

Guardianship Planning Among Grandparents Raising Grandchildren Orphaned by HIV/AIDS in Northern Vietnam

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Recommended Citation

Harris, L. M., Wilfong, J., Thang, N. D., Kim, B. (2017). Guardianship Planning Among Grandparents Raising Grandchildren Orphaned by HIV/AIDS in Northern Vietnam. *GrandFamilies: The Contemporary Journal of Research, Practice and Policy*, 4 (1). Available at: <http://scholarworks.wmich.edu/grandfamilies/vol4/iss1/7>

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Cover Page Footnote

Funding was received from Save the Children, the Pacific Rim Research Foundation, the UCLA International Fieldwork Fellowship, and the Pre-Doctoral Training Fellowship in the Social and Behavioral Determinants of HIV prevention in the Department of Community Health Sciences, UCLA School of Public Health. The authors would also like to acknowledge the support and guidance of Dr. A.E. Benjamin and Dr. Ruth Matthias.

Research Article

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Orphaned by HIV/AIDS in Northern Vietnam**

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Abstract

Increasingly, grandparents are raising grandchildren because of the absence of the parental generation due to HIV/AIDS in Vietnam. However, few studies have explored the strategies and plans of grandparents for the future care of their grandchildren in case they can no longer provide care. In-depth qualitative interviews were conducted with a purposive sample of 21 grandparent caregivers and seven key informants in both urban and rural communities in Hanoi and Hai Phong, Vietnam. Five grandparents were selected from the sample to complete participant observations. ATLAS.ti was used as a

qualitative data analysis tool. Transcriptions from interviews and field notes were analyzed through constructivist-grounded theory coding techniques. The analysis led with a category of “anticipatory coping of guardianship planning.” Within this category, four properties illustrated grandparents’ stance on guardianship planning for their grandchildren. These four properties included: (1) making plans with extended family, (2) investing in education, (3) not having options for guardianship care, and (4) seeing the orphan village as a final option. Whether and how grandparents planned and dreamed for the future were affected by key contextual factors such as the HIV status of their grandchild(ren), their financial situation, their family network, their personal health status, and the extent of community resources. Practice recommendations made in partnership with local nongovernmental organizations are discussed, which include incorporating conversations about guardianship planning into existing casework and incorporating the extended family network into these conversations. Recommendations for policy makers and community leaders include extending government grants to provide adequate benefits including financial, health, and social services to low-income grandparents and extended family members who are fostering grandchildren due to HIV/AIDS.

Keywords: guardianship planning, HIV/AIDS, Vietnam, grandparent caregivers, qualitative study

The current HIV/AIDS crisis in Vietnam has resulted in a significant number of deaths among parents with young children, which has increased the number of grandparents raising their orphaned grandchildren. According to the Joint United Nations Programme on AIDS

[UNAIDS], an estimated 54,000 children in Vietnam are orphaned as a result of HIV/AIDS (UNAIDS, 2014). In 2014 alone, 11,000 people in Vietnam died of AIDS-related causes, and among the 250,000 Vietnamese citizens living with HIV/AIDS, 80% are in the key parenting age range of 20 to 39 years old (UNAIDS, 2014). In developing countries, such as Vietnam and across the globe, grandparents are frequently called upon to raise orphaned grandchildren. However, grandparents' advanced age and frailty can ultimately threaten the long-term stability of these caregiving arrangements (Nyasani, Sterberg, & Smith, 2009), and there is limited information available about guardianship planning for orphaned grandchildren in the case that grandparents can no longer provide care.

Several key contextual factors have led to high rates of HIV-related stigma in Vietnam, which can complicate caregiving arrangements. First, the HIV/AIDS epidemic in Vietnam is *concentrated*, meaning that there are elevated rates of HIV/AIDS among high risk populations, including injection drug users, men who have sex with men, and female sex workers (The Socialist Republic of Viet Nam, 2008; UNAIDS, 2014), and that HIV/AIDS is mostly confined to cities such as Ho Chi Minh City, Hanoi, An Giang, and Hai Phong (Nguyen, Nguyen, & Trinh, 2004; UNAIDS, 2007). Due to the connection between HIV and high risk populations, both grandparent caregivers and orphaned grandchildren 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 (Harris, Boggiano, & Nguyen, 2016; Thuong, et al., 2007). In the case of grandparent caregivers, the discrimination faced by these marginalized populations carries over into their lives, even when their grandchildren are not HIV-positive (Orbach & HelpAge International,

2007; UNDP, 2006). Many grandparent caregivers in Vietnam would rather give informal care to orphaned children than provide information about their family to the local government in order to seek assistance (HelpAge International, 2008).

