Behind The Silence:

the untold stories of children affected by HIV/AIDS in Vietnam,

their concerns and coping strategies
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Preface

This study was inspired by the emotional stories that women living with HIV/AIDS shared with me while I was working in Ha Long, Vietnam as a project officer of a non-governmental organization. For more than two years, women have confided experiences of sadness, misery and even the dangers that mothers living with HIV/AIDS encounter in their daily lives. In all of the conversations with women, children were at the center of their narratives. Mothers often wondered whether the children knew about their HIV status and how the disclosure influenced their children. Children can provoke parents’ desire to live well, but they can also be a source of worry for parents and care takers. Parents were concerned about their own health, but more than that, they were very worried about their children’s future. I was deeply moved by their maternal love and would like this study to support people living with HIV through providing better care for their children.

Hence, this study was conducted as a personal gift for two Sunflower groups, for mothers and grandparents who are living with HIV/AIDS, or suffering the burden of HIV/AIDS. First of all, I would like to express my deep gratitude to my informants: To all the children I have met, the ones who trusted me and were open to share everything and also the ones who came to me with doubts, worries and wonders; I would also like to share my appreciation for the special relationships I have had with mothers, grandparents, teachers who were all very willing to share their life stories, careers, wonders, and even secrets with me.

I came alone to Quang Ninh but it ended up feeling like a second home with the generous support of the Ha Long Women’s Union and members of Sunflower groups, especially from the core members of these groups. I am grateful to Mrs. Bui Kim Dung, Mrs. Pham Thi Hien at the Women’s Union for their beloved care and support during my fieldwork. Moreover, I would like to thank Ms. Tran Thi Phuong and Dinh Thi Lan for their precious time and energy: guiding me to households; assisting with the selection of children, providing secondary data; and even vehicles for my work. I also would like to thank Ms. Nguyen Thi Huong for her lovely friendship and advice on fieldwork. I highly appreciate Mr. Bui Van Duc, Mr. Vu Dinh Thung and Mrs. Nguyen Thi Be for your organizational support; and above all, for the way cared for
me as a dear younger sister, a child, a grandchild, and for your constant encouragement to go on with this study despite the difficulties.

I would like to thank MCNV for giving me a chance to come back to conduct this study in Quang Ninh. Without the financial support from Netherlands Fellowship Programs, this study would never have been possible.

Very special thanks to Pham Hung Son for transcribing tons of tapes, and Ms. Michelle Allport for correcting my English and allowing the text to flow more smoothly.

I highly appreciated the technical support from Dr. Ria Reis, who has always been by my side, from my initial interest in the topic to the completion of this thesis. Not only was her technical advice valued but also her encouragement and support gave me the clarity and endurance needed to finish this work.

Finally, I would like to dedicate this thesis to my parents and my sister who have always supported me in everything that I do and for my boyfriend who has stayed by my side with so much care and love.
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>ARV</td>
<td>Anti-retroviral (drugs)</td>
</tr>
<tr>
<td>IDU</td>
<td>Injecting drug user</td>
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<tr>
<td>IDI</td>
<td>In-depth interview</td>
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<td>HIV</td>
<td>Human immunodeficiency virus</td>
</tr>
<tr>
<td>IGA</td>
<td>Income generating activities</td>
</tr>
<tr>
<td>MCNV</td>
<td>Medical Committee Netherlands Vietnam</td>
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<tr>
<td>MOH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-governmental organization</td>
</tr>
<tr>
<td>PLHIV</td>
<td>People living with HIV</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of mother-to-child transmission</td>
</tr>
<tr>
<td>SRV</td>
<td>Socialist Republic of Vietnam</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>United Nations Program on HIV/AIDS</td>
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<tr>
<td>UNGASS</td>
<td>United Nations General Assembly</td>
</tr>
<tr>
<td>VAAC</td>
<td>Vietnam Administration of HIV/AIDS Control</td>
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<tr>
<td>VCT</td>
<td>Voluntary counseling and testing</td>
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<td>WU</td>
<td>Women’s Union</td>
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Chapter 1. Introduction

A recent report published by the Vietnam Ministry of Health claims there is an upward trend in the rate of HIV/AIDS, due to the fact that people have access to anti-retroviral virus (ARV) medication therefore increasing life expectancy (MOH/VAAC 2009). In 2007, there were an estimated 220,000 people living with HIV (PLHIV) in Vietnam. By 2010, there will be 254,000 people living with HIV and the number will reach 280,000 by 2012 (MOH/VAAC 2009). People living with HIV in Vietnam are increasingly younger in age, and heterosexual transmission is becoming more significant. Currently young adults between the ages of 20-29 account for 50.5% of all HIV infections (Nguyen Tran Hien, Le Truong Giang, Phan Nguyen Binh, Deville, van Ameijdene, et al. 2001). This age group is motivated to get married and have children (Oosterhoff 2008), and as a result, the number of HIV affected children has increased over time (Hunter and Susan 2005). Although there are currently no official government statistics, it is estimated that there are 22,000 orphans of AIDS in Vietnam, and about 300,000 children affected by HIV/AIDS (SRV 2005).

"Children affected by HIV/AIDS" is a term that has more than one meaning. In this study, I define the term as: a group of children whose parents are HIV positive, no matter whether they themselves are infected. However, children not infected, are receiving insufficient attention from researchers and intervention programs (Evans 2008; Grainger, Webb, and Elliott 2001); the issues these children face have been presented in several reports, commonly divided into four main categories: economic, social, education and health care (Bourdillon 1999; Dangizer 1994; Kamali, Seeley, Nunn, Kengeya-Kayondo, Ruberantwari, et al. 1996; UNAIDS 2001; UNAIDS and UNICEF 2004). The vulnerabilities of children affected by HIV/AIDS are related to stigma, discrimination and human rights violations (Madhavan 2004; SCF 2001; Townsend and Dawes 2004; Young and Ansell 2003). Children whose parents have HIV have to deal with issues that affect their development over the long term, some of the problems are: mental torment, lack of nutritious food, restricted access to education, overwhelming workloads, and emotional burden (UNAIDS and UNICEF 2004). The psychological impact due to parental illness and loss is receiving greater attention from researchers and programs (Atwinea, Cantor-Graaea, and Bajunirwe 2005; Richter, Foster, and Sherr 2006; Wood, Chase, and Aggleton 2006). The
common belief regarding children affected by HIV/AIDS is that they become the caretakers of ill members of the family, which leads to these children being denied basic care from their parents, dropping out of school and having to work. In Vietnam, there are a few reports that have discussed the main issues facing children affected by HIV/AIDS, which include: dropping out of school, starting work at an earlier age, and being abandoned if suspected to be HIV-positive (Hoang Thi H 2004). A recent research project concluded that poverty and stigma were the main problems facing children affected with HIV in Vietnam (SCF and CPFC 2007). Although psychological problems of children affected by HIV/AIDS were attentively noted in research conducted in Africa (Atwinea, Cantor-Graee, and Bajunirwe 2005; Wood, Chase, and Aggleton 2006), children’s mental health has not been mentioned in studies conducted in Vietnam.

In addition, these previous research findings do not shed light on children’s needs or on children’s perspectives. The question of how children perceive their lived experiences, and how they deal with their life events has yet to be studied thoroughly. Most research studies and intervention programs do not include or analyze children’s agency. The fact that this vital concept is missing from the literature explains why UNESCO continues to raise the point that the needs and concerns of children in different settings have not been met or explored properly (Wijngaarden and Shaeffer 2005). Meanwhile, understanding children’s viewpoints and coping strategies would assist in creating a more child friendly approach and provide greater efficiency in social programs.

**Research questions**

This study will contribute to the program “Comprehensive Care for Children Infected and Affected by HIV/AIDS” implemented by the Medical Committee Netherlands – Vietnam funded by Dutch Embassy in Vietnam. The aim of this research is to provide a better understanding of the lived experiences of children whose parents are living with HIV/AIDS. Children’s ideas and perspectives will be taken into account to contribute to a more practical, effective, and comprehensive childcare program for children affected by HIV/AIDS. The main question for this research is: How does HIV/AIDS affect the lives of children whose parent(s) suffer from HIV/AIDS? It has been divided into 4 specific research questions that this study aims to explore:
• How is the daily life of children affected by HIV/AIDS?
• What are the issues that concern children affected by HIV/AIDS?
• How do children deal with and make sense of the issues related to the HIV status of their parent(s)?
• What do children want and need to overcome their difficulties?
Chapter 2. Background information

2.1. HIV/AIDS in Ha Long – Quang Ninh

This study was conducted in Ha Long city, the center of Quang Ninh province. The economy of the province has been developed by the coal mining industry and tourism due to the large amount of visitors drawn to the famous Ha Long Islets every year. Quang Ninh province is located in the mountainous northeast of Viet Nam, bordering China and the "Golden Triangle" of South-East Asia, a centre of drug use. (Bui, Pham, Pham, Hoang, Nguyen, et al. 2001). Aside from its successful economic development based on tourism and coal mining, Quang Ninh is also well known for having the highest HIV prevalence in Vietnam, with more than 1% of the population infected (VAAC 2005). In Ha Long, the annual report of AIDS Committee in 2008 showed there were 5744 people living with HIV/AIDS (Quang Ninh AIDS Committee 2008).

The HIV epidemic in Quang Ninh is concentrated among high-risk populations, mainly injecting drugs users (IDU), while there is a low prevalence in the general population. HIV infection is spreading rapidly, and is predominantly being transmitted among IDUs through sharing needles and syringes with an aggregated rate of 49.6% in 2000 (Nguyen, Vu, Nguyen, Ton, Kamakura, et al. 2002). The high HIV prevalence among drug users in Quang Ninh has been influenced by the development of the coal mining industry, which has lead to an increase in the number of migrants and in the mobility of the population. These groups are involved in other high-risk behaviors such as participating in unprotected sexual contact with sex workers (Nguyen, Vu, Nguyen, Ton, Kamakura, et al. 2002).

In 1999, ten years after the first HIV case was discovered in Ha Long, the first Sympathy club, a self-help group for people living with HIV/AIDS and their family members was established by the Women’s Union (WU) in Ha Long. This model has become one of the most successful models of self-help groups, attracting international and bilateral aid agencies. Since then, this has been a popular site for research and intervention projects; for example, Life-Gap CDC, Global Fund, Care International, UNICEF are all working in this area. Ha Long city is the center of Quang Ninh, where most health care services are situated. The Provincial General hospital provides
testing, ARV and PMTCT services. The Ha Long Health Preventive Center is also working with the Global Fund to provide ARV for HIV positive people. The United Nations International Children’s Emergency Fund (UNICEF), the Family Health International (FHI) and the Medical Committee Netherlands – Vietnam (MCNV) have started to build programs supporting children affected by HIV/AIDS in this province also. Therefore, Ha Long has many advantages in its fight against HIV/AIDS, not only its strong economic potential, but also a large amount of care and support from international and national organizations working in the area of HIV/AIDS assistance.

2.2. Relationships between adults and children in Vietnam

Vietnam’s children, who make up 36 per cent of the total population, have been given top priority in the country’s developmental plans. Vietnam has either met or is on track to meet the Millennium Development Goals in children’s health and education (UNICEF 2009). Not only are laws and policies devoted to providing children with the best environment to develop, Vietnam’s value system considers children to be a precious but vulnerable group that need the best possible care and protection.

Looking at the position and status of children in a society is not new, but there is a tendency to view children’s rights through how they are supported by legislation and public policies, while the cultural aspects of how children are situated in a society are rarely studied. The enormous literature on women’s status and role in society is in great contrasted to the sparse interest in children’s positions in a society. In this study, children are the central focus and the gathered data will be used in understanding children’s problems and how they cope with difficulties. Specifically, I will describe the way Vietnamese adults think about children, what they expect from a child, and the relationship between adults and children in general.

Similar to many cultures, the Vietnamese follow a Confucian tradition and believe that children are innocent and kind to everybody (Nhân chi sơ, tình bán thiên). The socialization process allows people around children to shape the moral and characteristic development of him or her. When discussing children, people will initially evaluate them to be either a “good” (ngoan) or “bad” (hu) child. These two terms are relative, depending on the norms of each community or family. Still, there are several important points when deciding whether a child is good or bad. A good
child (ngoan) always obeys everything that an adult says and never talks back. He/she should study hard and eat and sleep when adults tell them to. If a child does not meet these demands (except for infants) they are evaluated to be “bad” (hu). When children start school, the most important tasks for them are to study well, pass all exams and avoid evoking complaints from their teachers. The school environment continues to emphasize the importance of children obeying adults. Children only receive compliments if they follow everything that their teacher says. New ideas are still unwelcome, although recently, people have started to realize that conforming in the classroom can prevent children from being creative.

Depending on the areas where children live and their gender, children have additional rules to follow. Children are socialized to social norms strictly, especially gender norms. Girls are expected to be “ngoan hơn”, which means follow the rules better than boys, being gentle and express their feelings and emotions more than boys. Adults tend to tolerate boys who do not follow the rules and consider a disobedient attitude as part of boy’s natural character. “He is lazy/ stubborn. You know, boys are like that!” is a common sentence. If girls disobey their parents in the way boys do, or ignore the rules completely, adults evaluate or punish her unacceptable behavior more seriously. It is normal that boys often keep quiet and talk little with caregivers, especially if they are adolescences. Concurrently, girls who do not show their love to others are considered to “know nothing” or even as “badly behaved”.

