the vegetables in salt water. It is difficult for a family living with HIV, because our immune system is always weak. I have to go to the market every morning at 5:30 AM, because that is when the fresh meat and fish are available. I come home and I wash carefully and this is a lot of work. When the electricity is out at night, I also stay up to fan the children so that they can sleep because if they are sleepless because of the heat, they will fall sick easily. (Tam, 55)

Getting Used to a Hard Life

When asked how they managed all of their responsibilities, the majority of caregivers reflected on “getting used to” a hard life. In their eyes, life had been full of hardship, and they

expected to have several encounters with tragedy. Besides the deaths of their adult children, and sometimes the deaths of other children and family members, grandparents endured family suicide, divorce, widowhood, disability, drug and alcohol abuse, and seeing their adult children turn to sex work. Mai and Huan, a grandparent couple, explained their family situation:

We have been living a hard life since we were young so we got used to it naturally. We grew up and earned our living by ourselves. Then we got married and had four children, but they all died very young. Of all the sufferings we have gone through, there is no other way but to face them. (My, 68)

When I asked Kien about how her life had changed since she began caregiving for her 13-year-old grandson, she explained the process of “getting used to a hard life:”

I have always worked hard so since I started caregiving for him, nothing has really changed, I just have to try and work a bit harder. I have been familiar with hardship. I just try my best to help my grandson to have as good of a life as other children, maybe not as good of a life, but I will try my best to help him as much as possible. (Kien, 74).

When I asked Kien how she managed all of her responsibilities she replied, “I have to manage the time in everything that I do. I don’t know, this is just what I have been doing for all of my life. I have a schedule that I use throughout the day, and I work out from what time to what time that I do what.”

Another grandmother, Khuyen said, “As long as I am still healthy, I will still work. I am used to sacrifice and hard work. When I cannot work anymore, I will have to stop.” These grandparents faced daily challenges with resiliency throughout their caregiving careers and accepted that the future would not be easy. They had “gotten used” to hardship, struggles and burden and never changed their expectations that this was part of their caregiving role. Grandparents used work not only as a mechanism for survival, but also as a way of managing stress.

Relying on Others

A common challenge that grandparents experienced was feeling overwhelmed by caregiving responsibilities. In response, they turned to friends in their community to seek emotional and social support. In Vietnam, the culture encourages support systems, especially in rural communities, another way in which context was related to coping for grandparent caregivers. Binh, a single grandmother living in rural Hai Phong reflected, “I go to the neighbor’s house and we talk and visit for a change of scenery. This changes the environment a little bit. After that, I come back home to cook for my children and return to my routine feeling a little better.”

The endless pressures of daily chores and caregiving tasks, assisting children with school work, earning money, and thinking about finances were ameliorated by sharing their experiences with others in the community. Grandparents knew many others in their community who were skipped-generation caregivers and could rely on them for support and could share similar experiences with them. Grandparents who lived in urban locations and did not know other grandparents in similar circumstances, indicated that they felt less support and more isolation. In addition, I noted that caregivers who received formal support through self-help groups were more likely to feel that they had adequate coping strategies and were knowledgeable about government decrees. Quyen, a key informant who worked as a social care worker said, “I think that the people who are involved in self-help groups are more comfortable, have more knowledge, and have the ability to cope better with their situation of raising grandchildren.”

“Rationalizing” with Grandchildren

Grandparents often struggled with their grandchildren’s emotions related to coping with personal and economic losses following the death of their parents. Grandchildren compared their

living and family situations with their peers and had many questions about why they were different. Grandparents met this challenge by explaining and justifying their hardships to grandchildren and by encouraging them not to make comparisons with other families and peers. Binh, who was raising two teenage grandchildren said, "They sometimes act very naughty and childish but I talk to them and explain that we are very poor and that we can't eat delicious food like they do in other families that are rich." Grandparents were thus able to rationalize with grandchildren: they encouraged them not to compare themselves with others, and helped them understand the family's current financial situation. This was a way that grandparents could share their understandings and the limitations of their caregiving role with their grandchildren.

Balancing Hope and Realism

Grandparents often balanced their lives between hope for their grandchildren's future and the reality of the limitations of poverty. For example, several grandparents noted that their grandchildren were very intelligent compared with their classmates but that they were unable to afford a tutor and were insecure about paying school fees to ensure a brighter future for the grandchild. Binh explained her coping process:

I just think that I am lucky to still be alive so that I can bring up my own grandchildren. If I can manage to stay healthy enough, I can work hard to pay back the loans, maybe I can even do this before I die so that it will not be left on my grandchildren. If I die and I still do not have the money to pay, then my grandchildren will have to make the money to pay them back. They even persuaded me to let them continue going to school until they attend college. They said that they want to go to college and I could borrow money from the governance bank, and they would pay it back when they grow up with good jobs with high salaries. (Binh, 60)

Binh and other grandparents balanced hope and realism by planning for the future, a time when she assumed she would no longer be living. By creating both a plan and a backup plan, she hoped to ensure a positive future for her grandchildren.

Losing Rice, Saving Corn: Finding Benefits through Their Roles

For grandparents, caregiving was a balance of receiving benefits and dealing with challenges. Despite managing daily obstacles, grandparents often viewed their situations as “a gift” and “another chance to give care,” and they compared their lives with those of families who had suffered more in the AIDS epidemic. Sa was raising two teenage grandsons and said, “My grandsons are really like a consolation. I know some other families who are more unfortunate than me because their children have died young and they left no children. So people often tell me that - you are so lucky. You lost rice, but you still have corn.”

Similar to “having a future orientation” (see Chapter 6), grandparents explained that the importance of their caregiving role was a motivation to help them cope. Kien said, “I know that my life is very hard, but I still find pleasure in my life. Today, I am trying and tomorrow my grandson will have a better life. I just know that I need to try so that my grandson will have better life. That’s my joy, and I am ok with that.” Hue and Tuan had overcome many challenges, from caring for their 5-year-old grandson, along with an adult disabled child, another unemployed adult child, and a 95-year-old grandmother, all in a one-bedroom apartment, with a very limited income. When I asked Hue and Tuan how they had faced so many challenges, Hue replied, “That is because of our great love for our grandson...we just do what we can. Now we are still alive, so we try as much as we can to raise him. We don’t know what is ahead of us. We just play it by ear.”

This process of “benefit finding” was evident throughout the interviews with and observations of the grandparents. Grandparents valued the close bond that they had with their grandchildren and they valued “belonging to someone.” Holding the family together was a job to

be cherished. Mai, a grandmother who was raising Lan, an HIV-positive granddaughter, discussed their relationship:

I have Lan to be by my side. Sometimes I am tired because of everything that I have to do in the course of the day, but then I have this feeling that Lan is helpful because she replaces my children and lives with me. When I think about this, I feel very happy and consoled. Sometimes when I have a headache, I watch her and she is so busy; she goes around all of the time and makes my life less boring, and that brings me happiness. I do not think of Lan as having HIV, I just think of her as a normal child. Having her means that I am not alone and I am not isolated. The only thing that I avoid is when she gets scratches, because I do not want blood transmission between us, but we eat out of the same bowl and we share the same food, sleep in the same bed, I share everything with her. (Mai, 61)

Mai benefitted by being proud of Lan's community spirit. She noted that her granddaughter's personality helped them obtain support and assistance from the community: "They help us and they like us so much, because Lan is a very funny girl and she is happy all of the time and she transfers that happiness to others."

Lan could only be described as a force of nature. She was a very hyperactive and entertaining child and was always dashing here, there and everywhere. Throughout my time observing Lan, the only time she held still was when she took a nap or went to sleep for the night. Her outward appearance was that of a very sickly child. She was rail thin, had bald patches throughout her head of fine hair. However, she had a gigantic smile and contagious energy. She demanded love from all of those around her and was constantly crawling all over her grandmother for love and affection in the form of hugs and kisses.

Lan's grandma Mai owned a mobile stand where she sold beer throughout the day. She had an arrangement with another women who cooked and sold goose meat. The women were partners because they said that people like to dine on goose meat and beer together. Lan chatted

with customers who sat on the tiny tables and chairs and lunched on goose meat and drank beer throughout the course of the day. She danced and sang as they cheered her on.

The family dog recently had a litter of fuzzy black and white newborn puppies. Lan would run around with the puppies in her hand, and she constantly passed them to friends who came to visit and the customers from her grandma's beer stand. She even gave one to me to hold during the course of my field note taking. She was charming and obviously well-liked in the community.

During her childhood, she was expelled from both kindergarten and elementary school because of her HIV positive status but was then enrolled in an informal Christian school referred to as a "passion class" run by the local church. Throughout my month of observing them, Lan was never in school because her classes did not follow a typical Vietnamese school curriculum, where children study or attend school from the moment they wake up until the moment they go to sleep. The fact that Lan could not go to a regular Vietnamese school was a source of stress and sadness for her grandmother. Mai could not talk about the experience of her granddaughter being rejected from school without breaking down and crying. Despite her negative experiences with stigma in the Vietnamese school system, Lan had developed a strong network of supporters and friends, which served as a great benefit and a source of satisfaction for Mai.

Grandparents felt pride in their ability to provide stability, food, shelter, education and love for their grandchildren. This heightened sense of purpose brought meaning to their roles as skipped generation caregivers. Grandparents used phrases like, "He is the only hope of mine now" and "she is my encouragement" to describe the benefits that they experienced in their roles.

During my observations with Lan and her grandmother Mai, I told Mai that I can see how much she loved Lan. She responded with her positive attitude:

When I am with her, I have the feeling that my daughter is still alive. Lan is really lovely...I cannot express how I love her. I have raised Lan since she was just two and a half months. Raising her has been very hard. Without my hard work, I do not think that she would still be alive today. But she is the one that I cannot live without! (Mai, 61)

For Mai, her relationship with Lan made her feel fortunate; she was able to give care, and she had a second chance at raising a family. I told Mai that I could see how much Lan meant to her. Grandma Mai cradled Lan in her arms and gave her a big kiss on the cheek and said,

I can't even describe my feelings and my love for Lan, because I have taken care of her since she was so young. Because when her parents were alive, they cared about drugs only, so they did not pay attention to Lan, and it is I who has saved Lan's life. (Mai, 61)

Grandparents showed a significant amount of pride in the accomplishments of their grandchildren. Binh, a grandmother in rural Hai Phong who was raising two adolescents, repeatedly shared with me that her eldest grandson had been recruited by a provincial football team. Duong, the single grandmother whose husband committed suicide and who had lost one son to AIDS and the other to heroin addiction, informed me that her grandson, Thuc, was very intelligent. She said, "Luckily, my child is very smart, he always gets good marks at school and got good student awards every year without studying extra classes, because we have no money for them." She explained, "He's rather smart and is very good at studying. His study results are always excellent, so the teachers like him very much." Duong viewed Thuc's being well-liked in school as an asset to help him succeed; his accomplishments were a great source of gratification for his grandmother.

Grandparents also used the reciprocal love that they received from their grandchildren as a source of support and inspiration. Mien said, "I just use the courage from my love for my

children and my grandchildren to help me keep going. Those things help me to overcome the struggle.” Tam took pride in the generosity and helpfulness that she witnessed in her grandchildren:

The strength of my family is the care for each one to the other. Recently, I fell sick and the children showed their love and support for me. In addition, my children also care for other people. One of my children was very touched by the flood that recently happened and she was very willing to empty her piggy bank and donated 200,000 *dong* to the families in need. (Tam, 55)

Finding benefits through the caregiving role was an important dimension of problem-focused coping by the grandparents.