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 members. In the process of borrowing money, they often do not reveal their family members' status to avoid stigma. If HIV status is known, caregivers may no longer be able to borrow money from community members and extended family. Instead, they may need to borrow from moneylenders at high rates of interest (Harris & Kim, 2014; UNDP, 2006). The regional and cultural aspects of stigma can greatly impact grandparents' future care plans for their grandchildren and decision-making around who to disclose their situation. Studies have shown that HIV-related stigma can perpetuate feelings of isolation and create difficulties connecting to other parents and grandparents (Erhle, 2001).

The emergence of grandparent caregivers has been studied in countries other than Vietnam. For example, a quantitative study conducted by Giarrusso, Silversten, and Feng (2000) asserted that, as a result of a new sense of purpose, raising a grandchild has positive effects for grandparents. However, research indicates that grandparent caregivers also experience physical and emotional problems (Hayslip & Kaminski, 2005; Minkler, Fuller-Thomson, Miller, & Driver, 2000), financial difficulties (Nelson, Gibson, & Bauer, 2010), role confusion and overload (Emick & Hayslip, 1999), isolation and detachment from peer groups (Jendrek, 1994), depression and stress (Dunne & Kettler, 2007; Musil, 1998), and low self-esteem (Giarrusso et al., 2000). In addition, within a sample of grandmothers in the United States, Crowther, Huang, and Allen (2014) found that raising grandchildren

was stressful and overwhelming, and subsequently resulted in an inability to recognize the necessity of guardianship planning.

HIV incidence in Vietnam peaked in the early 2000s (UNAIDS, 2014) and can be seen as a critical life event for the older generation, who often had limited information on the biomedical aspects of the disease (Harris et al., 2016) and the impact of HIV on a global scale. In addition, interventions to battle high incidence of HIV were not fully acted on with formal local and international support from the President's Emergency Plan for AIDS Relief (PEPFAR) until 2004 (USAID, 2015). In the meantime, grandparents who resided in Northern Vietnam often carried the double burden of caregiving for adult children impacted by injection drug use and HIV/AIDS. The intersection of these factors created a significant financial burden for grandparents as they were reaching older age and retirement. For instance, grandparents are often responsible for rejoining the workforce to compensate for the income their deceased adult child could have earned (Harris & Kim, 2014). Other financial challenges are related to not having formal custody of the children in their care (Adato et al, 2005).

Grandparent, kinship, or familial caregivers can be an invaluable asset to a child who has been orphaned by HIV (Hayslip & Kaminski, 2005), however there is a paucity of research that relates directly to guardianship planning in the context of grandparents raising grandchildren, particularly in Southeast Asia. In collectivist societies such as Vietnam, the importance of family and intergenerational connections is a central part of life, which can enhance the impact of the grandparent caregiver role. Despite the strengths of grandparent-headed households, many significant challenges confront such families in Vietnam.

HIV/AIDS can be destructive to traditional support structures that sustain many families in Southeast Asia, as 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). The traditional familial support structure is often reversed in the context of HIV/AIDS, because current or future assistance from the adult children has likely disappeared. In addition, older people are faced with the process of providing care as their adult children become sick, coping with their eventual death, and becoming the primary caregiver to young grandchildren (Orbach & HelpAge International, 2007).