In Vietnamese culture, although people may be aware of children’s agency, no action has been implemented in order to improve the top-down relationship between adults and children. Children are meant to obey the rules, sharing information and communication between adults and children is not common. Communication occurs in a one-way method, with adults doing the talking and inquiring, while children listen or answer the questions. Vietnamese people have a expression that parents commonly use to teach children (Cá không ăn muốn cá ước, con không nghe lời cha mẹ, trầm đường con hư), it means that if children do not follow the requests of their parents, it is 100% sure that the child will become spoiled. When parents make mistakes, the mistakes tend to be ignored, while adults always evaluate children’s mistakes seriously. Parents rarely apologize to children for their faults. In the past, hitting children was an accepted and common form of punishing children. There is a
popular expression (Thương cho roi cho vợ, ghét cho ngọt cho bụi) that means that if you love your child, you should be very strict with them, by hitting them if they do not obey, so that they can grow up as a "good" child. Reversely, not hitting children because you love them means you are harming them. Over many generations, hitting has become a common method of raising children. Nowadays, violence has been mentioned more often and hitting children has been considered as a bad way to teach children, more young couples try to avoid hitting their children too often. Nonetheless, when children do not obey parents' demands after parents have warned the child, they will be hit because parents say that "It is the only way to teach them well", or "I hit them hard so that they know it is a serious mistake and they will never make it again", or "I used to be hit a lot and that's how I became a good person, hitting like that is not harmful, it is only harmful if you hit them too hard." Reasons for hitting children are plentiful.

Since children do not have enough knowledge about the larger society around them, in Vietnam, it is believed that they should be cared for and protected. If the child’s parents die, the clan decides who will have to take care of him or her; although, the definition of "good" care is not the same everywhere. In Vietnam, the basic demands given to parents are to (cho con ăn học đăng hoàng) be sure that children eat and study well. Only over the last few years have the psychological problems of children been given attention by society. For example, teenagers are labeled as "difficult to understand and control" but there is no attention paid to how to support them. The idea of mental health has not existed in daily life and therefore, is not talked about when discussing the definition of childcare and the standards of good care.

Structure of the thesis

This thesis will start with a short description of my field site – Ha Long, Quang Ninh in Vietnam. The socio-economic situation along with the features of the HIV epidemic in this area will be followed by the portrayal of Vietnamese culture in terms of children. I use chapter 3 to depict the way I conducted this study, the advantages as well as the disadvantages in the fieldwork. Chapter 4 outlines the theoretical framework that supports my argument. The main sections of this thesis are the study results that are presented in chapter 5; in which five different aspects of the life of children affected by HIV/AIDS are highlighted, while their coping strategies are the
core content of this chapter. Discussions regarding the problems of these children in the context of socio-cultural context of Vietnam will be provided. In the final chapter, the conclusion emphasizes the importance of evaluating the problems of children affected by HIV/AIDS in relation to the socio-economic-cultural context, and under the impact of international and bilateral developmental programs.
Chapter 3. Research methodology

When I returned to Vietnam from AMMA, I did not have to remind myself to use an anthropological approach which included a “thick description” (Geertz 1973). After one year far away from home and acclimating to a new life in Amsterdam, my experiences in Vietnam started to make me feel like an outsider. Questions of what, why and how often appeared in my mind, especially when I began my fieldwork in Quang Ninh. I reflected on many things that I used to think were normal and that would not have caught my attention in the past.

I chose to do my fieldwork in Ha Long, Quang Ninh because of the kindness shown to me from people living there with HIV/AIDS. I came to the field and introduced myself as a student of medical anthropology from Amsterdam, but everybody knew that I used to work for MCNV, and that my fieldwork was currently supported by MCNV and Ha Long WU. Hence, some people thought that I had lied about my role at MCNV and the WU’s project, and some of my informants doubted that one of the aims of this research was to access whether the support for them will continue in the future. Some people believed that I was only a student, but still hoped that I would come back to work for MCNV. Only a few people in the WU and the Sunflower groups understood my position as a researcher, however they were also my close friends or they felt that they owed me for helping people living with HIV, so they gave their support regardless of what they thought my intentions were.

First of all, I must point out that my position provided many advantages. No matter if people believed I was a project officer, or a researcher, I received a warm welcome from almost everybody. All of my informants knew me, or had heard of me when they first joined the group, so they never refused talking with me. I could have visited them everyday and they would have kept on talking and assisting my research. The close relationships that I have formed allowed me to observe the daily life and communication between caregivers and children. Also, I had the opportunity to collect the most up to date, or occasionally confidential data and information about the Sunflower groups and HIV/AIDS in the province. The most important issue was the voluntary work of my two gatekeepers. They are the heads of two Sunflower
groups, so they were told by the WU to be of assistance on this research project, but, luckily they were also willing and happy to be involved.

However, my ambiguous role also had disadvantages. There was a rumor circulating that I had asked for additional support from MCNV for Quang Ninh’s Sunflower group, which gave some people hope and is why many thought I was researching this group’s children. Whether consciously or unconsciously, people tended to talk about their problems when discussing their lives with me. Even after I said that the interview had stopped and I just wanted to chat, more and more information was given. In a few extreme cases, my role seemed to make my informants tell lies about their situation in order to gain extra support, especially financial support.

Timing of the study

My study proposal was developed in April and May 2009. The fieldwork started the second week of May. The first week, I negotiated with the WU because as sponsors they had to agree with my research plan. I also talked with the gatekeepers about my plans and made schedules for interviews. Over the following three weeks, I was pulled in every direction of the city for interviews, talks, group discussions and household visits. During my so-called spare time, some mothers living with HIV/AIDS, who are also my informants, invited me to “parties”, where people from the Sunflower group gathered together to have lunch or dinner and talked, or they called me for a “private talk” in which they would disclose many details of their lives. I left the field for one week in order to gain a clearer perspective and peruse the data I had collected. I began to transcribe audiotapes and looked for main themes and information that was lacking. The last two weeks was for collecting and filling gaps in my data. The writing of the thesis took 5 weeks.

Sample selection

The study sample was selected according to the principle of maximum variation, which includes a wide range of extremes, and was in combination with convenient recruitment. The informants of this study were recruited through the two Sunflower groups in Ha Long. These groups are affiliated with the “Comprehensive Community-Based Care for Children Infected and Affected by HIV/AIDS” of the Medical
Committee Netherlands-Vietnam, in collaboration with Ha Long Women’s Union. The first Sunflower group was founded in 2006, its mission was to support women living with HIV/AIDS (mainly serving mothers). Another group was started in 2008 that aimed to provide support for caretakers of orphans - most are grandparents taking care of their grand children whose parents have died of AIDS. Through these groups, all members can access medical, social and economic support to improve the quality of life for themselves and/or their children. As of June 2008, there were 124 mothers, 86 caretakers and 241 children participating in Sunflower groups (Narrative report of Ha Long WU to MCNV 2008). The children of this study are part of the Sunflower groups.

I worked with the leaders of two Sunflower groups in selecting children between 11-15 years old. According to the member lists of the two groups, the first group for mothers had 148 followed-up children, and there were 26 children in this age group. There were 71 children of this age group, out of 194 children in the second group, which worked with children whose parents died of AIDS, or one parent died and the other had left and they now lived with their grand parents. Next, we had to filter through all the children that could not be found because their caregivers had left the group, or provided fake addresses or phone numbers. We also had to limit our search to local children rather than recruiting some of the many children from the several far-away communes, which could take 2 or 3 hours to reach by car.

I decided to talk with 10 grand parents and 10 mothers living with HIV/AIDS before talking with children, so that I could choose around 8 children with different life circumstances. This had a double purpose: First, I needed children for both deep interviews and focus group discussions, and I needed their guardians' permission; Second, I did not lose any time with children whose guardians would not allow their children to participate. In the end, I followed 8 children closely for this study (see table 1). In addition, I met and had short conversations with 10 other children.
Table 1: Gender, Age and Guardianship

<table>
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<th>Feature</th>
<th>Number</th>
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</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
</tr>
<tr>
<td>Female</td>
<td>3</td>
</tr>
<tr>
<td>Living with</td>
<td></td>
</tr>
<tr>
<td>Both father and mother</td>
<td>1</td>
</tr>
<tr>
<td>Mother</td>
<td>3</td>
</tr>
<tr>
<td>Grand parent(s)</td>
<td>4</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>11-13</td>
<td>5</td>
</tr>
<tr>
<td>14-15</td>
<td>3</td>
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</tbody>
</table>

All of the children in this study were HIV negative. The children who were HIV positive in the groups all belonged to a lower age bracket: from infants to 7 years old. A common characteristic of children in the Sunflower group 1 was the loss of their fathers. The majority of mothers living with HIV/AIDS in this group were widows, or their husbands were in prison or in rehabilitation camps. In another words, they were similar to the children in Sunflower group 2 in that they were also, in a sense, orphans.

**In-depth interviews**

There were twenty interviews conducted with grand parent(s) and mothers living with HIV/AIDS at their homes. They were asked about their life, family situations and the discussions focused on their children. The interviews lasted from 45 minutes to 3 hours, depending on the informants’ availability and how much they wanted to share about their stories. In some cases, when the informants had limited time, or if I forgot to ask something, I came back for another meeting. At the end of the interviews, I asked for permission to work with their children.

In-depth interviews were also employed to gather data reflecting the opinions, feelings and emotions of children and their lived experiences and concerns. The data regarding children’s daily activities such as their study activities and chores at home was gathered at these interviews. However, interviews with children were not just one or two appointments like with adults. Depending on the child’s characteristics, he/she agreed to talk to me after one or two meetings, and in some cases, it took 5 or 6 times
before they started to talk. Normally, girls were more open than boys and boys often hid their feelings and preferred to talk about objective events rather than discuss their emotions. Children of 14 and 15 years old were more open than the smaller children. The length of each in-depth interview was flexible depending on time restraints, concentration level, and the interests and emotions of children. The place where in-depth interviews were conducted was flexible in order to make children feel comfortable. Some children were interviewed in a café, on a beach, or at their homes. Children could choose whether or not to have their caregivers present at the interviews.

The most difficult part of working with children was the process of persuading them to join the study. I thought that the power relations between myself, as researcher, and the children could make them feel as if they had to answer my questions because I was the adult, however I believe that the children were comfortable telling me when they did not want talk anymore. Some children were more comfortable talking and sharing stories during the first interview. However, some children were very difficult to talk to, and at the first meeting some kept silence the entire time. It took me at least 2 or 3 household visits to make friends with them. There was an instance when I decided to discontinue the relationship during the first visit because the child said: “You came here with Mr. Z (my gate keeper), so I know, you want to talk about that disease (HIV). I lost my parents and that’s it. Why the hell did you come here to ask me more about it!” I did not want to intrude or cause him any additional suffering, so I elected not visit him again.

Caregivers were very helpful but their overwhelming support might have created barriers when I was approaching their children. In several cases, caregivers pushed their children to talk with me and the latter were angry with me or resentful during our time together.

There were two cases when the children did not provide enough information; in order to fill this gap in data, I conducted in-depth interviews with their schoolteachers.

In addition, informal talks were conducted with the Women’s Union staff, other Sunflower members, and a project officer of a support program for children in Hạ Long, and neighbors or siblings of several informants.
Focus group discussion

Initially two focus group discussions were held, one group of grand parents and another of mothers living with HIV/AIDS. They are caregivers of children affected by HIV/AIDS in the age group of this study. General problems of family life were discussed, including the relationship between adults and children and caregivers’ concerns about their children. The focal point of the discussion was children’s life such as their daily routines, their education, and their difficulties. Themes that came up in the group discussions were poverty, stigma, social evils and support for children. Data collected from the FGDs was used as context information and lead to topics and questions for the IDI. The separation of the two groups was due to the schedules of two different types of informants. The group of grand parents preferred to meet weekend mornings so that they could do their work during the week, while the group of mothers could not meet in the morning because they had work at the market every morning, including weekends.

One focus group discussion was conducted with a group of children affected by HIV/AIDS. This group contained 7 children who knew about the HIV status of their parents and did not join in my previous interviews. I purposely chose children from 11 to 13 years old because they were more comfortable together and talking. I chose this age group due to feedback from several children about the previous activities they had joined. Children of 15 said that they did not want to talk with children of 11 or 12 years old, since the latter were “childish” (words used by interviewees). Furthermore, it is a common perception that children from 14 to 15 years old belong to the pubescent group, so caregivers suggested that I interview them individually. Among children in the FGD, three children were living with grand parents, one child was living with her parents and the other two were living with only their mothers.

Projective techniques, a type of participatory tools (International HIV/AIDS Alliance 2006), were successfully applied in breaking the ice and encouraged children to talk and share their ideas. Overall, the discussion was used to gain an overview of children affected by HIV/AIDS daily activities, concerns, wants and needs. I started the FGD with a simple and funny game so that children could get “warmed up” before they introduced themselves to each other. Children were asked to draw a pie in which they described their daily schedule. They also talked about their fears, and their wishes in
life. A fictional case of a child living with his mother, whose father died of AIDS, was used and it had them discuss the child’s feelings and opinions. At the end of the group discussion, children asked me questions and said: “You need to answer as well.” I was surprised because all the questions were about complicated adult issues such as complicated situations in life related to love and marriage.

Observation

Participant observation was conducted during the study to gain better understanding about the context of children’s lives affected by HIV/AIDS. It was performed at children’s homes, several events for children affected by HIV/AIDS during Children’s Day and at their play spaces like Children’s House, the beach, and internet game shops. Communication between children and others including parents/caretakers, friends and strangers was observed carefully as part of accessing their daily activities, behavioral characteristics and their relationships. Interactions and children’s displays of emotion while with others in various settings such as school, home and entertainment spaces was observed and analyzed along with interview data.

Ethical issues

Participation in this study was voluntary. Every informant was informed of the content of the study, and children’s guardians gave consent. Every one of my informants agreed to join the study, except one pair of grand parents. They agreed to talk with me, but refused me access to their child, because they did not tell her the truth about her parents’ death being related to AIDS. I never did meet this grand child. All the adults who joined in the research signed the consent form, except one. She was an older grand mother who is illiterate and the consent was recorded on tape. Interviewees were informed that they have the right to end the interview at any time, and that they can refuse to answer any questions that they do not feel comfortable with. During the study, I verbally explained the methods and objectives, emphasizing those sensitive issues that may come up during the interviews and/or discussions. Every one of my informants said it would be fine to talk about the sensitive topics.

Children’s consent was recorded on tape. In several cases, children were forced to meet and talk with me by their caregivers, but when we were alone in a private space,
I let them do whatever they liked and clearly told them that they could answer my questions or refuse whenever they wanted to. All the interviews and discussions were arranged according to the preferences of my informants. Interviews with children were done with or without the presence of their parents based on the choice of children.