Understanding Limitations and Rules

When it came to understanding limitations and rules, grandparents presented this on two levels: 1) familial limitations, and 2) formal limitations and rules. Familial involved understanding the boundaries of their family structure due to having absent family members. On a formal level, grandparents tapered their expectations about receiving government grants and decrees to which they should have been entitled, but were blocked by government bureaucracy. The ways the grandparents understood the boundaries of familial and formal care are described to understand how they managed the challenges of caregiving.

Familial limitations. As discussed earlier, grandparents in Vietnam have expectations that they will depend on the financial care and support of their children as they age. For the skipped generation caregivers involved in this study, grandparents had to confront a reality in which filial responsibility was not possible. This went against the cultural norms of Vietnamese society. When I asked Quyen, a key informant, about the responsibility of children to their aging parents, she explained the unique position that skipped generation caregivers have because of their

children's absence. She elaborated, "It's even stated in the law on marriage and family that when parents are getting old, their children have the responsibility to take care of them."

Most of the grandparents who participated in this study had child(ren) addicted to heroin, a situation that had slowly diminished their expectations for receiving care as they aged. Duong described this process, "Yes, children have filial duties to their parents when they grow up. My son cannot do this; those addicted people are not aware of that responsibility." Having to understand these revised limitations and rules within the family caused grandparents to imagine a non-traditional future path. Duong understood that her situation did not reflect a normative experience, and her expectations shifted over time: "Normally, sons and daughters have to take care of their aging parents, but in my situation, it's impossible. Sometimes I joke that when it is time, the only place that I can go to is to the nursing house."

Kien described how she had let go of expectations of filial piety and instead focused on her 13-year-old grandson's future:

I'm getting old and weak so I just try to work as hard as I can to raise him until he is 18 to 20 years old so that he can work and take care of himself. It is very hard because you know, I am getting older and older. My health is getting worse and worse and I still have to take care of him. At this stage of my life, I should finally be able to rest, but I still have to work to take care of him; this is difficult. Because now, I still think of him as being a little child, so as a grandma, while I still have good health, I have to try my best to support him. I have to give him schooling and educational opportunities so that he will be educated, and he will not be illiterate. At least he will know how to read and write. (Kien, 74)

Experiencing a violation of cultural norms and rules caused grandparents to reassess the limitations of their adult children and the promise of their young grandchildren. This reassessment caused grandparents to let go of expectations of current filial and responsibilities for their future care in order to focus on the grandchild's future and education.

Formal limitations and rules. In addition to understanding limitations and rules at the familial level, grandparents also experienced limitations at the formal level. Most grandparents were very knowledgeable about their eligibility for government grants for low-income and disadvantaged families. The ward level (equivalent to a small community) is the initial level in the system of determining grant eligibility in Vietnam. To report a case to local ward authorities, grandparents had a government official come to their house and take inventory of their finances, belongings, and family members.

Thirteen of the 21 grandparents who participated in this study did not qualify for grants for “poor families,” though many struggled to find food on a daily basis. The income level for the means-tested grants is set so low that only the unemployed qualify. Eight out of the twenty-one grandparents qualified for government grants, most commonly known as Decree 67. This regulation states that any poor family with a registered HIV case is entitled to 120,000 VND per month (\$6.28 US dollars) (Duc, et al., 2008). However, many grandparents were raising grandchildren who did not have HIV or had not been tested and therefore did not qualify for this decree. Being a unique minority of the population, grandparents constantly struggled with policies that did not fit their family situation and needs.

When I asked grandparents if they were receiving Decree 67 or any other government grants, the majority replied “no,” and they had a variety of reasons for being rejected. Mien and Hieu explained that Decree 67 was no longer available to them, and that they had “applied many times, and had submitted the relevant documents for support to the authorities, but they were still refused.” They explained,

They cut that offer. Because only families that live in wood cottages can now claim that they are poor households. Brick houses like ours do not qualify as poor households

anymore. The Vietnamese government has one policy, but the local authority has another policy. They are cutting down on many, many allowances. (Mien, 57)

Loan shared how challenging it was to access Decree 67, although her family was eligible under the written law. She said, “Even if I register for the subsidies, I might not get it. It is very difficult to be accepted to receive the policy, because it is very bureaucratic. Dozens of people are awaiting the approval to be accepted into the program. It is very hard.”

Tam, the caregiver of four adoptive grandchildren living with HIV, was very knowledgeable about the government grants to which she and her family were entitled, yet she refused to apply based on her negative experiences with the government officers. She shared her frustration:

No, I do not like to access those grants from the government because it is too complicated. I do not like the attitude of the officers there. Once they came to my house but when they came, from the start of the neighborhood, they call aloud that “Here is the house of the AIDS.” This made me feel so insulted and angry. So I do not even try to apply for grants, because it is just about 200,000 *dong* per person per month, but the procedure is so complicated. (Tam, 55)

After my interview with Tam, I also interviewed Van, a key informant who worked at an NGO and had introduced me to her. I was struggling with the idea that Tam was raising four HIV positive, orphaned grandchildren and still did not qualify for Decree 67. I asked Van about her situation. He explained that there is government funding available for Tam and her family, but that Tam had experienced too much stigma and discrimination to pursue the funds:

The program offers caregivers 200,000 *dong* per child a month. Since Tam is caring for four orphans, this entitles her to 800,000 per month. However, she says that she does not want to access the funding because the system is too complicated and it is too much of a hassle. She also says that the government workers are extremely disrespectful and difficult to work with. (Van, NGO worker)

Grandparents were often knowledgeable about the government’s system of assessing need in great detail; they knew the limitations and the rules, even if they did not agree with them.

Duong, a widowed grandmother raising a seven-year-old grandson, had reached out several times to the local government authorities and although she did not qualify, she was able to access discounts for her grandchild through the school system. She explained her situation: “We are not considered a financially supported group in the policies. We only got our school fees reduced 100,000 *dong* at the beginning of the year as the school policy.” Through understanding rules and limitations of government and school system grants, grandparents adapted in different ways to organize their lives and finances and provide food and education for their grandchildren.

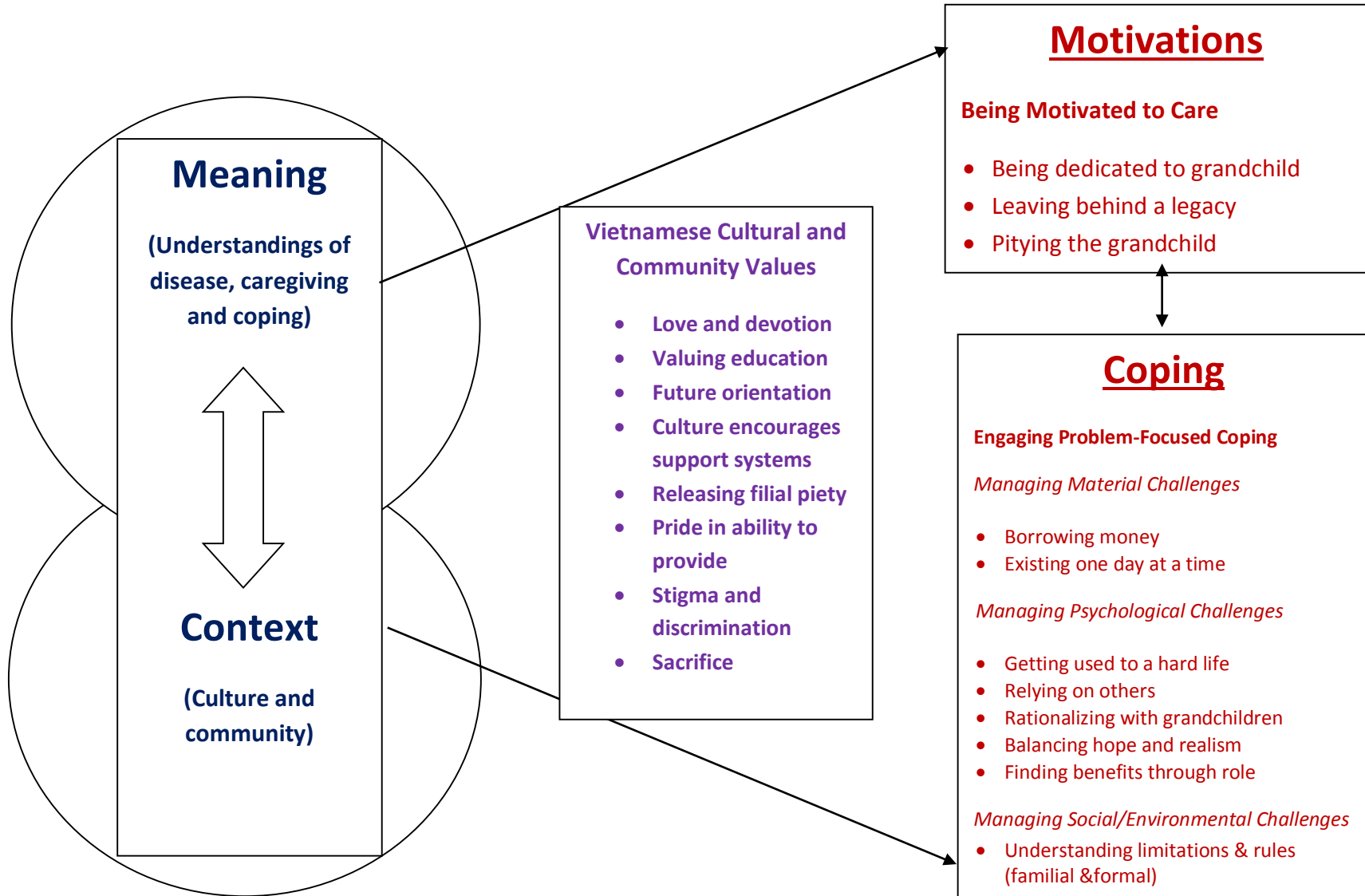
Conclusions

Chapter 8 has presented findings related to the final research question of the study: How understandings of meaning and context relate to motivations for caregiving and coping? This chapter brought together the findings from Chapter 6 (meaning) and Chapter 7 (context) to determine ways in which understandings of their role influenced grandparents’ motivations to provide care and how these informed problem-focused coping. Throughout the interviews and observations, grandparents shared their understandings of Vietnamese culture in their caregiving role. The impact of Vietnamese culture on their lives was profound and motivated them to continue to provide for their grandchildren in very difficult circumstances. The cultural context also impacted the problem-focused coping approach that grandparents engaged to survive through being a part of a culture which values support systems through the family, being dedicated to caregiving through pride and sacrifice, valuing education, believing in filial piety, and being a part of a culture where there is stigma surrounding HIV/AIDS.

Conclusion of the Results Section

The next chapter will discuss the aspects of the overall framework, and how this framework relates to prior research findings. It will also identify key implications from the findings.

Figure 8-1: How understandings of meaning and context relate to motivations for caregiving and coping



CHAPTER 9: DISCUSSION, IMPLICATIONS AND CONCLUSIONS

This study was designed to provide a deeper understanding of the experiences of grandparents who foster their grandchildren orphaned by HIV/AIDS in Vietnam. Worldwide, older adults have assumed responsibility for the care of family members affected by HIV/AIDS (Poindexter, 2002), and grandparents are emerging as a major source of support and the most reliable safety net for orphaned and vulnerable children (Nyasani, Sterberg, & Smith, 2009; Schatz & Ogunmefun, 2007). As referenced in my research, HIV-related illnesses and the death of an adult child have caused profound changes in family caregiving structures that have influenced grandparents' roles and coping mechanisms.