Respect for the elderly is built into the social fabric of most Asian countries, including Vietnam. The emphasis on social relationships among Asians (Ho, 1982) and their awareness of hierarchy within these relationships (Limanonda, 1995) has traditionally resulted in a special deference paid to the older generation. The value of filial piety, which is understood as respect and care for parents and the aged, has deep roots in Asian culture. This value serves as a standard by which attitudes and behaviors toward the elderly are judged (Sung, 1990). The HIV crisis in Vietnam has challenged the traditional role of filial piety in society. Instead of increasing the focus on elder care, grandparents who are raising orphaned grandchildren must shift their attention to caregiving and potential guardianship planning in case they are unable to retain their grandchildren within their household. Despite the HIV rates in Vietnam and increased number of grandparents raising grandchildren, there are no studies on guardianship planning among grandparent caregivers in Vietnam, and limited studies worldwide.

Given this information, there is a need to examine the environmental and psychological determinants of

grandparents' guardianship planning in order to design successful interventions to support families in Vietnam. Within the context of this study, we define guardianship planning as the plans that grandparents communicate for the future care of their grandchildren should the grandparent become incapacitated or die. Therefore, the purpose of this qualitative study is to explore and describe how grandparents in Vietnam articulate guardianship plans for their grandchildren, and to understand what contextual factors contribute to their guardianship planning and options.

Methods

We conducted a qualitative field research project that was informed by ethnographic principles and methods. We engaged in the core principles of ethnography, undertaking observational fieldwork with grandparent caregivers and their families to understand their everyday lives, and we conducted in-depth interviews with members of this population (Agar, 1980). This research was part of a larger study that sought to understand the lived experiences of grandparent caregivers in terms of role, context, and coping strategies.

Study Participants

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, 2004; Knodel, VanLandingham, Saengtienchai, & Wassana, 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 developing countries (World Health Organization, 2010) and the fact that people aged 50 and

above are largely unrepresented in the international data on HIV/AIDS (Mall, 2005; Nyasani et al., 2009).

The grandparents included in this study were engaged as primary caregivers for grandchildren, due to the HIV/AIDS-related death or absence of both parental adults. The study's secondary subject group consisted of key informants involved with the grandparent caregivers and included staff members 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 grandparent caregivers in Vietnam.

Due to the stigma surrounding HIV/AIDS in Vietnam, we employed a purposive "snowball" sampling strategy for the study. Purposive sampling requires the selection of information-rich cases to yield insights and understandings of the phenomenon under investigation (Patton, 1990; Silverman, 2000), and we relied heavily on community workers to suggest grandparents that might be interested in sharing their stories. To increase the variation in this sample and to capture grandparent caregivers in different settings, we recruited participants from both urban and rural locations in the northern cities of Hanoi and Hai Phong. We selected the locations of the study based on the high and concentrated rates of HIV/AIDS in those areas (Nguyen et al., 2004). In addition, we recruited participants who were involved in home-based care programs and support groups and those who were not involved in any social services. This method was used to ensure that the sample represented grandparents who experienced a range of support.

Procedure

After receiving approval from the University of California, Los Angeles Institutional Review Board, we conducted in-depth interviews and participant observations

between June and September of 2009, July and September of 2010, and between April and July of 2011, with 21 grandparent caregivers and seven key informants. We based the interviews on semi-structured interview guides (See Appendix). We conducted the unstructured participant observations with five grandparent caregivers and their families and used ethnographic field notes to gain a deeper understanding of the everyday lives of grandparent-headed households.

The length of the participant interviews ranged from 73 to 126 minutes. For each study participant, we arranged a time or series of times that were convenient for the participant to meet, either at their home or at another convenient location. The observation periods ranged from five hours to three days and included daily routines, such as caring for their grandchildren and preparing meals, and caregiving-related tasks outside the home, such as going to the market, making doctor's visits, and running errands.

All of the grandparent caregivers and several of the key informants did not speak English; therefore, an interpreter joined the research team for all of the interviews and observations. We used the interpreter as co-researcher approach (Harris, Boggiano, Thang, & Linh, 2013), so that the interpreter (Thang) was actively engaged in all aspects of the research process, including recruitment, co-interviewing, data analysis, and the dissemination of the final results.

After the data were collected from the participants, we conducted member checking (or respondent validation) with three grandparent participants and two key informants (Lincoln & Guba, 1985). These sessions enabled us to share our initial findings from the interviews and field notes, to confirm the results, and to obtain participant feedback on the preliminary findings. Participants for the member checking sessions were selected based on their prior consent and their ability to attend the sessions.