The interviews with children were conducted in a variety of atmospheres, and I always considered the emotional effect on children when sensitive issues were mentioned. In those situations, children were asked if they would like to continue with the interview; in several cases, children actively rejected the questions.

The permission to record the interviews was collected in the consent form in the beginning. Tape recording was carried out after the consent form was signed, and in case the consent form was not signed, the agreement to join in the research was recorded. All of the recordings were kept in a safe place and access was given only to the researcher and a transcriber. The transcriber had to sign a contract agreeing to keep the information confidential.

All of the participants provided their real names, however, in this thesis, I have used pseudonyms and have changed all identifying information to ensure privacy and confidentiality.

Interviewees received a box of biscuits as a gift when I made a visit to their home. When they came to the WU’s office for a focus group discussion, minimal compensation was given to cover travel expenses. Children were given study materials as presents for joining the research.

The main findings of this research have been discussed with a group of caregivers, a group of children, and to the WU’s president. Further results will be presented to MCNV’s staff.
Chapter 4. Theoretical framework

This study is centered around Hardman’s call to researching children in a way that is “concerned with beliefs, values, or interpretation of their viewpoint, their meaning of the world” (Hardman 2001). The emergence of Hardman’s approach in part reflects a move away from seeing children as passive recipients of adult socialization. Children should be recognized as social actors that actively participate in the construction and determination of their experiences, and the societies in which they live (O’Kane 2008). Agency is considered as the “capacity of agents to act independently” (James and James 2008: 9), and more specifically, it is “the capacity of human beings to affect their own life chances and those of others and to play a role in the formation of social relations in which they participate” (Barfield 1997: 4).

The concept of children’s agency in this study is connected to Anthony Giddens’ definition (1984) that claims that agency is related to power and interaction. Children’s agency has a close relationship with social structure; agency is socially constructed and shaped within a cultural context. In this study, the context of HIV/AIDS and Vietnamese culture is outlined in exploring the agency of children affected by HIV/AIDS. By carefully considering the cultural context, we can understand children’s own views and priorities, and their strategies for dealing with difficulties.

Adolescence, the target group of this study, has been traditionally characterized as an unavoidably difficult and strained stage of development with stresses related to developmental demands (e.g. Freud 1958; Hall 1908). Research, however, has shown little evidence to support these theories (Coleman 1995). In my study, children whose parents are living with HIV/AIDS, not only have to deal with distress of the developmental process, but also suffer from poverty, parental loss or neglect. It has been shown that the past experiences of children in difficult situations and current demands of the developmental process may lead to psychological or behavioral problems, for example, they are likely to use non-productive or harmful coping strategies when dealing with the problems of daily life (Browne 1998). This study examines whether children find constructive or harmful coping strategies for their problems, and if the demands of a particular situation are beyond their capabilities.
Hauser and Bowlds (1990) admit, “adolescents vary dramatically in how they cope” (p 391). The concept of coping used in this study is taken from Lazarus and his colleagues, in which coping refers to the "cognitive and behavioral efforts made by individuals to master, tolerate, or reduce" (Folkman and Lazarus 1980: 223). Thus, coping is seen as an active and purposeful process mediating an adaptation outcome. Coping efforts, strategies, or responses are the actual things individuals think or do to deal with a particular problem (Murphy 1962; Pearlin and Schooler 1978; Zeitlin 1980). According to Murphy (1962), through his coping experiences, the child “discovers and measures himself, and develops his own perception of who and what he is and in time may become. We can say that the child creates his own identity through his efforts in coming to terms with the environment in his own personal way” (p 374).

In order to analyze coping strategies, Pollard’s (1982) model of integrating both the macro and the micro levels is employed. Children’s way of dealing with their situations should be seen under the effect of ideological, structural, and individual factors. In the process of forming identity, culture can be seen as an ideological and a structural factor affecting children’s coping strategies. Socio-economic factors in which children are socialized will be analyzed. I will consider the various situations and factors of each individual informant in order to explain the differences among those who are in similar positions.

Somatization and expressing distress are two concepts used in this study to understand children’s coping strategies. Furthermore, the analysis on health and suffering as being patterned by culture (Kleinman 1986; Kleinman 1988) will be used to understand children’s problems. The local world of experience including moral, political, economic factors mediate the effects of different events in ways that are reflected in cognitive, affective, and physiological changes. The result is the manifestation, exacerbation, and/or alleviation of symptoms (Ware and Kleinman 1992). When a person struggles with disease or problems of mental health, subjectively experienced distress may be dampened or intensified, and functioning improved or further impaired, by different variables. The variables include the nature and number of major events and difficulties in the life world of an individual (Brown 1989), the changes in the emotional climate of that world (Vaughn and Leff 1976), or
the manner in which the ill person chooses to engage with social life (Corin 1990). The problems of mental health are not only connected to how you evaluate them, but also on how you can express them in your community. Nichter (1981) in his study with Havik Brahmin women in South India, used the notion of “idioms of distress” to discuss expressive modes of distress in association with culturally pervasive values, norms and generative themes. He identified the ways that women maintained their socially constructed gender role and still expressed their personal distress. Parson (1984) continued to expand this concept of idioms of distress, which can not only be seen as symptoms of sickness, but also refers to cognitive-verbal expressions of distress, or how people talk about their stressful experiences; and the somatic-behavioral expressions of distress, or the non-verbal manifestations of distress. In this study, the notion of idioms of distress will be used to understand the psychological problems of children, in order to avoid the routine reaction of the “insider” - which may neglect social problems due cultural norms.
Chapter 5. Children’s problems and their coping strategies

I decided to look at the daily life of children to find out whether they were equipped with the basic resources a child needs in order to survive and even excel in life; for example, did they have shelter, a proper nights rest or provided enough food, clothes and school supplies. In a focus group discussion, I asked them to draw a pie to show how they spent their time, and during in-depth interviews, I often asked children to describe a normal day.

Among the children, studying was the most common activity, and I did not notice a difference in the studying habits of children affected by HIV/AIDS and those not. Children study at school for 4-5 hours a day. On some days, they participate in extra classes, which are optional but almost all children attended an extra class. Although the fee for extra classes is much higher than official school fees, all the children I met and talked to joined in both mandatory classed and extra classes, no matter if they were poor or rich.

Besides studying, children are expected to help with the housework, such as cleaning the house, washing the dishes, cooking or washing clothes. Some children also help parents or grandparents in taking care of younger sisters or brothers. Caregivers said that it is useful for children to help with housework if they have free time. “Their situation is like that ... we have to teach them to live independently. We do not know what will be in future, so we have to prepare them” (FGD of grandparents). However, several caregivers tried to do most of the housework so that their children had more time to study. Children also did not feel that it was a burden to help their parents. Nonetheless, girls seemed to have heavier workloads than boys. An eleven-year-old girl drew her schedule, it included activities like taking care of her younger sister, cooking and washing clothes (by hand); this is considered a moderate workload for girls, but boys do not have to do as much housework. One grandmother believed it was normal and common that her fifteen-year-old grandson never did any housework: “He is a boy, you know, boys are lazy and we can not push him.” (grandmother, having a 15-year-old grandson)

Communication with caregivers was also mentioned as a daily activity for children. Although all caregivers and children said that they spent time talking to each other,
the amount of time was little and the topics were limited. Discussing school studies is a common topic between parents and children. “Even if you want to avoid (talking), you have no way, my mother often spends the whole meal talking about my study and telling me that I should not do this or that. It is tiring” (FGD of children). Some of the children said that they could talk to their grandmothers about their school life and their friendships, which they called “confidence”. When I asked if caregivers and children had ever talked about children’s feelings: their sadness, anger or desire, little information was provided. Parents often felt confused when I asked about their children’s dreams and they answered, “My child is still too small, all she needs to do is to study well” (mother, HIV+, 32 years old).

Remarkably, television and internet were mentioned in every talk and discussion. Like most children around the world, children in Vietnam have limited options for entertainment. Sports are encouraged, but in reality, there is little room or materials available in order to play. With the lack of resources for children to join in healthy activities, children are left with television and computer games. This can be harmful to children if it is combined with insufficient care from parents.

“You know, there are a lot of bad things on TV and the internet now, so I do not have a TV, and I never give him cash, so that he can not play internet games” (mother, HIV+, 35 years old).

I did not find children of my target group being kept by unexpected work, for example taking care of old or sick people in the family:

“He is a nice child. When I am ill, I can ask him to bring me a glass of water” (grandmother, has a 11 y/o-grandson).

“When my mother was sick ... I visited her sometimes, talk a little bit. No, I do not have to do much, sometimes she called me to bring her water then I did it.” (Dan, male, 15 years old)

When any person in the family is ill, children are kept isolated to avoid infection. Adults do not want children to worry about them, so that children can concentrate on their school studies. All the children that I talked with did not have to take care of ill
people in the family. Even if it was their parents who were ill, children did not have to do anything, except visit them sometimes, or bring food or water to the bed. Other adults have to take care of the ill people; they can be cousins, aunts, uncles or grandparents.

Of all the cases in this study, Hao, was the child living in the most difficult of circumstances. She lives alone with her grandmother. I asked if she had to do much housework or take care of her grandmother. Her grandmother insisted that Hao did not have to do anything, except for study, cook basic rice and sometimes take care of her shop. In contrast, Hao told me that she had to take care of all the housework because her grandmother had to work hard to earn money. I have witnessed Hao at a small shop selling drinks in the market during the summer holiday.

All the children that I approached knew about the HIV status of their parents. There was only one case where the grandparents did not tell the truth to their grand daughter. The girl’s parents died because of AIDS, but they said that the father died in a car accident and the mother died of cancer. They also did not agree to be recorded and refused to let me approach their grandchild.

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\text{Once, she asked me “Grandma, why do people say that my parents die of AIDS?” And we have tried a lot to convince her that it is not because of AIDS. Who can prove that my grand child will not suffer from shock if she knew the truth? We feel that it is better now. We thank you for all help that you have tried to give us, but it is better to keep children out of these problems.}
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I was not able to access this child because I could not get permission, but it was the only time I was denied. In other cases, it was common that children received information from people around them, from the neighborhood or from school. Adults always said that it was because of stigma that their children knew about the HIV status of their parents, the fact that people talk about it is one expression of stigma. On the other hand, they feel relieved because it made their children actively ask them about it. Being in that situation, grandparents find easier to talk with their children: “Your parents did not follow the right path, now, I only have you, you should study well and should not follow your parents’ example.”
When asking adults what their children thought about HIV/AIDS, I usually received the answer: “He is still small and cannot fully be aware of the problems.” Therefore, according to my informants, children are encouraged to lead a so-called “normal” life; they can go to school, do housework and communicate with caregivers. Children rarely have to earn money, take care of sick family members or take responsibility for all of the housework. Yet, there was a gap when I looked at the activities of children that no one seemed to notice. For example, cooking and having meals alone was mentioned as a normal occurrence because the caregivers were too busy with earning money. Parents did not pay attention to the fact that there was a shortage of healthy outdoor activities and children spent too much time playing internet games or watching television.

Children’s daily activities of caring for an ill family member, which could affect their emotional state, did not worry parents. Some parents were proud to talk about how their children remembered to tell them to take their medicine on time. But I noticed that children did not like to mention the things they did for their parents, instead they talked a lot about their own life, children tended to avoid talking about their parents’ illness. While trying to understand children’s feelings and emotions surrounding their ill parents, I was sensitive to a hidden psychological distress behind their choice of keeping silence towards those issues.

5.1. Death, loss and unrecognized psychological problems

Case 1: “Why do we have to be sad? Going out, playing games! Then all the sadness will go.”

Dan is a special case because I did not choose him from the list of the two Sunflower groups; one day I confided to a my gate-keeper, Lan, that I could not find a way to get a boy named Phu, to talk more about his family. My gatekeeper suddenly remembered that I should talk with one of Phu’s closest cousins, Dan. She said, “Dan is one year older than Phu, but they are very close. More than that, Phu’s parents also died of AIDS. He is living with his paternal grandmother.” She also added that Dan is an “open and lovely child, not like Phu.”

We met Dan’s grandmother at the market where she was selling meat. She seemed to be a strong woman, greeted me warmly and said “I told you, he is going to speak
about everything, ask him, if he doesn’t answer, tell me, I will solve it. What kinds of children do not answer adults’ questions?"

Dan impressed me the first time I met him, with his confidence, and open and friendly attitude. After our introduction and some small talk, I told him about my research and my intention to interview him. He seemed comfortable and said, “Ok, ask what? Come on, ask me!” He often used slang, smiled and kept calm during the interviews, even while talking about the death of his parents.

Dan’s parents both died of AIDS, his father died when he was seven years old and his mother died when he was eleven years old. He has been living with a grandmother and one single uncle since his father passed away and his mother returned to her own family. Since then, every cousin knew the truth but did not say anything about his grandmother not letting his mother stay with them because she was addicted to gambling. They live on the money that the grandmother earns by selling meat in the market, and sometimes they get support from Dan’s aunt. When I asked him if he received any other support from international and national programs, he laughed, “My grandmother knows about it more than me. They give us some money every month, and she called it ‘salary’. Awesome! What a strange salary!”

In the conversation about his school life, it was clear that Dan had made and chosen fine friends and a good lifestyle:

*There are 5 groups in my class, and the most extraordinary group is “Hong Huong hoi”. The name of the group was created from the name of 2 strict teachers. This group includes children who are bad at studying and do not follow the school rules. I went out with them twice. They ate a lot of stuff and spent too much money. And they just used bad words so I left.*

*Fighting? Several times in the past. Reasons? We do not have a real reason for fighting. Childish! When we are small, we wanted to be a hero, and that’s why we hit others. “Dĩ hòa vi quy” (being peaceful can bring you the best) I do not like fighting. Crazy things. If I can let it go, then I will make concessions.*
Although Dan loves internet games, he started to realize that it waste of money and time. He also wanted to spend more time studying.