In this discussion, I will summarize the results of the study on the topics of 1) the meaning of skipped generation caregiving 2) the context in which meaning is formed and 3) how meaning and context related to motivations for caregiving and coping. I will show how the findings from my research reflect those of broader academic scholarship on the topic of grandparents raising grandchildren.

The Four Phases of the Caregiving Career

The findings of this study were complex. Many caregivers had families with significant problems long before they had to provide care for their grandchildren or their adult children with HIV. The substance abuse of the adult child created a cycle of instability within the family unit. Many grandparents shared that they had experienced conflicted relationships with their adult children. Grandparents tried desperately to redress this situation through their relationships with their grandchildren. Above all, grandparents wished to live long enough to see their grandchildren gain independence from their care. This was a serious worry, because most of the

grandparents had significant health issues and were going without medical treatment or care. Grandparents also faced chronic poverty and resource deprivation, in addition to heavy burdens of psychological and social stress, all of which have been associated with physical and mental health difficulties (Emrick & Hayslip, 1999; Hayslip, Shore, Henderson & Lambert, 1998; Jendreck, 1994; Minkler, Fuller-Thompson, Miller & Driver, 2000). Similarly, Mall's 2005 study of Cambodian grandparents found that grandparent caregivers were in very poor physical and mental health, exacerbated by increased workloads and caregiving responsibilities.

Each caregiver in this study told the story of a caregiving career: each one was the constant source of care and survival for the family over long periods of time. The caregiving career had four different phases, the first involving caregiving for their own young children. This phase transitioned into phase two as caregivers had to provide care for their adult child(ren) battling drug addiction and HIV-related illness. The third phase occurred after the grandchildren were born. This phase was the most stressful and worrying time of the grandparents' lives, because they were simultaneously caregiving for their grandchildren and their adult children dying of AIDS. Echoing my findings about this, Joslin's 2000 study on grandparent survivors of the AIDS epidemic found that the natural life transitions are interrupted when grandparents are placed in the position to care for multiple generations. Cox (2000) also explored the tremendously challenging roles of grandparents who were raising grandchildren due to HIV/AIDS. Having to attend to their grandchildren's grief, confusion and loss related to watching their parents slowly die while dealing with their own grief was an overwhelming task for grandparents. The fourth and final caregiving phase took place after the death of the adult child, when they solely cared for their grandchildren.

Goodman and Silverstein (2002) also studied custodial grandparents and describe some of their challenges. Grandparents found their caregiving roles to be “unanticipated, involuntary and indefinite.” They also found this transition to be disruptive, the result of serious issues within the parental generation. The authors identified two different kinds of grandparents, those who were “custodial” and those who were “co-parenting.” A classic example of custodial would be grandparenting due to a death of the child’s parent, whereas a typical co-parenting arrangement would be to provide assistance to a teenage mother. The four phases of caregiving defined by my study challenge the boundaries of the “custodial” and “co-parent” roles because these Vietnamese grandparents experienced both roles during their caregiving careers. They were co-parenting during phase three, and then they were custodial grandparents during phase four. Goodman and Silverstein’s study did support our finding that cultural beliefs about family roles dictate the way that grandparents react in unexpected situations.

Only one other study has addressed grandparents’ transitions into and out of the caregiving role. This qualitative study took place in Ohio, and found that grandmothers often underwent a two-stage process of (1) being a primary caregiver or being a caregiver in a multigenerational home and then (2) losing the caregiving role and no longer residing with their grandchild (Standing, Musil & Warner, 2007). The researchers believed that the patterns and transitions of caregiving were directly related to health and wellbeing. The American grandparents in this study expressed mixed feelings about the caregiving role, feelings that related to the direction of the transition (i.e. moving in or out of the caregiving role) and the reason for the caregiving change (i.e. parental reunification with child vs. incarceration of parent). These findings differ from those of my study, where all of the grandparents shared the

same reason for the caregiving change (death of adult child to AIDS) and most were living in a traditional multigenerational household, in accordance with Vietnamese culture.

The Meaning of Skipped Generation Caregiving

Understandings of Caregiving

My first research question asked, “What is the meaning of skipped generation caregiving in families affected by HIV/AIDS in Vietnam?” This question involves caregivers’ understandings of caregiving, coping and disease. Grandparents indicated that they were burdened by the caregiving role --materially, psychologically and social/environmentally. The burden was greater for grandparents who had less support from extended family, schools, the government and the community. The significant financial burdens challenged grandparents who struggled to provide necessities for their grandchildren, such as tuition fees, food and clothing. Financial problems have been universally documented in studies of skipped generation caregivers across the globe (Burton, 1992; Mills, Gomez-Smith, & De Leon, 2005; Jendrek, 1994; Minkler, 1999; Minkler, Roe and Price, 1992; Nampanya-Serpell, 2002) and by the literature on grandparent care (Cox, 2000; Kelley et al., 2001).

Hash’s 2006 study on caregiving in later life for same-sex LGBT partners focused on caregiving and post-caregiving experiences of older adults impacted by HIV/AIDS. The Vietnamese grandparents in my study shared themes with the LGBT caregiving older adults. Both caregiver groups experienced emotional and physical strain and both had difficulty managing caregiving and employment. Both shouldered most of the caregiving responsibility, they valued the opportunity to show love and commitment through providing care, they

continuously dealt with policies and practices that were not sensitive or supportive of their relationship, and they faced complex disclosure issues.

A significant challenge in the lives of the grandparents revolved around the lack of access to grants authorized by government decrees. Practices of government officials on the local level were not sensitive to the unique situations of grandparents who were raising grandchildren due to HIV/AIDS. Often grandparents' requests for assistance were ignored. Other times, they feared that the government officials would identify their home as being an "AIDS house." Since Decree 67 was designed to support children orphaned by AIDS, or elderly low income persons, the role of the grandparent caregiver due to HIV/AIDS was not clearly laid out in government policies and prevented grandparents from benefiting from this Decree. In addition, the fear of HIV stigma from government officials and the surrounding community contributed to disclosure issues, associated with having a family member with a stigmatizing disease.

Similar to the caregivers in my study, older LGBT caregivers have also experienced both positive and negative effects of losing their caregiving role. For example, negative impacts included grief that was not recognized, and a sense of loss for their loved one. They also experienced positive aspects, such as increased physical health, increased social interaction and more time to attend to their own needs after the death of their loved one. Thus the LGBT sample, whose caregiving career did not end after the AIDS-related death, differed from my grandparent sample. Whereas many studies have focused on the transition from grandparent to caregiver (Ehrle & Day, 1994; Jendrek, 1994; Waldrop & Weber, 2001), my study differs in the sense that the grandparents have never been free of the caregiving role. The majority had been providing care their entire lives, either to the second or the third generation, or both generations simultaneously.

Several studies have shown that a grandparent's health status declines when caregiving begins (Joslin & Brouard, 1995; Minkler et al., 1996; Orbach & HelpAge International 2007; Waldrop & Weber, 2001). This study had a different finding and was similar to Hash's study on LGBT caregivers. Grandparents said that the transition from the death of the adult child (simultaneous caregiving/phase three) to solely caregiving for grandchildren was marked by an improvement in physical health and a decrease in stress level. Even so, my study and others showed that caregiving for grandchildren brought new burdens such as obtaining food, water, and medicine, and assisting with feeding, bathing, dressing and providing their grandchildren an education (Joslin & Harrison, 2002, Kipp et al., 2002; Emlet & Poindexter, 2004; Orbach & HelpAge International, 2007).

Understandings of Coping

Grandparents' understandings of coping can be described in terms of future planning and stress.

Future planning. Grandparents' understandings of coping focused on the future for their grandchildren. Given this future orientation, grandparents worked diligently to ensure the survival of their grandchildren after they had passed away. They made future care plans with extended family, and they invested in the grandchildren's education with the hope of a brighter future. Grandparents agreed that having their grandchild reside in an institutionalized setting was the least desirable care option, but for some unfortunate ones it was the only option.

These future-focused findings matched other studies' findings. Nyasani, Sternberg & Smith's (2009) study of grandparents raising grandchildren in the wake of HIV/AIDS in South Africa showed that, in a similar resource-deprived setting, African grandparents assumed

caregiving roles because they had no other options. With no other options, the South African grandparents also worried about the future and who would care for their grandchildren after they died. Foster and Williamson (2000) found that there was a significant fear of grandchildren becoming “grand-orphans,” and awareness of this risk negatively affected the wellbeing of older caregivers with failing health.

Very few studies have asked questions about future care plans for children who could potentially be orphaned by AIDS. In a study of HIV positive mothers living in Philadelphia, Marcenko & Samost, (1999) found that the degree to which women established future care plans for their children was dependent on the length of time of their HIV diagnosis. Women who had been diagnosed with HIV for a longer time were able to think about and establish future care plans, whereas women who had a shorter time since diagnoses thought that making such plans for their children would mark the end of their lives. My study found four categories related to future planning (making plans with extended family, investing in education, not having options for future care, and seeing orphan village as final option). These categories focused on the content of the grandparents’ plans. Marcenko & Samost’s study found four categories of future care-planning which were focused on planning processes, which included: 1) those who had not thought about the future, 2) those who felt as though they would live and felt that future planning would mark the end of life, 3) those who were somewhere in the planning process and had talked to family members or a lawyer and 4) those who had finalized their plans.

The majority of the Vietnamese grandparents had not established a future care plan and simply hoped for the best. One category that was especially salient in my study was “investing in education.” This category encompassed grandparents who had no plans due to a lack of contacts and resources, but dreamed that their grandchildren would one day survive based on the

sacrifices that the grandparents made to keep them in school. They were focusing on the education of their grandchildren in hopes of assuring their future independence after they had passed away. In contrast to the United States, education is not guaranteed in Vietnam. Without the financial support of the family, children cannot pay their school fees and will be pressured to drop out. Children will also drop out of school early to support their families through employment. In a country like the United States, where education is free and child labor is illegal, caregivers do not report the same strategies in their approach to future planning.

The findings about “future care” in my study were similar to findings from a South African study of parents affected by HIV (Drimie & Casale, 2009). These parents were unable to plan for the future because they were too focused on meeting immediate needs of survival on a daily basis. Moreover, despite the desire to make long term plans for their children’s future, parents lacked the resources and options to do so (Casale et al., 2007). Similar to the Vietnamese grandparents, the parents in South Africa made investments in their children’s education, knowing that this could potentially be the child’s only option for future success or formal employment. Also similar to the Vietnamese grandparents, South African parents acknowledged that they could not maintain their child’s education unless their financial situations changed. Combined with financial vulnerability, the weakening of family networks in the wake of the HIV epidemic led to significant barriers to future planning for children.

Stress. Regardless of the HIV status of their grandchildren, grandparents experienced a significant amount of stress. One surprising finding of this study was that there was no noticeable difference in grandparents’ understandings of coping with stress across the three categories of having grandchildren who were HIV positive, HIV negative and unknown. Other studies have examined the difference between caregiving for HIV positive and HIV negative grandchildren in

terms of the depression and stress levels of the grandparents (Burnette, 2000; Joslin, 2002) and found significant differences. Although this topic warrants future investigation, I believe that this has something to do with the intense fear surrounding future caregiving plans for their grandchildren. It is possible that from the grandparent's perspective, having an HIV positive grandchild die before them and being able to provide care for them during that challenging and painful time might be less worrisome than thinking about their grandchild having to survive on their own. In Vietnam, street children are extremely vulnerable to trafficking for labor exploration. Grandparents may also fear their grandchildren becoming addicted to injection drugs based on their experiences with their adult children's addiction. Living on the street and struggling to survive would increase the likelihood of the grandchildren becoming vulnerable to drugs, human trafficking and sexual exploitation.