Data analysis

We entered quantifiable data into a statistical software package (SPSS) to conduct basic analysis on age, income, and number of caregiving years for grandparent caregivers. Transcripts and field notes were uploaded to ATLAS.ti (Muhr, 2010), a qualitative software program that facilitates data organization. Using constructivist-grounded theory techniques (Charmaz, 2014), we conducted initial coding, followed by focused coding. Using the family network manager in ATLAS.ti, we clustered and sorted our initial codes into focused codes. The most frequent and significant focused codes were elevated to become code families, or major categories in our final analysis (Corbin & Strauss, 2008). We used memos, field notes, early hunches, and diagrams throughout the data analysis to conceptualize the data in various ways (Charmaz, 2014; Creswell, 2013). We then described and interpreted the data to identify similar and differing views among grandparent caregivers.

Issues of Trustworthiness

Issues of trustworthiness in this study were addressed through addressing credibility, dependability, and transferability (Guba & Lincoln, 1989; Lincoln & Guba; 1985). The criterion for credibility was determined by whether the findings are accurate and credible from the standpoint of the researcher, the participant, and the reader (Creswell, 2013; Creswell & Miller, 2000; Mason, 1996; Maxwell, 1996 Miles & Huberman, 1994). To enhance this study's methodological validity, the research team 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). To enhance the interpretive

validity of this study, as a research team, we clarified our assumptions, and the steps through which interpretations are made were charted through journaling or memo writing (Charmaz, 2014). 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, 2014; Miles & Huberman, 1994; Morse & Richards, 2002; Strauss & Corbin, 1998).

In order to enhance dependability, inter-coder reliability (Miles and Huberman, 1994) was considered through the use of a coding partner for data analysis. In addition, the research team maintained an audit trail (Lincoln & Guba, 1985) that recorded the development of thoughts throughout the research process and documented the rationale for all of the choices and decisions made in the field and in the analysis.

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 (Lincoln & Guba, 1985). 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, such as different regions of Southeast Asia in which there are significant numbers of grandparents raising grandchildren due to HIV/AIDS.

Results

Characteristics of the Participants

The average age of the grandparent caregivers was 65 years ($SD = 6.83$, range: 55-78). The participants' mean

monthly household income was 1,328,235 Vietnam Dong (about \$63), which is considered low income in Vietnam. However, we observed a wide range in their income, from zero to 4,000,000 Vietnam Dong (\$0 to \$190.39). Regarding marital status, 41% were married, 35% were widowed, 12% were separated, and 11.8% had other situations, such as a missing husband due to alcoholism. The caregivers had spent an average of 9.24 years as caregivers ($SD = 4.99$), with a range of five months to 17 years. In terms of the self-reported HIV status of their grandchild(ren), 23.5% reported HIV+, 47.1% reported HIV-, and 29.4% reported that they did not know. Thirty-five percent of the caregivers lived in urban locations, whereas 65% lived in rural areas. The majority of the caregivers were paternal grandparents (58.8%), 29.4% were maternal grandparents, and 11.8% were non-biological relatives/adoptive grandparents. The sample included four couples and 17 single grandmothers. On average, the grandparents cared for 1.47 grandchildren ($SD = 0.8$).

The Anticipatory Coping Strategy of Guardianship Planning

Below, we describe the four main properties that emerged from the data analysis that related to the category of “the anticipatory coping strategy of guardianship planning.” Although this research was exploratory, we try to emphasize the frequent and significant views and experiences among the participants for each theme.

Due to their own advanced age and their grandchildren’s HIV status, grandparents enacted anticipatory coping strategies through thinking about the future, a time when they would no longer have the capability or requirement to continue their caregiving role. Grandparents’ resources dictated their future hopes and dreams for their grandchildren’s future. With the category of anticipatory coping strategies, four properties illustrated

grandparent's understandings of coping, and their stance on guardianship plans for their grandchildren. These four properties included: (1) making plans with extended family, (2) investing in education, (3) not having options for guardianship or future care, and (4) seeing the orphan village as the final option. Whether and how grandparents planned and dreamed was affected by key contextual factors such as the HIV status of the grandchild, their family's financial situation, their family network, their personal health status, and the extent of community resources.