When I asked Dan whether he felt sad when I asked about his parents, he told me “Being sad for what? It passed. It is useless to be sad” and then continued “Well, ask me then, what do you want to ask? Come on! I need to cook also.” When I suggested that we could cook together, Dan said “Hey, why don’t you write all of your questions on a paper, give it to me, I will answer all of them for you.”

I asked him whether he missed his parents, he said “Miss? Miss what? Missing is for nothing. If you miss someone, just find something to enjoy. Like me, go to internet games, or go out, then life is beautiful. We should not live in misery, should we?” Referring to the past, he told me “Of course, parents die, everybody is sad. But I was sad for only 10 minutes, and then went to play internet games and everything was fine. Playing to forget, why should we be sad?”

Talking about HIV, he knew about the disease but said that it was in the past. He doesn’t have any difficulties with friends, he said: “Friends are good, when we are good and they are good to us. Of course, we are different from one another. If your parents are alive, friends can use their names to tell jokes about you, but with me, they don’t dare to do that.” He added “In all family parties, people keep saying ‘don’t be like your father, it is not good. Okay, I knew it also. They talk about it too much, that made it become so boring.” Asking what he missed about his parents, he told me a story from when he still had both his father and mother, and they all spent the evening together. “The most interesting thing,” he said, “is that ice cream at that time was very cheap.”

When I asked if he spent time talking with his grandmother, Dan told me “What would we talk about? Games, fighting, gossip, what else? Nothing more... Talking with grandmother? She can’t understand, she knows nothing about games. Of course, we talk, but about daily stuff, and I tell her what the teachers ask me to tell her.”

There is little communication with Dan and his grandmother, and he also said that he never talks to friends, cousins or other family members about his feelings or emotions. This was a common feature in many children that I met. No one ever
seemed to wonder why children did not show their sadness when their parents died; it is common for people to think that the death of a loved one can be overcome quickly, especially in children who have “little awareness” or can “easily forget.”

I do not think that the loss of parents can be easily forgotten. This made me think about how Vietnamese tend not to talk much about their feelings and emotions, especially personal tragedy and torment. Children have even less chance to show emotions. If the caregivers feel that their children are suffering from sadness or low self-esteem because of the loss of parents, they try help the children by providing good food or letting them go out, or giving them money to play games. Talking about emotions is not familiar. Some grandparents say things like: “It passed. You do not need to be sad.” But listening to children’s feelings and talking about emotions is not a common practice.

My observations confirmed the fact that children avoid talking about their sadness and emotions. Clearly aware of the loss, Dan still prevented himself from expressing his feelings; “Give me a paper and I will answer you” is what he told me when I asked about his feelings. Dan’s reaction is similar to many other children.

These children are called “ngoan” as they do not cry everyday, go to school and obey all the demands. In other words, adults do not have to worry about them. Grandparents who take care of children often tell me “When his/her parents died, they were still small, they knew nothing”, or “It has been a long time since his parents died, he has had enough time to recover.” While some grandparents felt that their grand children were suffering and sad because of having lost their parents, others do not accept it. Lonely mothers often reject the idea that their children still hurt from the impact of their fathers’ death. According to the mothers, fathers did not take care of the children anyway, or that the children were too small to have “grown up” ideas and thoughts about the loss.

Calmness, smiling faces, and forgetting about the past easily were some of the characteristics that children gave to describe their caregivers. Children whose parents died of AIDS did not speak about their sadness, while other children tried not to mention their fear of losing parents. Almost all the children that I talked to preferred keeping quiet, or talking very little when I referred to the illness or death of their
parents. An 11-year-old boy wrote about three things he was most afraid of; one of them was that his mother would die. When I raised this issue to other children in the group discussion, all of them suddenly went from talking happily to silence. After that, one of them said: “Of course, who is not afraid of that? I think we should change to a different game now.” Rejecting my questions or providing general answers is how they showed their avoidance of this topic. When I asked if they missed their parents, they often talked about happy memories with their parents. Only one child told me about his fears when he witnessed his father’s “lễ thay áo” (a ceremony that takes place over a single night, about three years after the death of a person; the coffin is opened in front of family members, they wash the bones of the corpse and rebuild the tomb).

Death is not the only way that children lose their parents. Because AIDS is highly stigmatized, the death of one parent can cause a child to lose them both. Looking at the list of children in the Sunflower groups, there were many of them who were described as “both side orphan” because their father or mother died and the other parent left the child with their grandparents. Hao is an illustration of that abandonment. Her mother left when her father died. She did not cry when she talked about the death of her father, but cried a lot when I asked about her mother “I don’t know why she left me.” The abandonment of living parents might make the feeling of loss even more painful.

The caregivers said that they could feel that the children were sad because of their parents’ death or because they were afraid that their living parents would die at any time. “Of course, she lost her parents. I think she has self-pity (Tủi thân)”. Yet, caregivers did not know what to do, or what to say. “One night, she cried, and I told her that there was no need to cry. It passed and we must live with what we have. Now she is better.” Most adults tended to believe that the grief would pass with time, and their children would overcome that grief.

Discussion

The loss of parental protection and support has negative effects on all aspects of children’s lives such as lost opportunities for schooling; the necessity to work at an
early age; declining access to health care; increased malnutrition; and increased exposure to sexual and physical abuse (Hunter and Susan 2005).

In several studies, it has been shown that the loss of parents is linked to a reduced quality of life as children often have to move to a new place, are deprived of the necessary care and love from caregivers. Additional problems arise if caregivers have limited resources and they still have to take care of their own children (Richter, Foster, and Sherr 2006). In Vietnam, 98% of vulnerable children, including children affected by HIV/AIDS, and orphans, are living with their families (Hai Huu 2002). The group of children that I work with stayed with their grandparents when neither of their parents was able to take care of them. In these cases, children were usually provided with not only a home but also love and care from the closest cousin who are the grandparents. Many of them had been living with the grandparents since they were born, or from when they were very young; therefore, they had no problem adjusting to the new environment. The close relationship between grandparents and children in Vietnamese culture allows children to enter into their new life with more ease and confidence. However, the generational clashes with adopted children (Wijngaarden and Shaeffer 2005) makes it harder to assuage the suffering of children.

Children affected by HIV/AIDS think about their parents’ death regardless of whether their parents have passed away or their parents will likely live a long life. Losing one’s parents is painful, even if children do not express it verbally. The psychological distress of children whose parents have died of HIV/AIDS has been analyzed in many studies (Atwinea, Cantor-Graeca, and Bajunirwe 2005; Wood, Chase, and Aggleton 2006). Children also suffer severe trauma when their parents or family members are sick, especially if children have to take care of sick persons because dying of AIDS is long and often very difficult process (Hunter and Susan 2005). The psychological impact of HIV/AIDS on children does not follow a model. There is a consensus that children are “able to bear and recover from significant suffering when they are surrounded by people who love and care for them. The sense of belonging and hope that is nurtured in these relationships enables children to cope better with hardship, including hunger, discomfort, and other privations of poverty and loss” (Richter, Foster, and Sherr 2006). However, the definition of love and care, and how it should
be expressed, is not agreed upon, which is responsible for the lack of proper support for children.

In Vietnamese culture, like many other cultures, not talking about emotions pushes children into finding other ways to cope with their feelings. The death attached to HIV/AIDS creates stigma; and self-stigma prevents children from confiding in others, especially their friends (who are often the people children talk to during their adolescence). Communication is “luxurious” in poor families, whose parents have to work hard to earn money rather than spending time with their children. Parents are also restrained by their own psychological problems such as fear, sadness, worries... when they talk about illness and HIV. In this socio-cultural context, children have little chance to express their distress by talking and complaining. Instead, keeping silent and avoidance is what they chose. We cannot easily conclude that children can overcome the grief of losing parents just through the passive actions of listening to the advice of their caregivers or by observing caregivers calming expressions. Ware and Kleinman (1992) have shown that there can be an alleviation of symptoms due to cultural factors. When I gave children the opportunity to express emotions, it was still difficult because they did not know how to communicate them. This difficulty can create a number of lasting problems for children and alter interactions with family, schoolmates, and peers. However, we should think twice before we try to assist children in expressing feelings or talking about painful experiences as it may cause unnecessary grief for children who have accepted their situations.

For children whose parents are both still alive, feelings of insecurity and the fear of losing parents creates psychological distress; this distress has not been given the same attention as the psychological issues of orphans. In fact, both groups of children have to deal with issues of death. It is hard for children to talk about death because it is taboo in Vietnam. It is even harder for children whose parents are still alive. Talking about death can bring bad luck. No one ever wants to talk about it, and children are told not to think about it because it may harm their psyche. In addition, many parents hope to minimize the impact of loss by avoiding the topic, which has been called a “conspiracy of silence” (UNAIDS 2001). In fact, when children know that their parents have HIV, it may be ignored as if it has no importance. Therefore, children internalize the situation, and keep their fears and worries to themselves.
Although the need of safety and a sense of belonging can be met with a strong family network, it is clearly not enough for children to build a positive coping strategy for their loss. The children in this study had various ways of expressing their suffering and coping with their pain. The “idioms of distress” employed by children is associated with their families’ conditions and the social values and norms they have been taught by adults. The coping strategy they often choose is the consolation of forgetting, or pretend to have forgotten. In this case, distress might be expressed through behaviors rather than talking. While crying is easy for adults to recognize – worry, avoidance and denial – are more difficult to identify. If distress cannot be expressed it can change into other forms, such as avoidance through internet games, or breaking school rules, etc; the coping strategies of children to the loss of parents, in this situation, were experienced as somatic behavioral expression (Parson 1984). The child’s distress may be greater agitated when caregivers misunderstand avoidance and punish children for their “bad behavior”, therefore causing children to suffer more.

5.2. Poverty and the untold wishes behind children’s silence

Case 2: You came? Again?

The first time I met Den’s mother, Ha, 3 years ago, she was dying of AIDS. Her CD4 at that time was 12, and she was very sick. It was a miracle that she recovered after receiving ARV treatment. Since I was one of the people who helped her get ARVs at the time, Ha welcomed me into her home warmly.

Ha’s family is known as one of the poorest families in the city. The house is located right at the foot of a mountain, which means it has almost no value according to the standards of the people in the area. It was sad to see her house, which was made of soil and contained no valuable things. There was only an old bed donated by a company 3 years ago; some old broken cupboards from the 60s, given to her last year, that were used as a children’s study table; an old broken fan for a hot summer. The kitchen and the bathroom, which were next to one another, are really just an open space with an unstable roof that smells very badly because the space is also used to raise their pig. She sells some alcohol to coal miners who work near their house, and goes to the mountains to get trifling coal to sell for money. She often gets ill and cannot do much. She receives support from the community and local charity groups.
She said the support helped “a lot”, but I found that was not a sustainable solution for her economic situation.

Together with his mother and younger sister, 12-year-old Den lives in the house and waits for community donations that will help to build a small, but proper house. His father died of AIDS when he was 7 years old. His mother only took a test 3 years ago when she became seriously ill. Since then, Ha has always felt ashamed of having HIV and has wanted to die. Ha’s parents have died already and the family in-laws do not help her at all, they actually discriminate against her; She told me that Den did not go to his father’s house for the death ceremony because he knew that the family had treated his mother badly after his father passed away.

Her two children still go to school. They do not have to pay any fees because she is very poor. She only has to pay 10000VND (40cent) per month for her son, which is only the savings account that all pupils must pay in to. At the beginning of each school year, she has to buy books and clothes for her two children, but international projects that she belongs to provide her with some of the needed materials or assists in paying for them. When I asked about her children, the first sentence she said was that:

*The small girl is good, but you know, my son, since he is a boy, is terrible. He is so naughty, does not obey, and also studies badly. He makes me crazy and when I go crazy, I will hit him (Diễn lên là quất).*

I asked her whether she thought the child may feel low-esteem because he does not have money like other children, she said “He should be ashamed, but not because he is poor, but because he studies badly.”

Having no transportation, Ha has to walk when she wants to go anywhere. When she was told that her son had to retake the exam to move to the next grade, she walked 5km in the rain to his teacher’s house to find out what had happened. She cried when she told me the story. “I’m afraid that he will be spoiled, and I will lose him. You know, if he stops his study, it means that there would be nothing more. My husband died early, all I want is to let the children go to school with the hope that it will lead them to a better life. If he studies well, the school will provide him school fees and books, but if not, it will be more difficult.” The next day when I visited her, Ha told
me that she had doubts about why her son had to retake the exam; maybe it was because she did not give a present to the teachers, like other parents.

She said: "Children cannot think deeply about anything. They love me and feel sorry for me when they see I'm sick. When I was sick, they cried and said 'Mommy, please don't die' but that is all. They knew I had HIV, I did not tell them but people came and talked together, they listened to them and they found out. If I have guests over and forget my medicine, they will remind me. Everyday, if they are not at school, at that time, both of them are at home to remind me of medicine".

Ha said, "Although I'm poor, I do not let the children do anything, or earn money. I can do everything to raise them well." Ha told me about when the community authority suggested that she should give her children to the orphanage.

Ha said her son has spoken only a little since he was a small boy. "I told him that Aunty Yen is just like your mother, your teacher, you need to talk with her, answer her questions, but he said that he was too shy. I am sorry." Sometimes, when I tried to talk with Den, I asked him to go out, but he refused to be alone with me and only agreed to talk if his mother was around. However, every time he refused to talk or felt uncomfortable in answering me, his mother shouted and hit him, which made me confused as to whether I should approach him.

In contrast with the warm and friendly attitude of Ha, Den looked at me with a lot of suspicion since the first time we met. Motivated to make friends with Den, I made daily visits, and as time went by, and we hiked the dangerous mountain together near his house many times (his favorite activity), he accepted me as a person; "strange and unavoidable" he called me. Despite how much his mother and his sister loved me, every time I came he took a deep breath and said: "You came? Again?"