Understandings of Disease

In Vietnam, HIV/AIDS is considered a concentrated epidemic, where there are high rates of infection among high-risk populations such as IDUs, FSW and MSM (Ministry of Health, Vietnam Administration of HIV/AIDS Control, 2009). The association of HIV with high-risk behavior contributes to stigma in Vietnam. This study's participants understood HIV as a social disease related to criminal and deviant behaviors. Due to the grandparents' familiarity with heroin addiction, they often associated HIV infection with a social disease brought about by being a "playboy" or as the result of "social evils." This caused not only negative attitudes and conflicted relationships with their adult children who had died of AIDS, but also self-stigmatization. As a result, grandparents internalized stigma. Some grandparents in this study shared stories of hiding the diagnoses of their children, isolating themselves from others, and feeling ashamed about being in a family affected by HIV/AIDS.

Grandparents showed significant knowledge deficits when it came to understanding HIV as a disease. This medical misinformation caused several of the grandparents to hide their grandchildren's HIV status or to remain unaware of their grandchild's HIV status. Among isolated, rural caregivers in this study, stigma, medical misinformation and a lack of resources prevented them from seeking treatment. It appeared as though the communication campaigns that were deemed helpful by many other grandparents had not reached this population. Other studies have discussed similar underlying factors in the community and society that are the cause of HIV-related stigma, such as: medical misinformation, lack of access to antiretroviral therapies (ART), the impact of media on understandings of HIV, understandings of HIV/AIDS as being incurable, and fear toward specific groups such as those who are IDUs or MSM (UNAIDS, 2005; Mahajan et al., 2008; Sengupta et al., 2010).

Rural grandparents were divided into two categories: those who did not know other caregiving grandparents who had lost adult children to the AIDS epidemic and those who lived in villages where almost an entire generation had died of AIDS, leaving behind a large community of grandparents who were raising grandchildren. Rural grandparents who did not know other grandparents like them experienced more fear and isolation. Urban grandparents tended to reside in areas that were heavily impacted by HIV, and had been involved in empathy clubs, which led to increased social support. My findings are supported by other studies that have shown that HIV/AIDS stigma interferes with the disclosure of the disease, which can have negative impacts on health. Such stigma prevents individuals from seeking treatment for HIV (Prachakul, Grant & Keltner, 2007; Sayles et al., 2007), and prevents families from seeking treatment for their loved ones (Bogart et al., 2008). Two recent studies in Southeast Asia showed

the effectiveness of stigma-reduction interventions that reduced HIV/AIDS stigma and encouraged testing and treatment (Apinundecha et al., 2007; Wu et al., 2008).

The complicated nature of stigma surrounding HIV/AIDS in Northern Vietnam was striking in this study. We know that availability of ART and testing is ineffective without stigma reduction. Even though there have been significant efforts in certain Vietnam communities to provide access to ART through the President's Emergency Plan for AIDS Relief (PEPFAR), actual access appears to be low. One quarter of my sample felt uncertainty about the grandchild's HIV status, demonstrating a reluctance to test and treat the grandchild. This group of grandparents gave three reasons for not having grandchildren tested: (1) they assumed that the grandchild was automatically HIV positive based on the parent's status, (2) they "knew nothing about HIV" and did not have the means or knowledge to get to a testing site, and (3) they feared the result of the HIV test. Other studies have shown a similar reluctance to get HIV testing in high-risk populations. Reasons for avoidance or delay in testing were fear of stigma associated with HIV, or fear of the backlash from the treatment centers and community (Chesney & Smith, 1999; Myers et al., 1993; O'Dowd, 1988, Stall et al., 1996). These reasons are all closely related to the third reason from my findings for not getting tested, that of fearing the results.

In East, South, and Southeast Asia, 37% of people needing treatment are able to access it (WHO, UNAIDS, UNICEF, 2009). Among the Vietnamese grandparents in this study, not accessing treatment for their grandchildren was based on multiple factors such as the distances and money needed to travel to health clinics, lack of HIV/AIDS education information, and fear of stigma. This population was not only old, but financially and often geographically challenged. The cycle of HIV/AIDS and poverty contributed to a disinterest in pursuing testing and treatment for their grandchildren.

Grandparents' understandings of HIV/AIDS matched other literature on cultural beliefs about drug addiction in Vietnam. As a country, Vietnam has a distinctive relationship with those citizens addicted to chemical substances, because of the severe consequences facing anyone caught with illegal drugs. Vietnam treats drug use as a "social evil" and punishes individuals severely, using tactics such as mass arrests, forced detoxification, and imprisonment (Vuong et al., 2007). The international community has often criticized Vietnam's initial response to the HIV epidemic, because Vietnam was "committed" to fighting the disease through a "Social Evils Campaign" (Da Nang AIDS Committee & World Vision, 1998).

Vietnam continues to expand compulsory detoxification centers and "re-education" through labor camps, the largest expansion being in 2006. The facilities in which drug users are placed emphasize "moral education." These centers attempt to embed in the individuals the moral strength to resist the "evils" of drug use and to educate them on the severe legal consequences of continued drug use (Ruxrungtham, Brown & Phanuphak, 2004). It can thus be assumed that grandparents' descriptions of HIV as a disease "which is brought about by social evils" reflects the ethos of the Vietnamese cultural context.

The Context in Which Meaning is Formed

Perceptions of Vietnamese Culture

The need for grandparents to provide care was reinforced by cultural and moral obligations to keep the family unit together. HIV/AIDS can be destructive to traditional support structures that sustain many families in Southeast Asia where multigenerational households remain common. Study grandparents wished to retain their grandchildren within the family circle, but there were controversies over which side of the family should be responsible for care.

Some grandparents believed that it was the role of the paternal grandparents, as governed by the traditions of Vietnam. Others believed that as long as the daughter-in-law was still alive, her family (the maternal side) should be in charge of caregiving. Overall, grandparents approached the caregiving role with pragmatism, considering the resources of both maternal and paternal sides before deciding who would be the primary caregiver for the orphaned grandchildren. However, many of the caregivers still believed that Vietnamese cultural norms had been violated in their current caregiving situation, emotions which I believe they dealt with internally.

This study was the first of its kind to explore familial responsibility of orphan care in the wake of the HIV/AIDS epidemic in Vietnam. Other Vietnamese studies have examined the role of women in the family system in terms of HIV-related stigma. These studies found that women who contract HIV from their husbands are often blamed for bringing HIV into the family by their husband's family (Hong, Anh & Ogden, 2004; Nguyen et al, 2008; UNDP, 2006). Grandparents harbored a lot of animosity toward their daughters-in-law, especially if they were alive and living with HIV/AIDS in other villages or cities. However, it is difficult to say if the negative feelings toward the daughters-in-law had anything to do with the preference for sons in Vietnamese culture, since most of the grandparents who had lost sons and had living daughters-in-law would favor their biological child. Conversely, the maternal grandparents favored their daughters and blamed their sons-in-law for their injection drug use, so these findings may indicate the need for more research exploring the gender norms and traditions in the grandparent caregiver population in Vietnam.

This study addressed the need for research on whose responsibility it is to care for orphans in Vietnam (Foster & Williamson, 2000). In Vietnam, a patriarchal society, this responsibility typically belongs to paternal relatives (Oosterhoff, 2008). However, in the face of

the HIV epidemic, many of the family structures and traditions had to be reordered. My study determined that the use of pragmatism, negotiation between the paternal and maternal side, and personal beliefs redefined customs and beliefs about whose responsibility it is to care for orphaned grandchildren.

Perceptions of Community

All of the grandparents reported that stigma and discrimination had decreased in their ward (or neighborhood) within the past ten years as a result of “communication campaigns” led by the government and non-governmental organizations (NGOs). These campaigns had the goal of educating the general public about HIV/AIDS transmission. Therefore, stigma had lessened but not disappeared.

Stigma—negative. Grandparents experienced both the negative (e.g. stigma) and positive (e.g. support) effects of the culture within their community. This paradox and contradiction is something that few studies have explored. In Southeast Asia, most research has focused on the negative aspects of the community’s response to the AIDS epidemic. For example studies have shown that despite the growing visibility and efforts of groups in Vietnam to offer ART, support groups, and microcredit, many individuals and families are still in hiding. This indicates that stigma against this population is still highly prevalent (Nguyen et al, 2008). In other studies of grandparent caregivers, grandparents experienced isolation, which contributed to intense stress (Poindexter, 2002).

Studies have shown that HIV/AIDS stigma plays out differently than many other forms of stigma, because people often believe that someone *did something* to contract the disease. Because of the association in Vietnam with social evils and “bad boys” and “play boys,”

grandparent caregivers and their grandchildren felt the effects of this stigma. Older caregivers faced the same challenges, even though they and the orphans that they cared for were not members of the “bad” groups (HelpAge, 2007; UNDP, 2006).

One study on stigma in Vietnam found that families affected by HIV/AIDS faced significant challenges in their communities (UNDP, 2006). Their social interactions were often stigmatized and so they wished to keep their family member’s status a secret. For example, when borrowing money from family or friends, they never revealed that they had an HIV+ family member for fear that they would be rejected by the potential lender.

My study and other studies on grandparent caregivers show that AIDS stigma continues to exist. In Vietnam, AIDS is considered a family disease that affects everyone in the household, even after the person living with AIDS has died. Therefore, grandparent participants and their grandchildren felt the residual effects of stigma and discrimination. The context of the parent’s substance abuse contributed to the social context of HIV/AIDS, further complicating the lives of the grandparents who were struggling to survive and living in poverty. I am convinced that the substantial, and very negative, impact of stigmatization often prevented grandparents from seeking testing and treatment for their grandchildren. However, to date there is no literature with similar findings from other studies conducted in Vietnam.

Studies on HIV prevention programs in Southeast Asia have shown that stigma and discrimination against persons living with HIV/AIDS prevents communities from coming together and normalizing the disease, which is different from other diseases, such as cancer and terminal illness (Busza, 2001). For example, there have been well-defined categories of “guilt” and “innocence” associated with the transmission of HIV. Those who are engaged in high-risk

behaviors, such as IDUs, MSM and FSW, and who have contracted HIV are found to be guilty by society. In addition, shifting degrees of stigma have been attached to family members of those living with HIV/AIDS (Busza).

Grandparents reported that stigma had lessened within the past decade in their communities through the implementation of “communication campaigns by the Vietnamese government.” While stigma continued to play an active role in these grandparents’ lives, it was less stress-inducing than worries about finances, health and providing education for the grandchild. However as previously discussed, stigma often prevented grandparents from seeking testing and treatment for their grandchildren.

Stigma—positive. One key theme in this study was the “stigma paradox,” meaning grandparents felt simultaneously stigmatized and supported by their communities. Grandparents in my study often reflected about the positive aspects of community support. This is an area that is not well documented in the literature. To date, most literature on social support and grandparents raising grandchildren has focused on isolation, lack of supportive relationships and loneliness (Giarrusso, Silverstein et al., 2000; Minkler & Roe, 1993; Musil, 1998; Wohl et al., 2003), or beliefs that peers cannot relate to their experiences (Erhle, 2001; Kelley et al, 2000). Although these studies took place in Western countries, with different cultural contexts, the positive aspects of the stigma paradox open up a new area of inquiry. Positives of community support reported by grandparents included being embraced by empathy clubs and the HIV community. In addition, many grandparents had the assistance of a caring individual who granted them special favors, such as a physician who checked in frequently (and for free) on grandchildren living with HIV, or having a person step in and provide financial assistance to

keep their grandchild in school, or having community members assist in the making of kimchi to generate income for a struggling single grandmother.