Making Plans with the 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 (N = 5). 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 raising a 9-year-old granddaughter and did not know her granddaughter's HIV status. 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 were referenced by the grandparents as creating "burdens" for others. Hien

expressed doubts about future plans for her two grandsons, who were 13 and 18 and both living with HIV:

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 guardianship of the grandchildren, grandparents often coped through relying on hopes and dreams for their grandchildren's future (N = 5). 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 their grandchildren forward in life. Binh (60), a grandmother raising a 9-year-old HIV-positive granddaughter 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 with a local doctor 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 Guardianship or Future Care

Grandparents, especially those with extremely limited resources, were not able to provide a plan of care for their grandchildren’s future (N = 7). 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-HIV-negative 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 an injection drug user 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 our 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 illnesses. 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 endured directly contributed the notion that they could not plan for the future.

For grandparents who were unable to provide a plan, they dreamed of future situations that 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 (ages 3, 6, 8, and 12) 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.

Kien was also concerned about providing a residence for her 13-year-old grandson who was HIV-negative. 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 that was different than his 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 guardianship 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 struggled 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 can 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 (N = 4). Bich (64), a grandmother raising a 9-year-old HIV-positive granddaughter 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 guardianship or 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. It was known to the grandparents as a place that accepted "disabled" children and AIDS orphans. 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 (78) was the oldest caregiver in the study and was deeply concerned about what would happen to her 5-year-old, HIV-positive 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 institutional 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 data-collecting visits and observations as opportunities to test her grandson’s reaction to other forms of care when he would be taken away by strangers. 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 recover from his addiction to heroin and come home to care for his 9-year-old, 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.

Discussion

Grandparents expressed deep concern about the future care of their grandchildren after they passed away, but were limited by other guardianship options and caregiving resources. Anticipatory coping strategies described and enacted by the grandparents included: creating guardianship plans with extended family, and investing 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, it was the only option.

These findings matched the results of other studies. Harris and Kim's (2014) qualitative study of grandparent caregivers in Vietnam revealed that grandparents engaged in what is known as problem-focused coping, or a series of daily activities that led to their family's survival. These activities included borrowing money from multiple sources to invest in their grandchildren's future, while understanding the limitations of what they could provide due to poverty. At the same time, grandparents engaged in "balancing hope and realism" which included staying optimistic about their grandchild's skills and talents, while creating plans, and backup plans in case they could not support their grandchildren's educational and care needs.

Nyasani, Sterberg & Smith's (2009) qualitative study of grandparents raising grandchildren in the wake of HIV/AIDS in South Africa showed that, in a similar resource-deprived setting, grandparents assumed caregiving roles because they had no other options. Without alternatives, the South African grandparents also worried about the future and who would care for their grandchildren

after they died. Foster & 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 guardianship plans for children who could potentially be orphaned by AIDS. In a qualitative 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. Mothers in this study, similar to the grandparents in our study faced barriers and facilitators in three realms of their lives: individual and family, organizations and providers, and policy and community.

The majority of the Vietnamese grandparents had not established a guardianship plan and simply hoped for the best. One property that was especially salient in this study was “investing in education” which 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 they made to keep their grandchildren enrolled in school. They focused on education in hopes that their grandchildren could become independent after they 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. Children will also drop out of school early to support their families through employment.

These findings were similar to findings from a South African study of parents affected by HIV (Drimie &

Casale, 2009). South African parents were unable to plan for the future because they were too focused on meeting immediate needs of survival on a daily basis. 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, the South African parents acknowledged that they could not maintain their child's education unless their financial situation changed. Combined with financial vulnerability, the weakening of family networks in the wake of the HIV epidemic led to significant barriers for guardianship planning.

Grandparents in our study also shared that it was their responsibility alone to take on the caregiving role instead of others in their extended family network. This finding is shared in other countries in the region. For example, concerns about grandchildren's future were also mirrored in a qualitative study on grandparent caregiving in Thailand (Safman, 2004). This study revealed that grandparents were the preferred caregiving source for orphaned grandchildren in comparison to other members of the extended family, such as aunts and uncles. The logic behind the preference for grandparent caregivers was that grandparents viewed their grandchildren as competing for resources with the biological children of their aunts and uncles, and therefore they feared that their grandchildren would not be accepted due to resource scarcity.