Den talked very little, and used bad words and cursed. He never looked directly at others' faces, which is impolite and untruthful behavior according to Vietnamese norms. The fact that Den has to retake his exam would normally make a child feel ashamed -- in Vietnam failing an exam is a source of great shame to all pupils. However, I visited Den a lot, and I never saw him studying. I asked him about his study habits and he said that he could not study, and that is the only reason he gave.
Most of the time, Den liked to keep silent; for many days, we just walked together and talked about the mountain, how people made money with coal, or how people were creating many new roads around the mountain. “People who come here to work are all poor, but the company which they work for is very rich. You see, that company is there... They can even build a long road like this”.

Yen: What about you, Den? Have you ever thought of working to earn money?
Den: (Silence)
Yen: Your mother often goes to the mountain to collect coal, doesn’t she?
Den: Yes.
Yen: Everyday?
Den: Do you help her?
Yen: Yes. Once a week. We can take a few kilograms. We go up to that mountain (point the highest mountain) to get a lot of coal. But it is tiring...

Den refused to answer me when I asked how he felt when he did the job. I also asked him if any of his friends had to did the same daily errand. He said “Several. They live near here.” They are also his best friends in class.

Once, when I walked with Den and his younger sister, I asked the girl about her wishes, and she said: “A nice house.” I asked Den “What about you Den?” He said “Yes, I want a nice house, a real house.” When I left the field, the community started to build a small house for them, although they cannot build a toilet. I called and his mother could not get a hold of him for me “Well, he’s driving me crazy. He spends all day with the workers watching them build the house.”

Den’s story is typical, and illustrates the issues of poverty in children affected by HIV/AIDS. He is different from other children and avoids talking about sensitive issues; Den simply did not want to talk about anything. Through a psychological lens, Den may have several psychological problems, but I was most clear about his lack of self-confidence. I started to understand more about the child when I looked at him and noticed what those who saw him for the first time did – the poverty.

When children still go to school and do not have to earn money, caregivers do not recognize some of the other impacts of poverty on their children. I asked Den’s
mother if she thought Den lacked self-confidence, and she said, “Of course, he is not self-confident. He studies badly, and that’s why he can not be self-confident with others.”

Yen: What about other reasons? For example, your HIV status, or poverty, or because he has no father?
Ha: Well, we are not like others. But how can he complain? He still can go to school and he must know that he has to study well. I only need him to study well.

In Den’s case, he has few friends and they are poor and live in the neighborhood. They collect coal for their family, although caregivers never admitted that it was a real paying job. Children like Den have access to only second-hand books and clothes. They cannot play the games that most children play because it costs money. They have no toys, extra books or television to watch. When they go to school, they cannot have breakfast like many other children, because they only have very simple and in nutritious food at home. At school, they never have money for water and snacks at break time. In other words, children like Den go to school but are recognized easily as being poor children, because they are different from other children. Unfortunately, parents neither think about that difference, nor evaluate the psychological effects of it on their children.

Since HIV/AIDS in Ha Long is linked to heroin addiction, poverty is a main theme in households living with HIV/AIDS. Poverty was mentioned in almost all of the interviews. The grandparents complained about financial difficulties more than parents, even though grandparents often have a better and more stable income. In addition to a pension, children or other family members may also support grandparents. Depending on the ability of each family, children will provide their aging parents with money, housing, and other necessities. Parents also complained about their incomes, but less than old people.

Parents feel differently about whether it is a good idea for their children to be involved in financial matters. Almost all caregivers would like to keep children out of this issue, but there are some mothers who did not care about their children’s emotions and problems related to money. Le, a young mother often tells her son to
ask his grandmother for money and told him “I can raise you, but if your father is a useless person, your grandmother has to take responsibility. She should be reminded that you are her grandson and she should think about your heritage now.”

Whether parents decide to involve children in money matters or not, they usually know about the financial status of their families. In the group discussion, poverty was listed as both a worry and a priority for children. 5 out of 7 children wrote that they are afraid of being poor, and 4 out of 7 children wrote that they wanted to have money to buy a computer, clothes, or a bike. In interviews, except for a case when a girl lied about the poverty of her family, children are the most trusting group. I often asked children whether they knew about the economic status of their family, and whether they were provided enough study materials and clothes. Some children defined themselves as poor and some not. Ideas on wealth are subjective and are based on how children have been informed on the matter. Almost all the children admitted that they cannot live like rich people do, but they still have enough materials to live well. Except for children that were very poor, children seemed to avoid talking about the financial problems of their families. Firstly, it is because money is not a topic that children should discuss in Vietnamese culture. Secondly, Vietnamese have a quote (Con không chế cha mẹ khó, chó không chế chủ nghèo) to teach children, which means that children must not complain about their parents being poor. And finally, financial issues are always sensitive topics for people to talk about.

Despite different economic problems, poverty did not prevent children from going to school. Poor children are often supported by the school and do not have to pay school fees. The schools and teachers also provided old books for poor children by collecting the books from other children at the end of the school year. In addition, my group of informants now belongs to many NGO projects that provide money to supplement school fees and study materials. Moreover, children earning money was not an option for the caregivers that I spoke with, no matter how poor they were. Ha, mother of Den, one of the poorest people in this study said:

> Some people asked me to let my son go with them on a summer holiday, he could earn money by helping them by doing the small work of building a house (thợ phu) but I refused. He is a child, and what he needs to do is study. I can do whatever I have to do in order to earn the money to let him go to school. I don’t
need him earning money or doing anything. At home, he only has to study, play, and sometimes sweep the floor. You see, he even cannot sweep the floor properly, how can I let him go out into life?

Basic needs are met, but poverty influences children in many other ways. Some of them said that they feel sad about the low income of the family. They may feel sad because they cannot have what their friends have, like Phu’s story of a class picnic:

In the end of the school year, everybody in my class came to Bai Chay (the beach in Ha Long) to have a picnic one day. But we had to contribute 300,000 VND and my mother said that she could not afford it, so I’m the only one in my class that had to stay home (Phu, male, 13 years old).

Children may be sad, but also dream about having a better life, like Den’s dream of having a nice house to live in. Or, as in the case of an 11-year-old-girl name Ly, children can also be determined to study hard to earn money, but she was also jealous of friends who had a house on land, while she was living in a raft. Phong, another child whose grandmother is poor, just simply accepted the situation without complaining. His grandmother said: “I sell food at the market, so we do not have much money; my older child also helps, but little. Sometimes Phong wanted to have more meat but I couldn’t afford it. I feel sad but I cannot do anything. He is a good child, he never demands anything.” When I talked with him, he told me that his family has a normal life “We can not be rich but I think it is fine.”

Children in poor families also helped their caregivers earn money, but both parents and children do not consider it “child labor”. Den helps his mother collecting coals, Ly went with her mother selling drinks, and Hao sold traditional weed for hair washing at the market. They work during their free time, but they also make time for studying, therefore, no one ever called it a job. Adults even said: “She stays here (at the market) so that I can take care of her. If I let her stay at home, she will hang out with bad friends and it harms her” (Hao’s grandmother, has a 12-year-old grand daughter).

Accepting poverty is what adults want from their children, and these children have showed their acceptance to adults. Children who complained about poverty were
evaluated as “bad”. Hao’s grandmother shouted at her when she said she was sad because she always had to wear old clothes: “Don’t say that. You must know you are lucky to have cold clothes to wear.”

Poverty is a problem that limits the resources and chances for children to improve their quality of life; The lack of nutritious food, working to earn money or living in poor quality houses are visible illustration of poverty’s impact. Children suffer from poverty, but how children internalize the situation of poverty has yet to be fully revealed.

Discussion

Poverty is emphasized as one of the biggest problems for people living with HIV/AIDS (Hunter and Susan 2005). HIV may deepen or lead to poverty when people lose their jobs, or earn a reduced income due to illness, while their health care expenditures rise (Barnett and Whiteside 2002; UNDP 2005). Children are most vulnerable to the effects of the economic status of a household (Harper and Marcus 2000; Harper, Marcus, and Moore 2003). Studies show that differences between orphaned children and other children are less significant than those between poor and non-poor households (Ainsworth and Filmer 2002: 19). In addition, children in poor families have many other disadvantages including: difficulties in accessing financial, material and environmental assets; lower status, prejudice, less chance in accessing and improving entitlement or political rights (Harper, Marcus, and Moore 2003).

Poverty has been known to cause many problems for children, such as dropping out of school, working in childhood, and malnutrition (Norman 1991). Many children in my study suffer from poverty, but its impacts vary from child to child. The children in this study still had the opportunity to go to school on account of education policies and supports from developmental projects. On the other hand, poverty may be an indirect cause to caregivers’ distress, lack of health care, family conflicts, and stigma (Moore 2008; Moore and Henry 2005; VanLandingham, Knodel, Im-em, and Saengtienchai 2000). My study did not focus on the issues of poverty, but it has been shown that poverty affects the family environment of children in terms of the quality of care that children receive. Poverty reduces the capacity of caregivers in terms of resources, time and energy to take care of children both physically and mentally.
Although many income-generating activities have been established to develop sustainable economies for families living with HIV, reports have shown that these programs have not reached the poorest group (Navajas, Chreiner, Meyer, Gonzalez-Vega, and Rodriguez-Meza 2000; Oosterhoff 2008).

The impact of poverty on children is expressed in various ways but adults rarely ask children how they feel about it. Caregivers focus on their roles by providing children with all the needed materials for daily life. Children are aware of the economic difficulties and changes within a household (UNAIDS 2001), but their reaction based on the awareness of family's financial problems is different. Acceptance is considered a positive reaction for children, and often referred to as a type of adaptation (Hornby 2003). However, this term does not address the internalization process of children and their individual psychological struggles. Poverty may prevent children from integrating with friends at schools because of bullying and low self-esteem. Comparison among children is normal, but children affected by HIV/AIDS may be more sensitive and may have trouble achieving or maintaining self-confidence.

Children who cannot talk about their problems may have more difficulties in reducing distress. Low self-confidence, low self-esteem and self-pity can be expressed in different ways, verbally or nonverbally. Stealing is an example of children’s behavior when dealing with poverty. In other cases, children may adapt to the situation in a more positive way but keeping their worries or feelings of self-pity to themselves and keeping silent. Other children keep in the forefront of their mind their dreams of having a better life outside of poverty. The type of coping strategies used depends not only on socio-cultural factors, but also on individual choices. Since caregivers are not sure of the actual reasons behind their children’s behavior, they may misunderstand why children are behaving in a particular manner. Therefore, poverty attacks children not only through material factors such as the lack of necessary resources and opportunities (Harper, Marcus, and Moore 2003), but by also reducing the psychological strength and confidence of children, which would allow them to take advantage of the opportunities that did come their way.

5.3. Stigma, abandonment, lies and the desire for affection

Case 3: I do not miss my mother, she left me!
Hao’s small house is situated in an isolated place up on a mountain, and it can only be reached by foot. I never knew about this family until that day I met them; a gatekeeper introduced us and told them that I was the one who established the Sunflower group 2 for grandparents and now I was conducting research about children. Ly, an elderly grand mother, welcomed me with a story; she was shedding tears from the first word:

_I am suffering, baby (con)._ (She called me “con” – the word used to call a child in the family) I have no one to rely on. I have two sons, one died when he was very small, and the other one, this child’s father, died at the age of 28. Her (the child’s) mother left when she was only 2 years old, at the time her father went to prison. How miserable I am! My son was a good one. He got married when he was only 18, and then worked hard as a cyclo driver. He used to say that he hated drug users. God knows how he became involved in it. My daughter in law ... how could there be such a mother, leaving the child without any information of her whereabouts?

Talking about her grand child, she said:

_She is not matured like other her friends. She is tall, grown up but knows nothing at all. She used to cry because she missed her mother, but now, she does not cry anymore. Now, I am disappointed because all she needs to do is to study well, but she can’t... I try to give her everything I can, she has enough food, but how can she not love me by studying well? ... Anyway, having a grand child is nice because I have someone to be my friend, rather than being alone. But I don’t know whether I can live to raise her until she is grown up._

Mrs. Ly cried when remembering the time she took Hao to a market where Hao’s mother was staying. She said that the mother hid the child and left the child alone in the market, while she was waiting outside. After that, she never wanted the child think of her mother again. “I hurt so much. I heard that she (the mother) has 2 other children and her second husband also died of AIDS. She can not raise the child, I know, but at least, she should have a look at her.”
A few days later, Hao came to see me in an old and bad-quality uniform. Her dirty white blouse made of rough and thick material was surely uncomfortable in the hot summer temperatures, which can reach up to 40 degrees Celsius. We had our first interview in a café, since her grand mother said that it would be the best place if I wanted to have a private conversation with her.

To my surprise, Hao agreed to join the study without reservation. She shyly answered all of the questions, and always remembered to use “yes” correctly. (In Vietnam, it is important that children say yes in the right way, called “dạ” or “vâng” after every sentence to show respect for adults).

When I asked about her family, she cried and started to talk more, “She left me. I don’t know why she left me.” It was a challenge to decide whether I should continue to ask her questions. I chose to continue the interview although she was crying I believed that it would be better to let her talk. Her stories were about struggling and living a hard life, fighting against poverty, stigma and psychological problems.

- I miss my daddy, he used to take me to the Children’s house, and then we had ice cream together
- I want to become a policeman … I want to arrest all the drug sellers. They killed my father.
- I am afraid that my grand mother will die at anytime. She is so sick and I have nowhere to go.
- I have no friends at all. I have only one friend called Tra. Others say that I am a “no father, no mother person” (a term in Vietnamese used with indication that the person has no education and is spoiled) I don’t know why they treat me like that.
- I cry alone at night, without letting my grand mother know. When my grandmother did see it, she told me “You do not need to be sad” but I am still very sad.
- My grand mother sells votive papers objects (“vâng mạ”) (money, gold and stuff in papers for worshipping, or used to burn for Buddhist and dead people in ceremonies). I help her prepare the meals and sometimes look after her shop.
When we do not have money, we still have rice to eat, but we have no other food.

She said: "I only want to go to school. I know it is the only way to have a better life. I got good results last term, and I will try more." At this point, I started having some doubts about what she was saying because it was in contrast to what her grandmother told me.