How Meaning and Context Relate to Coping Strategies

Engaging in Problem-Focused Coping

The caregiver stress process model (Pearlin, 1975) informed the study of important categories related to caregiving: sources of stress, intervening resources and manifestations of stress. In addition, this model takes into consideration a person's background and socioeconomic characteristics, which was useful when considering the role of culture in the caregiving process. However, the analysis of the interviews and field notes steered the research in a new direction. In the end, the theory of problem-focused coping (Lazarus & Folkman, 1984) was a better lens to consider caregiver stress and role management within the Vietnamese cultural context.

Lazarus & Folkman's (1984) theory of problem-focused coping was developed to explain how different individuals deal with stressful situations, and very aptly describes the coping shown by the grandparents in my study. As opposed to emotion-focused coping, a person engaged in problem-focused coping looks at the source of stress in practical ways in order to remove or reduce the cause of stress. According to Lazarus and Folkman, this is a three-step process: 1) defining problems, 2) weighing the alternatives in terms of costs and benefits, and 3) choosing among them and acting. The caregivers' ways of coping with life challenges and caring for their grandchildren were not methods that they recognized, evaluated, or examined. They were simply everyday parts of life that occurred without awareness or acknowledgement. In most cases, this problem-focused coping happened on a daily basis and helped create opportunities and loving environments for their grandchildren. The Vietnamese cultural and community values

of educational success combined with grandparents' personal understandings of struggle, family history and loss led grandparents to engage in problem-focused coping.

Grandparents in this study appeared to embrace Lazarus and Folkman's first component of problem-focused coping, -- defining problems. Almost universally, grandparents defined their main problem as financial, as a result of assuming the caregiving role for their grandchildren. They did not dwell on past problems of losing the parental generation; they remained in the present. Their focus stayed on the constant concerns related to finances and the ability to pay numerous bills, particularly school fees. In Vietnam, education has the highest priority and is essential for childhood development, but it is also very expensive for most families. Caregivers viewed a lack of affordable education as a problem and in general did not have adequate resources to fund tutors or pay for school fees.

Hence, grandparents moved on to the second aspect of problem-focused coping, which is "weighing the alternatives in terms of costs and benefits." This aspect of problem-focused coping is illustrated by my study's identified theme of, "balancing hope and realism." Caregivers had to construct new expectations while addressing the challenges of providing a quality education for their grandchildren. Caregivers "went without" and borrowed money from friends and moneylenders. When bills went unpaid, grandparents reluctantly decided to go to community loan sharks to make ends meet. This meant that they had to pay unregulated and "outrageous" interest on their loans, but this risk was worth being able to keep their grandchildren in school. Throughout this process, they weighed the costs and benefits of having to pay back the debt at a very high interest rate versus the grandchild falling behind in school. Successful problem-focused coping depends on the availability and mobilization of resources and is balanced by constraints.

Caregivers acknowledged that the future was uncertain, but they invested in education despite the risk, illustrating Lazarus and Folkman's final process of problem-focused coping, "choosing among the alternatives and acting." Grounded in the activity of caring for others, caregivers used such coping as a pragmatic way of handling stress, a process echoed by this study's theme of "getting used to a hard life." Grandparents reflected on several obstacles and tragedies that they had endured and concluded that "there's no other way but to face them." They built upon previous experiences and learned adaptive strategies that enabled them to take control of their grandchildren's welfare.

Another aspect of problem-focused coping is the notion that a person's ability to use resources is contingent on one's appraisal of a stressful situation (Cohen & Lazarus, 1983). Caregivers viewed their social circles as valuable resources not only for support but also as a preferred financial resource for borrowing money. This study reinforces the need to include cultural meanings and appraisals in models of problem-focused coping.

The positive aspect of this approach is that individuals who use a problem-focused coping style when faced with life's difficulties have less caregiver role strain (Pruchno & Resch, 1989). However, it is not always effective or possible to engage in problem-focused coping strategies. This study's grandparents were handling multiple losses while they were caregiving. They struggled with the loss of their adult children, the loss of their parental roles, and often, the shame of their children's drug addiction or sex work. Handling this level of loss often requires emotion-based coping. Almost all of the caregivers needed to engage in a problem-focused approach to ensure the survival of their grandchildren, which may have hindered their grieving process and lessened their emotion-focused coping.

The Vietnamese grandparents in this study said that they survived through “getting used to a hard life.” They coped through solving problems as they came and worked hard to survive. This finding lies in contrast with other studies’ findings where grandparent caregivers coped by using spiritual and religious beliefs to deal with hardship and loss (McKelvy et al., 2002; Musil, 1998; Musil et al, 2000; Standing, Musil & Warner, 2007). The previous studies were conducted in the United States, which indicates that the unique cultural context of Vietnam leads to different coping strategies. I would argue that this has to do with the culture of Communism, Confucianism and Buddhism in Vietnam. The majority of the grandparents who participated in this study reported that they had “no religion.” However, they all participated in ancestor worship, which meant that they cared for and maintained alters for their deceased relatives within their homes and rice paddies. The combination of the larger cultural values, combined with private religious ceremonies that happened on a daily basis such as lighting incense and placing fruit at the altar of their relatives, may add a complicated element to the differences between problem-focused coping and spiritual and religious beliefs.

Other studies have focused on “erosive coping strategies” in families affected by HIV/AIDS in low-resource settings (Drimie & Casale, 2008; Haan, Marsland & Oliveria, 2003; Rugalema, 2000). Erosive coping strategies are defined as those which provide a short-term solution, but eventually erode a person’s ability to cope in the long run. Grandparents did display erosive coping strategies within the themes engaging in problem-focused coping. For example one grandparent said, “We stay hungry so that the child can be full.” By reducing their own food intake, grandparents often faced serious, negative health consequences, consequences that in the long run could interfere with the provision of care for grandchildren.

Support from the System. The Vietnamese grandparents in my study, although technically eligible, had problems accessing a monthly social welfare grant meant for AIDS orphans or low income elderly persons (Decree 67). However, they were facing a system that did not take their unique needs into consideration. For example, the majority of the grandparents were not receiving support from the government, but many had tried to access the grant based on a) being a low income elderly person or b) caregiving for an AIDS orphan. As suggested earlier, there was not a category of Decree 67 that encompassed both roles. This was further complicated by grandparents not wanting to reveal the HIV status of their grandchildren. For example, one grandmother who was caregiving for two grandsons tried to apply for Decree 67 as a low income elderly person. She was the only grandparent in the study that reported that she had no monthly income. However, the government officials came to her house to do an inspection and determined that she had too many household assets to qualify. She explained to me that she never mentioned that her son was living in a rehabilitation camp with AIDS, and that her two grandsons were relying on her for care. This is consistent with literature from the United States that reports that grandparent caregivers do not receive as much financial assistance as other family members who fill the caregiving role (Goldberg-Glen, 2000; Kelley, 1993; Landry-Meyer, 1999). Within my sample, grandparents who were not receiving the grant had several reasons for not further pursuing Decree 67. Fear of stigma and rejection, being rejected in the past, waiting to hear back from the government, and not wanting to apply were all listed as reasons for not receiving the benefits of Decree 67. Because financial constraints were the most significant problem in the lives of the grandparent caregivers, this finding is very concerning and warrants further exploration.

Sometimes, grandparent caregivers face challenges in obtaining government resources because they did not have formal adoption, legal custody or guardianship of their grandchildren (Adato et al., 2005). Only one grandparent in this study spoke about obtaining custody of the grandchild through the legal system in Vietnam. This could mean that many grandparents were excluded from the monetary support that came from obtaining legal custody. Grandparents in my study were unable to establish custody, or were not aware of the concept of legal custody and did not know how to go about this process, especially those living in isolated rural communities. Some of the grandparents also distrusted the Vietnamese government and system, which is consistent with other literature on older caregivers in different cultural contexts (HelpAge International, 2008). Grandparents did not want to interact with government officials or draw attention to their families for fear of stigma and discrimination from the community, even if they were eligible for government assistance.

In summary, grandparents might have had access to more financial support, but that would mean more interaction with government and government programs. These grandparents were not able to do that for a number of reasons: they did not know how to access the assistance program; they were not aware of advantages of getting legal custody; they did not know how to obtain custody; and they were afraid of discrimination if they did apply.

Finding Benefits through Role. Although most prior studies have focused on the negative aspects of coping, I found that grandparents made sense of their roles by finding benefits in caregiving for their grandchildren and by taking pride in meeting their caretaking obligations in later life, obligations that deviated from the traditional notions of filial piety. In addition, Vietnamese grandparents had already experienced overwhelming responsibilities and tragic

events. Therefore, skipped-generation caregiving was normalized, although these grandparents faced a reorganization of the traditional Vietnamese family structure.

The theme of “finding benefits through role” observed in this study was consistent with another study that found that those who undergo the tragedy and stress of the caregiving role often benefit greatly from the experience (Kim, Schulz, Carver & Charles, 2007). My results also parallel McCausland & Pakenham’s (2003) research outcomes showing that benefit finding was positively correlated with social support use, seeking social support coping and problem-solving coping strategies. Vietnamese grandparents who perceived benefits in their caregiving roles found a stronger sense of community support through empathy clubs and identifying with others affected by the HIV epidemic. They also used benefit finding as a problem-focused coping strategy.

Other studies in different cultural contexts found similar perceived benefits. In studies across the globe, the close relationships that grandparents forged with grandchildren and the tremendous responsibilities associated with caregiving created a greater sense of purpose (Giarrusso, Silversten & Feng, 2000; Hayslip & Shore, 2000; Standing, Musil & Warner, 2007; Waldrop & Weber, 2001). Grandparents experienced satisfaction and rewards from their experiences in caregiving for grandchildren, which was a universally observed important outcome of this role (Minkler & Row, 1993; Morrow-Kondos, Weber & Cooper, 1997).

Studies from the U.S. found that while grandparents showed commitment to the grandchild, they struggled with changes in their loss of independence (Standing, Musil & Warner, 2007). But, whereas these grandparents struggled with such intangible losses, the

grandparents in my study struggled with even more difficult losses—financial, social stigma, health—so that regardless of culture, perceived benefits are tempered by definite costs.

In the context of the HIV/AIDS epidemic in Vietnam, a responsible grandparent may be the only person to save the life of an orphaned child. Older caregivers have been shown to be invaluable assets in the face of drug abuse, sex work, or an AIDS-related death of the parental generation (Hayslip & Kaminski, 2005). My study provides further evidence to augment prior research that has shown that grandparents are the most supportive and consistent form of care for orphaned and vulnerable children (Nyasani, Sterberg & Smith, 2009; Schatz & Ogunmefun, 2007).

Recommendations

These findings have important implications for minimizing the socio-economic and emotional challenges and enhancing the well-being of grandparent caregivers of orphaned children in Vietnam. Although the incidence of HIV/AIDS in Vietnam is not on the rise as it was in the late 1990s and early 2000s, challenges remain; grandparents raising grandchildren constitute needy but forgotten families devastated by the AIDS epidemic.