The stigma confronting the grandparents in this study is also consistent with research from other countries (Erhle, 2001; Carr, Gray, & Hayslip, 2012). However, due to the unique context of the HIV epidemic in Northern Vietnam, which has been spread

through injection drug use, this created an extra element of stigma which grandparents anticipated would negatively impact others in their extended family network from offering care and support to their grandchildren. HIV prevalence in Vietnam has been and is currently concentrated among injection drug users (IDUs) (Go et al, 2011). This is different than other countries in the region (i.e. Thailand, Laos, and Cambodia) in which the virus is most frequently transmitted through sexual transmission. Families who have sustained AIDS-related losses may also be less resilient than community members who face other financial consequences, particularly among the population living in Vietnam. Other studies on grandparent caregivers have reported tremendous hardship related to the impact of having an injection drug user in the household living with HIV who often stole assets from the family in order purchase drugs (Harris et al., 2016).

Our analysis of grandparents' narratives around guardianship planning revealed similar anticipatory coping tactics regardless of the grandchild's HIV status. 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, however these studies did not focus on guardianship planning. Our findings indicated that grandparents experienced intense fear surrounding guardianship planning 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. Grandparents also expressed fear that their grandchildren could become

engaged in injection drug use, due to family history and the high rates of injection drug use in their region. Living on the street and struggling to survive would also increase the likelihood of their grandchildren becoming vulnerable to gang violence, human trafficking, sexual exploitation, and forced labor.

Practice Recommendations

Throughout the course of this study, the research team worked closely with a non-governmental organization (NGO) and studied the current literature around guardianship planning in order to create several practice recommendations.

Concerns about the ability to provide needed education for grandchildren were expressed by the custodial grandparents in this study. Global research suggests that school officials and educators often do not understand the complex needs of skipped generation caregivers and the context in which caregiving takes place, which impacts their ability to understand the needs of these families (Shakya, Usita, Eisenberg, Weston, & Liles, 2012). This effect may be even more pronounced in Vietnam, where there is significant stigma in the school system shown towards children impacted and living with HIV, along with resistance to integration into the school system (Boggiano, Katona, Longacre, Beach, & Rosen, 2014). There is a need for NGOs and social care workers to provide education about the unique needs of grandparents raising grandchildren in Vietnam at the school level in order to increase access to educational opportunities for grandchildren.

A third of the grandparents in this study did not see any options for guardianship or the future care of their grandchildren. There is a growing need for social care workers engaged in home visits and casework to address guardianship plans with grandparents who are raising

grandchildren. Therefore, we suggest guardianship planning and conversations with social care workers who operate services in partnership with NGOs. Assessment guidelines when working with custodial grandparents (Poehlmann, 2003) have been developed when working with grandparents who are raising grandchildren. Recommendations most relevant to the findings of our study within the Vietnamese cultural context include: taking into consideration the child's age and developmental capacities when discussing guardianship planning, and assessing the skipped generation family's current situation in terms of strengths and risk factors, along with perceived needs. In addition, it is important to understand what the grandparents have told their grandchildren about their current living situation to gain deeper insight into what the grandparent's unique view is of their current situation, needs, and future care plans. When working with a skipped generation family, it is important to take into consideration all perspectives, including the grandparents, grandchildren, and other family members involved.

Our 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. Best practices for orphaned and vulnerable children programming, including guardianship care planning (PEPFAR, 2012) include: psychosocial care support in the form of family support, peer and mentorship programs, and community caregiver support. In addition, programming that includes economic strengthening is needed such as: money management and savings, as well as income promotion for households using low-risk strategies. Due to the finding that the orphan village or institutionalized care was seen as the least desirable option, we also recommend that social care workers engage with the family for activities such as family mapping and contacting the grandchildren's relatives at an

early stage to discuss alternative plans. In addition, NGO workers, social workers, and doctors should be highly sensitive when grandparents reveal that their grandchild's HIV status. This status can directly affect guardianship plans and potentially the ability for the child to be retained within the extended family unit.