This emotional interview made me curious to why the Sunflower group did not help them, and why would they let them live such a hard life. I went around and talked with the Women’s Union staff, core members of the Sunflower group but they said that they did not know about these problems. One day, I came back to visit Hao and her grandmother, without notice; They were all in the market at that time, so I chatted with one of their neighbors and found out that Mrs. Ly and her granddaughter were isolated because they often bought and sold stolen items.

Another day, I visited a child who was living near their house, and found out that this child and Hao have been classmates for many years. I asked the child if he knew where I could find Hao and her grand mother in the market and he showed me the way. On the way, he told me stories about Hao at school. He said that Hao was known as a bad girl at school. She stole a lot of money from her grand mother, and used the money for snacks, sweets and even used the money to take a taxi around the city – which is considered as incredibly luxurious. She gets low marks at school, and cannot pass the exam to move up to the next grade.

I had a chance to talk with Hao’s teacher, she complained to me about the girl’s behavior at school. She said that Hao was not loved by other children because she liked to flirt and make male friends, and wore too much make up for being so young. Girls confided to the teacher that they did not like Hao because she was a bad girl, while boys said that she was “vô duyên” (having no charm and annoying).

I decided to come back to the market a few days later, after spending some time reflecting on the differences between what others told me and what I had heard from Mrs. Ly and her granddaughter. Far from the place that Hao was sitting, I saw her selling a kind of traditional hair wash. She did not only help her grand mother, but
also worked there at another small stall. I said that I would be passing by some households nearby theirs and would like to visit the both of them. The grandmother felt uncomfortable and told me that the reason why her grand child was working in the market was to keep her away from bad friends and useless games. After that, I tried to talk with the child, but this time, she refused to talk much. I asked her if I could come back to visit her at her home, but she refused, she said, "I have told you everything." I felt that they were ashamed and worried to see me in the market, and somehow, they knew that I had found out about some of the lies. This was only confirmed to me later through informal talks with people around town. There was gossip being spread around the Sunflower group that Mrs. Ly and her grandchild were blamed by other members for telling me (I was considered the girl who came to help them) a lot of lies. This was an unforgivable mistake to this group. To avoid making it a serious problem, I explained to the core members and some other people that it was a misunderstanding and I came back to their house twice to make people believe it. However, I did not gain much information in my later visits.

Stealing and telling lies are what people see when they look at Hao. She was classified as a "bad" (hu) child according to social norms. While the children who thought to be "good" often received sympathy from others, children like Hao are blamed and kept away from others. HIV/AIDS in this situation is one of the many reasons for isolating her.

Closely related to stigma is the issue of disclosure. It was common that children heard about their parent or parents' HIV/AIDS diagnosis through other sources rather than a conversation with their parents. It could have been a conversation among adults in which they overheard. They may have heard about it from neighbors and friends. Children then asked their caregivers to confirm the information. However, caregivers often tried not to go into detail or explain the issue to children. People told me that it is a traditional thought that children should not know too much about problems as they may worry. Nevertheless, when I asked if it was hard to talk about it, some people, especially parents admitted they did not want to explain the situation to their children. The conversation would lead to issues of drugs and sex, and parents had emotional difficulty in talking about these issues. Children were not guided how to think about HIV, instead, they are asked to pretend that nothing is happening and
focus on their studies. Children are also asked not to disclose the information to others.

Enacted stigma was not a serious problem for my adult informants, since many of them kept their HIV status confidential. For children, they get enacted stigma related to HIV/AIDS only when they are young. When parents are afraid that a child is HIV positive, they do not want their children to play with him or her. However, when they grow up, this may become resolved. The fact that a child is alive until they are around 10 years old is considered a sign that the child is not HIV positive. The idea came from the realities of the past, when there was no medicine, and children with HIV/AIDS died very quickly, normally before they reach the age of 5.

Parents tend to hide their HIV status; therefore their children did not report experiencing enacted stigma. In contrast, almost all grandparents reported that stigma was a problem and affected their grandchildren, because the death of the parents revealed the presence of the disease to rest of the community.

Like my oldest child... (crying) He asked me “Grandma, why did my father get addicted to drugs?” I said “This, you have to ask your dad because I don’t know. Why do you ask me so?” He told me Today when I went to school my friends teased me, then they told me that “Your father is a drug user”, they made sounds “Ehhh” like this. Frankly, when other children go to school, their parents pick them up, my grandchild does not have parents, so their friends hurt him, it is so pitiful. (FGD of grandparents)

Our children, if they go out, they fight each other, even adults are not aware of what they are saying, they said, sorry everyone when I repeat it here, they said “Me (like “fuck” in English”) children of drug users ...” See, even adults are not well behaved...(FGD of grandparents)

Children were most affected by stigma created by their friends. I found little complaint about stigma from other family members. There is only one child who refused to contact his parental cousins, because he witnessed them discriminating against his mother who was living with HIV. Talking with children, I could see that enacted stigma was shown in many forms. Some children reported bullying when
their parents died of AIDS, but HIV was not always the direct reason these children were isolated. Coming back to the case of Hao, “no dad no mom” is the term her friends call her. Hao said she did not know the reason why her friends treated her like that, but a classmate of hers said they did not like her and teased her because she stole money and told lies. A teacher at the secondary school also confirmed that children are bullied due to their life at school, and how they integrate with other children, but not because of their family issues. The term “no dad no mom” can be raised if the child does not behave as expected; It might not be that the child is being behaving badly or doing something wrong, the term only implies the differences of the child from the rest of the class. Poverty that leads to a different appearance and lifestyle can be a reason for bullying.

When I referred to emotions during interviews with children, they were likely to hide their feelings. This was not a surprise since talking about feelings and emotions is not a common thing to do in Vietnamese culture. In a conversation with Diep Anh, a 15-year-old girl whose parents both died of AIDS, talked a little about bullying:

Yen: When you were young were you teased by your friends?
Diep Anh: Yes, sometimes.
Yen: Why? How did they tease you?
Diep Anh: Well, just normal. They teased me.
Yen: How?
Diep Anh: For example, I have no parents.
Yen: What did you feel at that time?
Diep Anh: (Silence) Well, it past. A little bit sad at that time, but it passed.
Yen: Did you talk with your grand mother about that?
Diep Anh: No. It’s ok.

Again, avoidance and efforts to forget is what I can see from children who have to struggle with their negative emotions. Children’s emotions related to stigma, isolation and bullying could be linked with self-stigma; yet, I did not succeed in making children talk about that. Firstly, I did not have enough time to be a close friend, in which it would have been easier for them to share their emotions. More importantly, even when they wanted to share, they could not find the way or words to express their feelings. Some children just cried and used the word “sad” to talk about their feelings.
about everything in their life. The reason for being sad could not be pointed out clearly. In Hao’s case, her low self-esteem may be caused by HIV/AIDS, but also by the loss of her father, the abandonment of her mother, poverty, or a combination of these factors. Ly who is 11 years old talked about many private stories and worries, but she refused to talk about the HIV status of her parents. Other children also avoided talking about their ideas about HIV/AIDS:

- What do you know about HIV?
- (Silence for a while) Well, it is a disease. Could you please ask other things?
  (Phong, 15 years old, male)

Discussion

Many studies have described and analyzed the stigma of children with HIV-infected parents, especially the relationship between courtesy stigma and the disclosure of parents’ HIV status to their children (Antle, Wells, Goldie, DeMatteo, and King 2001; Armistead, Summers, Forehand, Morse, Morse, et al. 1999; Reyland, Higgins-D’Alessandro, and McMahon 2002). Courtesy stigma refers to the prejudice and discrimination against individuals who are associated with stigmatized others (Scambler 1998). An individual who is stigmatized possesses “a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us” (Goffman 1963: 5). Stigma towards PLHIV in Vietnam is due not only to the fear of transmission but is also related to the exclusion of social evils (Khuat Thu Hong, Nguyen Thi Van Anh, and Ogden 2004). Hence, children are also stigmatized because of their families’ economic status, and their parents’ status and lifestyles.

The Vietnamese evaluate a person on many factors; one of the most important factors is his or her family. The popularity of the expression, “like father like son” is an example of how important one’s family is and why people usually ask about a child’s family. Adults are likely to ask about the family of their children’s friends right away. They decide to let their children spend time with that child based on their opinion of their family, which includes the family’s economic status or their type of work. Many adults prevented their children from hanging around with children affected by HIV/AIDS not because of the fear of infection, but because of the situation of the
families and the involvement of social evils. Since parents choose friends for their children it was even more difficult for children affected by HIV/AIDS to integrate. Parker and Aggleton (2003) reject the individualism underlying conventional approaches to stigma and its alleviation, instead they insist on the point of intersection between culture, power and difference as “central to the constitution of the social order” (Parker and Aggleton 2003: 17). In this study it was clear that judging a person by cultural traditions and standards of what a family should be deepened the stigma and reduced the ability of integration for children affected by HIV/AIDS.

The stigmatization of children affected by HIV/AIDS, between 11-15 years old, is not related to the denial of school admission as other studies have shown (Gielen, O’Camp, and Faden 1997; Ingram and Hutchinson 1999); rather it affects the school environment in which children are studying. Bullying is a form of isolation that negatively affects children’s emotions and it also causes or emphasizes self-stigma.

Self-pity (tủi thân) was often emphasized as a problem by caregivers of children affected by HIV/AIDS. Caregivers described the feeling of self-pity through expressions like sadness, crying, and a feeling of inferiority. According to Link et al (2001), these expressions of low self-esteem can be understood as self-stigma by children affected by HIV/AIDS. Yet, caregivers could not explain why children were stigmatized or what children felt about it. They could not recognize which of their children’s behaviors or expressions were affected by stigma. Children’s distress due to stigma can be made worse when adults do not recognize its expression. The core problems were not defined, therefore caregivers were confused in defining ways to help children to overcome low self-esteem and self-confidence, which affects children’s capacities. Children’s desire to be loved will be hidden or expressed in a negative way under the impact of self-stigma. The hidden psychological distress can be more serious if children discover their parents’ HIV diagnosis on their own. Without the support and guidance from parents and caregivers from the start, the distress might be expressed through negative behaviors affecting children’s well being (Bogart, et al. 2008; Wood, et al. 2006).

Coping strategies of children due to the distress caused by stigma is complex and difficult to understand. Bullying at school in many cases can produce both isolation and self-isolation. Some children lose self-confidence and keep distance from their
classmates, which make them more lonely and sad. Other children may strive for attention from others, like Hao who stole money and spent it on snacks for her and her only friend.

It has been shown that there is a correlation between self-stigma and children’s psychosocial adjustment to having a parent with HIV with delinquent behavior (Forehand, et al. 1998; Goffman 1963). In reality, adults are also likely to ignore this connection. Attention and listening to children who suffer from stigma and bullying should be promoted, for not only those affected by HIV/AIDS, but all stigmatized children. This would allow a glimpse into the internalization process of children who have parents infected with HIV, and explore how this diagnosis affects their identity.

5.4. The relinquishment, neglect, and disappointment towards caregivers

Case 4: “Don’t tell me any more lies mom, I will never believe you again!”

Le and her son are a special case; it was her confidence that inspired me to conduct this study. Le is a strong woman, who dares to do whatever it takes to get what she wants. In Vietnam her case is not typical, it is even considered a bad example. She hits her husband, threatens him with a knife, and attempts to harm others with dangerous tools. However she has been very friendly with me since our first meeting, and we have become good friends.

Le used to have a caring husband until he began his work in a coal mining company. He was able to earn more money than he was accustomed to and used that extra money for drugs, and then became infected with HIV through sharing needles. At that time, Phu was 5 years old. Now they quarrel often and the life of this young couple has changed radically. However, Le confirmed that Phu had a peaceful childhood because she always tried to keep him away from his parents’ quarrels, which were full of bad words. When Phu was 7 years old, his father was sent to prison for selling drugs. He came back home when Phu was 10 years old, but one year later, he was sent back to prison. This time, Phu has to wait for his father’s return; he will be 15 years old when that day comes. Le said it must have been sad for Phu to witness his father going to prison.
Le openly shared the story of her life, love, marriage and romantic affairs with me. Even though she had extra marital relations and does not love her husband anymore, Le decided not to get divorced. She wanted to wait for her husband’s return, so that he could ask his mother for the inheritance that was expected for Phu.

Ever since finding out that she was infected with HIV 2 years ago, getting revenge in this life was all that Le wanted. She thought of suicide in the beginning, then she became addicted to alcohol and gambling. When she joined the Sunflower group, I had a chance to talk with her while she was still an aggressive person. Over time, she has become more optimistic and happy due to the support of the Sunflower group, taking ARVs and making friends. However, there are times when she is sad or displeased with something, and goes back to gambling, drinking alcohol and staying out for more than a week at a time. Because of this lifestyle, she cannot hold a job and lives on the money she receives from her “lovers” and cousins.

Le always said that she provided for Phu the best she could. He has enough books and clothes to go school. Le said every time the teacher called her because of Phu’s bad behavior, she put aside all that she was doing to come and “teach” him a lesson, which meant she would beat Phu terribly (according to her). Hitting her son is her main form of disciplining him, “I am hot tempered, I can not wait more than two seconds before going crazy and hitting him. But you know my son is the most stubborn guy in this world. I know he would love me to talk gently and sweetly, but I can’t do that. Hitting him is the only way I can make him listen to me. If you are sweet to him, he will manipulate you, remember that.” Nonetheless, sometimes Le is very “sweet” with him. I often witnessed Le telling Phu lies, she promised him incredible things to get him to agree to do what she wanted. And when he did not do as she said, and I was there, and insisted that she not hit him, she would give him money instead.

She was proud to tell me:

You are my friend, so feel free to do anything with him. You can ask him anything. He knows that I am infected with HIV. How could he know? I put every piece of paper and medicine for the disease on the table at home. He reads it! And once, when his teacher was dealing with his bad behavior, she told
him my status. She (the teacher) told me that he even cried. You know, he also witnessed his aunt die of AIDS two years ago. He knows everything.