Grandparent caregivers were ready and willing to participate in any program that would provide assistance to their families. Among the supports that they wanted and needed were income-generating activities, support groups, home-based caregivers, cash transfers, and access to government decrees and advocacy when decrees were denied. They also wanted support from the school system, such as after-school tutoring and cost reductions for books and school fees. Accordingly, my recommendations are to: (1) reduce isolation, (2) provide assistance for family caregiving after grandparents have died, (3) increase pensions to AIDS caregivers, (4) provide

grant access assistance, (5) increase access to testing and therapies, (6) sustain international attention, and (7) improve social work's interface.

Reduce isolation

It is critical to recognize that without social support from family members, neighbors, and friends, many skipped-generation caregivers of families affected by HIV may experience isolation from their communities, which can contribute to feelings of stigma and stress (Poindexter, 2002). Although stigma is a reoccurring theme in the HIV caregiving literature, caregivers stated that their solid and supportive relationships at the local level mitigated their feelings of stigma, isolation, and stress. Policymakers should thus support programs to prevent isolation, creating caregiver support groups and connecting skipped-generation caregivers.

Provide assistance for non-grandparent family caregiving

One of the grandparents' greatest worries was the future care of their grandchildren after they passed away. When that occurs, maintaining their care in the family unit should be supported with government assistance. There is also a growing need for service providers to address future care plans with grandparents who are raising grandchildren. My recommendation is to focus on the normative act of planning, rather than express the need for planning based on the grandparent's failing health and older age, which may unnecessarily increase stress. NGO workers, social workers and doctors should be highly sensitive when grandparents reveal that their grandchild is HIV+. This can directly affect future care plans, and potentially the ability for the child to be retained within the extended family unit and the odds that the child will be sent to the orphan village after their grandparent passes away.

Increase pensions

Pension schemes in Vietnam are designed to maintain older adults after retirement but are not meant to sustain a household. Policy makers should be educated about the factors that influence economic well-being for skipped-generation caregivers who are suffering from financial strain. It is therefore important for policy makers and community leaders in Vietnam to consider extending government grants to provide adequate benefits including financial, health, and social services to low-income skipped-generation populations affected by HIV/AIDS-related illnesses.

There is also need for the Vietnamese government to acknowledge that the care of orphans is the responsibility not only of family, but also of the state. Many of these families cannot survive without financial protection or a safety net from their government. New policies are needed, policies that foster alternative models to institutionalization for children in “orphan villages.”

Provide grant access assistance

All but one of the grandparents in this study had an interest in accessing government grants. The majority of the grandparents had tried to access Decree 67 government funding, but had failed due to bureaucratic problems at the local or ward level. Decree 67 states that any poor family with a registered HIV case is entitled to 120,000 VND (\$6.28 US) per month (Duc, et al., 2008). Whereas this effort by the Vietnamese government demonstrates changing attitudes towards AIDS orphans, it needs to be reinforced at the local level so that families are able to access the assistance for which they are eligible.

Access to testing and therapies

In addition, there is a need for increased access to both testing and ART in Vietnam. The lack of medical knowledge and the remote rural locations of many of the grandparent caregivers led to a lack of testing for the grandchildren. This created serious, significant and negative consequences for the grandchildren's health. Although access to ART is increasing globally, making it available to individuals is another story. Asian countries have shown significant problems in their efforts to offer ART while simultaneously expanding prevention programs to hinder the rates of new HIV infection (Ruxrungtham, Brown and Phanuphak, 2004). Genuine political interest and commitment are essential foundations for medical improvements, demanding advocacy at all levels.

Public health studies emphasize the importance of stigma reduction in the area of testing and treatment. Studies have shown that providing ART is useless unless there is less fear within the community. Therefore, stigma-reduction campaigns need to go hand in hand with testing and treatment. Effective stigma reduction interventions include both information and skill building (such as learning strategies for resolving negative attitudes and learning coping strategies), rather than just information alone (Brown, MacIntyre & Trujillo, 2003).

Sustain international attention

There is a need for continued international attention, funding, and support. This study's grandparents said that current and past programs reaching out to their communities had worked, and they wanted more engagement. However, grandparents and key informants questioned the sustainability of international funding and NGOs. Past experiences with short-term programs to

assist the AIDS community caused grandparents to rely on themselves, close friends, and family for support, rather than have faith in aid from the international community.

The NGO culture in Vietnam has shifted significantly between the time that this study took place (2009-2011) and today (2014). International NGOs focused on HIV prevention and care are in the process of scaling down and withdrawing from Vietnam due to the end of President's Emergency Plan for AIDS Relief (PEPFAR) funding. At the time of this research, there were several NGOs operating in Hai Phong, including Save the Children, the American Red Cross, and Cooperation and Development (CESVI), but several of these organizations have lost PEPFAR funding in the past two years. However, we know that grandparents are continuing to care for their orphaned grandchildren, and will continue to do so in the wake of HIV/AIDS. This population is in dire need of services and attention from the local and international community. My research will hopefully shed more light on their situation, and highlight the need for continued interventions.

Improve social work's interface

While social work is a new and growing profession in Vietnam, the complicated nature of social problems, stigma, policy, and health among these families provides an ideal setting for the skills of a social worker. The social work profession is one that combines knowledge of policy and practice, and is a good fit for tackling the complex problems of this population. Social work organizations and social work programs at the university level should partner with local organizations and international NGOs to provide services to grandparent caregivers and orphans.

In 2012, USAID partnered with San Jose State University to fund the enhancement of social work education in Vietnam. Vietnamese Universities, the Ministries of Labor, Invalids and Social Affairs, and various community stake holders are on board to support this effort. This

three-year program has the goal of improving the social work model in higher education, with a particular focus on improving technology and leadership skills. This recent attention is a move in the right direction for the development of social work as profession in Vietnam. My hope is that the growing nature of this field will lead to further collaborations between community organizations and academia to provide valuable assistance to the HIV community.

In addition, the important role of social workers in the field of substance abuse treatment is well established. Unexpectedly, this research revealed perspectives on and experiences with grandparents' interactions with rehabilitation/reeducation camps. Vietnam's approach to dealing with individuals with substance abuse disorders were revealed through interviews and key informants and grandparents. There is a need for research on supportive interventions for grandparent-headed households affected by HIV/AIDS and a need for the inclusion of grandparents, spouses, and children in drug treatment programs. Because treatment always occurred in "the rehabilitation camp" which was away from the household, this approach limits the role of the family in the treatment process, as well as minimizes the impact of addiction on the entire family unit.

Future research

Whereas there is a significant amount of research on grandparents who are raising grandchildren (Joslin, 2000; Poindexter & Linsk, 1999; Standing, Musil & Warner, 2007), there is much less research on grandchildren who are being raised by their grandparents (Bauman et al., 2000). There is a need for research in the area of dyadic relationships between grandparents and grandchildren. Including both generation's perspectives in future research projects would clarify how the entire family unit copes. It was evident from many of the interviews and

observations that grandparents and grandchildren “relied on each other to survive,” and this warrants further exploration.

The key informants who participated in this study saw a need for “communication training” with grandparents, particularly when grandchildren began asking questions about what happened to their parents and why they are absent in their lives. Grandparents often struggled to answer these questions. In order to support future interventions, a study on grandchildren’s perceptions of their parents would be essential. This is an area of research that is missing in the current literature. Children’s understanding of what happened to their parents, why they are absent, and what they experienced in terms of drug addiction and HIV/AIDS would be valuable for future social work interventions.

One of the more surprising findings of this research was that one-quarter of the grandparents did not know the HIV status of their grandchild. More research is needed in the area of HIV/AIDS testing, treatment and medication adherence. Nearly 40% of the grandparents in this study were caregiving for grandchildren who were known to be HIV+ (more may have been); therefore, there is a need for continued research involving children who have been born with HIV and have survived until adolescence. Understanding the mechanisms of their survival and the caregiving strategies of their grandparents can help to inform peer support groups for grandparents who are raising HIV+ grandchildren.

Lastly, the opportunity to interview grandparents more than one time was an asset to this project because of I could see their lives unfold over the course of three years, and because I was able to share the results of the study with them to gain feedback. Therefore, I see the need for more longitudinal research that follows grandparents and grandchildren over the course of several years. Such research would gather data on critical developmental milestones and would

contribute to developing health and social work interventions to help grandparents with long term support.

In Vietnam and throughout Southeast Asia, there are programs that address the needs of grandparents, but evaluations of their effectiveness are limited. My hope is that my research has laid the groundwork for future interventions that can be evaluated and improved over time. There is an opportunity to improve grandparents' and grandchildren's lives through partnering with Vietnamese universities and their social work programs. This could potentially lead to participatory action research involving mutually beneficial collaborations between the community and the academy.

I also see the need for an intervention study focusing on the rural grandparents. All of the grandparents affiliated with a support group or NGO spoke about the benefits that these organizations had on their lives, and they all sought more support and engagement in any form. However, the rural grandparents were limited by location, and did not have the means to travel to a support group or empathy club. This more isolated and vulnerable population would greatly benefit from an intervention program to train lay home-based caregivers to visit rural grandparents on a weekly basis. The home-based caregivers could be recruited from social work programs or from the HIV community. The intervention could include addressing areas of need such as social support, stigma reduction, medication adherence, communication, health education and advocacy to access government decrees.

Limitations

Some limitations of this study should be noted. First, my purposively selected sample of grandparents was drawn from a two cities in Northern Vietnam, which prevents me from making generalizable statements. However, I believe findings have transferability to settings similar to

Hanoi and Hai Phong; that is other locations in Vietnam with large, concentrated rates of HIV/AIDS.

Another limitation is that the participants might have had a difficult time adjusting to an American researcher, a native English speaker whose Vietnamese language skills were limited and needed the assistance of an interpreter. Therefore, the participants' responses might be influenced or affected by these circumstances. It can be assumed that the grandparents might have withheld specific and traumatic details of their story based on the significant cultural differences between us. For example, the grandparents did not often reveal emotion-based coping strategies, and instead focused on their problem-focused strategies.

Another limitation is that the participants in our purposive sample were recruited by key informants working for home-based care programs. These participants, as well as the others who were recruited by snowballing, may be more inclined to take an active role. If so, this active stance may have influenced their perception of caregiving and coping related to raising their grandchild(ren).

I also acknowledge that various situational characteristics about each family's life and history influence their caregiving and coping strategies. I recognize that not all skipped-generation caregivers have the same challenges as my participants. I sought to recruit the most vulnerable participants in that each one was the sole caregiver for their grandchild(ren). Many other Vietnamese grandparent caregivers provide care with other family members and live in households comprised of extended family members and several generations. Despite these limitations, we identified a group of skipped-generation caregivers whose accounts provide strong evidence that caregiving for a grandchild in later life in the context of HIV/AIDS involves many processes and challenges.

In the beginning of the data collection process, my interpreter and I quickly realized that our relationship was complex. As a cultural outsider with limited Vietnamese language skills, I relied heavily on the insights and expertise of my Vietnamese interpreter to the extent that my interpreter and I developed into co-researchers. This was a complicated process, and can be seen as a limitation of this study. However, we were dedicated to working together and continuously reflected on our process in order better the study. To address the evolving nature of our relationship, we published a paper on how our researcher-interpreter relationship developed into co-researching and how we responded to challenges in the research and the relationship over the course of the project (Harris, Boggiano, Nguyen & Pham, 2013).