Policy Recommendations

In terms of policy implications, grandparent caregivers should be encouraged to maintain their caregiving role in the family unit and should be supported with government assistance. Pension schemes in Vietnam are designed to support older adults after retirement but are not meant to sustain a household. Policy makers should be educated about the factors that influence economic wellbeing for grandparent 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 grandparent 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 that foster alternative models to institutionalization for children in orphan villages.

If there are no other caregivers available in the extended family network, then institutionalized care may be one of the only options in Vietnam. However, with technical support from NGOs, the Vietnamese Government has promoted a community/family-based Orphaned and Vulnerable Children (OVC) care model, and with limited financial support from the state (Decree 67 and more recently Decree 136). In Vietnam, Decision 65/2005/QD-

TTg, on the approval of community-based care for orphan, abandoned, disabled, and children infected and affected by HIV/AIDS, has allowed state funding to be channeled to support projects for communities with the goal of keeping orphaned children in family-centered care rather than institutions.

Since 2011, the government has raised the monthly allowance from 167,000 VND to 270,000 VND (Equivalent from moving to \$7.40 USD to \$12.00 USD). However, grandparents reported difficulties in accessing this decree due to the monthly income allowance being set so low that grandparents would have to be living in serious poverty to qualify or not make any income at all, and therefore many grandparents in our study struggled to meet this standard. In addition, many grandparents in our study were caregiving for grandchildren because their adult child disappeared after contracting HIV, however they were not deemed “missing” under Vietnamese law, which requires a formal search and investigation. Due to the high rates of injection drug use in the area, many of the grandparents’ adult children were living with HIV, but in prison or rehabilitation camps, and therefore not formally assessed as “missing” under the law. We recommend that policymakers work with grandparent-headed households to investigate more thoroughly each family’s unique situation in order to a) decrease the standards for income so that more families can reach eligibility and b) create guidelines that increase access for families who have adult children who have been missing for over a year, or are in prison or rehabilitation camps.

Research from across the globe has suggested that grandparents with informal caregiving relationships with their grandchildren have more difficulty in accessing formal services, such as health and social services (Gibson & Singh, 2010). Grandparents in this study struggled with accessing services due to a lack of legal custody over their

grandchildren, which resulted in struggling to access and gain eligibility for services. Beyond changes needed at the policy level, there is additional need for advocacy from social care workers and NGO workers to help custodial grandparents navigate legal custody (Shakya et al, 2012) to gain eligibility for public assistance (Cox, 2002).

Directions for Future Research

Future studies should include longitudinal data collection to gain a deeper understanding of where children were placed or what guardianship supports became available from the local government. For orphaned grandchildren who might be placed in institutional care in the future, it is critical to understand the role of the family in terms of visitation and ability to offer social and material support. In addition, because so many of the skipped generation families who participated in this study were at risk of losing their grandparent as a guardian, more research is needed on the psychological implications of losing a second guardian. Lastly, the height of the HIV epidemic in Vietnam was in the early 2000s, and many of the orphaned grandchildren in the region are now reaching early adulthood. Understanding the lived experience of young adults who survived the HIV crisis in Vietnam is key to understanding the impact of guardianship and guardianship planning on this younger generation.

Conclusion

The NGO culture in Vietnam has shifted significantly since the time that this study took place (2009-2011) and today (2016). International NGOs focused on HIV prevention and care are in the process of scaling down and withdrawing from Vietnam due to the end of 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 continues to be in need of services and attention from the local and international community.

The results of this qualitative study provided insights into the depth and complexity of the problems the grandparents in our study were presented with, including poverty, age, and stress. This information has implications for future research and practice on the topic. Efforts should be made to support grandparent caregivers in creating succession plans if and when they can no longer care for their grandchild. NGOs should work in partnership with policymakers in order to increase access and eligibility for grandparent caregivers to access government decrees in support their orphaned grandchildren.

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Appendix

Qualitative Interview Guide for Skipped Generation Caregivers

1. Family

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

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 pleasure

3. Contextual Factors

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**

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**

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**

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?
- v. Who did you turn to?
- vi. How did the situation resolve?

7. Planning

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

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

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