Phu is 13 years old, and lives with his mother in a large clean, but not well-equipped house. Phu is tall and very thin; his dark skin is responsible for his nickname “Black Phu”. I met him for the first time at his home on a summer evening. He had a stern expression on his face and did not say anything. His mother apologized for his “annoyed reaction” (as she called it) and explained that it was because he was forced to stay home and welcome me.

Although Phu was rude and forcefully refused my initial invitation to come to the city center and hang out, he changed his attitude when I suggested to Le that he join me at the beach. I asked his mother to discuss with him my beach invitation and when I spoke to him next, he was more friendly and said: “Aunty, is it true that I can go to the beach? My mother said so but I do not believe her. When will we go?” Since then, I started to notice that Phu consistently doubted his mother; he had been disappointed so often that he no longer believed the things his mother said.

Presently, Phu and his mother live next to the family of a cousin, and both families eat together. Le often leaves home for long periods of time for gambling and drinking, sometimes for a few weeks at a time. She returns home when she is broke and drunk, or when she finds out that Phu had gotten into serious trouble at school. When she stays at home in the evenings, she calls it “going into the monastery” (di tu). The aunt cooks everyday for both families, and Phu’s mother gives her money.

Phu is known for being stubborn and addicted to internet games. At school, he often receives negative feedback for fighting, chatting with friends, and not doing his homework. However, he did pass the exam this year to move up to the next grade.

After the beach trip, he became my friend and was ready to talk about his “world of children” (Hardman 2001) such as his studies, school, friends, cousins, and his passion for internet games. He even told me about lying to his mother to get money to go out with friends. However, whenever I found a way to refer to issues about his parents, he would shut down and not talk. There were a few times when I insisted that he say some words about his parents, but he shouted gruffly “You have made me
not like you anymore, stop these stupid questions!” There was only one time where he spoke about his parents; he told me that his grandmother told him that his mother was a “prostitute” (đi – slang for girls who work as prostitutes). When I asked him more about it, he just said, “She is grandmother, how can I talk back? Let it be,” without saying how he felt.

Once, his mother observed a reaction that she called “not cooperative”, and she became angry. I attempted to calm her down by saying that it was a good and understandable reaction. She claimed that everything was fine, but 5 minutes later, she said, “Yen, you must believe me, he knows everything. Let me help you, and you can ask him anything.” Then, despite my attempts to stop her, she gave Phu a long lecture and went straight to the harsh realities, “Phu, you know, I have HIV. You know, I can die anytime.” A few minutes passed, Phu kept silent, and then Le said, “You know how HIV is, your aunt got it and died, you remember?” Phu shouted “I knew that, ok?”

Le complained that Phu loved her but that he was too addicted to hanging around (ham choi) to understand and “behave well” (ngoan). When talking about his mother’s illness, he told me “My mother has to take medicine everyday, and you asked me whether I feel sad? Stupid question!”

When I asked Phu why he did not try to work harder, rather than hanging out and playing internet games, he told me that he did try sometimes, but right after studying, he would forgot everything. So he thought it would be better not to try anymore. Another reason he said he did not study was that he did not understand the previous class, therefore it was hard for him to keep up with the next class. When I spoke with his closest cousin, who is also a child affected by HIV/AIDS, he said that Phu was interested in nothing but internet games; they only talk together about games and the feelings of winning a game.

Reflecting on this case, the most important factor in Phu’s life is the role of his mother. In 2006, when Phu’s mother collapsed from hearing that she had HIV was also the same period of time when Phu left home for days without anybody noticing. When I asked Le about this, she said that there was no connection because Phu did
not know that she had HIV at that time. Phu became so angry when I first mentioned his leaving that I couldn’t continue with the discussion until another meeting.

When I would talk about his father, Phu showed little interest. He said that he visited his father a lot the first time he was in prison, but this time, the prison is very far away from home, he has only visited his father once. At that time, both the father and son cried. I asked if he missed his father, he kept silent for sometime, then answered, “always awkward questions” and talked about other things. Rather than talking about his father, he told stories about rich people he heard of, about how children told lies to get money and how he thought a hero should be. Drinking beer and wine, having a nice girl friend, and having a special necklace was what he wanted in order to show others his “high class” taste and status (đăng cấp).

When I began observing Phu, I could not predict his attitude or behavior. His reactions to his mother, teacher and myself cannot be simply defined as “normal” or “abnormal”, “good” or “bad”. His behaviors change quickly and drastically, depending on whether his demands are met. This is also a child who is partaking in adult activities and vices, such as gambling and drinking; he also has been found stealing. I cannot get a reasonable explanation from Phu, his mother or his teacher for his behavior.

After talking with Phu, I tried asking other children about what made children behave “badly” (htr). Children might explain that their friends were involved in deviant behaviors because of “following bad friends”, or having “no strong will” (không có ý chí). Noticeably, the most popular explanation for deviance was the lack of care children received from their caregivers. “They get bored because their parents did not care about them. I think they did that (involve in deviant behaviors) to irritate their parents” (Phong, male, 15 years old)

Phu is not the only child who is addicted to internet games, aggressive with others or has poor study habits. When I asked various people if it is his mother’s HIV status that contributed to Phu’s problems, I got “no” in response. People, even children, gave examples of other children like him:
Diep Anh: I have a classmate who stopped going to school this year. He is not good, he steals a lot of money and stuff from others to have money for internet games. He failed the exam so he left school. We came to ask him to come back to school but he refused.
Yen: Is it because his family has difficulties?
Diep Anh: No, his family is very rich.
Yen: How do you know?
Diep Anh: His father works in Hanoi and earns a lot of money, and his mother has a big shop in the central market.
Yen: Do they care about him?
Diep Anh: Of course not. His father comes home once a week and his mother is busy with her shop. I mean, it is easier to understand why poor people steal money, but he is rich...

Returning to the definition of care, only when there are serious problems like stealing or not going to school for many days do parents question whether they provide their children with sufficient care. Spending time with children - talking, sharing information, discussing emotions and difficult experiences - is strange for parents. Even when they realize that they need to do it, they do not know how, because they did not receive such care from their parents.

In the case of Phu, although the lack of care is the direct cause for his deviant behavior, HIV/AIDS is the indirect cause to his difficult and turbulent life story. HIV/AIDS has led to his mother’s emotional breakdown; since her diagnosis she has fallen into trouble and ignores everything, including her child. In addition, Le never recognized how her behaviors, such as telling lies, hitting him, leaving home for days at a time, or coming home drunk affected her son’s every day life and mental state. Unfortunately, parents often tell children how to behave rather than being an example of the behaviors and attitude they want their children to posses.

The discussions I had with caregivers on how to teach and punish children did not result in agreed forms of discipline, although it was an important concern of mothers and grandparents in the study group. In most families, physical violence is a popular way of teaching children. Parents hit children much more than grandparents. If the child does not behave, he/she will be hit and no one complains because they certainly
understand that it is for the child’s benefit. If the grandparents or other caregivers hit the children, other people may think of it as violence and feel pity for the child. Moreover, grandparents often thought that their grandchildren were unlucky to lose the parents so they should not be beaten. All the children in the study mentioned being hit at least once, but not one showed concern or anger about it. Children thought that caregivers had reasons to punish them, and hitting children can also be understood as an expression of love. Ly told me about a time when her mother hit her because she ran across the street without noticing a car was coming: “It was because I was wrong. She (her mother) was so worried about me, and that is why she hit me at that time” (Ly, female, 11 years old).

Discussion 4

Quality of care and maternal affection cannot be evaluated unless it is seen within a socio-cultural context. Mothers and grandparents in my study are affected by cultural norms and traditions. They also have their own concerns and environmental conditions influencing the way they take care of children.

Quality care giving in Vietnam revolved around children being able to go to school and be provided basic materials, such as safety, food, and clothes. Even though parents are encouraged to spend time with their children, not many people can do it. It has been shown that the loss of parental supervision and care affects not only homeless children, but also the welfare and behavior of children with parents. A 1998 study showed that 43% of all parents in Ho Chi Minh City spent only 5 to 15 minutes a day with their children on homework, while 22% said they did not have time to care for their children (Bernard 2000). Talking with children is rare, but more importantly, the list of things that should not be talked about with children is endless because children’s agency is not acknowledged. Children are not encouraged to talk about their emotions. Topics such as children’s marks at school or their friends are not enough to support and guide children in building effective coping strategies. Adults have power over children, so rather than having discussions, they simply ask children to obey. When children made mistakes, many parents punished them without listening to children’s reasons or providing children with a detailed explanation as to why they were punishing them, which makes children frustrated and angry. Caregivers are also challenged by family problems, their health status, and lack of time and energy.
Children, on the other hand, interpret the fact that caregivers did not listen to them as “not caring.”

The lack of communication between children and caregivers affects children’s ability to orientate themselves; they have difficulties following society’s values and norms. If children’s coping strategies are ignored or simply evaluated as bad behaviors – “hur”, it could lead to more deviant behavior. The family context affects children’s choice in expressing their distress. The feeling of having little affection and reassurance lead children to finding another ways to get attention; misbehaving causes caregivers to pay attention to them, while efforts to win at playing internet games gains respect from friends.

Studies show that the only way to effectively protect, promote and enhance the health and wellbeing of young children is to improve the quality and stability of the care they receive from those closest to them – from their caregivers and families (Richter, Foster, and Sherr 2006). In my study, caregivers were willing to do anything to support their children, but they did not know how to do it. Hence, parental skills training should be provided for caregivers of children affected by HIV/AIDS.

5.5. The need for extra care and early maturity

Case 5: I want to provide my mother a new life! She deserves it!

I usually had to think of how to attract children to this research, but Ly was very different, she actively called me to talk. She said that she liked me from the moment we met at her home, but didn’t know why.

I chose Ly as an example of a child who still had both her father and mother. Ly’s family lives in a raft that is like a “houseboat” (bè). In Ha Long, only poor people live on houseboats because it is dangerous and there is a lack of sanitation. The houseboats in Ha Long are made of only bamboo and bad-quality wood, and are kept floating with buoys. “You know, many people have died, especially when there are big storms. A lot of children have died.” Ly told me that she dreamed of living on land. I cannot say Ly has a life with fewer resources than other children, because they rarely talked about poverty and always confirmed that they earned enough to survive. Instead, it would be more accurate to suggest that Ly and many other children living
on the rafts have a poorer quality of life than many children in the town. Besides the lack of space for living, studying, and playing, they face the danger of the sea and have difficulties going to school everyday because there are not enough ferryboats.

Thu, Ly's mother, is an attractive and gentle woman. Even when she was sick, she was happy to talk, and was willing to tell me more about her life story. Thu was informed of HIV status when she was pregnant with her second child:

_I guess he (the husband) went to sex workers. I could not feel anything but misery. I walked for a long way, from the hospital to the "port". That night I told my husband, he then took the test himself, came home and cried. He asked me to forgive him, but in fact, I had already forgiven him. I love him, and more than that, we are a couple. Then, we decided to get abortion. I didn't want to take the risk. We are happy to have Ly and that's ok. We do not want any other children when we both know about it (HIV)._\n
Everyday, Thu brings seafood to the market and sells it, while her husband stays at home to raise the fish. The bad weather and the recession made it hard to sell fish at the proper price as a result they are having financial difficulties. In the summer, Thu uses her free time to sell "che" (a desert made from cooked fruits, or various kinds of beans with sugar) around the bay in a small boat.

Talking about her child, Thu smiled widely and said:

_She has not grown up like other children. She is very lovely. I told her about it (HIV) when she was 10. She needs to know about it. She was sad at the time but then she was fine. Loving me, she always tries to help me with housework. She tells me to take my medicine on time. When I am sick, she stays around to help me, and says, 'You need to get well soon, or I will be very sad'... She is an emotional child, she cries when she watches a drama._

Thu agreed to let her child come to my hotel and "play" so that she would feel more comfortable in interviews with me. When Ly was told that she could come with me, she clapped, smiled and said that she was very eager to come, and had hoped that this day would come. One day before going to work, Thu dropped Ly off at my place, and
said, “My child is very active, and I am always afraid that something will happen. I only have her. I believe you, so please take good care of her, be very very careful …”

By the end of my research, Ly and I enjoyed four pleasant meetings together at my place. Ly loved to come to on land. She talked about everything, played computer games and made paper stars (she believed that with 1000 paper stars she could make a wish) but more than anything else, she just loved the feeling of being in a real house on land.

Ly is a nice eleven-year-old girl whose main priorities were her mother and her studies. She was the youngest child among my informants, and she was the only one who openly expressed her affection for the people around her.

Ly: Every month, my teacher wrote a letter to my mother about my late school fee payment. And I always kept it a secret from my mother.

Yen: Why?

Ly: My mother has no money. If she has enough money, she would pay on time. I think my teacher should wait, rather than sending me home with those papers, because we will pay at the end of the month. You know, my mother has many things that need to be paid, such as food for our fish, the electricity bill, the contribution for the clan, the interest fee for the debt, and daily life expenses. We are having difficulties in selling our fish also. Then, am I supposed to give those papers to my mother? She will worry, for nothing, and she may get ill. It is best to store them somewhere. She will pay it eventually.

Yen: How do you know all about this?

Ly: I’m a daughter, so my mother confided in me so that I could understand and do my best to study.

I asked about her father and she replied:

*If my mother hits me, it hurts but not much. But you know, if it’s my father, it hurts very much. He never does it with a cane, he hits me with his hands, even makes me bleed. Terribly! But you know, I never cry when he hits me, because my father said if I cry, he would hit me more. But because of that, he rarely hits me, only two or three times. My mother always hits me.*
Ly, talking about her love for her parents, said, “My mother loves me and hugs me everyday. My father loves me too, but he does not express it to me, he keeps it in his heart.” I asked her how she knew about that, she smiled: “When my mother hit me, my father told her to stop and then told me that I should be well-behaved next time.”

Ly knows clearly that her mother is ill, she said, “Today, my mother is sick again. I asked her to stay at home to rest but she still went to work. I know that today she will come home and be sicker. It is lucky that I’m old enough to help her. I can cook for her now.” I asked Ly whether she knew which disease her mother had; she said very briefly “She is sick.” When I asked her more, she said, “I don’t know.” I brought up this confusion with her mother, and she said “Ly knows everything, but she will not tell you. I told her that it was important that she kept it a secret. No matter what or who asked her about it she must not tell anyone. I’m happy that she listened to me.”