Conclusion

These findings extend our understanding of grandparents as caregivers by describing their experiences in raising their grandchildren affected by HIV/AIDS. The findings show grandparents' perceptions of themselves, their roles, the contexts of their roles, and how they manage their everyday lives. This chapter has provided an examination of the study's major themes and compares findings with previous research. I have concluded with a number of recommendations, including implications for social work practice and policy, and lastly, suggestions for future research.

In the 33rd year of the AIDS epidemic, there is a need to consider populations that have long been ignored. Grandparent caregivers deserve attention in their own right, and also because they are vital to the survival of younger generations. Caregiving older adults are not only the providers of food, education and safety for children, but they are also the gatekeepers to testing and treatment for orphans who may have been infected through mother-to-child transmission. Previous studies on grandparent caregivers have shown that the stresses, challenges and trials

facing this population cut across race, country, culture and ethnicity. This dissertation has been designed to contribute to the field by examining Vietnamese grandparents who were raising grandchildren in order to determine how they understand their roles, the context in which this understanding takes place, and how these understandings inform their caregiving and coping strategies.

Appendix A: Screening Instrument

The following screening instrument will be used in order to select individuals that represent each of the full range of categories. Maximum variation sampling will be used to select a cross section of skipped generation caregivers in terms of gender, age, maternal/paternal, location, duration of caregiving, number of grandchildren, income, and other family involvement in caregiving.

Record the gender of the participant:

How old are you?

Are you a maternal or paternal grandparent?

Do you live in a rural or urban location?

How long have you been the primary caregiver for your grandchildren?

How many children do you care for?

What is your monthly income?

Do you have any other family members that help you with caregiving for your grandchildren?

- If so, then who helps you

Appendix B: Skipped Generation Caregiver Demographics Matrix

Basic:

Identifier	Commune/Ward	Urban/Rural	Age	Sex	Religion	Ethnic Group	Monthly Income	Migration Status	Rent/Own	Years in Home

Family:

Identifier	# Children	Age/Gender Children	# Grandchildren	Age/Gender Grandchildren	# OVC cared for	Age/Gender of OVC	Years caregiving	Marital Status	Maternal /Paternal

Kinds of Care and Involvement:

Identifier	Palliative?	Home-based?	Child Nutrition?	Stigma Reduction?	Social Welfare Grants?	HIV/AIDS information?

Access to Services:

Identifier	Government Subsidies?	Register HIV case?	Financial Support?	Support from Neighbors?	Support from Relatives?	Free Healthcare?	Free Education?	Fees/Books?	Decree 67?	Support group?

Physical Concerns:

Identifier	Eyes: close distance?	Eyes: far away?	Eyes: Date of last check	Eyes: Need glasses?	Ears: difficult to hear?	Ears: Loud noise?	Ears: Date of last check	Ears: Need hearing aid?	GH: Any concerning health issues?	GH: Date of last check up

Cognitive Impairment:

Identifier	Difficulty remembering?	Easy forget?	How often?	Difficulty administering meds?	How often?	Difficulty identifying symptoms?	How often?

Program Support Interests:

Identifier	Economic opportunities?	Support groups?	Legal/social welfare grant?	Educational/fun activities for children?	Educational/fun activities for grandparents and children together?	Suggestions?	Loan for Business?	Cash transfers?

Appendix C: Key Informant Demographics Matrix

Identifier	Involvement with Caregivers	Role/Position	Years working with caregivers	# of caregivers with OVCs	# of caregivers with PLWHAs	Challenges	Helpful services	Strengths	Visions/Future

Appendix D: Interview Guide

For Skipped Generation Caregivers

Demographic Information

- 1) What is the name your commune/ward?
- 2) What is your age?
- 3) Record the sex of the respondent:
- 4) What is your religion?
- 5) What is the name of your ethnic group?
- 6) What is your monthly income?
- 7) What is your migration status?
- 8) Do you own or rent the house that you live in?
- 9) How many years have you lived in your home?

Family Demographics

- 1) How many children do you have?
- 2) Record the ages and gender of the children:
- 3) How many total of grandchildren do you had / have total?
- 4) Record the ages and gender of the grandchildren:
- 5) How many grandchildren do you care for that you are primary caregiver?
- 6) Record the ages and genders of the children that the grandparent is the primary caregiver for:
- 7) How long have you been caring for the grandchildren?
- 8) What is your marital status?
 - If not “married” then, can you tell me about what happened to your spouse?

9) Are you the maternal or paternal grandparent?

Basic Information on HIV/AIDS

- 1) Has anyone close to you been affected by HIV/AIDS?
- 2) Were you involved in palliative care for the children (who passed away)?
- 3) Can you tell me about what kind of HIV/AIDS information you have access to?
- 4) What is the availability of HIV/AIDS information about for you?

Please let me know which kind of care you were involved in, if any. (Circle the response):

Palliative care – yes or no

Home-based care – yes or no

Child nutrition – yes or no

Stigma reduction – yes or no

Social welfare grants – yes or no

Can you tell me about your involvement in the care that you selected?

Access to Services

- 1) Do you receive any government subsidies (social welfare grant) from the ward or district?
- 2) What is your access to services?

Circle the response:

Did you register the child as an HIV case? – yes or no

How often do you receive financial support? weekly or monthly or yearly

Do you get any support from neighbors /relatives? - yes or no

Do you have free health care for children? – yes or no

Do you have free education for children? – yes or no

Do you pay for the fees / books? – yes or no

Have you accessed Decree 67? - yes or no

Are you already part of a support group or club? - yes or no

Physical Concerns

For Eyes:

- 1) Do you have difficulty seeing things in close distance?
- 2) Do you have difficulty seeing things that are far away?
- 3) When was the date of your last eye check?
- 4) In your opinion, do you think you need glasses?

For Ears:

- 1) Do you have difficulty hearing people when they are talking to you?
- 2) Do you have difficulty hearing the television or radio?
- 3) Have you ever not heard a loud noise that other people have heard?
- 4) When was the date of your last ear check?
- 5) In your opinion, do you think you have a hearing impairment/need a hearing aid?

General Health:

- 1) Do you have any other health issues that concern you?
- 2) When was the date of your last health check up?

Cognitive Impairment

- 1) Do you ever have difficulty in remembering day to day things?
 - If so, how often?
- 2) Do you easily forget things?
 - If so, how often?
- 3) Do you ever have difficulty administering medications to your grandchild?
 - If so, how often?

4) Do you ever have difficulty in identifying symptoms of illness?

- If so, how often?

Qualitative Interview Guide

1. Family

- a. Let's start by talking about your family. Tell me about the grandchildren who live with you?
 - i. How grandchildren came to live with you
 - ii. Extended and immediate family structure
 - iii. Status of the grandchildren's parents (HIV/mortality, etc.)
 - iv. Role of other family members in care of children

2. Caregiving

- a) Describe your daily routine with your grandchildren.
 - i. Have them walk through a typical day, morning, noon, night
 - ii. Compare this to a time prior to having these children.
 - iii. Caregiving burdens or difficulties
 - iv. Caregiving joys and pleasures

3. Contextual Factors

- a) Tell me about your community.
 - i. Relationship with neighbors and extended family ties
 - ii. A time when people were helpful
 - iii. A time when people were not helpful to you
 - iv. Describe how people with HIV/AIDS are treated in your community.
 - v. Relate this experience to what you have heard about other neighborhoods/communities, families

4. Social Support

- a) Tell me about people that come and visit you and your family
 - i. Kind of support
 - ii. Formal support
 - iii. Informal support
 - iv. Usefulness of support
 - v. Support that has not been useful

5. Stigma/Discrimination

- a) When you tell people that your son/daughter had HIV/AIDS, what is their typical reaction?

- i. Can you tell me about a bad reaction, or a time when someone hurt your feelings?
- ii. Can you tell me about a positive reaction, or a supportive reaction
- iii. How about the ways that people treat your children?

6. Coping

a) How do you manage your new responsibilities?

- i. Sources of comfort
- ii. Worries and concerns
- iii. Ways to deal with stress or fatigue
- iv. Describe a time when you felt overwhelmed, what did you do?
 - iii. Who did you turn to?
 - iv. How did the situation resolve?

7. Planning

a) Expectations for the future

- i. Future of family and children
- ii. Plans for where the children will live after (you) pass away?
- iii. Future hopes for the children

8. Strengths/Resilience

a) What makes being a part of your family special?

- i. What brings you happiness?
- ii. Tell me about a time when you faced a great challenge.
 - iii. What happened?
 - iv. How did you deal with it?

9. Transition to caregiver's ideas program support

a) If someone were to give you lots of money, then how would you help other families like you?

- i. How this idea would help families

Appendix E: Interview Guide in Vietnamese

For Skipped Generation Caregivers

Hướng dẫn Phỏng Vấn

Đối với người chăm sóc khác thế hệ

Thông Tin Nhân Khẩu Học

- 1) Tên phường/xã của ông/bà/anh/chị?
- 2) Ông/bà/anh/chị bao nhiêu tuổi?
- 3) Hãy ghi lại giới tính của người được phỏng vấn:
- 4) Tôn giáo của ông/bà/anh/chị?
- 5) Ông/bà/anh/chị thuộc nhóm dân tộc nào?
- 6) Thu nhập hàng tháng của ông/bà/anh/chị?
- 7) Tình trạng di trú của ông/bà/anh/chị?
- 8) Ông/bà/anh/chị có sở hữu hay thuê ngôi nhà mà ông/bà/anh/chị đang sống?
- 9) Ông/bà/anh/chị sống ở nhà mình được bao nhiêu năm rồi?

Nhân Khẩu Học Gia Đình

- 1) Ông/bà/anh/chị có bao nhiêu con?
- 2) Hãy ghi lại tuổi và giới tính của những người con đó:
- 3) Ông/bà/anh/chị có/đã có tổng cộng bao nhiêu người cháu?
- 4) Hãy ghi lại tuổi và giới tính của những người cháu này:
- 5) Ông/bà/anh/chị chăm sóc bao nhiêu người cháu (ông/bà/anh/chị là người chăm sóc chính)?
- 6) Hãy ghi lại tuổi và giới tính của những người cháu mà những người ông bà đó là những người chăm sóc chính:
- 7) Ông/bà/anh/chị chăm sóc các cháu đó được bao lâu rồi?

8) Tình trạng hôn nhân của ông/bà/anh/chị?

- Nếu không phải là “đã kết hôn”, ông/bà/anh/chị có thể cho tôi biết điều gì đã xảy ra với vợ/ chồng của ông/bà/anh/chị?

9) Ông/bà/anh/chị là ông/bà ngoại hay ông/bà nội?

Thông Tin Cơ Bản về HIV/AIDS

- 1) Có người nào gần gũi với ông/bà/anh/chị bị nhiễm HIV/AIDS không?
- 2) Ông/bà/anh/chị có tham gia chăm sóc xoa dịu/giảm đau đôi với người cháu đó (người đã mất) không?
- 3) Ông/bà/anh/chị có thể kể cho tôi biết về loại thông tin HIV/AIDS nào mà ông/bà/anh/chị đã có quyền sử dụng?
- 4) Đối với bạn sự sẵn có thông tin về HIV/AIDS nghĩa là gì?