During the interviews with Ly, I shared some details about my childhood. She asked me a lot of questions about how I could have a house on the land and about my research. I was impressed when at our last meeting, she said, “Now I know why you do this research, because you used to be poor and you understand us. You want to write about poor children, don’t you? If so, you should write that I will study hard, during my 12 years at school, earn the best salary, then I will have a good job and provide my mother a new life, on the land…”

Many girls seem to develop like Ly, which confirms the Vietnamese saying that “girls are better”. Different from many other children, Ly is open, extrovert and caring. Every time I offered her any food, snacks or drinks, she asked the price and refused it if it was expensive. She might have really wanted to have them but still said: “You also need money, so you should not buy me those expensive things.” I was surprised that children at the age of 11 could take care of other people, and even adults like myself.

Ly is not so special if I compare her with the other girls that I spoke with. Girls were often more open, warm and comfortable with interviews and group discussions than boys. One girl talked about a boy living next to her house whose mother had HIV like hers: “Well, he knows everything but he is too silly. He is sad but does nothing to help his mother. When his mother was ill, he cried and called my mother. But when
my mother was ill, I knew that I had to make soup for her” (girl, 11 years old). Girls often helped their mothers with housework and taking care of others. A few boys did these jobs but much less. The difference between girls and boys in helping adults in housework does not mean that girls are more mature than boys. Although children are not expected to take care of adults, caregivers did not think these behaviors were special. They did not think of cooking and reminding parents to take medicine as “taking care” but called it an expression of love. They were also proud to talk about their children’s efforts as it means their children were smart and caring.

Children like Ly are classified as “ngoan” (good) and adults tend to think that they do not need any support since they follow the norms as expected. However, they are still different from other children in the way that they think and act. These children do not allow themselves to enjoy what others often do, such as playing with friends or having a nice meal. They spend their time worrying about others and taking care of adults. They control their emotions and chose a way to express them so that their caregivers did not have to worry about them. At the same time, they develop their knowledge, thoughts and affection independently beyond adults’ awareness. At the focus group discussions, children asked me about topics that I have never imagined their age group thinking about:

- When will you get married? Are you afraid of not having a husband?
- What would you do if you found out that your boyfriend was a drug user? Will you still stay with him or leave him?
- What would you do if you got pregnant before marriage?
- What would you do if you got pregnant from a man that you did not love? Would you get an abortion?

I asked the children why and how they thought of these problems, and they said that they saw these issues on TV programs. Surprisingly, when I said, “You know, living with a drug user may be difficult and I am not sure I could do it”, one child whose father was a drug user said “You are smart sister. You should think twice about living with him. I don’t think I could do it.” The ideas on marriage, family conflicts and love have been built in these children’s minds and no one can say how they will affect their future. One girl was fearful because her parents had HIV that she could not have a
husband. Children in this age group usually do think about their future plans, but many of them have. Dan had thought of selling the house and sharing money with his uncle if his grandmother died. In other cases, some children thought of their future marriage, family and career.

The point is adults did not recognize that children are preoccupied with future plans and do not know it is an important issue for them. When I discussed this with a mother, she said, "Well, it is because of the Korean films that they see on television. Even adults are influenced by those films" (Le, mother, having a 13-year-old son). When parents minimize the seriousness of children's worries, they do not support their children in having a joyful childhood.

Discussion

Children's agency and its expression have been presented in other studies. It has been proven that children notice stressors within a family and sense that there is something seriously wrong. Children can feel anxious, guilty, depressed and misunderstood but they often do not express these feelings because they do not want to upset the situation further, or they may be afraid of being overwhelmed by their feelings, therefore, they keep their emotions under control by repressing them (UNAIDS 2001). Children in families living with HIV/AIDS understand their situations and unconsciously prepare themselves for it without letting caregivers know. The choice to obey the rules of caregivers and silently support the caregivers as a way to reduce their own stress was chosen by several children who participated in my research. In a study in Africa, children said, "We have to act like adults because no one else treats us like children and we have to do what adults do" (UNAIDS 2001). In my study, the contrary was the situation for children. Caregivers believe that children know little about life and should only care about studying. Adults hide information from children and think that they are protecting children. Children in this situation have to take care of adults because they are worried about their parents or loved one, and keep on pretending to know nothing.

While many children do not work hard at school, several children were dedicated to their studies. Academics gave them hope for a better future; this coping strategy is very typical for Vietnamese youth. A long history of war and poverty has created a
culture in Vietnam that adapts to all types of unfortunate events. Adults often teach children to forget the past, accept the present and live with hope for future. For many children education is the bridge to a better life than their parents had. In this sense, a better future means good health, stable employment, and a life free of poverty. The general belief in Vietnam is that psychological torment and grief can be forgotten when people have a better life.

Caregivers are happy with their children because it seems they have adjusted well to the struggles in their lives. This belief allows adults to bypass children’s inner problems. Being good at school and helping parents with housework is not enough to confirm that the children are developing well. If parents and grandparents do not pay enough attention, it can lead to deviant behavior. For example, children may be involved in illegal work if they have the desire to help their parents.
Chapter 6. Conclusions and recommendations

The aim of this study is to explore the concerns and coping strategies of children affected by HIV/AIDS in Vietnam. I used an anthropological approach that employed qualitative methods in order to better understand children’s lives and the problems they encounter on a daily basis.

The most striking observation during my fieldwork was the silence, avoidance and denial of children whose parents are living with HIV/AIDS or have died of AIDS. The children and I could talk about daily life activities, events, and thoughts about them, but the conversation often went silent when we reached issues related to feelings, emotions, grief or torment. Keeping silent, refusing to answer questions or changing the topic were politely chosen by children when avoiding my questions. Anger, aggression or walking away from an interview was how other children dealt with my unwelcomed questions. As a Vietnamese woman who had a difficult childhood, I sometimes misjudged the reactions of children by filtering their life stories through my memories and experiences. After reflecting on the data - my observations of children, their situations and their reactions to problems - I have come to the conclusion that behind their silence, children affected by HIV/AIDS are suffering from distress.

The distress of children affected by HIV/AIDS should be put in the socio-cultural context of Vietnam, or to be exact, Ha Long. The relationship between adults and children is top-down; therefore the communication between caregivers and children in a family is not beneficial for children. In addition to the time and energy limitations, the lack of awareness to children’s psychology also prevents caregivers from understanding their children (even when they would like to). Parents and grandparents in this study wanted the best for their children, they were determined to stay alive, worked hard and tried to earn enough money. They were unwavering in their desire to send children to school and in taking care of housework so that children could spend more time studying. Caregivers’ efforts are not only physically demanding, but also emotionally challenging. Children in these situations understand their parents and grandparents; despite the poverty, the conflicts, and the burden of stigma, children still show their deep love, affection and sympathy for their caregivers. In order that
the latter do not worry, children find their own way to express and solve their distress. Speaking about their issues is not an option, as almost no one encourages children to verbalize their feelings. The coping strategies of children are diverse and individual. That makes it harder for caregivers to understand children's distress especially when the concept of mental health does not exist in daily life.

HIV/AIDS in relation to poverty, the death of parents, abandonment, caregivers’ neglect, and stigma, all attack children in every aspect of their lives. Although the tradition of using the clan network to protect children has proved efficient in part, through providing children with the basics such as a shelter, food and study materials; however, children still lack adequate support to improve their quality of life. Despite caregivers’ belief that their children are given the things they need to lead a normal life, children are lonely and struggling with their intrusive feelings and emotions. The distress does not have a single cause, for example, the combination of losing parents, poverty and bullying from other children all work together to cause suffering. The amalgamation of these unfortunate problems gathers and affects children silently, invisibly and only children can fully describe their experiences. Since children do not talk about their problems, caregivers lack an understanding of their children’s concerns and their children’s difficulties in assisting them.

HIV/AIDS creates many additional problems for families; therefore interventions should consider the impact of each factor. Although HIV is a struggle for PLHIV and their children, HIV was not listed as a priority or a concern for children. Therefore, supportive interventions should not only focus on HIV itself as a medical issue, but on life skills and sustainable activities for fighting against poverty, self-stigma and discrimination. Ha Long has one of the highest rates of HIV/AIDS in Vietnam, and is a targeted location for many support programs. The informants that I met received support from at least one of these assistance projects. The programs being implemented in Ha Long for people living with HIV/AIDS vary from health care to socio-economic, which support both people living with HIV, their family members and children. The success of these programs can be measured by the heightened awareness of HIV that people have and by the fact that more people can access ARV treatment. Children's lives have also improved with interventions for families affected by HIV, especially when medical care and treatment are provided. That fact that all
children can go to school is an illustration of that success. However, there are still limits to what these programs can do, for example, income-generating activities do not meet the needs of the poorest groups, and there is still a lack of support for children, especially mental health services. Furthermore, the collaboration among different programs for PLHIV is not well organized, which waste resources due to the overlap in programs and activities.

Children affected by HIV/AIDS are exposed to poverty, stigma or loss of parents, thus other children, not affected by HIV/AIDS, but who are living with these same problems should also benefit from support programs. In this study, I did not have the opportunity to compare the impact of each factor on children’s lives. HIV is a “hot” issue internationally and nationally; children who are suffering from poverty or orphans who do not HIV infected parents have to bear their difficult situation with little comprehensive care and support from developmental programs. I would suggest widening the group of beneficiaries in support projects for children affected by HIV/AIDS. Theses programs should provide assistance to all vulnerable children, while promoting integration and reducing stigma towards PLHIV and their family members.
Reflections and learning experiences

This was an exploratory project that included six weeks of fieldwork and data collection; however, in order to evaluate the role of HIV/AIDS in relation to the complex factors that affect children’s lives, additional data on vulnerable children is needed. Because anthropological studies on children in Vietnam are limited, the background information for this study was inadequate. As this is also my first study employing an anthropological perspective, it was challenging but satisfying to be able to apply theories to the realities of my fieldwork.

The first few days in the field were frustrating as children refused to talk to me. I approached children through their caregivers and the supportive approval of the latter in many cases became the barrier in getting close to the children. As their caregivers were strict and even threatened to hit them if they did not show me respect. Children agreed to spend time with me but angrily refused to talk, or just kept saying “yes” or “no”. It took me quite a long time to overcome this situation, which I did by visiting them everyday or taking them to the beach. I did not have a chance to try to meet children at school, because the administrative procedure to be able to work within a school is complicated. According to my experience, children are more comfortable to be in a group rather than being alone. Hence, focus group discussion should have been conducted more from the start of the study.

Being a “native” and having an insider’s view of the studied culture has both advantages and disadvantages. With six weeks in the field, being Vietnamese helped save time and energy in understanding the culture of the community that I was studying. As a person who used to work in Quang Ninh, I was also familiar with the people and lifestyle there. I did not have difficulties adjusting to my new home, meeting people and even joining in their important life events in order to get a better understanding of the specific culture in this area. My experience working with PLHIV for more than 2 years also provided me with a deeper understanding to my subjects’ daily life and concerns. Nevertheless, it was hard to step back from my position as a Vietnamese woman in order to reflect on what I saw and heard. For example, we Vietnamese have two words for poverty – “nghèo” and “nghèo doi”. “Nghèo doi” is a notion to imply that people do not have the basic resources for their life, such as food,
clothes and primary education for their children. “Nghèo”, on the other hand, is a relative notion referring to people who do not meet the standards of a good life. As Vietnam is a developing country where many people have difficulties reaching the standard of a ‘good life’, poverty is often described as “nghèo đói”. During my study, I was distracted by these distinctions and misjudged the seriousness of poverty in several cases.

Last but not least, my private and sad memories of childhood were the motivation for this study. My childhood was linked to poverty, family conflicts, broken relationships, and psychological problems: a past that was advantageous but also a challenge in this study. In several cases, my personal history helped in talking with children and understanding their feelings. It even broke the ice and we sometimes felt that we were “the same” and could talk about “our” problems. Concurrently, at moments it prevented me from observing the children from an outsider’s point of view. I was also restrained by my emotions; at times, I was not able to understand or explore deeply the feelings and emotions of children (as avoidance is also my coping strategy acquired in childhood). When I was in the field, some stories reminded me of the past and brought up sad memories; therefore, when talking with children, I tended to think that I knew what they were feeling so I did not ask them for details. The results of this study hopefully point out several aspects of children’s lives affected by HIV/AIDS that can be utilized by international, national and bilateral aid agencies in creating comprehensive support programs for vulnerable children.
Summary

Due to the increasing number of young PLHIV in Vietnam, the number of children affected by HIV/AIDS is also rising. Although international and national programs are providing more resources in order to support children affected by HIV, the voice of children has been blurred among the international and local discussions about the problems that this group has to deal with.

This anthropological study focused on children’s concerns and priorities between 11 to 15 years of age. Although children are the main informants of this study, it is not easy to approach children and it is even more difficult for them talk about their problems. It is challenging to become close to children who might have low self-confidence, especially when cultural norms prevent children from raising their voice or talking about their feelings and emotions, particularly if the stories are about their families.

Although HIV was not a main concern or priority for children, the data illustrates how HIV has affected children through the loss of parents, poverty, stigma, and parents’ neglect. Employing the concept of “idioms of distress” and analyzing coping strategies, it was clear that the calmness and silence of children had meaning and significance caregivers where unaware of. Children do not simply forget and adapt to their situations, indeed, they suffer in silence because they do not want to bother their caregivers and there are not many opportunities for them to talk about their affliction. Coping strategies of children vary and are complex. Some children try to forget or overcome their problems with deviant behavior and addiction to internet games. The choice of coping strategies depends on their socio-economical situation, but also on individual characteristics.

As HIV/AIDS is only one of the many factors affecting children whose parents are living with HIV/AIDS, I recommend that developmental programs pay more attention to building sustainable income generating activities, providing life skills training and psychological support for children affected by HIV/AIDS, in addition to assisting all vulnerable children in these impoverished communities.
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