Xin vui lòng cho tôi biết ông/bà/anh/chị đã tham gia loại hình chăm sóc nào, nếu có. (Hãy khoanh tròn câu trả lời):

Chăm sóc giảm đau/xoa dịu	–	có	hay	không
Chăm sóc ở gia đình	–	có	hay	không
Dinh dưỡng cho trẻ	–	có	hay	không
Giảm sự kỳ thị	–	có	hay	không
Trợ cấp phúc lợi xã hội	–	có	hay	không

Ông/bà/anh/chị có thể cho tôi biết về sự tham gia của ông/bà/anh/chị trong loại hình chăm sóc mà ông/bà/anh/chị đã chọn?

Quyền Sử Dụng các Dịch Vụ

- 1) Ông/bà/anh/chị có nhận bất cứ khoản trợ cấp nào của chính phủ (trợ cấp phúc lợi xã hội) từ phường hay quận không?

2) Ông/bà/anh/chị có những quyền sử dụng nào đối với các dịch vụ?

Hãy khoanh tròn câu trả lời:

Ông/bà/anh/chị đã đăng ký đưa trẻ đó là một trường hợp bị nhiễm HIV chưa? – rồi hay chưa

Ông/bà/anh/chị nhận sự giúp đỡ về tài chính thường xuyên như thế nào?

Hàng tuần hay hàng tháng hay hàng năm

Ông/bà/anh/chị có nhận bất kỳ sự giúp đỡ nào từ những người hàng xóm/bà con thân thuộc không? - có hay không

Ông/bà/anh/chị có nhận được sự chăm sóc sức khỏe miễn phí cho trẻ? – có hay không

Ông/bà/anh/chị có nhận được sự giáo dục miễn phí cho trẻ? – có hay không

Ông/bà/anh/chị có chi trả cho các khoản phí/sách vở không? – có hay không

Ông/bà/anh/chị có biết đến Nghị Định 67 không? – có hay không

Ông/bà/anh/chị đã là một phần của một nhóm hay câu lạc bộ hỗ trợ? – có hay không

Các Vấn đề Sức khỏe

Về Mắt:

- 1) Có gặp khó khăn trong việc nhìn những vật ở khoảng cách gần không?
- 2) Ông/bà/anh/chị có gặp khó khăn trong việc nhìn những vật ở xa không?
- 3) Ngày kiểm tra mắt gần đây nhất của ông/bà/anh/chị là ngày nào?
- 4) Theo ông/bà/anh/chị, ông/bà/anh/chị có nghĩ ông/bà/anh/chị cần kính đeo mắt không?

Về Tai:

- 1) Có gặp khó khăn trong việc nghe khi họ đang nói chuyện với ông/bà/anh/chị?

- 2) Ông/bà/anh/chị có gặp khó khăn trong việc nghe ti-vi hay ra-đi-ô không?
- 3) Ông/bà/anh/chị đã từng không nghe được một tiếng động lớn mà những người khác nghe được không?
- 4) Ngày kiểm tra tai gần nhất của ông/bà/anh/chị là ngày nào?
- 5) Theo ông/bà/anh/chị, ông/bà/anh/chị có nghĩ ông/bà/anh/chị có sự sút kém về thính lực/cần một dụng cụ trợ thính không?

Sức khỏe tổng quát:

- 1) Ông/bà/anh/chị có bất kỳ vấn đề sức khỏe nào khác làm ông/bà/anh/chị băn khoăn không?
- 2) Ngày kiểm tra sức khỏe gần nhất của ông/bà/anh/chị là ngày nào?

Sự Sút Kém về Nhận Thức

- 1) Ông/bà/anh/chị có từng gặp khó khăn trong việc nhớ các sự việc ngày này qua ngày khác không?
 - Nếu có, mức độ thường xuyên như thế nào?
- 2) Ông/bà/anh/chị có dễ dàng quên các sự việc không?
 - Nếu có, mức độ thường xuyên như thế nào?
- 3) Ông/bà/anh/chị có từng gặp khó khăn trong việc cho cháu của ông/bà/anh/chị uống thuốc không?
 - Nếu có, mức độ thường xuyên như thế nào?
- 4) Ông/bà/anh/chị có từng gặp khó khăn trong việc xác định các triệu chứng bệnh tật không?
 - Nếu có, mức độ thường xuyên như thế nào?

Hướng dẫn Phòng vấn Định tính

2. Gia đình

- a. Chúng ta hãy nói chuyện về gia đình của ông/ bà nhé. Bây giờ ông/ bà ở với bao nhiêu cháu nội cháu ngoại?
 - i. Các cháu đến ở với ông/ bà trong hoàn cảnh nào?
 - ii. Cấu trúc gia đình nhiều thế hệ và gia đình hạt nhân
 - iii. Tình trạng cha mẹ của các cháu (mắc bệnh HIV/ đã qua đời, v.v.)

iiii. Những thành viên khác chăm sóc các cháu như thế nào?

10. Công tác chăm sóc

- a) Hãy miêu tả những việc ông/bà cùng cháu làm hàng ngày.
- i. Cùng cháu làm các việc quen thuộc từ sáng đến trưa, chiều, tối, đêm
 - ii. So sánh cuộc sống hiện nay với cuộc sống trước khi có cháu.
 - iii. Những gánh nặng hoặc khó khăn trong việc chăm sóc cháu.
 - iii. Niềm vui khi chăm sóc cháu.

11. Những yếu tố ngoại cảnh

- a) Xin cho biết về cộng đồng nơi ông/ bà sinh sống.
- vi. Quan hệ với hàng xóm và họ tộc.
 - vii. Khi mọi người giúp đỡ
 - viii. Khi mọi người không giúp đỡ
 - ix. Miêu tả cách đối xử với người bị nhiễm HIV/AIDS tại cộng đồng nơi ông/bà sống.
 - x. Liên hệ kinh nghiệm này với những điều ông/bà được biết về các cộng đồng/địa phương, gia đình khác.

12. Hỗ trợ xã hội

- a) Xin cho biết những ai đến thăm ông/bà và gia đình.
- i. Hình thức hỗ trợ
 - ii. Hỗ trợ chính thức
 - iii. Hỗ trợ không chính thức
 - iv. Hỗ trợ hữu ích đến đâu
 - v. Những hỗ trợ không hữu ích

13. Sự kỳ thị/ Phân biệt đối xử

- a) Khi ông/bà cho mọi người biết con mình bị nhiễm HIV/AIDS, họ thường phản ứng như thế nào?
- i. Hãy kể về một phản ứng tiêu cực hay một lần ông/bà bị ai đó làm tổn thương.
 - ii. Hãy kể về một phản ứng tích cực hoặc khi có ai đó hỗ trợ ông/bà.
 - iii. Mọi người đối xử với cháu của ông/bà như thế nào?

14. Cơ chế thích nghi

- a) Ông/bà đảm đương trách nhiệm mới như thế nào?
- i. Nguồn an ủi, động viên
 - ii. Những lo lắng, quan ngại
 - iii. Cách khắc phục sự căng thẳng hoặc mệt mỏi
 - iv. Hãy kể về một lần ông/bà cảm thấy quá sức, ông/bà đã làm gì?

- iii. Ông/bà nhờ ai giúp đỡ?
- iv. Vấn đề được tháo gỡ như thế nào?

15. Lập kế hoạch

- a) Mong đợi trong tương lai
 - i. Tương lai của gia đình và những đứa trẻ
 - ii. Dự định lũ trẻ sẽ sống với ai sau khi ông/bà qua đời?
 - iii. Hy vọng tương lai cho lũ trẻ

16. Nguồn sức mạnh

- a) Gia đình ông/bà có điểm gì đặc biệt?
 - i. Điều gì làm ông/bà hạnh phúc?
 - ii. Xin hãy kể về một lần ông/bà gặp phải một thử thách rất lớn.
 - iii. Việc gì xảy ra?
 - iv. Ông/bà xử lý như thế nào?

17. Sáng kiến của người chăm sóc về hoạt động hỗ trợ của chương trình

- a) Nếu có ai đó cho ông/bà rất nhiều tiền, ông/bà sẽ giúp đỡ những gia đình đồng cảnh ngộ như thế nào?
 - i. Sáng kiến này sẽ hỗ trợ các gia đình như thế nào?

Appendix F: Interview Guide

For Key Informants

- 1) In what capacity do you work with older caregivers?
- 2) How many years has your organization been in existence?
- 3) How long have you been working with older caregivers?
- 4) How many of the caregivers that you work with care for orphans and vulnerable children (OVCs)?
- 5) How many of the caregivers that you work with care for people living with HIV/AIDS (PLWHAs)?
- 6) Can you tell me about role of older caregivers affected by HIV/AIDS?
- 7) How did the majority of these caregivers come into this role?
- 8) Can you tell me about their daily lives?
- 9) Can you tell me about the contextual or environmental factors that affect their lives?
- 10) What are some of the greatest challenges that you think older caregivers face?
- 11) What services do you think would be most helpful to older caregivers?
- 12) What are some of the strengths that you see in the families that you work with?
- 13) What are your visions for the future of your organization?

Appendix G: Interview Guide in Vietnamese

For Key Informants

Phụ lục G: Hướng dẫn Phỏng vấn

Dành cho Người cung cấp thông tin chính

- 1) Anh/chị làm việc với người chăm sóc cao tuổi ở cương vị nào?
- 2) Tổ chức của anh/chị đã hoạt động bao nhiêu năm?
- 3) Anh/chị đã làm việc bao nhiêu năm với những người chăm sóc cao tuổi?
- 4) Anh/chị đã làm việc với bao nhiêu người chăm sóc trẻ mồ côi và trẻ dễ bị tổn thương?
- 5) Anh/chị đã làm việc với bao nhiêu người chăm sóc người mắc bệnh HIV/AIDS?
- 6) Anh/chị hãy cho tôi biết vai trò của người chăm sóc chịu ảnh hưởng của HIV/AIDS?
- 7) Đa số những người chăm sóc đảm nhận vai trò này trong hoàn cảnh nào?
- 8) Xin cho tôi biết những việc họ làm trong một ngày bình thường?
- 9) Xin anh/chị cho biết những yếu tố hoàn cảnh/ môi trường ảnh hưởng đến đời sống của họ?
- 10) Hãy kể một số thách thức lớn nhất mà người chăm sóc cao tuổi gặp phải?
- 11) Theo anh/chị, những dịch vụ nào hữu ích nhất cho người chăm sóc cao tuổi?
- 12) Thế mạnh của những gia đình anh/chị làm việc cùng là gì?
- 13) Anh/chị có tầm nhìn gì về tương lai của tổ chức nơi anh/chị làm việc?

Appendix H: Ethnographic Fieldnotes Template

IDENTIFIER: *Participant code*

DATE: *Month/day/year, day of week, weather, critical current event(s).*

TIME BEGIN: *Time onset of interview.*

DURATION: *Duration of interview in minutes.*

LOCATION: *Location and setting description.*

TIME: *Time observation completed.*

GENERAL COMMENTS: *General impressions of setting, participant. Participant reaction to observation/observer.*

EVALUATION COMMENTS: *Analytic, theoretical notes (interpretation of activities reported, behavior observed).*

METHODOLOGICAL NOTES: *Notes regarding methods, thoughts about approach being used, the need for modification, addition or deletion of strategies in the future.*

TECHNICAL NOTES: *Suggestions for future work*

PERSONAL NOTES: *Personal notes, impressions, reactions, feelings, related to the experience, concerns about the self as researcher, reflexive thoughts, judgment, bias.*

Time	Descriptive Notes	Reflective Notes

***Note: Modified template from the following sources:

- (1) Anderson, N. L. R. (1987). Computer assisted analysis of textual fieldnote data. *Western Journal of Nursing Research*, 9,(4), 626-630.
- (2) Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage.

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